

**COPING WITH CANCER**  
**A COMPARISON OF BRITISH SOUTH ASIAN AND BRITISH WHITE**  
**PATIENTS FOLLOWING REFERRAL TO A UNITED KINGDOM**  
**CANCER CENTRE**

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## Abstract

**Coping with Cancer: A comparison of British South Asian and British White patients following referral to a UK Cancer Centre, a cross sectional study.**

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### Abstract

**Aim:** To explore how British South Asian (BSA) and British White (BW) cancer patients coped during the nine months following referral to a UK Cancer Centre.

**Material and methods:** This quantitative cross sectional study compared symptoms of anxiety and depression between 94 BSA and 185 BW patients at baseline, at three and nine months. Associations between mood and coping strategies and selected environmental factors (symptom burden, cancer beliefs and the therapeutic relationship) were analysed. Questionnaires, available in English, Gujarati and Hindi, were the Hospital Anxiety and Depression Scale (HADS), Patient Health Questionnaire (PHQ-9), Emotion Thermometers (inclusive of the Distress Thermometer and Problem Checklist), Cancer Insight and Denial Questionnaire (CIDQ), Mini MAC, Brief Illness Perception Questionnaire (BIPQ), Physician/Patient Trust and Cancer Beliefs.

**Results:** BSA patients reported higher rates of depressive symptoms compared to BW patients longitudinally e.g. (HADS D $\geq$ 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). A similar ethnic gulf was detected in rates of anxiety until 3 months (HADS  $\geq$ 8 at baseline (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). BSAs used potentially maladaptive coping strategies more frequently at baseline, e.g. hopelessness/helplessness (p=0.005), fatalism (p=0.0005), avoidance (p=0.005). The symptom burden was greater on BSA patients. This was reflected in an ethnic difference in depressive symptoms. Some cancer beliefs and preferences for the therapeutic relationship influenced how patients coped.

**Conclusion:** Health professionals need to be aware of the greater probability of psychological distress occurring among BSA cancer patients and how this may present clinically if this ethnic disparity in mental wellbeing is to be addressed. Clinicians need to establish the cultural context in which an individual experiences cancer.

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## Abbreviations

AnxT	Anxiety Thermometer
BFO	British Forces Overseas
BIPQ	Brief Illness Perception Questionnaire
BME	Black and Minority Ethnic
BSA	British South Asian
BSI	Brief Symptom Inventory
BW	British White
$X^2$	chi-squared for independence/trend/goodness of fit
CiDQ	Cancer Insight and Denial Questionnaire
CI	Confidence Interval
CMD	Common Mental Disorder
DepT	Depression Thermometer
DT	Distress Thermometer
EMPIRIC	Ethnic Minority Psychiatric Illness Rates
ET	Emotion Thermometers
FET	Fisher's Exact Test
FT	Freidman Test
HADS	Hospital Anxiety and Depression Scale
HRQOL	Health Related Quality of Life
ID	Indices of Deprivation
ISC	Indian Sub Continent
LCC	Leicestershire Cancer Centre
MW	Mann Whitney U Test
MDD	Major Depressive Disorder
Mini MAC	Mini Mental Adjustment to Cancer Scale

MRS	Mean Rank Score
NIMH	National Institute of Mental Health
ONS	Office for National Statistics
PASW	PASW statistics 18
PHQ-9	Patient Health Questionnaire 9
r	Pearson Product Moment Correlations
WSRT	Wilcoxon Signed Rank Test

## **Section 1: Background**

### **1.1 Introduction**

One in three people in the United Kingdom will develop cancer during their lifetime. One in four will die due to the disease (Cancer Research UK, 2009). Historically the focus of clinical research has been to boost survival rates by developing medical treatments while accepting high levels of toxicity as an undesirable necessity. With the improvement of survival rates in developed countries, the quality of a patient's life has become increasingly important (Brown et al. 2000). Research now focuses not only on devising treatments to balance optimal survival with least side effects, but also on supporting people to adapt to living with cancer.

An individual, receiving a diagnosis of cancer, is faced with various challenging tasks, all of which are potentially stressful and are a risk to psychological stability. Tasks include:

- Coping with the symptoms of illness

- Managing the hospital culture and treatment procedures

- Developing effective relationships with health care professionals

- Preserving emotional stability

- Preserving self-image

- Preparing for an uncertain future and maintaining relationships with friends and family (Moos & Schaefer 1984).

Most people will adapt well to these life changes. Feeling anxious, sad, low in mood or angry are initial emotional responses to a stressful life event and is part

of normal adjustment, if of short duration. For some individuals, however, the symptoms of distress persist making them vulnerable to disorders such as anxiety, dysthymia (a chronic mood disorder when a depressed mood is present on most days for at least two years) and depression.

Anxiety describes feelings of fear, dread, and uneasiness that may occur as a reaction to stress. An individual may sweat, feel restless and tense, and have a rapid heartbeat. This state affects one's ability to manage emotions, relationships, and work life. It may or may not be associated with depressive symptoms.

Depression is a mental condition marked by ongoing feelings of sadness, despair, loss of energy, and difficulty dealing with normal daily life. It can range along a continuum, from sadness, dysthymia to major depression. Other symptoms of depression include feelings of worthlessness and hopelessness, loss of pleasure in activities, changes in eating or sleeping habits and thoughts of death or suicide. A diagnosis of depression requires that these symptoms are present on most days for at least two weeks (National Cancer Institute, 2012).

Depression can result in poor health outcomes. Associated with cancer, it has been attributed to worsening quality of life (Stark et al. 2002, Clarke et al. 2003, Hoyer et al. 2011), reduced compliance with treatments (Colleoni et al. 2000), prolonged hospitalisation (Prieto et al. 2002), pain (Ciaramella & Poli, 2001, Bair et al. 2003, Hopko et al. 2008) increasing psychological burden on family

members (Cassileth et al. 1985, Kornblith et al. 1994, McPherson et al. 2007, Hudson et al. 2011) psychological distress (Akechi et al. 2001, Roy et al. 2005) and suicide (Walker et al. 2011, Levene & Parker, 2011). Such distress, which can occur at any stage of the cancer pathway, should be considered as a treatable complication of cancer (Fallowfield et al. 2001).

How individuals respond when diagnosed with cancer is an important area for research if psychological complications are to be addressed. Cultural norms and expectations influence coping but there remains a paucity of knowledge about how people from UK ethnic minorities cope with cancer. Awareness of this is required if the psychological needs of patient of all ethnicities are to be met.

Successive UK governments recognise that there are ethnic disparities in health and healthcare and removing them has been the subject of inquiries and legislation, notably through the Independent Inquiry into Inequalities in Health 1998, The NHS Plan 2000, and The Race Relations Amendment Act 2000 (Department of Health, 1998; Department of Health, 2000a; Great Britain, The Race Relations Amendment Act, 2000). In recent years objectives in the Cancer Reform Strategy included the reduction of major ethnic inequalities in cancer outcomes, improving patient experience and support through the cancer journey and beyond (Department of Health, 2007). The All Party Parliamentary Cancer Inquiry into inequalities in Cancer, UK, 2009 followed, and more recently the DH' Improving outcomes: a strategy for cancer', 2011 was published (Department of Health, 2009, Department of Health, 2011). The latter

acknowledged that better data was required to improve understanding about health inequalities and key performance indicators were needed to measure improvements. Of particular importance is 'The Marmot Report', 'Fair Society, Healthy Lives', 2010, which stressed that removing health inequalities is about tackling social injustice. This report is a catalyst for action. For example, the publication of 'Working for Health Equity: the role of health professionals' incorporates this principle into a programme of work. One recommendation is that clinicians gain an understanding of a patient's social and cultural context as part of a clinical assessment (Marmot, 2010; Allen et al. 2013).

In the UK the South Asian population is a large ethnic minority. The 2011 UK census reported that those with Indian ancestry accounted for 1,412,958 people in England and Wales with those from Pakistan, 1,124,511 and from Bangladesh, 447,201 (ONS, 2012a). However there are few studies examining how these groups cope when cancer is diagnosed. Of concern is evidence of delays in presenting symptoms of cancer across the UK in South Asian populations (Velikova et al. 2004, Randhawa & Owens 2004, Szczepura et al. 2008). Furthermore, not only do some ethnic minorities appear more vulnerable to mental illnesses, (Weich et al. 2004) there is also a suggestion of greater psychological morbidity associated with the diagnosis of cancer among British South Asian patients (BSA) (Roy et al. 2005). Lower participation in the uptake of cancer screening services and in cancer trials among UK ethnic minorities is also reported (Department of Health, 2009).

## 1.2 Ethnicity and self-identity

This section briefly considers the term 'ethnicity' and its use before clarifying the ethnic terminology used in the study. Although not central to this research, the opportunity was also taken to establish how participants identified themselves and whether the results reflected national trends towards 'self-identity'.

'Ethnicity' is not a clearly defined concept. The following definition illustrates both its lack of clarity and its fluidity. It is "a field of enquiry helping ....to locate the material and cultural context within which ethnic identities, premised on notions of shared descent, heritage and culture(encompassing religion and language) are constantly redefined and contested by different social groups." (Craig, 2012, p 22). It is the product of social interactions between groups of people which change over time rather than an inherent human quality. The term is often used interchangeably with 'race' and although not mutually exclusive the latter implies a similarity between peoples based on, for example, genetics. The debate about the differences between these terms and their use and misuse falls outside the scope of this study.

'Ethnicity' and 'culture' should not be confused. The former is about 'identity', the latter is "a set of conventions which structure the 'way of life' of a distinct population" (Ali, 2006). 'Culture' applies to a majority or minority population or sub group of either (Ali, 2006). It is therefore one element of ethnic identity.

In the UK 'ethnicity' or 'ethnic' are terms commonly used to refer to immigrant or minority groups by the majority population. This risks the majority white

population regarding people from minority ethnic groups as 'the other' while ignoring the fact that all individual have their own ethnic identity and that there are also minority white ethnic groups. The inherent danger is that ethnic minorities can be regarded as inferior, risking disengagement, discrimination and disadvantage in all spheres of life, for example politics, education, health and employment. This, perhaps unconscious, undercurrent may contribute to the slow progress of successive governments in reducing ethnic health inequalities inspite of policy statements and legislation.

While this study refers to ethnicity as a key variable the author is also aware that doing so risks being insensitive to other associated factors of interest such as deprivation, education and employment which can independently affect health and health outcomes.

### **Self definition**

One's sense of identity is a strong personal value (ONS, 2009a) and there is a trend within the UK to facilitate 'self-identification' of ethnicity as one way of engaging all sectors of the population to feel valued and to actively participate and contribute to UK society.

This approach was partly a response to criticism of the use of pre-designated categories (Smith, 2002) as referred to in the 1991 UK census where people were expected to select a self-identity which did not reflect their beliefs. The ONS found that the results from that census were dissimilar to information gathered by free text responses (ONS,1992; Bradby, 2003). An example

demonstrating the strength of feeling that can be generated by this issue were the objections voiced in Parliament and in the media that there were self-identification categories for Scottish or Welsh people but not English in the 2001 Census. British White was the only option available (Johnston, 2001).

### **Trends in ethnic identity**

Ethnic identity can change over time and has been observed in a shift in self assessment among BW people in England where 'Britishness', however that is defined, is thought to be 'in decline' and 'Englishness' on the increase (Economic and Social Research Council (ESRC), 2006). A cross cultural sample of people living in England (n=8803) was randomly selected by postcode and asked whether they considered their national identity to be British, English, Scottish, etcetera (ONS, 2009a). Most (60%) considered themselves to be English with 44%, British and 2%, Scottish. The 2011 census for England reports a similar figure for those considering themselves as English 'alone' (60.4%) however 19.2% felt British 'alone', less than previously reported (ONS, 2013).

Locally a not dissimilar trend was reported for the predominantly White population of Leicestershire (67.8% regarded themselves as English only; 16.4% British only). This resembles the national ethnic balance. However in Leicester 40.7% regarded themselves as English only and 33.7% British only (ONS, 2013). The latter reflects the ethnic diversity of the city.

Devolution of Scotland and Wales was thought to have encouraged people to re-assert their connections with England, however the report "Devolution and

Constitutional Change”, (ESRC, 2006) a composite of several studies examining the impact of devolution, downplayed its influence. It instead pointed to a generational trend across Great Britain with younger people not having the degree of attachment that older generations do, steeped as they were in empire and war. It is, however, nearly 70 years since the end of World War Two and it was among the over 75 age group where there was a greater sense of Englishness. It was far less so among the under 50’s (ONS, 2009a).

The same study suggested that within BSA ethnic groups there was a tendency to include the term ‘British’ in their self identity far more than among the indigenous White population (ONS, 2009a). This supported findings from a study conducted for the Commission for Racial Equality (N=96) which used focus groups, word association exercises and sentence completion exercises among a cross section of ethnic groups (ETHNOS Research and Consultancy, 2005). In England, White participants described themselves as ‘English’ first and ‘British’ second. In contrast the majority of ethnic minority participants used ‘British’ as a prefix. One focus group of Pakistanis and Bangladeshis in London suggested an explanation for this,

*“There is a difference between being British and being English. English is being indigenous, being white and from this country. But being British, the primary thing that comes to my mind is that you have a British passport. The second thing is that you live here and you function here, in this society. [...] I am British. I am not English”.*

(Pakistanis and Bangladeshis, London) (ETHNOS Research and Consultancy, 2005, p. 22)

## **Ethnic Terminology**

Various terms are used in publications to describe the same ethnic group causing confusion about which population was being referred to (Bhopal et al, 1997). This inconsistent use of terminology risks flawed comparisons between studies (Aspinall, 2002).

The use of the term 'Asian' is one example. Strictly speaking the word applies to anyone from the continent of Asia (Bhopal, 2004). In the USA however, the term 'Asian' is used to describe people from the Far East such as China, Japan and the Philippines. In contrast, in the UK the term tends to refer to people with ancestry in the Indian sub-continent. It may also be 'regionally specific' (Bhopal et al, 1991; Aspinall, 2002). A study in Leicester indicated that the term was commonly recognised by people as referring to themselves when asked unprompted, but in the northern city of Newcastle, few used it (Rankin & Bhopal, 1999).

To avoid confusion and enable clear comparisons with other studies, terms for the main ethnic groups referred to in this study are clarified. The term 'British South Asian' (BSA) was used to describe a person whose ancestry is in the Indian subcontinent, including India, Pakistan, Bangladesh and Sri Lanka and who identifies with, or is identified with, their host country, Britain. In using this term the author was mindful that South Asia is a huge area covering a variety of ethnic groups and use of the term risks neglecting important differences.

Use of the term can miss health differences between British Bangladeshi and other South Asian groups just as using the term 'White' can hide the poorer health outcomes amongst Irish immigrants (Clucas, 2009). For example, Bangladeshi men have the highest smoking rate in the UK (40%) followed by Irish men (30%) in contrast to Indian men (20%), the national average being 24% (Sproston & Mindell, 2004). The Bangladeshi and Irish are therefore at a higher risk of smoking-related diseases, trends which might be overlooked or understated if broad terms are used, a danger recognised by the Commission on the Future of Multi-Ethnic Britain (Parekh, 2000).

Nevertheless the term 'BSA' was retained. The vast majority of patients recruited were of Indian descent which is largely representative of our local population so results are likely to reflect their experience. Statistical comparisons between groups based on ethnic identity within the BSA sample would produce meaningless results. However, the self-identity of each participant is reported and some comparisons based on place of birth were possible.

'British White' (BW) describes a person with European ancestral roots and who identifies with or is identified as White and who associates themselves, or is associated with, Britain. 'White' is becoming more commonly used as an alternative to the term 'Caucasian', the latter being a hangover from efforts of European anthropologists to classify racial groups through commonly-observed physical features in the 17<sup>th</sup> and 18<sup>th</sup> centuries (Aspinall, 1998). Although scientifically flawed, 'Caucasian' continues to be used. There were no minority

White ethnic groups represented in the study sample which would have required separate ethnic identity.

### **1.3 Population profile**

Outlining the profile of both ethnic groups provides a perspective for this study. Population numbers, religions, linguistics and literacy of the local population and the migration of BSA people to Leicester and its county are described.

#### **British South Asian migration**

The city of Leicester is situated in the East Midlands of England and has one of the most ethnically diverse populations in the UK. A large population originates from the Indian Sub Continent (India, Pakistan, Bangladesh, Sri Lanka and Nepal). Although migration to the UK from India occurred before World War Two, the first large scale migration occurred after Partition in 1947 when people were displaced from their homeland during widespread ethnic violence. They sought a new life. Many were attracted to the UK with its former colonial connections and their entitlement to British Citizenship as past subjects of the British Empire. There were also employment opportunities as a consequence of post World War Two labour shortages in the UK. For migrants from India the textile industry in Leicestershire gave opportunities for employment.

In addition, some who had served in the Leicestershire Regiment under the British Empire 'moved to the home of the regiment' (Herbert, 2008), a trend repeated recently with the migration of Ghurkha soldiers and their families to

reside near to the Headquarters of the Gurkha Brigade in Upavon, Wiltshire, and Church Crookham Barracks, Aldershot.

Immigrants who settled in the UK largely came from specific regions in the Indian sub-continent. They include the provinces of the Punjab and Gujarat, Sylhet and Chittagong. Those from Sylhet account for 90% of the immigrations to the UK from Bangladesh (Islam, 1995). East Pakistan saw emigration from the Punjab, Azad Kashmir and the Campbellpore district. Factors other than the Indian Partition prompted emigration, for example the construction of the Mangla Dam in 1963 which displaced Mirpuri people from Azad Kashmir (Peach, 2006).

Indian Partition saw another large group of people move to states in East and Central Africa including Uganda, Tanzania, Kenya and Malawi. The East African Indian population formed the middle classes in those countries through their education and often spoke English as a second or third language. They provided their adopted African countries with civil service workers, bankers, accountants and lawyers with a consequent increase in their wealth and influence. During the 1970's with the Africanisation of these states, state politicians engineered their 'expulsion' (Herbert, 2008).

Some from Africa made a planned emigration to the UK bringing capital assets to invest in their host country (Peach, 2006). Others, particularly Ugandan Asians, were forcibly expelled and, having British passports as a result of the British Nationality Act 1948, sought refuge in the UK. A number of 'African

Asians' settled in Leicester, possibly attracted by the resident Indian population. Approximately 30% of BSA people living in the UK today can trace their families from this African exodus. By 2001 this accounted for 40.6% of BSA people living in Leicester (Bonney, 2003). There was also an influx of people from the largely impoverished state of Bangladesh which peaked in the 1980's.

### **Population profile of Leicester and its county**

The 2011 population of Leicester was 329,839, a 16.6% increase on the 2001 total (ONS, 2012b). The BW (English, Celtic and British White) population was 148,629 (45%). Including all minority White people this accounts for 50.6%. By this definition the city just missed being defined as a plural city (a term which describes a city where there is no single ethnic group as a majority). The significance of this change in population balance is arguably overstated. Finney and Simpson comment that focus on the issue can be used negatively to promote unfounded fears that long-standing values within the White population would be suddenly undermined (Finney & Simpson, 2009). In fact Leicester thrives on its diversity (BBC News, 2012).

The main BSA populations (Indian, Pakistani and Bangladeshi) total 108,686 (32.9%). This figure excludes those of mixed ethnicity. The figures should be treated with caution because of the estimated 37,000 people who did not complete the census in 2011. This 'hard to reach' group included those from ethnic minorities (BBC News, 2011). This has required the Leicester City Council to arrange further surveys to gain more accurate figures.

In the surrounding county of Leicestershire the 2011 population was 650,489.

The ethnic mix does not reflect that of the city. The BW population of the county accounted for 88.9% and the main BSA populations 5%.

The Pakistani and Bangladeshi populations are relatively small in both city and county but, with the average age being of child bearing age, the percentage increase of the population is high - a trend which is reflected in these populations nationally since 1990's (Finney & Simpson, 2009). Migration is an overlapping factor in population increase since 7.5% of Leicester's population migrated to the UK within the last 5 to 10 years, a figure which is ranked 20<sup>th</sup> out of 348 'districts' in England and Wales (ONS, 2012c).

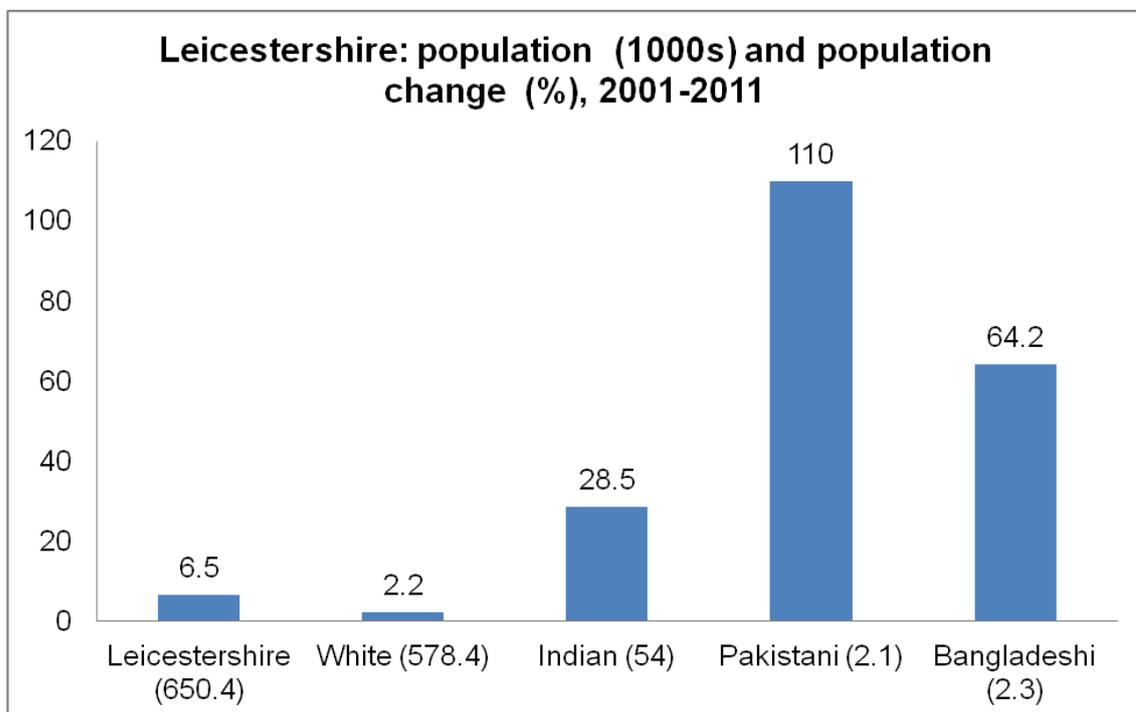


Fig 1

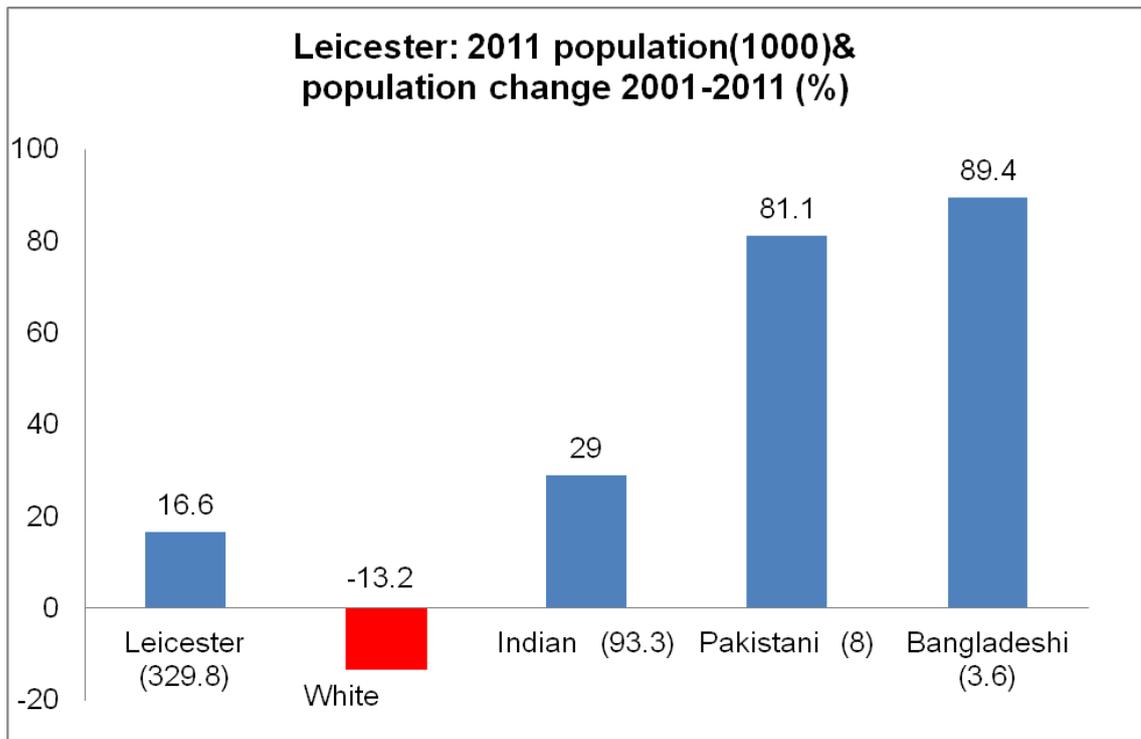


Fig 2

## Religion

The most recent figures relating to religious affiliation are from the 2011 Census (ONS, 2012d). In Leicester 32.4% described themselves as Christian, down from 44% in the 2001 census. Hindus account for 15.2% (15% in 2001). 18.6% are Muslim, an increase from 11% (2001) and Sikhs represent 4.4%. Over 22.8 % have no religious affiliation. Those people originating from Pakistan and Bangladesh are almost exclusively Muslim. In contrast Indians represent multiple religions, the Muslim population there being larger than resides in Pakistan. The representation of religions in Leicestershire is different. 60.3% described themselves as Christian (74% in 2001), 2.8% Hindu, Muslim 1.4% and Sikhs each account for 0.4%. Those with no religion or where religion is not stated account for approximately 27.1% in 2011 up from 22% in 2001.

## **Socio-economic status**

Although Leicester's BSA population, as one entity, is not concentrated in the most deprived areas of the city, this conceals the considerable deprivation experienced by the British Pakistani and Bangladeshi populations (Leicester City Council 2008). The city was ranked the 20<sup>th</sup> most deprived local authority region in England in 2007. Employment rates are one indicator of deprivation. Before the recent economic depression, in 2002-3 BW people had an employment rate of 76.3%, compared to British Indians of 68.5% and Pakistanis and Bangladeshis of just 42.4% (Leicester City Council, 2008).

## **Language**

Estimates from the UK 2011 census suggest that 8% of the population have a foreign main language and 2% do not speak English well (Jivraj, 2013). There remains a lack of reliable language data both at national and at local level (The National Centre for Languages (CILT), 2012).

In 1998 it was estimated that "approximately 23% of immigrants to Britain born in China, Bangladesh, India and Pakistan had no functional skill in English, and 70% could not function fully in an English speaking social environment" (Free & McKee 1998). First generation migrants to the UK, in particular the elderly, were much less likely to understand English in an ethnographic study in the northern city of Sheffield, and younger people who lacked competence in English were often first generation immigrants (Gerrish, 2001). Unsurprisingly, given the compulsory education for children in the UK, those migrants educated in this country were more likely to speak English (Modood, 1998).

The most recent data available for Leicester indicates 72% of people preferred English as their main language, 11.5% Gujarati, 2.4% Punjabi and 1.1% Urdu, 0.6% Bengali and 0.3% Hindi (Leicester City Council, 2011). Of interest is a local hospital Trust audit which provides a snapshot of requests for interpreting skills by patients in the first month of a revised interpreting service. Most requests (30%) were for Gujarati translation, 12% for both Polish and Slovak, 10% for Punjabi with Hindi accounted for 3% (University Hospitals of Leicester NHS Trust, 2011). Many BSA people are multi lingual.

In healthcare settings, language barriers inhibit free expression of concerns, risking isolation from the therapeutic relationship. Patients may rely on family members to translate although this is contrary to good practice. This results in a lack of confidentiality for the patient and possible inaccurate understanding. In addition, in cultures where familial rather than patient decision-making is common, reliance on translation from within the family can, at worst, leave the individual without a voice and with a flawed understanding of their condition. However at best, familial translation can ensure a supportive environment for a family member in distress.

To acquire more reliable information about linguistics the Department of Health pressed for questions to be incorporated into the 2011 census, including English proficiency (ONS, 2009b). Preliminary results indicate that 4.3% of households in England and Wales have no person who speaks English as their first language (English/Welsh in Wales). This applies to 17.8% of Leicester

households and 1.9% in Leicestershire (ONS, 2012e). More detailed results have yet to be published.

## **Literacy**

There is even less national literacy data than language data in the UK. In 2000, based on 1994 data via the Second Health and Lifestyles Survey it was estimated that of 927,463 living in Leicester and Leicestershire over 11,128 (1.2%) had literacy difficulties (Johnson et al. 2000). This is probably an underestimate given that one in five UK adults would struggle to read a medicine label (Jamal & Dugdale, 2010).

Indian languages are largely spoken not written due largely to formal education being minimal in rural, largely agricultural, regions of India. In Leicester (2008) 68% of White, Pakistani and Bangladeshi people had low literacy skills (Leicester City Council, 2008). NHS information leaflets are produced in English and other selected languages but for some they will be of limited use. Furthermore, low proficiency in English and poor health literacy levels can compromise health outcomes. They were implicated in poorer control of diabetes among Spanish-speaking patients in the USA and poorer control of asthma among newcomers to Canada (Schillinger et al. 2002; Poureslami et al. 2011). A better understanding of population literacy is required for health service planning.

#### **1.4 Pilot studies**

Two pilot studies preceded this study. The first considered the information needs of Asian and White British cancer patients and their families (Muthu Kumar et al. 2004). Of particular interest was that Asian patients preferred to receive information from their general practitioner (GP) in contrast to White British patients (Asian 66.2 v White British 5.1  $p=0.001$ ). It was thought that this was because Asian patients preferred to discuss their illness in their mother tongue.

A second study compared how Asian and White Caucasian patients coped with cancer (Roy et al. 2005). Asian patients were significantly more fatalistic ( $p=0.0001$ ) and felt more hopeless and helpless ( $p=0.007$ ). Furthermore, when asked to comment on the MAC indicator of denial, "I don't really believe I have cancer", more Asians agreed ( $p=0.019$ ). Since these coping strategies risk anxiety and depression the authors hypothesised that Asians were more at risk than Caucasians.

Asian patients did indeed self report higher levels of depressive symptoms (HADS D  $\geq 10$  BSA 20.7% v BW 10.4% ( $p=0.001$ )) although not symptoms of anxiety ( $p=0.257$ ). It was further noted that there was little ethnic difference in 'fighting spirit' ( $p=0.179$ ) or anxiety preoccupation ( $p=0.14$ ). The current study sought to verify these findings and to explore whether there were changes in the use of coping strategies and of psychological outcomes longitudinally.

## **1.5 Purpose of the study**

The purpose of this study was to learn more about the needs of BSA cancer patients by determining how BSA and BW cancer patients coped following presentation at a UK Cancer Centre. It considered the extent to which there were ethnic differences in the use of coping strategies and how cancer was interpreted. In addition, it was postulated that environmental factors such as cancer knowledge and beliefs, trust in the patient/physician relationship and symptom burden were associated with symptoms of anxiety and depression. The study was clinically focused referring to both psycho oncology and ethnicity research.

## **1.6 Research questions**

- 1) To what extent did the reporting of symptoms of anxiety and depression differ between BSA and BW cancer patients who were referred to the Leicestershire Cancer Centre during the first nine months?
  
- 2) Why might local BSA cancer patients be more at risk of developing the aforementioned symptoms? The question is sub-divided;
  - a) Did ethnic groups differ in their use of potentially maladaptive coping strategies and to what extent were they associated with anxiety or depression?
  
  - b) Did ethnic groups differ in reports of physical, emotional and socio- economic problems which caused distress? If so, were they implicated in patterns of anxiety or depression?

- c) Were there ethnic differences in perceptions of cancer and were they implicated in how patients cope?
  
- d) Were any cancer beliefs and elements of patient-physician trust associated with ethnic differences in anxiety or depression?

## **Section 2: Literature review**

### **2.1 Search strategy**

A preliminary search was carried out in 2007 via medline, pubmed, cinahl, psycINFO, psycARTICLE, social science citation and science citation indexes, 1980-2007. The date range was wider to identify seminal works relating to psychological coping (1970+) and migration (1946+). An extensive variety of terms were used to cover the subject under study. For example, literature concerning recruitment of BSA patients to research used terms inclusive of 'patient selection', communication barriers', 'language', 'culture', 'attitudes, 'research', 'trials', 'ethnic minorities', 'ethnic', individual ethnic groups (eg Asian, South Asian, and Indian) and countries including UK, India, Pakistan, Canada and Australia. Reference lists from publications were scanned for additional articles and were followed up with particular focus on researchers known in the field. This was done in a more iterative manner.

In addition, USA and UK government websites were searched for details of national policies and statistics; for example, the UK Office for National Statistics. Local council reports, and articles from both national and local newspapers, were searched and texts relating to ethnicity, psycho-oncology and seminal works were consulted. Journal 'alerts' were arranged to highlight relevant articles as they were published. More thorough searches were carried out periodically to identify relevant works throughout the research period.

## **2.2 Prevalence of psychological morbidity**

This chapter considers the prevalence of anxiety and depression among sub groups of cancer patients in contrast to the general population providing perspective for this study.

### **Prevalence of anxiety and depression in general populations**

Globally over a 12 month period 9% of people are estimated to have a depressive episode and during their lifetime between 2.5-5% experience dysthymia for more than two years (Waraich et al. 2004). In the UK, regardless of the psychological classification, in any one year 1 in 4 adults will experience an episode of mental ill health (Singleton et al. 2001). For example, 6% of adults experience an episode of depression in one year and 15% of the population experience an episode during their lifetime (National Institute for Health and Clinical Excellence (NICE) 2011). Similar rates were reported in the USA population where the range for mood disturbances in one year was 9.5%. 6.7% of the population had a major depressive disorder, of which 2% had severe symptoms. 1.5% had dysthymia (National Institute of Mental Health, 2008). However, depression remains overlooked and under-identified. In Mitchell's meta-analysis of 118 studies reporting accuracy of unassisted diagnosis of depression by GPs, depression was correctly identified in only 47.3% of patients (Mitchell et al, 2009). The positive predictive value of the GPs' diagnosis was only 42% with a negative predictive value of 85.5%. These findings suggest that GPs often correctly identify persons who are not depressed.

Anxiety disorders in the general population were considered in a systematic review of English language publications between 1980 and 2004. The one year risk was 10.6% with a lifetime risk of 16.6% (Somers et al. 2006). More recently not inconsistent results were reported from a study of anxiety disorders across six European countries where 5-16% were anxious via the DSM IV criteria (Diagnostic & Statistical Manual of Mental Disorders IV) (n=7209). 1.5-13% had panic syndrome. As a subset of this study, within the UK general population 11.3% (n=100) of women and 8.4% of men (n=37) had anxiety disorders although the male sample was low (King et al. 2008).

There are no reports relating to the national prevalence rates of anxiety and depression in the Indian Sub-Continent. Two studies in rural Pakistan suggest far higher rates of common mental disorders (CMDs), particularly among women. Among 515 people assessed via the Brief Symptom Inventory and clinical interview, 46% of women and 15% of men suffered mental illness. A second study reported rates of 66% of women and 25% of men (n=664) (Patel & Kleinman, 2003).

### **Prevalence of anxiety and depression among ethnic minorities**

There are no national figures in the UK relating to the prevalence of mental illness among ethnic minorities. In a European study higher levels of depressive symptoms among ethnic minorities were present than in host populations in 19 out of 23 countries. Six were statistically significant using an 8-item version of the Center for Epidemiologic Studies-Depression scale (Radloff, 1977, Missinne & Bracke 2012). This was certainly the case in the

subset of UK studies (patient n=1740) where the mean depression score for the general public was 5.58 (0-24) with ethnic minorities (n=111) having a higher score of 6.3 (Missinne & Bracke, 2012).

The Ethnic Minority Psychiatric Illness Rates (EMPIRIC) in England found 15% of ethnic minorities experienced anxiety and depression in community settings which is a similar figure to the UK adult population (Sproston & Nazroo, 2002). However, this figure conceals variations. Higher figures were reported among elderly BSA people in Bradford where 20% (n=213) suffered depression as diagnosed by a BSA psychiatrist as a researcher (Bhatnager & Frank, 1997). Even higher figures of CMDs were reported among Indian women attending a general practice in London (30%, n=100) (Jacob et al. 1998).

Differences in depression rates among ethnic groups within the BSA populations exist suggesting that generalising prevalence figures for 'ethnic minorities' is an oversimplification. Significantly higher incidence of CMDs were found among 35-54 year old Pakistani men (12.6%, n=289) than White men 11.6% (n=360) and higher percentage cases of CMDs were detected among Indian and Pakistani women, particularly aged between 55-74 compared to White counterparts (Indian 23.8%,n=329, Pakistani 26% (n= 435), White,19% (n=477) (Weich et al. 2004).

With a shortage of consistent results in the UK, research findings in the USA were considered. However there was a lack of evidence relating to the national prevalence of mental disorders in ethnic minorities (U.S. Department of Health

and Human Services, 1999). Publications tend towards considering the impact of demographic, social and cultural influences associated with mental disorders rather than generating broad national prevalence data. Findings often appeared contradictory, as in the UK. Non-Black Hispanics were reported to be 40% less likely and Hispanics 20% less likely than non-Hispanic Whites to experience mood disturbances during their lifetime, (NIMN). The reverse was reported in another US study with higher estimated rates of lifetime MDD among African Americans 56.5% (n=3570) and Caribbean Blacks 56% (n=1621), in contrast to Non Hispanic Whites 38.6% (n=891) (Williams et al. 2007). Fewer than 45% of African Americans and 24.3% of Black Caribbeans met the criteria for MDD therapy despite the fact that they reported more severe symptoms than Non-Hispanic Whites.

However, lower rates of depression were present in migrants in a community study in the UK, except for people originating from Pakistan. A notable exception was among those speaking fluent English where rates were the same as among host nationals (Nazroo,1997). One explanation for this inconsistency has been attributed to the psychological impact of migration and acculturation. Pre-migration trauma including forced expulsion from one's homeland, as in the case of the Ugandan Asians, culture shock, conflict with host individuals, cultural and social isolation and discrepancy between achievement and expectations in a host country can place a migrant at increased risk of mental ill health (Bhugra & Ayonrinde, 2004). Bhugra cites historical studies which observed a higher prevalence of mental ill health among migrant students than host students. It has been suggested that the mixed results for the prevalence

of depression in ethnic minorities were due to the different times along the migratory pathway at which the data was collected, reflecting the extent to which individuals and generations adapted to their new environment (Bhugra & Ayonrinde, 2004). There is a plethora of other factors influencing prevalence rates including socio-economic status, gender and age.

### **Prevalence of anxiety and depression among cancer patients**

The prevalence rates cited for anxiety and depression among cancer patients varies widely but generally they are believed to be higher than in the general population (Massie, 2004; Hinz et al. 2010). Reported prevalence for MDD ranges from 3-38% and broader depressive conditions between 1.5-52% (Kissane et al, 2011). Recently 10-30% of cancer patients were thought to develop anxiety disorders (Levin & Alici, 2010) and one specifically related to the UK reported 3-16% (Jenkins et al. 1998). A rate, much higher than in the general population, was reported for symptoms of anxiety in a cross-section of UK cancer patients who were asked to respond to a touch screen questionnaire using the State-Trait Anxiety Inventory and the HADS (48%, n=178) (Stark et al. 2002).

Of interest is a recent meta-analysis of 70 studies across 14 countries which included 10,071 individuals in oncological, haematological and palliative care settings (Mitchell et al. 2011a). This suggested that interview-defined anxiety and depression is at the lower end of the reported ranges. Via the DSM IV criteria, 16.3% (CI 95%:13.4–19.5) cancer patients were affected by depression with 14.9% having major depression (CI:12.2-17.7). This is two to four times

the prevalence seen in the general population using equivalent criteria (Hinz et al. 2010). 19.2% (9.1—31.9) had minor depression. In addition the prevalence of adjustment disorder was 19.4% (14.5—24.8) anxiety was 10.3% and dysthymia 2.7% (1.7—4.0). There was little difference in prevalence of depression between palliative or non-palliative settings. Even with the lower prevalence the authors calculated that 340,000 people with cancer in the UK had major depression (Mitchell et al. 2011a).

In India and Pakistan, cancer services are far from comprehensive. Currently the focus of clinicians is on promoting longevity. Quality of life is arguably of lesser importance. Psychological care is therefore under researched (Patel et al, 2003; Pandey, 2004). Some studies among these host populations have been published. For example via HADS $\geq$ 11, which was translated and validated in Malayalam, 8% (n= 240) of patients, receiving treatment with curative intent in Thiruvananthapuram, India, had symptoms of severe anxiety and 11% had borderline mood disturbances. Those with severe depressive symptoms accounted for 7.6% and 13% with mood disturbances (Thomas et al. 2005). Using the same methodology, a further study among 117 patients having chemotherapy for a cross-section of malignancies in India, 18(15.4%) had severe anxiety and 19(16.2%) severe depressive symptoms (Pandey et al. 2006).

At lower HADS threshold scores, inclusive of those with borderline symptoms, 100 patients in Bangalore were assessed pre and post-radiotherapy. At initial consultation 42% were depressed (HADS D  $\geq$ 8) and 46% anxious (HADS A  $\geq$ 7).

Anxiety rose markedly just prior to commencing treatment at 64% (n=51) with 50% being depressed. Immediately post treatment these figures decreased (anxious 47%; depressed 44% (n= 57) (Chaturvedi et al. 1996a).

Studies in Pakistan suggest similarly high symptom scores for anxiety and depression. 43.3% (HADS A  $\geq$ 7) of outpatients having chemotherapy in Faisalabad Pakistan, had symptoms of anxiety and 61.6% had depressive symptoms (HADS D  $\geq$ 7) n=60 (Dogar et al. 2009). Not dissimilar figures were reported among cancer outpatients at Multan, Pakistan using a self-administered 25 item assessment tool (AKUADS) where 66% (n=150) of cancer patients had anxiety or depression versus 40.7% (n=268) in a control group without cancer (Jadoon et al. 2010). We can postulate that these patients are more vulnerable to developing symptoms of anxiety and depression than in the UK but the findings are not universal enough to represent whole populations.

### **Prevalence of anxiety and depression among ethnic minority cancer patients**

There are few studies reporting the incidence of depression among cancer patients within ethnic minorities and even fewer concerning anxiety. Among 472 low income ethnic minority women in the US with early stage breast cancer, 30% were depressed. Depression affected 17% of women with gynaecological cancers (Eil et al. 2005). Within the local BSA cancer population there was an incidence of 20.7% (HADS D  $\geq$ 11), this being significantly higher than among Caucasians (10.4% p=0.001) (Roy et al. 2005). US Hispanic patients too were found to be significantly more distressed (p=0.0001) and depressed (p=0.041)

than those from the majority population in a meta-analysis of twenty one articles. Curiously the ethnic difference was not detected among minorities described as Asian, Pacific Islander or Hungarian (Luckett et al. 2011). The analysis was limited by minimal studies from outside the USA, a lack of data for non-Hispanic groups and few studies relating to anxiety.

Further evidence of differences between host and ethnic minorities was observed when examining predictors of health-related quality of life in the US (HRQOL). Bivariate analysis found that Latino breast cancer patients (n=183) had a lower HRQOL than patients from the majority population (n=179)  $p=0.0001$ ) (Ashing-Giwa et al. 2007). More distress was also present among ethnic minorities with cancer in Canada (E and SE Asian, South Asian, Aboriginal, 'other' n=852) in comparison to the majority population (European, Canadian, British, n=2170,  $p=0.0001$ ). Greater distress was also found among those with lower income ( $p=0.001$ ) (Carlson et al. 2004). A recurring comment in publications is the need to acknowledge that socio-demographic factors are complex and researchers should differentiate each one to clarify their relative influence on health outcomes.

### **Prevalence of anxiety and depression by cancer type**

The type of cancer appears to affect the prevalence of psychological morbidity. Patients with pancreatic cancer, with its poor prognosis, are often cited as having the highest risk of depression, up to 50% being reported (Makrilia et al. 2009). Lung cancer is also associated with depression. At various points along the cancer trajectory, in a systematic review over 35 years, between 11%

and 44% of lung cancer patients were depressed (Montazeri et al. 1998; Buccheri,1998). In contrast, several studies suggest fewer depressive symptoms among patients with prostate cancer, colon and lymphoma (Massie 2004; Admiraal et al. 2012). The differences in psychological morbidity across cancer types is demonstrated in a Canadian cancer centre which used HADS to triage 3035 new patients for psychological assessment (threshold  $\geq 10$ ). 25.7% of the sample self-reported symptoms of anxiety and depression. Of these 40.8% had lung cancer but only 14.3% had prostate cancer (Sellick & Edwardson, 2007). Other studies report similar trends (Zabora et al. 2001; Salvo et al. 2012).

There remains an incomplete map of longitudinal patterns of psychological morbidity by cancer types. Lung and breast cancer are briefly considered here. In two UK studies lung cancer patients appeared to become more anxious and depressed over time. At diagnosis 11% of Scottish lung cancer patients (n=129) had symptoms of depression and 6% borderline anxiety (HADS $\geq 7$ ). By three months (n=96) this had increased to 22% and 11% respectively. Of patients who initially self-reported the most severe symptoms, (HADS $\geq 11$ ), depression 10 (12%); anxiety 8(10%), there was an increase of 10% of those with depressive symptoms with a reduction of 1% in anxiety scores (Montazeri et al. 1998). Similarly among 987 English patients with lung cancer 33% (HADS D  $\geq 8$ ) had depressive symptoms before treatment (n=322). Post treatment this increased to 121/206 (58%) (Hopwood & Stephens, 2000).

Of particular interest to this study with its cohort of breast cancer patients (n=114), are the longitudinal patterns of anxiety and depression which appear to decrease over time. Breast cancer is associated with improving survival rates and a prominent and positive media profile but whether these factors affect the following results is unclear.

In a five year study of breast cancer patients diagnosed at an early stage (n=170) 50% had anxiety, depression or both in the year after diagnosis. This fell to 25% in the second, third and fourth years and was 15% by year five, similar to that in the general population (Burgess et al. 2005). These results support findings in a recent paper considering prevalence rates in 39 longitudinal studies of breast cancer patients. Post treatment prevalence rates for depression were up to 30% with a range of between 21-48% during the six months post treatment. The range decreased to between 21-34 % in the year following the end of treatment. In those studies considering borderline depression there was a rate of 23% between one and two years post treatment and 15-32% between two and five years. Symptoms of anxiety during the first six months post treatment was 45-48%. Although there was fewer studies considering anxiety after that period, rates of 23% were reported one to two years post treatment and were similar to rates in the general population between two to five years (15%) (Harrington et al. 2010).

Broad prevalence figures are simplistic. Methodological differences across publications contribute to the wide variety of statistics reported in various populations. Furthermore, rates do not reflect the impact of multi-dimensional

factors along the cancer pathway from the patient's perspective. Nevertheless prevalence figures provide background perspective to this study.

### **2.3 Coping theory**

The literature related to coping psychology is wide ranging. The nature of coping processes, the influence of demographic factors and psychological outcomes have been studied and measurement tools designed and validated, but there remains continuing debate about whether coping strategies can be clearly classified as either adaptive or maladaptive. Clarity on this issue would result in greater confidence in identifying and assessing individuals at risk of developing psychological morbidity. This section considers the concept of 'coping' with reference to cancer patients.

'Coping' is a multi-dimensional mechanism or process in which the individual evaluates whether a stress, such as a diagnosis of cancer, is a threat to the self and then 'considers' coping options. The appraisal processes include the individual's thoughts, behaviours and emotions, together with the identification of tasks to be undertaken and the coping strategies to be employed.

#### **The psycho-analytic tradition**

The study of coping evolved from psycho-analytic ego psychology with its roots in Freudian theory. This theory concentrates on maladaptive coping or 'defence' with an emphasis on diagnosing specific stable personality traits, which predispose individuals to develop mental illness. For example, repression is regarded as an antecedent to hysterical neuroses and denial to

anxiety and depression (Lazarus,1993). There remains debate about whether these internal psychological characteristics are conscious or unconscious, with psychoanalysts believing them to be largely automatic and unconscious while later theorists such as Lazarus and Folkman considered them to be both (Haan, 1969, Vaillant, 1979; Lazarus et al,1984). A purist psychoanalytical interpretation of this approach reserves the word 'coping' for adaptive behaviours only. This perspective was challenged during the 1970's (Lazarus et al,1984).

### **Transactional model of stress and coping**

The Transactional Model of Stress and Coping developed through debate about whether 'coping' was purely dictated by 'personality traits or dispositions' or were, in addition, shaped by different stressful situations and over time. Lazarus and Folkman, originators of this theory, defined 'coping' as "a process of thoughts and behaviours that people use to manage the internal and external demands of situations that are appraised" (Lazarus et al, 1984). Hence an individual's traits are considered within the context of their environment rather than in isolation. The external environmental context for an individual with cancer 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 (Moos & Holahan, 2003). Cancer-related influences include the type and stage of disease. Psychoanalysts argue that whatever environmental factors exist, an individual will be strongly influenced by their dominant personality traits,

beneficial or not; traits being regarded as having a stronger influence on coping outcomes than environmental factors (Brennan, 2001).

The current trend considers personality traits within the environmental context – ‘an integrated framework’ (Moos & Holahan, 2003). For the purposes of this study ‘coping’ describes both adaptive and maladaptive psychological processes within this framework (Salander & Windahl, 1999).

### **Classifications**

There remains a lack of consensus about both coping terminology (styles /strategies/skills) and the classification of coping strategies. One commonly used classification concentrates on coping responses or skills from a contextual perspective (Folkman & Lazarus, 1980). Problem-focused coping describes methods for confronting the problem with the aim of reducing the cause of the stress, for example seeking information and support. Emotion-focused coping allows the individual to change the way they think about a stress, for example, by restructuring it into a more positive form.

A second perspective is that of Roth and Cohen’s ‘Approach versus Avoidance’ classification which combines the contextual and trait perspectives into four types of coping response, cognitive approach, behavioural approach, cognitive avoidance, behavioural avoidance (Roth & Cohen, 1986).

The two avoidant strategies “focus attention away from either the source of stress or away from one’s psychological/somatic reactions to the stress” (Suls &

Fletcher, 1985). More specifically behavioural avoidance - “a conscious or unconscious defence mechanism through which a person responds to a threat by actions to escape” includes actions of disengagement such as displacement, distraction, venting emotions, risky behaviours such as drug and alcohol abuse, and seeking alternative rewards (Sykes, 1982). Cognitive avoidance are thoughts related to wanting to escape, and refers to mental disengagement strategies such as avoidance, minimization, alexithymia and repression. Cognitive and behavioural avoidance are interlinked as an individual appraises and responds to a stressor.

Attempts to classify coping strategies as either adaptive or maladaptive as a means of diagnosing whether an individual requires psychological intervention is a focus for researchers. Lazarus was pragmatic in proposing that there may be no positive or negative coping strategies, only those that are helpful or unhelpful (Lazarus, 1983). Strategies should be assessed in terms of the costs and benefits to the individual within their internal and external environments. Psychoanalysts, in contrast, regard behavioural avoidance as automatically maladaptive requiring intervention (Dunkel-Schetter et al. 1992; Gass & Chang, 1989).

### **Clinical perspective**

From a clinical perspective psycho-oncologists tend towards pragmatism. An individual’s dominant personality traits, together with influencing environment factors related to a specific stress, are assessed at a point in time, for example,

at initial diagnosis or recurrence of disease. Studies demonstrate that coping changes longitudinally as people respond to different stages of the cancer journey and different types of stress (Brennan, 2012; Paradis, 2012). The psychological impact on an individual may therefore need assessment at different points in time. Intervention is required if a patient continues to use a strategy which prevents them from appreciating their true feelings or results in them acting in a manner which is self harming (Lazarus, 1993). For example, not attending hospital appointments for curative treatment to avoid stress associated with experiencing its unpleasant side effects.

Although the greater body of work associates avoidant coping strategies with poorer psychological outcomes, contradictory findings indicate an incomplete understanding of coping processes in action. Given the theories that coping strategies change longitudinally, between different types of stress and are strongly influenced by a raft of environmental influences, this is perhaps not surprising.

## **2.4 Coping strategies and associations with anxiety and depression**

### **2.41 Hopelessness/helplessness**

Hopelessness is widely regarded as a negative cognitive (attribution) style or personality 'trait' and is implicated as a causal risk factor for depression, although the two are distinct concepts (Beck et al. 1985; Grassi et al. 2010). It is closely affiliated with helplessness where the individual holds 'unrealistically low concepts of their own capabilities' (Beck et al. 1985). A person who has a

helpless/hopeless trait misinterprets reality producing a negative view of themselves, the future and their environment (the cognitive triad) (Beck et al. 1985). They believe that bad things will inevitably happen to them and that the outcome will invariably be poor. Beck postulated that a personality trait resurfaces if triggered by a stressful event leaving the individual vulnerable to developing depressive symptoms. When diagnosed with cancer, instead of regarding the event in isolation, these individuals believe that there is nothing they can do about their condition and/or that the future outcome is inevitably fatal. They may also develop a negative attitude towards the medical environment, for example, believing that the suggested treatment will not work for them. The theory suggests that just one of these three attributes needs to be interpreted negatively for an individual to develop symptoms of hopeless depression such as guilt, low self esteem, fatigue, sadness and feelings of worthlessness. This forms the foundation for the cognitive theories of helplessness on which cognitive behavioural therapies are based.

Building on Beck's work that hopelessness and depression were distinct, Abramson developed the Hopelessness Theory of Depression (Abramson et al, 1989). This focused on *how* the individual explains negative events. For example, "Everything bad happens to me, it's all I can expect" or "I've brought this on myself".

It would be a mistake to consider possession of a 'negative attribute cognitive style' as the sole antecedent to hopelessness depression. Abramson points to other factors such as genetics, demographics and the extent of social support

(Abramson et al, 1989). For example research has examined whether helplessness is associated with increased cortisol levels which can negatively affect neuropsychological functioning leading to a vulnerability to depression (Henkel et al. 2002).

### **Helplessness/hopelessness and depression**

This trait is an acknowledged predictor of depression and anxiety among cancer patients across nationalities, cancer types and longitudinally. Its relationship to depression is so close it has been referred to as a surrogate. Among 365 Canadian patients with gastro intestinal or lung cancers, helplessness/hopelessness were predictors of depressive symptoms using the Beck Hopelessness Scale and Beck Depression Inventory-II (Beck et al. 1974; Beck et al, 1996; Lo et al. 2010). Similar results were generated among randomly selected post operative breast cancer patients in Japan where it was one of four determinants of psychiatric morbidity (n=148; HADS  $\geq 10$ ). In those who had depressive symptoms the mean helpless/hopeless score was significantly higher than among those with no evidence of symptoms (symptomatic (n=34) mean helpless/hopeless score 11.2; asymptomatic (n=114) mean helpless/hopeless score 7.9 p=0.0001) (Akechi et al. 2001).

Further evidence was observed in 312 European nationals representing a cross section of cancer types with helplessness/hopelessness explaining 30% of the variance in depressive symptoms (HADS D; threshold greater than 11) (Grassi et al. 2010). Other findings among Australians with breast cancer and Swedes

with laryngeal cancer add further evidence of the close link with depressive symptoms (Osborne et al. 1999, Johansson et al, 2011).

Initial helplessness/hopelessness predicts depression longitudinally. Scores at zero months predicted the maintenance of depressive symptoms at four months in a small study of 67 American women after diagnosis of recurrent disease (BHS/Center for epidemiological studies depression (CES-D cutoff 16) (Brothers & Andersen, 2009). This is consistent with findings among a Norwegian sample of women with early stage breast cancer. Pessimists who demonstrated a helpless/hopeless coping style when diagnosed with breast cancer, had a three times greater risk of experiencing depression one year after breast cancer surgery, than pessimists who were not (n=245) (Life Orientation Test (LOT-R  $\geq 18$ ) HADS D  $\geq 8$  (Schou et al. 2004). In a far larger study among 1323 adult cancer survivors in Australia, being helpless/hopeless at diagnosis placed individuals at two to five times more likely to become depressed (Boyes et al. 2011).

### **Helplessness/hopelessness and anxiety**

This trait is strongly associated with symptoms of anxiety. Boyes reported these patients were two to eight times more likely to be anxious at six months. Another Australian study among a ethnic cross section of 731 cancer patients concurred having been corrected for age, education, country of birth and stage of disease (HADS A  $\geq 8$  adjusted OR 1.41 (1.31–1.52) (Osborne et al, 2003). The same association was detected in a European study (n=312; r=0.51

$p=0.001$ ) (Grassi et al. 2010) and among Swedes with laryngeal cancer ( $N=95$ ) (Johansson et al, 2011).

## **2.42 Cancer fatalism**

Fatalism is the belief that all events are predetermined and therefore inevitably fatal. When applied to cancer it offers no opportunity for the patient to alter or influence the fact that death is inevitable (Powe & Finnie, 2003). This chapter considers cancer fatalism, its antecedents and health outcomes.

Cancer fatalism is generally regarded as being psychologically damaging, prompting behaviour such as disengagement from health care, avoiding medical information, surrendering the role in decision making or refusing the option of treatment altogether (Livneh, 2000).

### **Antecedents**

The antecedents to cancer fatalism are multi dimensional and include socio-economic factors, age and being a member of an ethnic minority (Lannin et al. 1998; Facione et al. 2002).

Poverty invites a fatalistic outlook since individuals have a day-to-day struggle with finance, substandard living conditions and unemployment (Lannin et al. 1998; Straughan & Seow, 1998). A lack of education is also implicated and can affect any ethnic group (Freeman 1989, Facione et al. 2002, Osborne et al, 2003). It existed among poor white Floridians in the USA, where lower levels of education were a major factor in their cancer fatalism (Barroso et al. 2000), and

among those living in India (Kishore et al. 2007). In computer based interviews of 2018 adults representative of the UK population, it was socio-economic status that was influential. Those in lower skilled jobs were more likely to feel too frightened to see their GP with symptoms they associated with cancer (14%) than those in managerial positions (6%) (Beeken et al.2011). Similarly, individuals in less skilled jobs doubted the value of early detection of cancer and in a Cardiff survey 26% of 4,200 smokers continued to smoke, in part due to their fatalistic attitude (Lewis et al. 1989).

Since ethnic minorities often have lower average socio-economic status than host populations there may be undue emphasis on ethnicity as a precondition for being fatalistic. Cancer fatalism is also present in host populations (Lannin et al. 1998; Nelson et al, 2002). Nevertheless, the inevitability of death was a theme among the Bangladeshi population living in London, where attitudes towards cancer were explored through focus groups.

*“Cancer is invariably fatal. If you have it you will die, that’s certain, It’s always fatal”* (Dein 2005, p149).

In addition, South Asians living in Luton perceived cancer as an incurable or a ‘terminal’ disease. Chattoo, cited by Randhawa, pointed to “the stigma, bleakness and hopelessness associated with cancer” among South Asians patients with advanced cancer (Chattoo et al. 2002, Randhawa & Owens, 2004). In Leicestershire cancer fatalism was reported to be more common among BSA cancer patients than Caucasians (84.9%v 50.4%, p=0.0001). (Data about the socio-economic status of participants was not collected) (Roy et al. 2005).

Cancer fatalism exists in other ethnic minorities. Among self identified 'Non-Hispanic White' Americans (n=6369) 27% were fatalistic about cancer prevention, agreeing that "*there's not much people can do to lower their chances of getting cancer*" (Niederdeppe & Levy 2007). Similarly in the Canadian South Asian population a study of first generation immigrants from the Indian sub-continent found that only 5% believed that cancer could be cured (Choudhry et al. 1998).

Being older with lower average educational levels affects the incidence of cancer fatalism. For example, older and less educated African Americans displayed higher fatalism than the general population (Powe et al, 2006). Many will have 'learnt' to be fatalistic having lived when medicine had less to offer. In addition, racial and financial discrimination have influenced attitudes towards health care in this US minority population. These factors can make accessing health care difficult and risk omission of screening activities (Freeman, 1989).

### **Health outcomes**

When entrenched, fatalism has been described as the 'surrender of the human spirit to perceptions of pessimism, hopelessness, worthlessness and social despair' (Powe, 1997). It is associated with several maladaptive behaviours predicting low colorectal cancer screening uptake among 60-69 years old adults in England (n=529) (Miles et al, 2011) and also contributed to the late presentation of cancer symptoms (Powe & Johnson 1995; Szczepura et al. 2008). In an Indian study 48% of those with cancer held fatalistic views. There was an associated average delay of 2 years in presenting symptoms of cancer

as a consequence (Kishore et al. 2007). Fatalism was also a theme behind a refusal to accept treatment for lung cancer in a qualitative study in the USA (Sharf et al. 2005).

There are associations between fatalism, poorer adjustment to diagnoses and increased rates of distress and depression (Heim et al. 1997, Carver et al. 1993). 70% of Indian head and neck cancer patients (n=50) used helplessness and fatalism to cope. Both were associated with anxiety and depression via HADS  $\geq 7$  (Chaturvedi et al. 1996b). Similar findings were reported in Japan (HADS  $\geq 10$ ) (Akechi et al. 2001).

Although anxiety was associated with cancer fatalism in one study (Schou et al. 2004) no links was found between fatalism (or helplessness, anxiety pre occupation) with negative emotional function in men diagnosed with prostate cancer (Bjorck et al,1999). One explanation for this may be that some patients can survive for many years giving time for adaptive coping to take place (p 204).

Encouragingly individuals who hold fatalistic health beliefs are not necessarily fixed into disengagement strategies. They can adapt. A lack of control over one's life has the potential to be adaptive within spiritual coping through positive reframing (Pargament et al. 2004). Religious observations and developing a network of contacts for social support were activities by which African Americans coped and lessened distress when faced with an uncontrolled life situation (Morgan et al. 2008). Fatalistic participants in a UK qualitative study were also described as being able to move towards using more positive coping

strategies such as positive thinking and endurance, to manage ill health (Bolam et al. 2003).

### **2.43 Denial and its domains**

There is a lack of consensus about the nature and clinical significance of denial. It has no universally accepted definition (Moyer et al.1998; Salander & Windahl 1999; Vos & de Haes 2007). The concept attracts attention because individuals who 'deny' reality are thought to risk anxiety and depression (Lazarus, 1993). This section reviews the dominant theoretical interpretations and prevalence of denial and its associated domains, such as avoidance. The use of the term 'denial' in clinical settings and health outcomes is described.

One's preferred interpretation of denial reflects a philosophical affiliation to either the dispositional or contextual theoretical framework. Denial, from a dispositional viewpoint, can be defined as "an unconscious defence mechanism characterised by refusal to acknowledge painful realities, thoughts or feelings" (Mitchell, 2007). A definition combining both traditions is "the conscious or unconscious repudiation of part or all of the total available meaning of an event to allay fear, anxiety or other unpleasant affects" (Weisman & Hacker, 1961 cited in Hackett & Cassem, 1974).

It is, however, the way that denial has been 'operationalised' which has been the focus of criticism from psychoanalytic psychologists rather than a search for an accepted definition. It is argued that it has become "over inclusive of both psychotic and normal processes" preventing the use of more accurate

terminology to describe psychological behaviours (Janis, 1958, cited in Vos & de Haes, 2007). For researchers the terms frequently overlap and the same domain is referred to by different terms across publications. This is one explanation for apparent contradictory findings.

True denial, - “the psychotic repudiation of reality” as interpreted by the psychoanalytical tradition, is rare (Carver et al. 1993). The term tends to include other distinct domains such as avoidance, minimization, alexithymia and disavowal. Greater distinction between them has long been sought (Rabinowitz & Peirson, 2006). For example, over fifty years ago Janis pressed for the term ‘minimization’ to be used rather than ‘denial’ to describe the response when an individual either inwardly or outwardly understates the probability of getting bad news at a medical consultation (Janis, 1958). Associated with minimization are the domains of repression and suppression where there is a conscious minimization of emotional complications alone without cognitive denial, for example “I know I have this disease but I don’t want to keep worrying about it” (Mitchell, 2007). Likewise alexithymia describes individuals “who have difficulty articulating any emotion” when they are, in fact, “experiencing it internally” (Newton & Contrada, 1994). An individual may worry about cancer but show few signs of concern to their family with whom they may decline to discuss the issue. They do not deny to themselves (Mitchell, 2007).

Criticism of the merging of terms is not confined to those from the psychoanalytic tradition since Lazarus pressed for ‘avoidance’ to be regarded

as distinct (Lazarus, 1981). He proposed that if a person prefers not to think or talk about their terminal illness but is aware of it; 'avoidance' is the accurate term to use. It can be sub-divided into cognitive avoidance, 'thoughts related to wanting to escape from a stressor' and behavioural avoidance, 'actions to escape from unpleasant situations or feelings'. Both can be either a conscious or unconscious defence mechanism. However, the terms are frequently blurred in a number of studies which illustrate co-existence between avoidance coping and distress (Carver et al. 1993).

Early studies interpreted denial as a damaging personality trait requiring psychiatric treatment (Freud, 1961; Goldbeck, 1997; Jarvis, 2004). During the 20<sup>th</sup> Century the view of denial as inflexibly maladaptive in adults was reinterpreted, generating theories about cognition, stress and coping. This tradition regards denial as having potential to be adaptive if it "allows a graded acceptance of bad news"... but "maladaptive if it interferes with rational actions" (Horowitz, 1988). For example, it is considered appropriate behaviour if a man denies he has been told he has cancer immediately after the cancer diagnosis has been clearly explained to him since he is cognitively using the strategy for emergency use (Watson et al. 1984) but maladaptive if he later refuses life saving treatment based on the belief that he did not have cancer. When denial is continually used as a barrier to 'disrupt' reality testing or when it puts the person in danger, it is no longer of benefit to the person (Ersek, 1992).

Supporting the idea of the short term benefit of denial, Lazarus suggested that 'illusion is necessary to positive mental health' (Lazarus, 1981) and observed

that we live with illusions. For example, we may believe that being religiously observant will ensure a healthy and happy life but know this is not always the case. Lazarus suggested that this contradicts the use of reality testing methods embedded within the psychoanalytical tradition, as least for short term use.

### **Prevalence**

In the absence of a universally recognised definition of denial and a variety of classifications, precise information about its prevalence is not possible. A wide range of statistics is reported. Denial of cancer diagnosis ranged from 4 to 47%, denial of its impact 8-70%, and denial of affect 18-42% (Vos & de Haes, 2007). Adding to the uncertainty is that available figures suggest that denial may be under reported since, unless it is seen as interfering with treatment or is unnoticed or undetected, the condition is not recorded (Rabinowitz & Peirson, 2006). In spite of this, patterns of denial have been suggested. Vos pointed to one's cultural background. When comparing cancer patients living in Mumbai, India, with those living in London UK, a far higher percentage of patients denied having cancer in Mumbai, India (Mumbai 47%; London 4%). 43% of those in the Indian city denied the implications of cancer with 33% doing so in London (Vos & de Haes 2007; Chakravorty et al. 1993). However it is unclear whether some patients in Mumbai were informed of their diagnosis (see p 49)

In the few published longitudinal studies a gradual reduction in denial was found over the course of the illness. Among a study of cancer inpatients approximately 5-15% denied their illness but this reduced to 4% 6 months after diagnosis (Cannon et al, 2004).

## **Denial in clinical settings**

'In denial' is a phrase heard in clinical settings to describe individuals who appear not to acknowledge their diagnosis. They may minimise the implications of the disease, refuse or comply poorly with treatment regimens or appear detached from the challenges of coping with a chronic illness (Goldbeck, 1997).

The term, however, is frequently used in error.

- Individuals may not have understood information about their condition due to communication barriers, compromised cognition or by a clinician's use of euphemisms (Gattellari et al, 2001).
- Individuals may not have been informed. Collusion and paternalism occurs cross culturally in the UK inspite of 'informed consent' being UK law. In some countries it is the norm to expect a degree of paternalism (Chaturvedi, 2008). In those situations individuals with cancer are excluded from information about their condition. For example, in Mumbai, India, the husband or family member concealed the diagnosis of cervical cancer from two thirds of women (Muckaden et al. 2005; Chaturvedi et al, 2009). Other countries display similar trends (Chandra et al. 1998) (India); (Atesci et al. 2004) (Turkey); (Brokalaki et al. 2005) (Greece) and (Grassi et al. 2000) (N Italy).
- Individuals may interpret their situation differently to the clinician. A clinician may be aware of a patients' poor prognosis but the patient may interpret the chance of even short term survival as reason for optimism.

The clinician may 'label' the individual as 'denying' reality if an in-depth assessment is not carried out (Ersek, 1992).

- Individuals may not remember when shocked. 40-80% of medical information is forgotten immediately. Almost half the information given is remembered incorrectly (Kessels, 2003). Even when not distressed, recall can be less than 40% (Rimer et al. 1984).
- Individuals may select those with whom they wish to discuss their diagnosis. For example, they may display an apparent lack of concern to family members to protect them but converse with a friend, spiritual leader or financial advisor.

### **Antecedents to denial**

Traits and environment factors make some individuals more likely to use denial as a coping strategy. A history of poor mental health and a tendency to feel hopeless and helpless in the face of adversity are implicated (Taylor & Brown, 1988 cited in Ersek, 1992). A personal trait of denial means that an individual on hearing bad news, however well it is delivered, may reinterpret the information into an acceptable form (Gattellari et al, 2001).

High monitors, (those who seek information as a way of responding to stress), can use denial if some forms of information feed their anxiety to the extent that they use it to avoid panic (Miller et al. 1996). They demand more information but instead of this helping them gain psychological control over their situation, it

increases anxiety. They become less involved in their care without adapting to the situation (Wan Chan-Kuk 2000; Deimling et al. 2006).

Environmental factors affect the presence of denial. Cancer is interpreted differently among various ethnic minorities. The self sacrifice of women in maintaining the family honour and respect within the community is common in some cultures (Bottorff et al. 1998; Grewel et al, 2005; Gilbert et al, 2004; Anand & Cochrane, 2005). Being unable to fulfil one's family responsibilities due to ill health may induce denial of symptoms to maintain their role (Njoku et al, 2005). Denial is 'sanctioned' in some cultures (Butow et al, 2000 cited in Vos & de Haes, 2007). It was unclear whether this influenced the finding that local Leicester BSA patients had a higher incidence of denial than their White neighbours (Roy et al. 2005).

The need to adhere to cultural norms is common. Denzin studying alcoholics found that cultural disapproval of the condition was a stressor managed by sufferers through denial to "maintain a sense of control or power to fit into cultural norms" (Denzin,1987). Where blame is attached to the person due to their unhealthy living (LoConte et al. 2008) or through a negative interpretation of karma or fate, or of being associated with a lack of moral fibre (Latinos), denial may be used (Wheeler & Lord, 1999). Those stigmatised may disengage psychologically and to maintain a degree of self esteem, 'denial' may be observed (Njoku et al, 2005; Major & Schmader 1998; Conrad & Pacquiao, 2005).

## **Health outcomes**

There are contradictory findings concerning the psychological outcomes of avoidant coping strategies with publications reporting associations with both adaptive and maladaptive outcomes. Meta-analyses remain difficult due to the variety of research methods and tools used and the range of terminology uses (Vos & de Haes, 2007). There is a strong body of evidence suggesting that forms of avoidant coping are associated with poor outcomes.

## **Maladaptive outcomes**

Those who 'deny' are associated with *lower* anxiety than 'non deniers' although there are reports of higher anxiety when restricted to the domain of avoidance (Livneh, 2009).

Avoidant strategies are consistently associated with depression, distress and lower quality of life. For example, higher depression scores were reported in 49 older women post breast cancer surgery in comparison to 51 middle aged women (n=708) (Kelly et al. 2008). Furthermore, denial was associated with high rates of depression and cancer related worries in older adult cancer survivors (N=321) (Deimling et al. 2006). Of particular relevance to our study are results among Indian cancer patients in Mumbai. 89% (67/75) used forms of denial and there was significantly more psychological morbidity among the 62% (n=47) who delayed presenting symptoms for three months or more (Chakravorty et al. 1993).

Greater distress predicted avoidance among 117 women with breast cancer through pre-biopsy assessment of variables such as personality cognitive appraisal, coping and mood variables (Stanton & Snider, 1993). Distress was also associated with cognitive and behavioural escape-avoidance strategies in 20% of patients in California USA (n=603) (Dunkel-Schetter et al. 1992).

Other studies among cancer patients support this association (Miller et al. 1996). During the first year of illness low levels of denial and disengagement were observed among breast cancer patients but where present, there was evidence of greater distress (N= 59) (Carver et al. 1993). 'Negative psychological adjustment' affecting mood was also reported to be associated with avoidant coping in a meta-analysis of 3133 men with prostate cancer (Roesch et al. 2005).

### **Adaptive outcomes**

Although the weight of evidence points towards avoidant strategies being associated with maladaptive coping, there is evidence to the contrary.

Transient denial can be helpful and has been linked to less mood disturbance unless it persists, when it may place the patient at greater risk of increased distress. For example, in a small sample of 24 women undergoing primary surgery for breast cancer, those who denied the implications of their diagnosis at that time were, at least in the short term, likely to experience less mood disturbance as measured by POMs (Watson et al. 1984). In a literature review 'denying' had some benefit during the active phase of treatment for cancer. It was postulated that it is reasonable to use avoidance to cope with the side

effects (Glanz & Lerman, 1992; McCaul et al. 1999). The advantages of denial seem to be minimal and short term.

#### **2.44 Anxious preoccupation**

Individuals with anxious preoccupation have obsessional fears. When preoccupied with health, they have a heightened awareness of their body, excessively monitoring it for cues with a low threshold for detecting symptoms resulting in psychological distress. If found they are amplified and the individual is unable to distract themselves. It is a personality trait where the individual tends to focus on potential threats to the detriment of their well being.

When diagnosed with cancer these individuals are at risk of developing high levels of distress and are likely to respond by the aforementioned pattern of 'monitoring' behaviour. While constantly seeking information about results they fixate on searching for more threats to their health. The symptoms of disease or side effects of treatment may be continually interpreted and individuals seek constant reassurance. Requesting additional medical checks, seeking social support and venting emotions are in keeping with this trait but they do not tend to lessen the anxiety. Instead it generates higher levels of stress (Miller, 1996). The degree to which anxious preoccupation is observed may vary depending on the degree of threat associated with events along the cancer pathway. For example, an individual may not display this behaviour during treatment but may do so prior to a hospital appointment when test results are expected (Brennan, 2001).

The threat to psychological wellbeing originates not so much from intermittent anxiety but when the levels of anxiety are persistently out of proportion to the level of threat. These are symptoms of an anxiety disorder (Stark & House, 2000).

### **Psychological morbidities**

Concerns have been raised as to whether 'anxious preoccupation' should be conceptualised as a coping strategy or as the health outcome 'anxiety' since they are part of the same phenomena. Correlations between the two may therefore mislead since one would inevitably find that higher anxious preoccupation equated to higher anxiety (Nordin & Glimelius, 1998).

Nevertheless anxiety preoccupation is widely reported as being significantly correlated with higher rates of depression and anxiety as well as lower emotional well-being and quality of life (Johansson et al, 2011; Nordin & Glimelius 1998; Watson et al. 1991; Lampic et al. 1994; Grassi et al. 2004; Akechi et al. 2001). For example, high levels of 'anxious preoccupation' were associated with low levels of psychosocial well-being, more situation-specific anxiety and more cancer-related worry in 197 consecutive cancer patients at follow up visits (Lampic et al. 1994). Preoccupation with one's diagnosis was a predictor of acute stress disorder in 82 newly-diagnosed Australian patients with head and neck or lung cancer (Kangas et al, 2007). In addition, lower self efficacy - "the belief that one is able to control challenging environmental demands by taking adaptive action" (Bandura,1997) was inversely correlated with 'anxious preoccupation' among 684 women with breast cancer (Rottmann

et al. 2010). Having an anxious response, with little confidence in being able to control the situation, can lead to spiralling distress.

Longitudinally the use of anxious preoccupation decreased over a 12 month period among 94 people with laryngeal cancer (Johansson et al, 2011).

Nevertheless a recent study reported individuals with anxious preoccupation were 4.6 times more likely to be depressed (95% CL2.9-7.3) at 6 months and 8.4 (5.6-12.6) times more likely to become anxious (n=1323) (Boyes et al. 2011).

#### **2.45 Fighting spirit**

When seeking to define 'fighting spirit', there is a tendency to think of sports psychology and of metaphors of war. In these circumstances a 'fighting spirit' is to be fostered and harnessed as the only way to win. It is an adaptive coping strategy encompassing strength, optimism and determination to reach a goal. This attitude is often encouraged by friends and family of individuals diagnosed with cancer but there is little evidence to suggest that doing so helps one 'beat' cancer. A review of 26 reports found no link with increased survival (Petticrew et al, 2002). It was been suggested that the finding should calm those who believe that they are less likely to survive due to their depressive symptoms.

Greer suggested that 'fighting spirit' is regarding cancer as a challenge requiring a positive attitude (Greer, 2008). Most publications suggest it has an inverse correlation with both anxiety and depression. Among 121 US cancer patients a greater use of fighting spirit equated to lower mood disturbances (Cordova et al.

2003) and among 101 women with advanced breast cancer, fighting spirit and emotional expressiveness were associated with better adjustment (Classen et al. 1996). In the UK among 68 patients with oral cancer there was an inverse relationship between depression and fighting spirit (Hassanein, K, A, A, M. et al, 2001).

Fighting spirit appears to vary across the cancer pathway. There were no significant associations with mood disorders at the first measurement point among 95 laryngeal cancer patients in a Swedish study. However, a year later higher rates of fighting spirit equated to lower anxiety. This finding supports a US study of 30 prostate cancer patients where there was a non-significant association with anxiety and depression with participants providing data with a mean length of time since diagnosis of 3.3 years. With a fighting spirit arguably more important at the time of diagnosis, researchers suggested one reason for this result was that longitudinally the need for a fighting spirit may lessen (Bjorck et al. 1999).

The positive association with adaptive coping has raised concerns about the risk that having a fighting spirit may have a detrimental effect towards the end of life when an individual may find it harder to adjust to their impending death (O'Brien & Moorey, 2010). An opposing argument suggests that individuals who are optimistic about their illness even at advanced stages of disease merely replace one set of 'positive illusions' with others without 'catastrophic' mental breakdown (Taylor & Armor 1996). This requires further research.

## **2.5 Longitudinal adjustment to cancer**

Given the increasing number of cancer 'survivors' there is a need for greater awareness about how patients adjust over time to provide psychological support for those in need.

Several studies have considered trajectories of psychological distress and the physical symptom burden but to the knowledge of the author none among British South Asian cancer patients. Heim (1997) found that the greatest improvement in adjustment among breast cancer women was between hospitalization and three months with stability within three to five years. Further findings among 287 US breast cancer patients (data from 4 months post diagnosis) suggested that the majority (60%) showed improvements in mental and physical functioning within 13 months. A minority (12-19%) showed decline and chronic distress at 19 months (Helgeson, 2004). Similar to Heim's study, psychological stability was achieved among most of 285 Hong Kong Chinese women with breast cancer by 4 months (Lam, 2010) and after initial distress most (50%) were 'resilient' by 8 months. Another subgroup adjusted more quickly (12%) experiencing a lesser physical symptom burden but 15% experienced chronic distress. Ineffective symptom control during treatment was found to increase women's risk of persistent psychological distress longitudinally.

Better control of physical symptoms appears to be an important factor in mediation of distress. It predicted better function and less disability among 4903 US patients where 1 in 4 patients had a high symptom burden 1 year post

cancer diagnosis. Depression, fatigue and pain had the greatest impact on their quality of life (Shi, 2011). A similar high symptom burden at 12 months was reported among US cancer patients referred for control of pain and depression (n=405) (Kroenke, 2013) and among a high risk group for depression, fatigue and disabilities independently predicted depression among 987 UK lung cancer patients commencing treatment (Hopwood, 2000).

There is some evidence of ethnic disparities in symptom burden. Among 139 patients post breast cancer chemotherapy (Hispanic 58, Black 18 White 63) Hispanic women were more likely to report  $\geq 10$  symptoms in contrast to  $\geq 6$  symptoms among the majority. 76% experienced fatigue, a symptom frequently associated with lower mood (Fu, 2009) A similar study pointed to a greater 'unmet need' (at least one severe symptom) for symptom control among Black and Spanish speaking Hispanic women with breast cancer than White women (n=1219) (Yoon, 2008). More among the former groups cited the doctor not appreciating how much the problem bother her (p=0.03) which may suggest a lack of cultural awareness. No similar studies were found among South Asian populations.

## **2.6 Knowledge and beliefs about cancer**

How patients interpret a diagnosis of cancer influences how they cope.

Knowledge and beliefs vary between individuals and different ethnic groups.

There may be a marked variance between the beliefs of the physician and the patient (Dalal, 2000) especially if there is an under-appreciation of the influence of ethnicity or socio economic factors on the interpretation of cancer by the

physician. Such misunderstandings may cause distress to patients and interfere with the uptake and adherence to treatment. It is therefore essential to establish how the cancer diagnosis is interpreted by the patient as part of a medical assessment. Although there are excellent studies considering awareness of cancer among the general public (Robb et al, 2009) their knowledge does not reflect those of diagnosed cancer patients who have already entered health care settings where provision of information may already have changed their knowledge.

### **Awareness of cancer risk factors**

90% among UK adults, representative of the general population, acknowledged that smoking risked cancer (n=4233) (Redeker et al. 2009). Specific to Leicester, more BSA men under 50 years smoked than BW men but it is unclear whether this was purely influenced by knowledge of the risk (Smith et al. 2003a). Being overweight or having a diet with few fruit or vegetables are known risk factors but were regarded as such by only 33% and 32% respectively in Redeker's study. Furthermore, while that study suggested only 22% believed that being physically inactive was a risk factor for cancer, the figure was even lower among another UK representative sample (7%) n=1747 (Sanderson et al. 2009). Stress was regarded as a risk factor by 34% in spite of little supportive empirical evidence. Fewer men believed their risk would be increased if a close relative had cancer in comparison to women (44% and 61% respectively) (Redeker et al. 2009).

### **'Cancer is incurable'**

Cancer is frequently viewed as incurable. In West Bengal, only 58% of respondents believed that cancer was curable at an early stage (n= 900) (Ray & Mandal, 2004). The overwhelming view among six single sex focus groups in Luton, UK, representing the three main South Asian populations, was that cancer is a terminal disease. One member of a focus group defined cancer as

*"....something..., there is no medicine out there,..." there is no cure for it".* Randhawa & Owens, 2004, p65

One explanation for this view was that cancer was only associated with people who had symptoms of late stage disease and inevitably died (Randhawa & Owens 2004). Similar views were expressed among low income Black American women in Atlanta, USA (n=89). Not surprisingly these women felt screening was irrelevant (Gregg & Curry 1994). It was also linked to late presentation of cancer symptoms (Powe & Johnson, 1995; Szczepura et al, 2008) and to the development of anxiety and depression via feelings of fatalism and hopelessness.

### **'Surgery causes cancer to spread'**

This myth appears to be held cross culturally but disproportionately so among ethnic minorities. In a telephone survey conducted by the American Cancer Society, of 957 people thought to be typical of the continental US adult population in telephone households, 40.8% agreed with the statement "treating cancer with surgery can cause it to spread throughout the body" (Gansler et al. 2005). However more African Americans with breast cancer in Eastern North Carolina than White Americans believed surgery caused cancer to grow

(AA 61% (n=167); WA 52%, n=373) (Lannin et al.1998). The same ethnic difference in this belief was held in Connecticut at the same time although reported fifteen years later (Soler-Vila et al, 2005). The myth was also prevalent in 58% of 876 women in the USA Hispanic general population (Morgan et al, 1995). The belief was that it was the act of cutting which allowed air to get to cancer which hastened the spread of cancer (James et al, 2011).

This misconception can lead to refusal of potentially lifesaving treatment. It was the reason given by 19% of African American patients for refusing surgery (Margolis et al. 2003). It also predicted breast cancer being diagnosed at a later stage with a consequently poorer prognosis in a univariate analysis in the Eastern North Carolina study (OR, 2.8; 95% CI, 1.8-4.3) (Lannin et al. 1998). The origins of this myth remains unclear although falsely blaming surgery for the high post operative mortality in people with advanced cancer in the early days of surgery and anaesthesia may be a factor.

### **'Cancer is contagious'**

The belief that cancer is contagious is widely reported and appears to be more prevalent in collectivist cultures. The term is interpreted as both cross infection and genetic transmission. 21% (n=900) of the general population of West Bengal and 27% of cancer patients in Karachi implied that cancer was contagious (Ray & Mandal, 2004; Kumar et al. 2010). Similarly the concern that cancer was 'catching' was reported among Canadian South Asians among the 'old, superstitious or uninformed' (Johnson et al. 1999), among Asian Americans (Ashing et al. 2003) and Chinese immigrants in San Francisco

where 25% believed this myth (Wong-Kim et al, 2003). Cancer was associated with “death, incurability, contagion and feeling of dread” among Afro Caribbean, Asians and Chinese in the UK where this belief was also expressed among a cross-cultural sample of women’s views on cervical screening (Baxter, 1989; Box & Anderson, 1997).

This misconception can result in individuals with cancer being stigmatised. Some people in West Bengal were ostracised from family and their community and a similar observation was made among a Singaporean community where some cancer patients were avoided for the same reason (Ray & Mandal, 2004; Ong et al. 2002). Although many families may disagree with this attitude it may still influence how they respond to the outside world knowing that others in their social circle believe it. Some individuals with symptoms suspicious of cancer may respond by delaying seeking medical help and non disclosure of the diagnosis both inside the family and outside, the latter risking isolation from social support (Smith et al, 2005, Banning et al. 2010). (The first reference refers to research led by Leicester based researchers).

### **‘Collectivist’ and ‘individualist’ societies**

Behaviours are in part influenced by the social conventions in which individuals live. There are broad differences between collectivist societies, such as exist within the Indian sub-continent and individualist societies dominant in Western Europe and the USA (Tweed et al, 2004). A characteristic of collectivism is that individuals accommodate themselves to the good of the community, or family unit. Emotions are more closely linked to how one’s behaviour reflects on other.

In contrast, in individualistic societies, emotions such as pride and shame reflect on the self (Mesquita, 2001).

Faced with symptoms or a diagnosis of cancer those within collectivist societies are more likely to respond using emotion-focused behaviours (Tweed et al. 2004). These include self-control, distancing, accepting, waiting, denying and positive reappraisal. They manage emotions to avoid disturbing group harmony. In contrast those in individualist societies try to accommodate the environment to the needs of the self by using problem-focused coping such as seeking information, participating in decision-making and gaining support. It is however important to consider individuals as having a unique set of beliefs and behaviours within this context.

The maintenance of family honour and reputation is a characteristic of a collectivism and can affect the response of an individual or family to a diagnosis of cancer. A UK study suggested that having cancer brings Izzat (shame) on BSA families (Gilbert et al. 2004) which is similar to findings in Bengal where cancer is a stigma which attaches itself to the family (Ray & Mandal, 2004).

Ensuring a diagnosis of cancer remained a 'private matter' was described as a 'cultural norm' by Canadian Punjabi women with breast cancer (Gurm et al. 2008). The need for secrecy was more extreme among Indian cancer patients attending a radiotherapy department in Dehli where 60% (n=95) of patients were completely isolated by family and society (Kishore et al. 2007). Of concern clinically is the report in a qualitative study among Indian women with

breast cancer living in Lahore and London that some individuals preferred to visit homeopaths to receive treatment rather than inform their family of symptoms of cancer risking delayed presentation for treatment with consequent risk of poorer outcome (Banning et al. 2010).

Cancer has the potential to be socially contagious in some populations. The suspicion or confirmation of cancer, if known, was thought to put the marriage prospects of the younger generation at risk, particularly the women who are the focus for the maintenance of family honour (Bottorff et al. 1998, Karbani, 2011). It was thought that cancer would 'contaminate' and be transmitted to a family into which she married and to subsequent offspring. A Canadian South Asian focus group participant said...

*"Like suppose I have cancer. The other people will say, "Oh no. Poor things. The children are going to be a cancer cases....Today the mother has cancer. Tomorrow the children will have it..."* (South Asian woman) (Johnson et al. 1999 p.251).

This belief was also present in Western Bengal where over 11 % of people said they would not tell their neighbours that they had the disease for this reason (Ray & Mandal 2004). It was also reported within UK ethnic minorities (Department of Health, 2009). This attitude is not restricted to cancer since mental illness has also been reported as causing 'problems of appeal' in marriage in South Asian immigrants in the USA (Ahmed & Lemkau, 2000).

To add to the negativity surrounding cancer there can be a degree of blame attached to the individual or family for leading a poor quality life style, either related to perceived poor eating habits or a stressful life,

*“they just eat lots of meat” .....you don’t care for yourself and when your body doesn’t get the proper nutrition it needs, sicknesses, illnesses will grab you, right?”* (Johnson et al.1999, p. 249).

Furthermore in focus groups of Punjabi women with breast cancer in Canada, family elders appeared to blame them for having cancer,

*“Why did you get this disease; what have you done to cause this illness?..... they think...I must have sinned”.* (Gurm et al. 2008, p271).

The need to keep a diagnosis of cancer secret is associated with greater distress (National Comprehensive Cancer Network, 2011) and depression (Hipkins et al. 2004; Walker et al. 2006). A qualitative study among African Americans noted some participants experienced distress as a response to the negative reaction of other religious community members to their diagnosis of cancer (Roff et al. 2009). Fear of being stigmatised may be one of several reasons why some from ethnic minorities do not use screening services (Parsa et al. 2006; Karbani, 2011) or present symptoms of cancer late (Velikova et al. 2004; Randhawa & Owens 2004; Banning et al. 2010). This fear may also reduce participation in cancer research due to concerns about confidentiality (ch 8.2).

### **‘Alternative treatments are as effective as conventional treatments’**

The use of complementary and alternative medicine (CAM) varies globally. 83.3% (n=453) of cancer patients in Houston USA used at least one form of CAM after diagnosis. Spiritual methods were the most common (80.5%) (Richardson et al. 2000). This was far higher than the 32% (n=127) reported in a European survey across seven countries. Of this figure only 15.4% used spiritual methods, 48.7% used herbal measures and 20.5% homeopathic medicines (Molassiotis et al. 2005). It is however vital not to assume that all BSA people conform to a stereotypical set of beliefs within a rigid cultural identity if individuality is to be preserved particularly within clinical settings. The overlap in pre-existing religiosity and the use of spirituality within CAM may limit the significance of these differences.

Some patients reject conventional biomedical treatments. Reasons include a wish to avoid side effects of treatments, misconceptions about it, trust in cultural based traditional medicine and a poor patient/physician relationship. Some people have a strong need to control decision-making and others prioritize an holistic approach (Verhoef et al. 2008). Underinsurance prevents access to conventional treatments in some countries, including the USA. More positively for others, reliance on alternative therapies may be an informed decision through acceptance of their limited life expectancy and finding personal value in adhering to their beliefs.

Mistrust in conventional treatments is reported in a cross-cultural qualitative study. An African/American focus group of lung cancer patients, who preferred

complementary or alternative treatment to surgery doubting the efficacy of surgery, pointing to the previously mentioned misconception (George & Margolis, 2010). Furthermore, the belief that conventional treatments caused damage or harm to the body and would make no difference to the disease outcome were reasons given to decline treatment in a cross-cultural study in Hawaii (n=14) (Shumay et al. 2001).

There is a long tradition of Ayurvedic Medicine in the Indian sub-continent. Practices include the use of home remedies, dietary regimes, prayers and rituals (Hilton et al. 2001). Immigrants from Gujarat to the UK, including those in Leicester, have shown high confidence in alternative medicine and alternative practitioners (Jobanputra & Furnham, 2005; Karasz, 2005). Such trust may evoke an ambivalent attitude of some toward 'western' medicine (Department of Health, 2007).

The pragmatic use of both medical approaches is preferred by some. In a study of 230 cancer patients in Pakistan, 75.2% had received homeopathic treatments before seeing an oncologist (Kumar et al. 2010). Of interest is the finding that participants in a cervical cancer study in India (Kohli, Dala 1998) appeared to differentiate between treating the causes of their illness by consulting alternative healers and treating the symptoms of cancer by visiting the hospital. Such pragmatism was also found in a meta analysis of five studies across Indian hospitals (including the Kohli & Dalal 1998 study) where patients with a variety of illnesses did not regard the use of both forms of treatment as being a contradiction, more as a means of trying anything that might work (Dalal, 2000).

Similarly in the UK both Indian and British study participants appeared to explain health and illness in relation to the biomedical model of medicine dominant in Britain but Indians also appeared to retain and encourage adherence to traditional beliefs (Jobanputra & Furnham, 2005).

### **Supernatural explanations for cancer**

Spiritual beliefs are associated with both positive and negative coping. Feeling abandoned by God or feeling angry towards Him, although affecting a minority, predicted depressive symptoms and worse overall mental health (Herbert 2008). 'Blaming God' was associated with more depressive symptoms in a meta analysis of 147 studies (Smith et al, 2003b; Stefanek et al, 2005).

Nevertheless evidence of association between religious coping strategies and psychological outcomes is far from conclusive. There is contradictory evidence about whether deferring to spiritual beliefs is an engaging (adaptive) or disengaging (maladaptive) strategy (Livneh, 2000).

Within South Asian societies a belief in supernatural influences on life is a cultural norm and can be either a help or hindrance to one's psychological wellbeing, depending on the interpretation of that belief by the individual and their community. For example, God's Will and karma are thought to be major reasons for the development of cervical cancer among a sample of north Indian patients (Kohli, Dalal, 1998) and diagnosis and treatment of cancer was left to 'God's Will' by some patients in a survey in New Delhi (Seth et al. 2005). This finding is replicated elsewhere in other ethnic minorities (Conrad, Pacquiao

2005, Conrad, 1996 (US Indian Asians), (Dalal, 2000) (Indians), (Dein, 2004) (African Americans), (Pfeffer, 2004) (UK cross cultural focus groups).

Locally, disease was regarded as punishment for sin by Hindus in Leicester (Sirwardene, 2004) and by Muslims in the UK (Deepak, 2004). This association is more commonly observed in the older and less educated (Karim, Bailey & Tunna, 2000).

## **2.7 Patient/physician trust and preferences for the relationship**

This study investigated whether selected themes within patient/physician trust affected psychological morbidity. Literature relating to these themes will be briefly reviewed.

Culture and ethnicity are potential barriers to establishing and maintaining a trusting relationship between doctor and patient (Schouten & Meeuwesen, 2006). Within the therapeutic alliance trust has been described as the belief that a healthcare professional works in the patient's best interest, this being essential to the patient/physician relationship (McKinstry et al. 2006; Calnan et al, 2006). Hall derived several domains of trust, fidelity, honesty, competence and confidentiality with global trust, defined as the "irreducible soul of trust or aspects that combine elements from some or all of the separate dimensions". He regarded these domains as having "the core of commonality of conceptual analyses" (Hall et al. 2001).

### **UK trust in doctors and the NHS as an institution**

In the UK general public, doctors were the most trusted of all the professionals. 88% trusted their doctor to tell them the truth (Ipsos MORI / BMA, 2011) and 91% trusted GP based services the most (Ipsos MORI / Healthcare Commission, 2006). Although overall 77% believed the NHS as a health care institution was critical to British society, South Asian people showed less confidence (65%) (Ipsos MORI / Healthcare Commission, 2006). Expectations appear to vary between ethnic minorities too. Dissatisfaction among South Asians concerned hospital waiting times for non-emergencies and for consultant appointments but this was not reflected among British Black people in the same survey. A second Healthcare Commission report (2008) suggested that Bangladeshis in particular were more dissatisfied with the access and experience of the NHS than other ethnic groups. Enquiries into the views of South Asian patients in Newham University Hospitals NHS Trust implicated higher expectation of the NHS and communications issues as contributing factors for this lower trust (Department of Health / Healthcare Commission, 2008).

### **Patient/physician trust and cancer**

Trust was the most important factor in patient/physician communication in a group of 39 women with breast cancer (Wright et al, 2004). When a group of 569 seriously ill patients, of whom 166 had cancer, were asked what mattered most in end of life care, 434 patients listed “trust and confidence in the doctors looking after you” top out of 28 factors related to quality of end of life care. Family members also rated trust as the most important element related to the

quality of end of life care (Heyland et al. 2006). The UK finding that ethnic minorities were more likely to have negative experiences in relation to doctors and nurses is of concern (National Audit Office, 2005). A baseline survey (2000) suggested that 77% South Asian patients had lower confidence levels in doctors contrasting with than 83% of all patients (Department of Health, 2000b).

The trend towards mistrust among ethnic minorities was observed in the UK where a London-based study suggested significantly less trust in their GP among Indian (n=200) Pakistani (n=107) and Bangladeshi people (n=114) than White (n=3014, p=0.001). Specifically, out of 13 measures of trust including 'personal' 'communications' and 'overall satisfaction', 11 indicated less favourable scores among ethnic minorities than White, although there were differences between ethnic minority populations (Campbell, Ramsay & Green, 2001).

### **Competence and personal values**

The competence of doctors seems less a cause for mistrust in some studies involving African/Americans than perceptions of their personal values. African/American men, who received care in either primary setting or emergency department in Philadelphia, mistrusted the doctors' values rather than their competence (n= 255 individuals (144 African/American men; 92 White) (Armstrong et al. 2008). When exploring racial differences in patient/physician trust in a study in Georgia USA (n=320) a similar concern was expressed by African/American men. They detected more physician bias and financial problems with access to care than White men (Dilorio et al. 2011).

African/Americans with cancer and those requiring thoracic surgery also had lowered trust in physicians post first visit compared to pre visit due to a perception that the physicians were less supportive, less partnering and offered less information (n=103, 22% African/American) (Gordon et al. 2006). With the long and difficult relationship between African/Americans and the White population these findings are not unexpected. Although arguably less relevant to the UK setting they serve as a reminder that differences in personal values can have a detrimental effect on the therapeutic relationship.

### **Confidentiality**

Patient confidentiality is a core feature of the therapeutic relationship and is of concern among ethnic minorities. Fears about breaches were reported among South Asian women with mental illness in Derby (Gilbert et al. 2004) and in Newham where a barrier to seeking help from a GP for self harm was fear of disclosure. Interestingly this was of particular concern when the GP was of the same ethnicity or had close contact with the family (Husain et al, 2006). This perception was also reported among UK Muslim women (Muslim Women's Network, 2006) and among South Asian women in Birmingham (Ashram, 2008). If there is evidence that the reputation of the family or community supersedes the individual's right to confidentiality, in the UK this would be a serious breach of the medical code of conduct. There is however, little empirical evidence to support this suggestion.

Fear of disclosure and its negative impact on 'personal life, marriage, insurance and employment' was cited for non participation in trials in a meta-analysis of

six qualitative studies and one survey in India (Shah et al. 2010). This was specifically related to worry that the collection and publication of clinical trial data may not ensure confidentiality of the participant. The need for clinical information to remain private was of particular concern for 17% of participants (themes weighted) (Shah et al. 2010). Similarly a report considering disengagement of black and ethnic minority patients in the NHS from participating in patient surveys suggested that there was a reluctance to discuss health issues due partly to fears that information provided in a research setting may be the subject of social service officials. Furthermore, there was an unwillingness to talk about poor health for fear of being perceived as a burden on the state which may jeopardize asylum applications (Elam et al. 2001; Donovan et al. 2007).

### **Ethnicity and gender of doctor**

Given the aforementioned concern about confidentiality, it is of interest that some South Asian patients prefer to see a GP from a similar ethnic background or culture (Furnham et al. 2006). This appears to take precedence over preference for the same sex doctor unless there is a need to reduce embarrassment (Kerssens et al. 1997; Heaton & Marquez, 1990; Ahmad et al. 2002). The South Asian patient/physician relationship appears to be multi-faceted and under-researched.

### **Trust and health outcomes**

Patient/physician trust is widely considered to be a vital in optimizing health outcomes (Armstrong et al. 2008; Lee & Lin, 2009; Kaiser et al. 2011). It

impacts on patients' uptake of screening, help-seeking behaviour, accrual to clinical trials, adherence with treatment and psychological wellbeing (Baile & Aaron, 2005).

Among African/American patients with prostate cancer there was less trust in healthcare than White patients and this was associated with higher mortality and a more advanced stage at diagnosis (Halbert et al. 2009). Both delay in seeking medical help (Do et al. 2010) and participation in monitoring (Carpenter et al. 2009) were related to lower trust levels in Black prostate cancer patients. Low trust also affected screening uptake. In a review of 64 articles (1971-2009) lack of trust in hospitals and doctors were barriers to ethnic minority women accessing breast screening services in the USA (Alexandraki & Mooradian, 2010).

Trust in a regular physician was associated with earlier detection of their cancer in 119 patients in South Carolina with breast or colorectal cancer (Mainous et al. 2004) and commitment to health behaviours due to patient/physician trust was also observed in a majority white sample of patients in primary care settings in Houston, Texas (Berry et al. 2008).

Good communication may result in lower levels of depression. Among 135 German women commencing treatment for breast cancer, those who were satisfied with the patient/physician communication at the beginning of treatment were less likely to be depressed after three months although the effect was not present at six months (baseline depression was controlled) (Vogel, Leonhart &

Helmes, 2009). A caring approach appears to help adjustment to cancer. Factor analysis among 100 Floridian women surveyed six months post breast cancer surgery indicated that the physician's caring attitude was regarded by patients as the most important factor in assisting their psychological adjustment. Surgeons' behaviours believed to facilitate patient adjustment also included providing information, a partnership in decision-making and giving the patient time to absorb the cancer diagnosis (Roberts et al. 1994).

Furthermore, demonstrating a 'caring approach' reduced anxiety among women in Florida. 123 patients presenting with breast cancer and 87 healthy women participated in a randomised pre-test post-test control group study in which some women watched a standard video, while others saw an 'enhanced compassion' video in addition to questionnaires including the State-Trait Inventory. Those who saw the latter tape were less anxious than the control group pointing to the physician as being "more caring, sensitive and compassionate". These qualities were rated higher than involvement in decision-making and encouraging questions (Fogarty et al. 1999).

There are contradictory findings about whether patients adjust better by having more information and participating in decision-making with their doctor or not. Not all patients want an active role and some may feel added responsibility and burden if expected to do so. For others it is an important factor in adjustment. Among 152 acutely ill medical in-patients, 66% wanted 'extensive' information about their condition but 61% wanted a passive role in decision-making. Of

interest is that researchers found it was not possible to predict patient preferences by clinical or socio-demographic factors (Wilkinson et al. 2008). The tailoring of information with the degree of participation to the individual's preferences may result in greater satisfaction in the patient/physician relationship and lower depression scores (Vogel et al. 2009). An explicit discussion about the patient's preferences regarding decision-making has been recommended (Elkin et al. 2007).

## **2.8 Research gaps and hypotheses**

There is a lack of knowledge about how BSA patients cope longitudinally when diagnosed with cancer compared to the host population. Although one local study reported the incidence of symptoms of anxiety and depression during the first three months post diagnosis, none looked across a nine month period. Likewise it is unclear whether the use of coping strategies varies between the ethnic groups over this period. The knowledge and beliefs about cancer has been explored among a variety of ethnic minority and host populations globally but few compare BSA and BW patients. It remains unclear if they affect mental wellbeing. Although there are studies comparing the symptom burden of different ethnic groups, none consider BSA and BW cancer patients. Except for one study of trust among cancer patients who used complementary medicine there have been no other studies of trust between cancer patients of different ethnicities and doctors in the UK (Newsom-Davis et al. 2009). A recent review highlighted the need for more studies regarding trust in cancer clinicians (Hillen et al. 2011). This study considers these research gaps.

### **'Experimental' hypotheses**

- BSA patients self report a higher incidence of symptoms of depression and anxiety than BW patients across the first nine months after referral to the LCC.
- The use of coping strategies differs between ethnic groups during the first nine months after diagnosis and is implicated in ethnic differences in symptoms of anxiety and depression.
- There are ethnic differences in the representations of cancer (BIPQ)
- Cross culturally patients have different preferences for the patient/physician relationship at presentation at the LCC.
- There are ethnic differences in the beliefs and knowledge about cancer
- Specific beliefs and knowledge have a detrimental effect on mental health.
- There are ethnic differences in problems causing distress (DT checklist)
- Demographic factors influence the incidence of anxiety and depression in this sample

## **Section 3: Methodology**

### **3.1: Introduction**

This section outlines the methods adopted for this study. The choice of methodology is clarified and the questionnaires and method of translation discussed. The setting and population sampling techniques will be considered followed by a description of the data collection techniques and procedures. The scoring and processing of data together with the calculations used for statistical analysis will be outlined.

Quantitative methodology based on a scientific approach is an established and credible method of investigating many healthcare issues. It has a systematic approach which establishes hypotheses in narrow terms and tests them through the collection of nominal data by methods such as questionnaires, surveys and laboratory tests. Precise measurements of statistical power can be generated from such data. Quantitative methods are also better suited to facilitate the systematic analysis of data collected at separate points in time as in this study.

By their very nature these methods avoid incorporating the subjective values of participants and researchers into a study design, elements which risk introducing anecdotal data with minimal statistical power. The avoidance of subjective opinions is conversely a disadvantage since it eliminates potentially valuable participant insights of relevance to the research subject and possibly risks disengaging some participants, frustrated by now being able to offer their views. This study remains predominantly quantitative, but the author wished to provide patients with the opportunity to comment about their experience of

cancer. This had the potential to generate personal statements about how individuals coped to illustrate aspects of the study.

The observational study design selected is that of a cross-sectional survey. This measures variables through gathering data to provide a 'snapshot' of a specific population at a specific point, or points, in time. This study estimated the prevalence of symptoms of anxiety and depression within two ethnic groups and compared their relationship taking into account other factors such as demographics and specific beliefs. One advantage of this design is that data can be easily collected with consequent limited cost implications. However, although by comparing two variables at one time one can determine whether there is an association between the two, the degree of strength and direction of that relationship and its incidence, this design is less appropriate in determining causality since that requires data on the incidence of cases. Researchers also need to be aware of the concept of 'bias' which is a limitation of this design. For example 'selection bias' can generate results which do not reflect cases within a population. The data from patients too severely distressed to participate in the study is not represented in study findings. 'Underreporting' bias can be a problem, if for example some participants downplay their depressive symptoms in a study about depression (Delgado-Rodriguez & Llorca, 2003).

Reference was made to the 'Strengthening the Reporting of Observational Studies in Epidemiology' (STROBE) statement for observational studies (Von Elm, 2007).

## **3.2 Questionnaires**

### **3.21 Hospital Anxiety and Depression Scale (HADS)**

The HADS was first developed by Zigmond and Snaith as a clinical tool to screen for symptoms of anxiety and depression in 100 people attending medical outpatient clinics (Zigmond & Snaith 1983). The questions purposely excluded physical symptoms related to depression such as fatigue. Self administered, it consists of seven questions measuring depression and seven measuring anxiety, and excludes items relating to physical symptoms. Each question has a four point score (0-3) with three denoting the most severe state.

Approximately half the questions are worded positively, the rest negatively. The items are counted to produce two subscales ranging from 0-21. The scale is in common use particularly in Europe, (Wasteson et al. 2009) due partly because it is quick to complete in contrast to more time-consuming interview methods (Hotopf et al. 2002).

Through the use of threshold scores the severity of symptoms is indicated and referral for specialist assessment follows. The most valid threshold threshold is one which balances specificity and sensitivity of the score effectively to detect individuals with symptoms of anxiety and depression. There has been a wide variety of threshold points used across publications since the original work.

Then, ratings of  $\geq 11$  were regarded as indicative of a clinical disorder requiring assessment and likely treatment, with those between 8 and 10 being doubtful cases but requiring further assessment. Other threshold scores have been used in recent years among cancer patients in two studies HADS-D  $\geq 5$ ; HADS-A  $\geq 7$  and HADS-T  $\geq 13$  (Morse et al, 2005, Singer et al. 2009) while the

recommendation of  $\geq 15$  was proposed as the threshold to detect a Major Depressive Disorder after considering the sensitivity and specificity of various figures among Scottish cancer out-patients (N=361) (Walker et al. 2007).

It has been suggested that among individuals with cancer, threshold scores should be set at a lower level than the optimum for specificity and sensitivity since it is thought better to risk referring non cases of depression than to leave those depressed untreated (Morse et al. 2005). The originators of HADS revised their classification in 1992, lowering their recommended threshold points (normal 0-7, mild 8-10, moderate 11-14 and severe 15-21 (Zigmond & Snaith 1992; Snaith, 2003). More recently this was supported by a literature review of 747 papers using HADS where the best balance between sensitivity and specificity was achieved most often when using the threshold  $\geq 8$  for both symptoms of anxiety and depression, the Cronbach's alpha coefficient for both subscales being approximately 0.80 (Bjelland et al. 2002).

Given the range of threshold points used across publications HADS is not without its detractors since there are consequently differing rates of detection for symptoms of depression to those identified through psychiatric assessment. When assessing 50 studies which used HADS with a threshold at  $>10$ , the median prevalence rate for 'definite' depression was 29% (Interquartile range 19.5%-34.5%) (Hotopf et al.2002). Using the gold standard psychiatric interview method of diagnosing major depression disorder as a comparison, the prevalence rates had a median of 15% (range 5% - 26%). Therefore approximately 50% of those diagnosed as having depressive symptoms using

HADS would not be diagnosed as depressed when using interview methods (Hotopf et al. 2002).

Nevertheless, HADS has been validated against a variety of similar self report questionnaires such as Beck's Depression Inventory and EORTC core quality of life Questionnaire-C33, against PHQ-9 (Cameron et al. 2008, Hansson et al. 2009) and in cancer populations (Carroll et al. 1993; Walker et al. 2007).

HADS was used in this study because it measures both anxiety and depression and it is quick to complete. The threshold  $\geq 8$  was selected for both anxiety and depression since it follows the recommendation for a lower threshold among cancer patients and has a sound evidence base (Morse et al, 2005).

Although HADS is frequently referred to as the 'Gold Standard' in the assessment of anxiety and depression in the UK, unfortunately, although validated in Urdu (Roy et al. 2005), Punjabi (Lane et al. 2007), and in Malayalam (Thomas et al. 2005), it has yet to be validated in Gujarati, the second most commonly used language in our study. The HADS version in Gujarati used for this study was developed using the 'back translation' method.

### **3.22 Patient Health Questionnaire (PHQ-9)**

PHQ-9 was developed in general practice settings in the USA to measure depression (Spitzer et al. 1999). This nine item scale mirrors the nine criteria of the widely used Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) based on interview assessment (American Psychiatric Association, 1994). In

addition to each of these questions being analysed individually, two further methods of analysis are outlined (Table 1). 'System 2' was used for this study.

**Table 1: PHQ-9 scoring systems**

<p><b>PHQ-9</b></p> <p><b>Coding system 1</b></p> <p><b>Major depressive syndrome</b></p> <p>If answers to #1a or b and five or more of #1a-i are self assessed as at least "More than half the days" (count #1i if present at all);</p> <p><b>Other depressive syndrome,</b></p> <p>If #1a or b and two, three, or four of #1a-i are at least "More than half the days"(count#1 if present at all);</p> <p><b>Panic syndrome,</b></p> <p>If all of #2 a-e are "YES."</p> <p>(Spitzer et al.1999)</p> <p><b>Coding system 2</b></p> <p>Sum the scores for each indicator for each participant</p> <p>Use the following cut off scores <math>\geq 10</math>, <math>\geq 15</math>, <math>\geq 20</math></p> <p>(Kroenke et al. 2001)</p>
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The scale is of particular relevance to this locality since it has recently been translated into a variety of Indian languages including Gujarati and Hindi and validated against the English version of the Brief Patient Health Questionnaire (BPHQ) (Kochhar et al. 2007). The translations of the BPHQ were matched against the gold standard DSM-IV clinical interview predominantly used in the USA. The Kappa score denoting agreement was as follows (Gujarati 0.6628 (N=199) and Hindi 0.9174 (N=283) where a score of  $< 0.5$  was considered inadequate to confirm agreement.

In translated form PHQ-9 has been validated against the HAD-D (Cameron et al. 2008; Hansson et al. 2009). Hansson qualified this by noting that although the two scales did not always identify the same cases of depression, it does identify similar prevalence of depression. Similar discrepancies exist between studies because of the use of different assessment tools (Aujla et al. 2009). For example, in one recent study considering the management of depression in primary care settings in relation to questionnaires, the PHQ-9 classified 83.5% of patients as moderately to severely depressed in comparison to only 55.6% of patients with HADS (Kendrick et al. 2009). This issue remains one of concern and further investigations are needed if all individuals at risk are to be identified. In this study depression is measured by three assessment tools and anxiety by two. A comparison on the cases identified is illustrated and the trends commented upon.

### **3.23 The Mini Mental Adjustment to Cancer scale (Mini-MAC)**

The 'Mini Mac' is a 29-item scale measuring coping and adjustment responses to cancer through four subscales (Watson et al. 1994). It is a refined and shortened version of the original 58 item MAC (Greer & Watson 1987; Schwartz et al. 1992). The MAC scale was used in the pilot study (Roy et al. 2005) however the Mini-Mac scale is shorter making it more suited to participants completing multiple questionnaires. The Mini Mac was validated in 573 cancer patients who completed the MAC scale and an additional 'research scale' of 26 items. A factor analysis procedure testing the inter-correlations between the subscales determined which items were retained for the mini version. Items relating to cognitive avoidance were added to the mini version. The authors

viewed the new scale as a 'new measurement of adjustment' rather than a shortened version of the MAC (Watson et al. 1994).

**Table 2: Mini Mac scoring system**

<b>Subset</b>	<b>Items</b>
<b>Fighting spirit</b> (the tendency to confront cancer)	2,10,18,23 (4)
<b>Fatalism</b> (a resigned attitude towards the illness)	1,3,8,19, 24 (5)
<b>Cognitive avoidance</b> (actively avoiding connections with the illness)	11,17,26,27(4).
<b>Hopelessness/Helplessness</b> (the tendency towards pessimism)	4, 6, 12, 14, 15, 16, 20, 21(8)
<b>Anxious preoccupation</b>	5, 7, 9, 13, 22, 25, 28, 29 (8)
 <b>Each item offers the participant a choice of four responses</b>	
Definitely does not apply	raw score 1
Does not apply to me	raw score 2
Applies to me score	raw score 3
Definitely applies to me	raw score 4
Responses do not include a 'no view' option. Raw scores for each subset are summed with the higher totals to indicate higher use of the adjustment style. (Watson et al. 1994)	

### **3.24 The Brief Illness Perception Questionnaire (BIPQ)**

The original IPQ (Weinman et al. 1996), and its subsequent modified versions, are based on Leventhal's self-regulatory model which describes how patients deal with a threat to health with the ultimate aim of returning to, and maintaining their status quo, as a healthy person (Leventhal et al,1984). This three-stage model suggests that the person first interprets the threat to health, for example, by recognising symptoms of illness. Secondly they activate coping strategies. This may include seeking medical advice and activating personal psychological coping strategies, such as seeking family support. In the final stage the

individual evaluates the extent to which these actions are successful, changing plans as necessary, for example, changing treatment or seeking professional psychological support. The model has an inbuilt feedback loop with the patient again returning to reinterpret the changing threat to health.

The Brief Illness Perception Questionnaire (BIPQ) (Broadbent et al. 2006) is a shorter version of the IPR-R, (Moss-Morris et al. 2002) the latter being a comprehensive 80 item questionnaire assessing the cognitive and emotional representations of illness. The 'brief' version was designed to reduce the burden on those with serious illness and to be more transferable to a wider range of medical conditions. It established predictive validity among patients with myocardial infarction and discriminated validity by comparing scores of those with diabetes, asthma, colds, myocardial infarction and those with undiagnosed chest pain while under investigation. Since publication it has been applied in several studies including a cultural study comparing illness perception of Japanese and Dutch patients with non small cell lung cancer (Kaptein et al. 2011).

The questionnaire was selected for inclusion to establish whether there were cultural differences in patient's perceptions of their illness. Its brevity was an advantage. Reducing the variety of questionnaire formats also helps reduce patient 'burden'. Consequently the BIPQ was transformed, without altering the content, into a 'thermometer format' similar to the Emotion Thermometers where patients were asked to record their responses by marking a 'degree' score on each thermometer. The BIPQ comprises nine items including one

concerned with the comprehension of illness. Each item has a linear scale from 0-10 and encompasses the following representations of illness.

**Table 3: BIPQ Representations of illness**

<b>Representations of illness</b>	
<b>Identity</b>	the label the person uses to describe the illness and the symptoms they view as being part of the disease;
<b>Consequences</b>	the expected effects and outcome of the illness;
<b>Cause</b>	personal ideas about the cause of the illness;
<b>Timeline</b>	how long the patient believes the illness will last;
<b>Personal control</b>	the extent to which the patient believes that they can recover from or control the illness
<b>Treatment control</b>	the extent to which they think treatment will be helpful
<b>Concern</b>	the emotional impact of the illness
<b>Comprehension</b>	how well they feel they understand their illness
Item 9 asked patients to rank three causes for their illness.	
(Broadbent et al. 2006)	

### **3.25 The Emotion Thermometers (ET)**

This locally-designed assessment tool extends the more established Distress Thermometer (DT) recommended for use among cancer patients by the US National Comprehensive Cancer Network as a rapid screening for distress. (Roth et al.1998). The tool consists of five visual analogue scales in the form of an 11 point scale 0=no symptom; 10=severe symptom. Patients are asked to mark the degree of their symptom for the following domains (distress, anxiety, depression and anger) and one outcome domain ('the need for help'). The current recommended threshold point for the DT is  $\geq 4$  and this is retained in the ET (NCCN, 2011).

The ET was validated at the Leicester Cancer Centre among 113 patients newly attending to commence a course of chemotherapy. They completed the ET, HADS and the PHQ-9. Approximately half of those patients scoring  $\leq 3$  on the DT recorded emotional difficulties on the ET, suggesting that, with little additional burden on the patient, there was added value in using the ET (Mitchell et al. 2010a).

Using the same threshold score on all thermometers against the HADS anxiety scale, the optimal thermometer was AnxT (sensitivity 92%, specificity 61%) as measured by the Predictive Summary Index. Against the HADS depression scale, the optimal thermometer was the Depression Thermometer (DepT; sensitivity 60%, specificity 78%) and finally against the DSM-IV major depression, the optimal thermometer was the DepT (sensitivity 80%, specificity 79%).

A subsequent study of 130 patients tested the ET against the DT to determine whether there was added value in using the ET in the detection of depression, anxiety or distress. The ET depression thermometer was significantly more accurate in detecting depression than the DT and the anxiety thermometer improved the detection of those with elevated anxiety (Mitchell et al. 2010b).

The current study incorporated the ET as a means of gaining additional data relating to the levels of anxiety, depression, distress and anger among our newly-diagnosed patients. It also provides the opportunity to compare the PHQ-9, ET and HADS across the same sample of patients.

### **3.26 Cancer Insight and Denial Questionnaire (CIDQ)**

By choosing the Mini MAC scale over the MAC, items concerning 'denial' which has been included in a pilot study, were omitted. The CIDQ, using a likert analogue scale, was a locally devised tool in use in the psycho-oncology department and included eight items concerning the domains of denial. In addition four items concerned avoidance and a further four, information. The scale is not validated. Its main value is the inclusion of the original MAC item "I don't believe I have cancer" which allows comparison with pilot study findings. The questionnaire contained other indicators of denial indicators and information 'items'. The latter are of local service interest and provide additional data alongside the BIPQ item on the sufficiency or otherwise of information received.

### **3.27 Patient/Physician Trust and Cancer Beliefs**

This questionnaire was added after the initial pilot study. Recent publications suggested that some patients with cancer may be at an increased risk of distress due to minimally researched concepts which may shape how some patients respond (Baile & Aaron 2005; Herbert, 2008; Halbert et al. 2009, Vogel et al. 2009). These include the therapeutic alliance between patient and physician, and culture embedded beliefs about the causes of cancer, for example, the influences of karma, fate, God/Allah and wrongdoing. This questionnaire examined whether these concepts resonate locally and whether any predicted psychological morbidity.

Despite the growing number of publications about trust in health care there are few validated instruments measuring it and little consensus about the concept itself (Mechanic & Meyer, 2000; Hall, 2006). Most tools originate from the USA where the current focus is largely on the impact of health care costs in primary care on the patient physician relationship, for example, the Wake Forest Physician Trust Scale (Hall et al. 2002). No validated tools were found which were deemed suitable to assess trust among cancer patients in a UK NHS hospital setting.

An initial literature review of the therapeutic relationship and the cultural influences on patients with cancer took place and in consultation with several medical oncologists from South Asian backgrounds, one of whom had carried out a related study, a series of questions was generated. Sixteen items measured patient/physician trust and twenty two measured cancer beliefs and knowledge about the causes of cancer. After an exchange of views from the aforementioned people, the final design was reviewed by Professor A. Sheikh, Edinburgh.

Patient trust in both hospital and community doctors was measured with reference to the 'domains' of trust (fidelity, competence, honesty, confidentiality and global trust) (Hall et al. 2002). In addition, questions were asked about the type of relationship patients preferred to have with their doctor, for example, the degree to which patients wished to be involved in decision making.

Several questions sought to establish both the extent to which participants had accurate knowledge about the causes of cancer and to assess whether supernatural explanations for cancer were present. Others examined beliefs about cancer treatments. The likert analogue scale contained the following options as answers (agree strongly, agree, no view, disagree and strongly disagree). All statements of trust measured the patients' opinion of their doctors or the NHS. This was piloted as part of this study but is not validated.

### **3.28 Patients' understanding of their illness**

Four closed questions were asked about the written information participants received during their care. In particular there was a need to assess whether it was accessible and understandable, both important considerations for the cancer services operating in an ethnically diverse population.

Participants were also asked open-ended questions to clarify their understanding about their illness and secondly inviting them to comment on its meaning to them. This produced a wide variety of responses, some of which were accommodated within the results section. The qualitative data was not analysed for this thesis, given the word limit but provided a patient 'voice' to illustrate coping strategies in use. It was however logged for future analysis. Where participants seemed to be asking for help, a letter was sent signposting them to further assistance.

### **3.29 Patient profile (demographics)**

Participants were asked to describe their ethnic identity using the 2001 UK census criteria with the addition of 'English' as an option. A space was left for patients to describe themselves differently, if preferred. This confirmed ethnic identity for each participant. Country of origin was obtained to differentiate between those BSA patients born in the UK, Indian sub-continent or in Africa, the aim being to identify any trends in beliefs and coping strategies based on place of birth.

The level of education attained, religious affiliation and languages spoken were self reported. Postcodes enabled the researcher to assess the level of deprivation for each participant. This information was from the 2007 English Indices of Deprivation (ONS, 2011) originating from the 2001 Census (ONS, 2002). Seven domains including employment income and living environment are calculated to give the 'relative' deprivation of the area (highest deprivation =1 and lowest = 20). Confidentiality of individuals was secure with the figure calculating the degree of deprivation based on all the homes within each postcode.

### **3.3 Translation**

All but one questionnaire were translated from English into Hindi and Gujarati (PHQ-9 is available in Gujarati). A commercial translation service 'Pearl Linguistics' was instructed to do this by adhering to the iterative 'back translation' process (Brislin, 1970). Previous translations were found to use academic level vocabulary unfamiliar to many literate BSA patients so the

questionnaires were retranslated locally with specific instructions to simplify the language and refer to the process described by Brislin. The steps were as follows.

The English version was given to professional translators whose first language was Gujarati. One translated from English to Gujarati without conferring with the second translator. The latter then translated back from Gujarati into English. Although this process was repeated for Hindi the work was done by two bilingual clinicians, one a medical doctor, the other a radiographer. BSA clinicians working within the Leicestershire Cancer Centre were asked to comment on the finished product with the aim of achieving 'semantic equivalence' (Willgerodt et al. 2005). Minimal changes were suggested and alterations agreed through consensus.

## **Section 4: Data collection**

### **4.1 Procedure**

Between September 2007 and January 2010, 279 patients entered the study at the LCC. Eligible patients were aged 18-85, had been informed that they had cancer and were either BW or BSA. As many newly-registered BSA patients as possible were invited to participate, 94 being recruited. When the study was designed the ratio of new BSA to BW patients was 1:14. It was planned to recruit twice as many BW as BSA patients therefore we anticipated inviting 1 in 7 newly-registered BW cancer patients to enter the study. All those referred were recorded on the cancer register, part of an internal hospital system. BSA patients were identified via their surname with their ethnicity confirmed by hospital software. The surnames of BSA patients can often indicate not only ethnicity and religion but also region of their origin within the Indian sub-continent and their likely mother tongue. The advice of two BSA radiographers was sought to confirm those eligible for the study.

Efforts were made to recruit patients representing several cancer sites but it was largely a sample of 'convenience'. Table 4 indicates the recruitment and retention of patients which was a challenge to this research. In spite of 509 patients signing a consent form to take part in the study only 279 (54.8%) completed the first series of questionnaires.

**Table 4 Recruitment and retention**

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

The initial consultant outpatient appointment for individuals referred to the department frequently occurs promptly after registration with the LCC. When there was sufficient time to do so, a letter outlining the study and an invitation to participate was sent by post to eligible patients prior to their visit to the oncology department. Where appointments were imminent, the information leaflet was given to the patient in person. At least 24 hours passed between the information sheet being given and consent obtained unless the patient volunteered otherwise.

It was important to avoid causing harm by accidentally giving a patient a diagnosis they were unaware of during the process of recruitment.

Furthermore, since part of the study involved investigating the role of 'denial' as a means of coping with cancer, it was vital to be certain that patients had been informed of their diagnosis of cancer. Evidence of this was found in referral letters and medical notes. All those approached had been informed of the diagnosis of cancer in a previous hospital setting and were attending the hospital for information about future cancer treatment. In addition, every standardised consent form for treatment in the Cancer Centre explicitly

mentions the word 'cancer' as does the consent form for this study. Patients have access to an interpreting service as required. Nevertheless it is unclear whether all BSA patients understand what they are signing. The consent forms are written in English.

## **Consent**

Consent was sought asking patients to complete three sets of written questionnaires, the first as soon as possible after first consultation in the Cancer Centre, then at three months and nine months later. Patients were recruited by either an English-speaking clinical nurse specialist or one of two radiographers, who between them spoke English, Gujarati and Hindi. The vast majority of BSA patients were recruited by one of two radiographers who had received 'Good Clinical Practice' training. A minority were approached by a clinical nurse specialist or consultant oncologist. All BW patients were recruited by a BW clinical nurse specialist. The original signed consent form was placed in a site file with a copy lodged in the patient's medical notes and a third given to the patient. Patients were given the telephone number for the Primary Investigator to contact should they have any queries about the study.

The questionnaires were given in the preferred language of the patient with a stamped addressed envelope. They were available in English, Hindi and Gujarati or, if the patient was illiterate in their mother tongue, a translator was able to ask the questions. A translator was requested for two participants, one speaking Urdu, the other Gujarati. Due to the length of time it was necessary to be in the department for treatment, a minority of patients wished to complete the

forms immediately rather than take them home. The majority however preferred to return the questionnaires either by post or by placing them in a post box in a clinical area.

Prior to sending the follow up questionnaires the hospital database was checked to ensure that the patients were registered as alive. Questionnaires with a covering letter and a stamped addressed envelope (SAE) were sent out the same day in the appropriate language.

After a two week period those BSA patients who had not returned the questionnaires were contacted by a radiographer to see whether they wished to continue to participate, withdraw or receive another questionnaire. This was necessary due to the low returns of questionnaires from this ethnic group. When questionnaires given to BW patients were not returned, letters were sent with repeat SAE and questionnaires.

#### **4.2 Methods of administering questionnaires**

The initial questionnaires for the main study consisted of eleven pages. Following advice from a BSA researcher, the sheet enquiring about demographic details was placed last since it was thought that immediate questions concerning ethnicity and place of birth could risk early withdrawal from the study due to suspicion among some that the information might be used by the 'immigration authorities'.

Subsequent questionnaires were reduced to six pages and excluded the cancer beliefs and trust questionnaire, demographics and the open-ended questions. Questionnaires were sent with covering letters reminding participants of the aims of the project.

### **4.3 Ethical approval and consideration**

The study was approved by to the Leicestershire Northamptonshire and Rutland Ethics Committee and the Hospital Research and Development Department (HRDD). Funding was obtained after application to the Leicestershire cancer research charity 'Hope Against Cancer' for a Nursing Fellowship. This funding facilitated a clinical nurse specialist trained in oncology and palliative care, to participate in the project on a part-time basis. It also covered the costs of the 'back translation' of questionnaires and various running costs. LCC charitable funds facilitated the participation of two radiographers to recruitment of BSA patients. Project members completed 'Good Clinical Practice' training annually and received 'patient consent' training from the HRDD.

Permission was sought from all oncology consultants for patients under their care to be approached to participate. Nurses and clinic receptionists in out-patient clinics and clinical areas within the department were introduced both to the research subject and activities of project members through informal meetings.

#### **4.4 Pilot study and substantive changes**

A pilot study of ten patients was undertaken. This confirmed the experience of previous ethnicity studies in the department. Recruiting BSA patients was difficult. Until this stage an informal arrangement existed for two BSA radiographers to bridge the language barrier during the recruitment process. However it was difficult to release them from professional duties. Through liaison with the Clinical Director and Radiographer Manager of the LCC the BSA radiographers became funded members of the research team.

The original question “Do you believe you have cancer” produced 100% ‘yes’ comment in the ‘Patient’s Knowledge of Illness” section of the questionnaire. Given the question “I do not believe I have cancer” was already incorporated in the CIDQ questionnaire, this was replaced by a global question “What does (having) cancer mean to you?” having been adopted from a Taiwanese study (Dodd et al. 1985). Two additional questionnaires were added for the main study, the ‘Brief Patient Health Questionnaire’ (BPHQ) and the patient/physician trust and cancer beliefs. Questionnaires were retranslated at this point.

## **Section 5: Statistical methods**

### **5.1 Statistical analysis**

PASW version 18 software analysed the data. The software and Microsoft Excel generated tables and figures. Initially, to determine the minimum required sample size per ethnic group, a 2-tailed t-test study was computed using the power calculation  $N = \frac{[A+B]^2 * (p_1*(1-p_1)) + (p_2*(1-p_2))}{[p_1-p_2]^2}$ . Given an alpha level of 0.05, an anticipated effect size of 0.5 and a desired statistical power of 0.9, the minimum total sample size required was 172, 86 for each ethnic group.

All variable datasets were assessed to ensure no violation of normality, linearity and homoscedasticity. Normality of distribution was analysed by the Kolmogorov-Smirnov statistic, histogram or box plot and whisker, while linearity and homoscedasticity was assessed by scatterplot. Since the vast majority of data sets were abnormally distributed and the BSA sample at nine months was small, non parametric tests predominate in these analyses. Throughout the statistical significance level was considered as 2-tailed and  $p=0.05$  was retained as the level of significance.

#### **'Collapsing' data**

Patient responses from questionnaires such as Cancer Beliefs and Patient/Physician Trust were originally in five categories. These were collapsed to disagree, no view and agree for ease of analysis without compromising the integrity of the data. A further example includes indicators of trust which were

collapsed into binary form (0 =unsure and mistrust; 1=trust) to compute predictors of trust.

Binary and linear scores for HADS D $\geq$ 8, PHQ-9 and the ET, DepT. were identifiers for depression and HADS A  $\geq$ 8 and the ET, AnxT for anxiety. The DT was used to analyse longitudinal patterns of distress. Threshold scores were indicated by stating the assessment tool with threshold score, for example, HADS A  $\geq$ 8 and PHQ-9  $\geq$ 10. When linear scores are used in the analysis it was indicated by the absence of a threshold score.

## **Statistics**

Computation of frequencies, percentages and arithmetic median were conducted to identify patterns in the data. Since the continuous variables were abnormally distributed and the final data collection point had a low BSA sample, the median and interquartile range (IQR: 25%,75%) were identified. Wilcoxon Signed Rank Tests were performed for 'age' and 'deprivation' to compare the magnitude and direction of differences between the ethnic groups.

Mann Whitney U Tests were performed to quantify differences between two independent samples in relation to a continuous variable. The test compares median scores by converting the scores on a continuous variable to ranks across the categorical variable and detects whether the ranks for the two groups differ. The effect size was calculated as follows

$(r=z^2/\sqrt{\text{total number of cases}})$ . The Cohen criterion indicated the relative magnitude of the scores being compared (Cohen 1988). Chi <sup>2</sup> tests ( $X^2$ ) for

independence identified associations of significance between categorical variables with two or more categories. The Yates Continuity Correction was quoted for 2x2 tables. When the sample number was lower than six the Fisher's Exact Probability Test (FET) was performed. For 2x3 tables  $X^2$  tests denote trends of association.

The Spearman's Rank Order Test ( $\rho$ ) was selected to explore correlations between two continuous variables. For example it described the strength and direction of the relationship between depressive symptoms (HAD-D, PHQ-9 and DepT) and selected demographic variable such as deprivation and age. The coefficient of determination (the extent to which the variance was shared) was calculated.

Friedman Tests identified changes in anxiety and depression and the cognitive and emotional representations of cancer longitudinally across the study period within each ethnic group. The level of significance for the latter tests was maintained at 0.05 rather than using the Boniferroni adaption.

### **Predictors**

Multi-variable logistic regression modelling identified predictors of anxiety and depression. Data was coded so that 0 was assigned to the absence of a characteristic of interest. HADS A and D with a threshold of 7v8 were dependent variables. Data representing the whole sample and again for each ethnic group were analysed. Each variable was entered singly to identify their potential contribution to a model. The most significant single variables were

entered together using an iterative process to create the 'best fit' model of greatest predictive value.

The same statistical tool identified which physical or psychological issues predicted distress. The DT checklist was analysed with the DT 3v4 as the dependent variable. Models were generated for physical/social issues and then separately for psychological/spiritual factors.

A retrospective audit examined whether those with higher levels of anxiety and depression across the study period were identified in the clinical setting and what action was taken. The patients identified were all those who had completed all questionnaires or one and three.

### **Coping strategies**

Data from the first questionnaire was analysed to examine whether a patient's ethnicity, age, gender and other demographics influenced the psychological outcomes of anxiety and depression. The frequencies and percentages relating to the incidence of both outcomes were calculated.

Data from three points in time was analysed to indicate the use of coping strategies. Coping styles were represented by the Mini Mac and CIDQ summary scores as continuous variables at three points in time. Binary scores of the following assessment tools were used: PHQ-9  $\geq 10$ , HADS D  $\geq 8$ , DepT  $\geq 4$  (ET), HADS A  $\geq 8$  and the AnxT  $\geq 4$  (ET).

In addition to calculating relevant frequencies and percentages, Mann Whitney U tests using different assessment tools examined ethnic differences in coping. Longitudinal trends were illustrated by comparing the median scores of both ethnic groups with 95% Confidence Intervals (CI). Where absent on those graphs the CI was zero. Mean rank scores were tabulated to indicate subtle ethnic differences. Comprehensive details were tabulated in the appendices. Although Friedman Tests were performed only two results warranted reporting (Appendix 3.3).

### **Cognitive and emotional representations of illness (BIPQ)**

For each item of the BIPQ, the sample number, median and IQR for both ethnic groups was recorded for the three data collection times (see Appendix 6.10.2). Since the data was predominantly abnormally distributed, MW tests compared scores between ethnic groups to identify differences. Median scores are reported. Mean rank scores were tabulated. Friedman Tests analysed changes in illness representation *within* each ethnic group longitudinally. The level of significance for the latter tests was maintained at 0.05.

### **Distress Thermometer (ET)**

The DT 3v4 differentiated between patients with high and low scores for distress. Spearman's rank order correlation ( $\rho$ ) describes the strength and direction of associations between continuous demographic variables.  $\chi^2$  statistic identified trends in ethnic differences across scores at three points in time. The DT problem 'checklist' (physical, psychological & socio economic) was analysed as one sample and then associations between ethnic groups

were identified by  $X^2$  calculations. The percentages of patients scoring 'yes' to each 'problem' were ranked in descending order at each time interval.  $X^2$  calculations indicated differences of statistical significance between ethnic groups at each interview. Longitudinal trends between ethnic groups for each symptom across the study period were analysed by comparing percentage scores and then by  $X^2$  analysis for trend. Variables of interest are presented.

### **PHQ-9**

Two methods can be used to analyse data from PHQ-9 but the final analysis used the following threshold scores;  $\geq 10$ ,  $\geq 15$ , and  $\geq 20$  to detect symptoms of anxiety and depression.

Individual indicators of depression were analysed. With the exception of the indicator for suicidal ideation where scores  $\geq 1$  were included, scores  $\geq 2$  were summed for each of the other eight indicators for depressive symptoms. Data was generated corresponding to the times of presentation, three and nine months for each ethnic group.

## **5.2 Data analysis**

### **Coding**

Numbers were assigned to each possible response made by a patient to each question. This was initially recorded in a codebook and then logged within the SPSS software. Categorical data was converted into numbers. To facilitate a wider range of statistical analysis several continuous variables were also 'transformed' into two or more groups. Where coding was in two groups the

variable with the 'lack' of the characteristic was coded zero. There were several opportunities for free text responses which were recorded verbatim in Microsoft Word.

## **Section 6: Results**

### **6.1 Introduction**

This section describes the study results with a central focus on identifying longitudinal ethnic differences in the ways patients coped with cancer. Associations with symptoms of anxiety and depression are reported. Findings from an analysis of the knowledge and beliefs about the nature of cancer of study participants are conveyed. The degree of trust between patient and physician and the patient's preferences for that relationship are presented. Associations with psychological outcomes are reported for both cancer beliefs and patient/physician trust. How patients interpreted cancer across the study period and the causes of distress are reported together with predictors of distress. Finally the 'need for help' expressed by study participants and a retrospective audit are described.

### **6.2 Patient demographics and psychological morbidity**

This chapter describes the demographic profile of study participants and the relationship between selected demographic factors and self-reported symptoms of anxiety and depression. Ethnic differences are highlighted. Tests for normality and supporting data are tabulated in Appendix 6.2.1

#### **Place of birth and ethnic self-identity**

Just over half the BSA patients were born in the Indian sub-continent 50/94 (53.8%) (Fig 3 & Appendix 6.2.11). This figure includes two from Pakistan and one from Nepal. One person highlighted their pre-partition birthplace as 'India, now Pakistan', so it remains unclear if this refers to others in the sample. 31/94

(33.3%) were born in African states and 12/94(12.9%) in the UK. One BSA patient declined to complete their place of birth but did provide their ethnic identity.

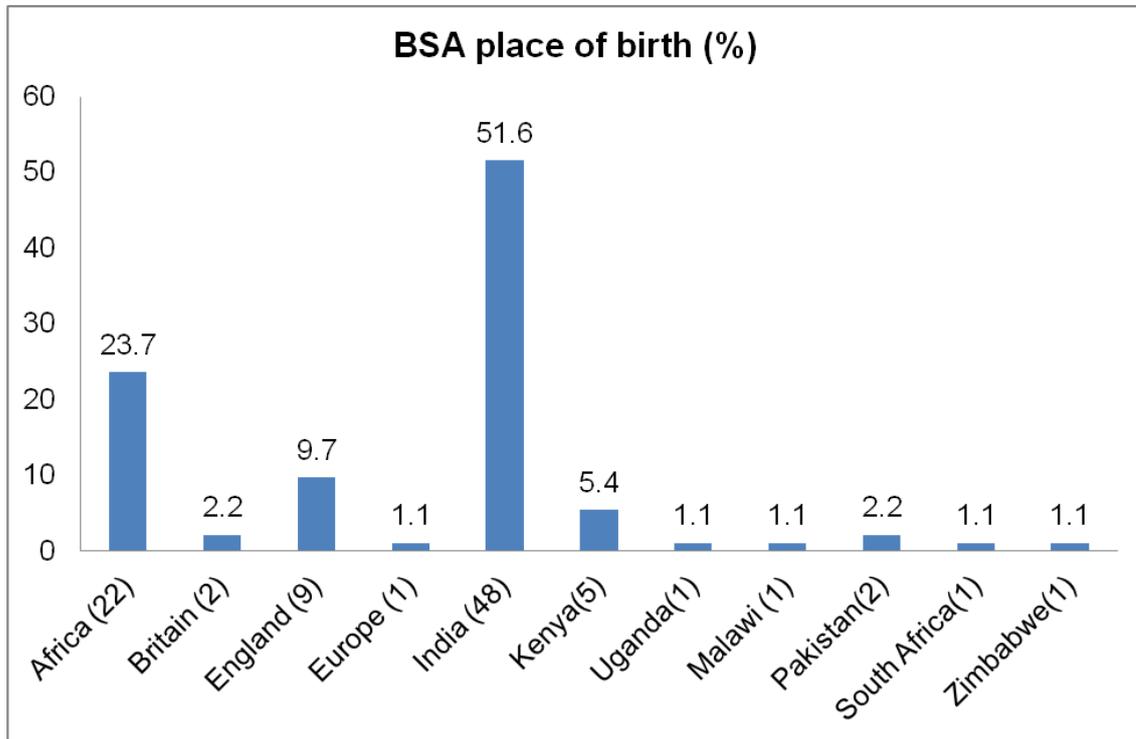


Fig 3

Analysis of self-identity among BSA patients produced some interesting results. Unsurprisingly among the 48 patients born in the state of India a high percentage, 43(89%), included a reference to India in their self-identity describing themselves as Indian (42) or British Indian (1). However family origins in the Indian sub-continent were also recognised even when it was not the birthplace of the patient. Of 94 BSA patients who volunteered their self identity, 74 (78.8%) included recognition of their family origins in the Indian sub-continent although only 50 (54%) were actually born there (Fig 3).

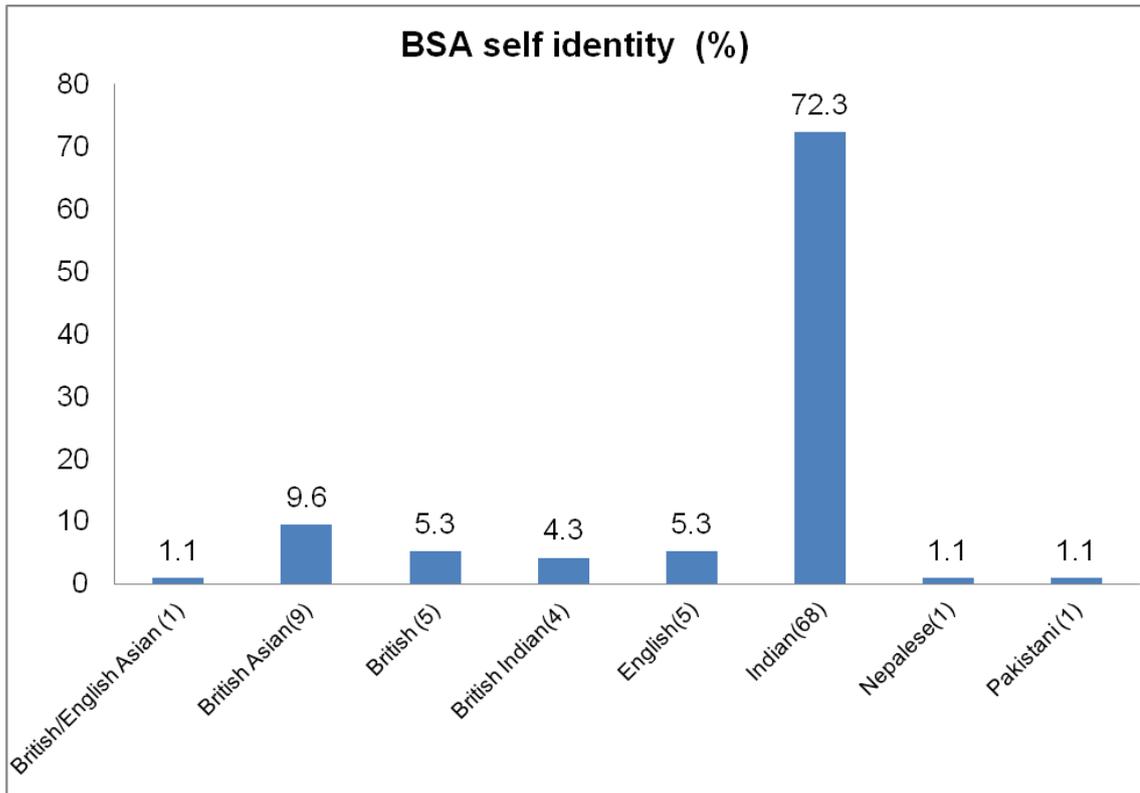


Fig 4

No BSA patients born in African countries referred to Africa in their self-description (e.g. African Asian) (Fig 4). 20/31 (64.5%) referred to themselves as Indian and the rest as either British Asian (4) British (3) British Indian (2) or English (2). In total 35% associated themselves with the UK, far more than those arriving directly from the Indian sub-continent (8%). Among the small number of BSA patients born in the UK there was a range of preferred self-identities with no clear pattern.

In spite of the fact that the terms 'Asian' and 'British South Asian' are commonly referred to in publications, only 9 (9.6%) of this sample referred to themselves as 'British Asian', one as British/English Asian and none with the prefix 'South'. The term 'Asian' used in isolation was not referred to by any BSA patient.

All but three BW patients were born in the UK and Ireland (Fig 5 and Appendix 6.2.11).

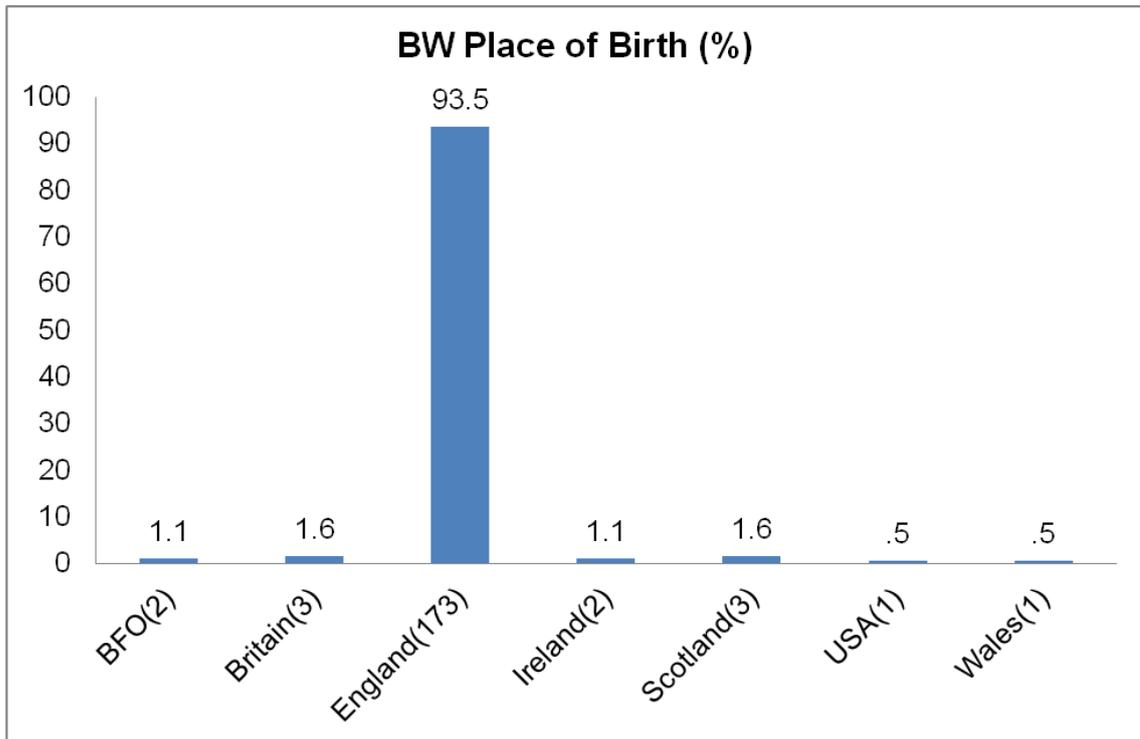


Fig 5

Those born to parents in the British Forces Overseas (BFO) were included in the UK figure. The vast majority described themselves as English, rather than British (English 162/185 (87.6%); British 15/185 (8.1%).

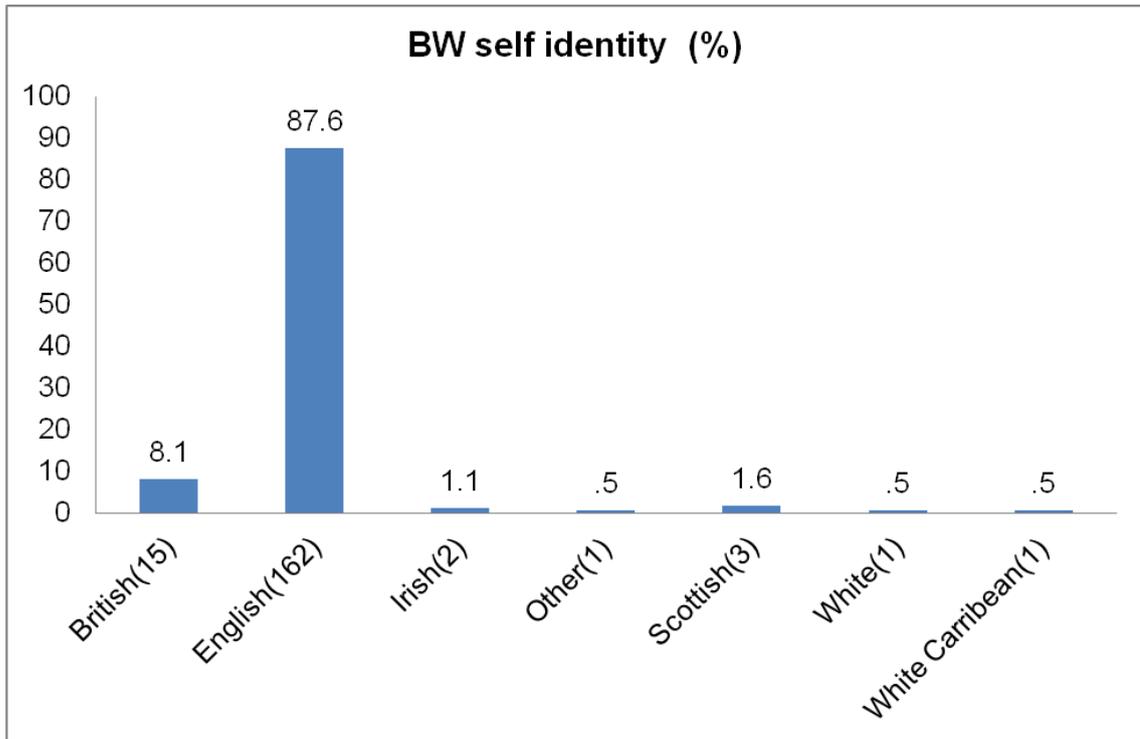


Fig 6

'Britishness' appeared to resonate among more BSA than BW patients (Fig 7). 19/94 (20.2%) BSA patients used the term 'British' as a prefix to self-description, for example, British Indian. Only 5/94 (5.3%) used the term 'English'. One might expect those BSA patients born in the UK to use the term 'British' or 'English' as part of their identity. Of the 11 BSA patients, five included the term British and two English leaving four who describe themselves as Indian (Fig 6).

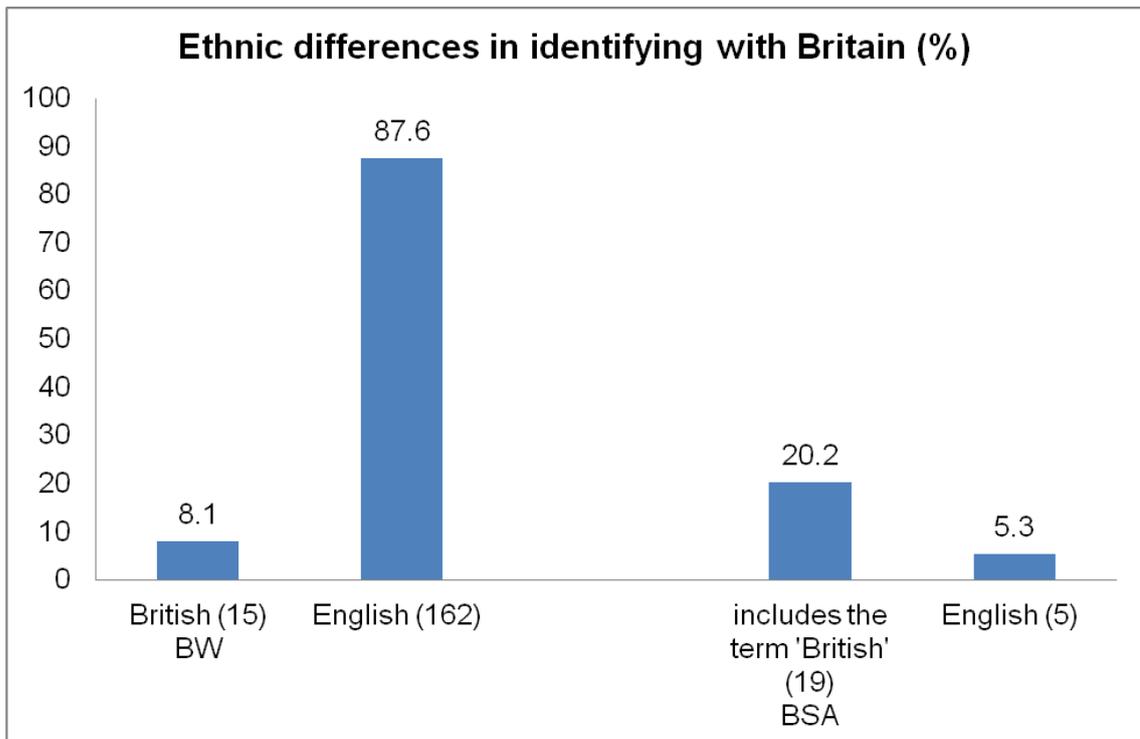


Fig 7

The study considered whether birthplace influenced the prevalence of anxiety and depression. 182/185 (98.4%) BW patients came from the UK which made analysis of that ethnic group superfluous. Within the BSA population with places of birth across three continents, analysis was possible but there were no differences in levels of anxiety and depression when three continents were considered nor when the small number from the UK were removed (Appendix 6.2.12 – 6.2.13).

### Age

The median age for the whole sample was 59 years (IQR 52-67). For BSA patients it was 57.5 years (IQR 48-67), approximately three years younger than for BW patients (61 years) (IQR 53-67) (Wilcoxon signed rank test  $Z=-14.480$   $p=0.0005$ ) (Fig 3).

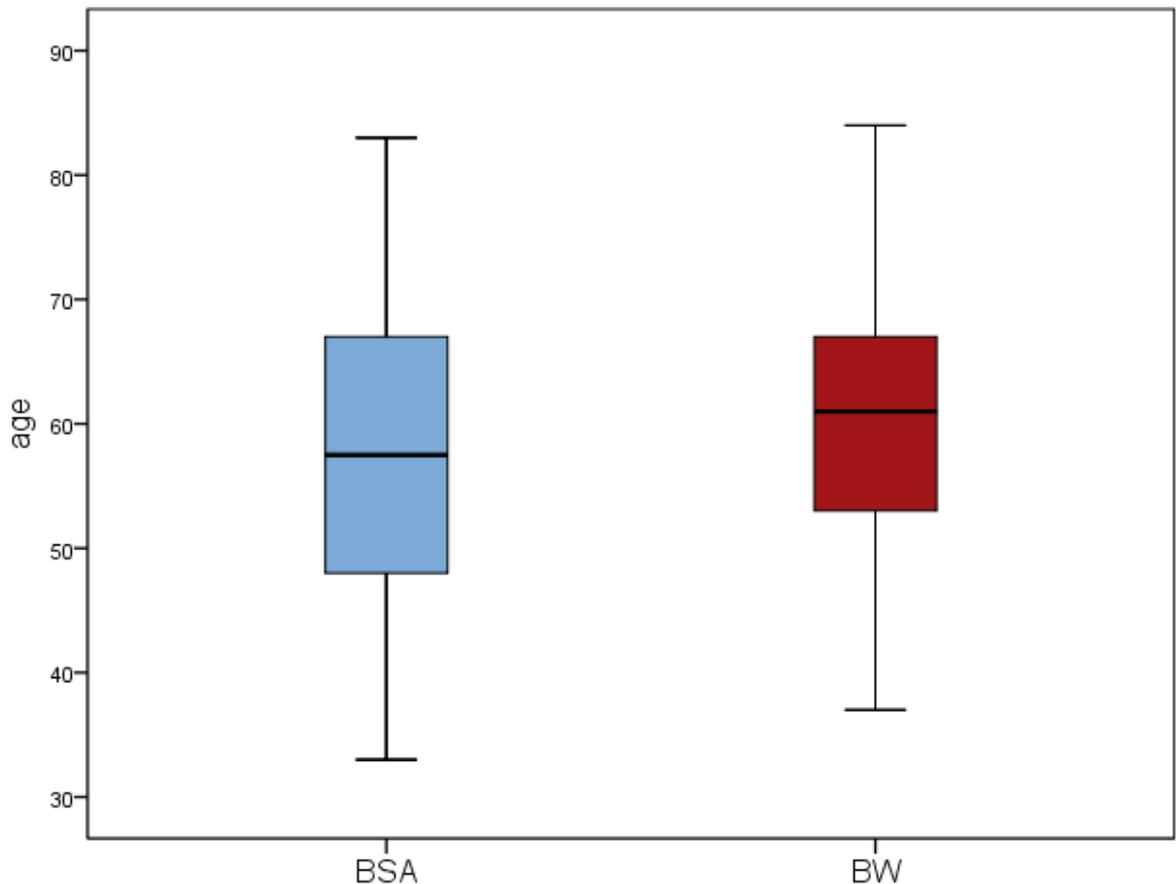


Fig 8 Distribution of age by ethnicity

Age was not associated with depression among BSA patients (rho: HADS D, (p=0.62); DepT (p=0.13); PHQ-9 linear scores; (p=0.46). Older BW patients were less likely to be depressed although the correlations across three assessment tools suggested the differences were slight (rho: HADS D (p=0.030); DepT (p=0.033), PHQ-9 linear scores (p=0.002)).

There was no significant association between age and anxiety among BSA patients (rho: HADS A (p=0.627) AnxT (ET) (p=0.380). However, there was a trend for older BW patients to report less anxiety via HADS A (rho, p=0.0005), a finding supported by the AnxT (p=0.0005) (Appendix 6.2.2).

## Gender

Female participants far outnumbered males and BSA males were represented least ( $\chi^2 = 0.233$ ) (Fig 4). At baseline females had a higher median depression score than males via HADS D but it was not statistically significant (females 4 (range 0-18) IQR 1,7) (males 3 (range 0-20) IQR 1,6)  $p=0.46$ . Depressive symptoms were experienced by 18/89 (20.2%) males and 46/190 (24.2%) females via HADS D  $\geq 8$ ,  $p=0.558$ . This was similar to findings via PHQ-9  $\geq 10$  (males 17/85 (20%) female 45/173(26%)  $p=0.36$ ). DepT. $\geq 4$  (ET) followed the same trend although more patients were assessed as anxious (males 25/85 (29.4%) females 66/177 (37.3%)  $p=0.26$ ). The latter scales did not report a significant difference between genders and the effect size was small. For example (MW:DepT.  $r= 0.109$ ; HADS D  $r=0.044$ ; PHQ-9  $r=0.014$ ).

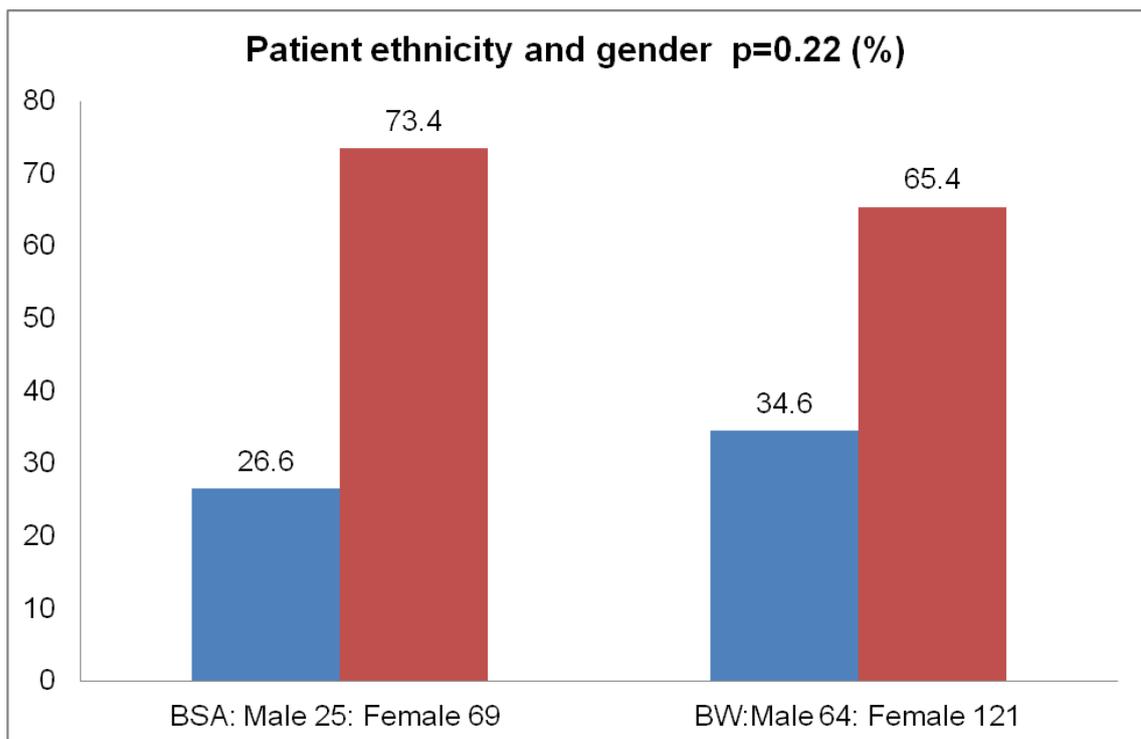


Fig 9

Females were notably more anxious than males via HADS A (Md 7 (range 0-20) IQR 4, 11) compared to males (Md 6 (range 0-21) (IQR 2,9)  $p=0.021$ ). The AnxT also reported a significant difference ( $p=0.001$ ). Anxiety affected a third of males via HADS A  $\geq 8$  30/89, (33.7%) and just under half of females (88/190 (46.3%)  $p=0.063$ . Via AnxT $\geq 4$ , the gender gap was greater with a quarter of males 39/87(25.8%) and three fifths of females feeling notably anxious (112/178 (62.9%  $p=0.008$ ) (Appendix 6.2.3-4).

There is little evidence, when analysing each ethnic group separately, to suggest a gender difference in symptoms of anxiety or depression among BSA patients although the number of male BSA patients in the sample was small. For example, HADS A  $\geq 8$ , male 10/25(40%) female 41/69 (59.4%)  $p=0.151$ , PHQ-9  $\geq 10$ , male 6/24(25%) female 24/61(39.3%)  $p=0.32$ . There was a greater risk of anxiety among BW females than males via AnxT. $\geq 4$  (male 26/ 64(40.6%) female 69/118 (58.5%)  $p=0.032$ ) but not via HADS A  $\geq 8$ , (male 20/64(31.3%) female 47/121(38.8%)  $p=0.389$ ). Other measures of anxiety and depression did not indicate gender differences.

Overall there was a trend towards females being more anxious as one sample largely due to higher anxiety among BW females but, with inconsistent results from different assessment tools, there is insufficient evidence to point to a strong association between a particular gender and depressive symptoms. Likewise there was little ethnic difference in anxiety or depression by gender in this study sample (Appendix 6.2.5).

## Diagnoses

Patients with breast cancer were the largest diagnostic group in the study (n=114). The next four groups accounted for between 45 and 19 patients.

Patients with a variety of other primary sites of cancer were represented but in small numbers (table 5).

Five primary sites had sufficient numbers to be analysed in relation to anxiety and depression. Those with lung cancer, who generally have a poor prognosis, had the highest median depression score via HADS D of 5 (IQR 3,7) on a scale of 0-21. The lowest score was attributed to people with prostate cancer (Md 1 (IQR 0,5)). There were higher levels of symptoms of anxiety than of depression at presentation. Again those with prostate cancer had the lowest median via HADS A (Md 6 (IQR 2,7.5)). Those with gynaecological cancers had the highest median anxiety score (Md8 (IQR 5,11) (Table 5, Fig 6 and Appendix 6.2.7)

**Table 5 Diagnoses by ethnic group**

<b>Primary cancer site</b>	<b>BSA</b>	<b>BW</b>
Breast	34 (36.2%)	80 (43.2%)
Colorectal	15 (16%)	30 (16.2%)
Gynaecology	19 (20.2%)	15 (8.1%)
Prostate	3 (3.2%)	20 (10.8%)
Lung	6 (6.4%)	13 (7.0%)
Head and neck	5 (5.3%)	4 (2.2%)
Bladder	1 (1.1%)	7 (3.8%)
Gastric	3 (3.2%)	4 (2.2%)
Oesophagus	1 (1.1%)	6 (3.2%)
Brain	1 (1.1%)	2 (1.1%)
Hepatobiliary	2 (2.1%)	1 (.5%)
Pancreas	0	2 (1%)
Lymphoma	2 (2.1%)	0
Peritoneum	1 (1.1%)	0
Sarcoma	1 (1.1%)	0
Melanoma	0	1 (.5%)

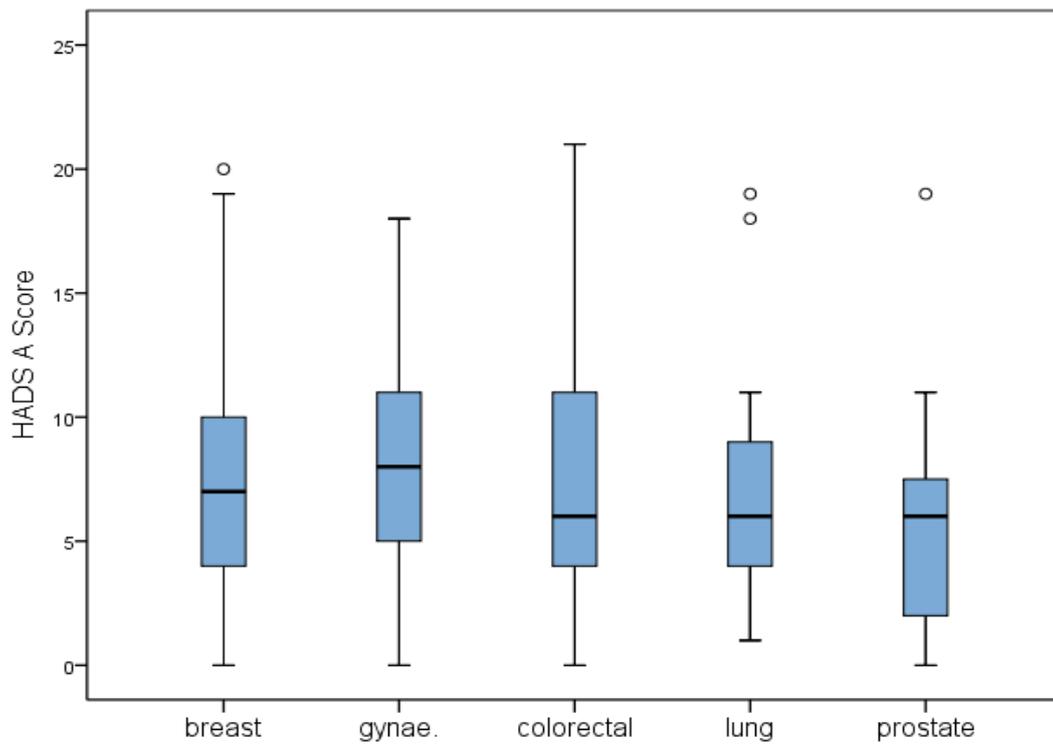


Fig 10 Comparison of anxiety scores by selected cancer primary sites

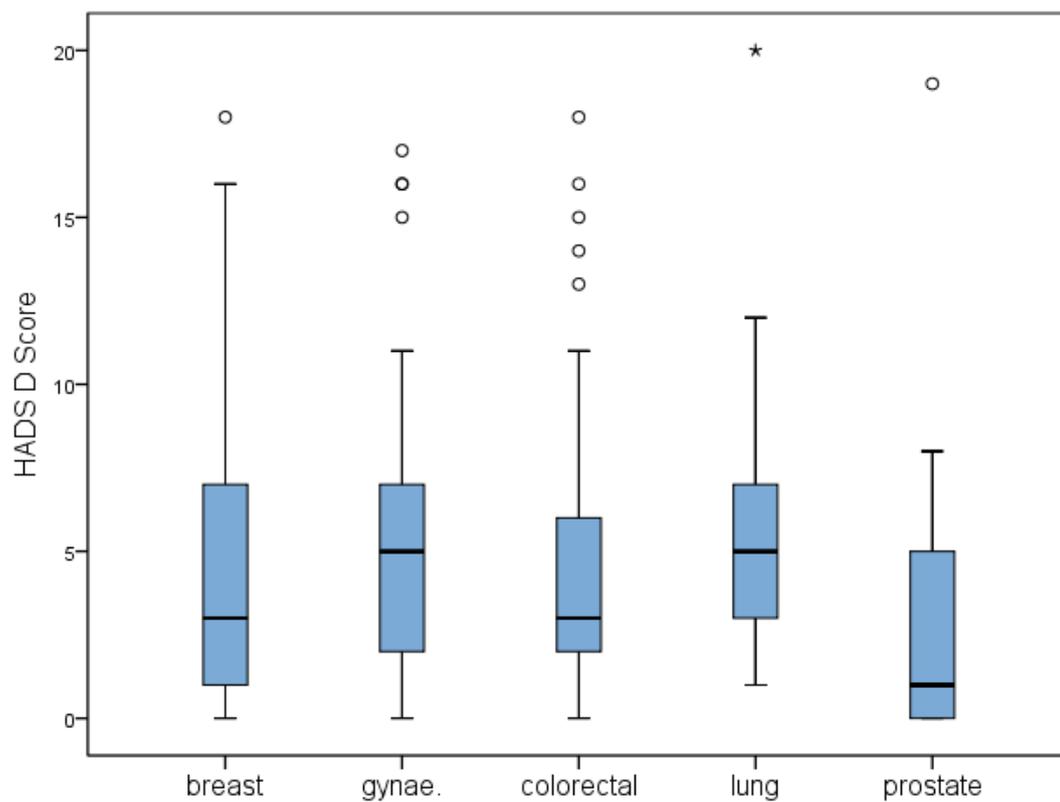


Fig 11 Comparison of depression scores by selected primary cancer sites

## Treatment intent

Patients presented at the LCC at various stages along the cancer pathway.

188/279 (67.4%) patients received radical treatment with the aim of cure or long term control of disease. Palliative treatment is given to improve quality of life with no expectation of cure and was relevant for 91/279 (32.6%) participants.

For patients with recurrent disease the onset of recurrence was considered to be the onset of disease. Ethnicity did not influence whether an individual had radical or palliative treatment since both ethnic groups had the same percentages of patients in either category (BSA radical 64/94 (68.1%), palliative 30/94(31.9%), BW radical 124/185(67%) palliative 61/185(33%)  $p= 0.96$ ) (Table 6 & Appendix 6.2.8).

**Table 6 Longitudinal treatment intent for one sample and by ethnic group**

Time	Type of Treatment	Whole sample n= (%)	BSA (%)	BW (%)	X <sup>2</sup>
<b>Baseline</b>	Sample	279	94	185	$p=0.96$
	Radical Palliative	188 (67.4) 91 (32.6)	64 (68.1) 30 (31.9)	124 (67.4) 61 (33)	
<b>3 months</b>	Sample	204	51	138	$p=0.47$
	Radical Palliative	136 (66) 68 (33.3)	40 (80) 16 (32)	96 (66.6) 52 (37.6)	
<b>9 months</b>	Sample	147	31	116	$p=0.29$
	Radical Palliative	105 (71.4) 42 (28.2)	25 (80.6) 6 (19)	80 (68) 36 (31)	

There was no consistent evidence that treatment intent was associated with anxiety or depression. Only HADS A generated a significant result at nine months when those receiving radical treatment were more likely to report symptoms of anxiety than those receiving palliative treatment (HADS A  $\geq 8$

radical 40/111 (36%) palliative 8/45(17.8%)  $p=0.041$ . Unexpectedly, knowing one was incurable did not appear to affect patients emotionally more than those receiving radical treatment who had the hope of full recovery from cancer (Appendix 6.2.9 – 6.2.10).

## Deprivation

The distribution of deprivation scores for each ethnic group was abnormal (Fig 12 & 6.2.14). The median of deprivation for the whole sample was 13 (IQR 7,17) (highest deprivation =1 and lowest = 20). BSA patients were far more likely to experience deprivation than BW patients (BSA Md 6.5(IQR 4,10) BW 16 (IQR 11,18) (Wilcoxon Signed Rank Test  $Z=-14.435$ ,  $p=0.0005$ ).

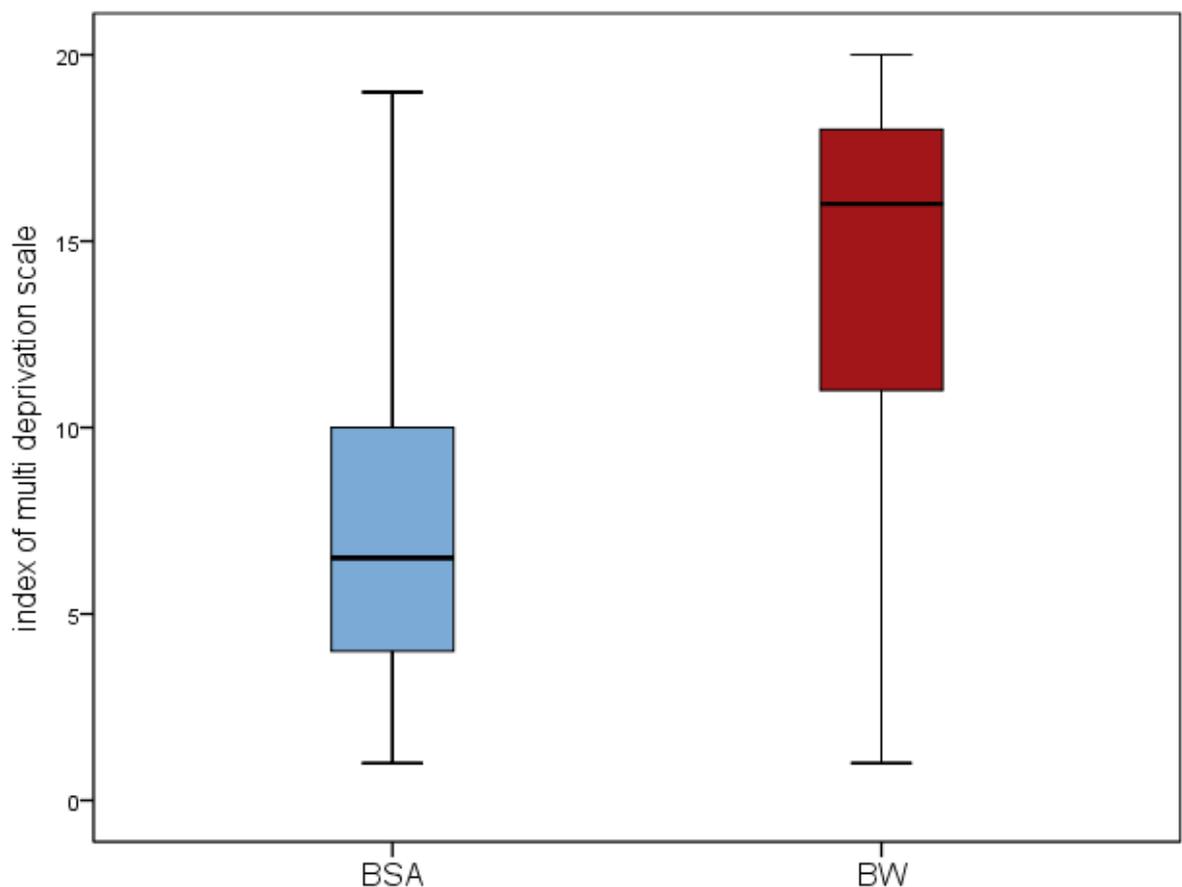


Fig 12 Patterns of deprivation by ethnicity

There appeared to be no associations of significance between either ethnic group and anxiety or depression using five scoring tools. The exception is via PHQ-9 where BSA patients with higher scores of affluence were associated with fewer depressive symptoms ( $p=0.021$ ) (Appendix 6.2.14).

When collapsing the deprivation scores into three groups (1-6; 7-14; 15-20) there was an association between higher deprivation (lower scores on the Indices of Deprivation Scale) and more depressive symptoms (PHQ-9, 1-6, 20/62 (32.3%) 7-14, 24/83(38.7%) 15-20, 18/113(29%)  $p=0.022$  for trend), but this was not supported by other assessment tools. There was no association between deprivation and anxiety (Appendix 6.2.15). It was important to determine whether differences in anxiety and depression were explained by ethnicity or deprivation since phenomena overlap. Partial correlation analysis was performed (p 136).

### **Educational attainment**

There was a clear difference in the educational profiles of BSA and BW patients (Fig 13). More BSA than BW patients had no formal education (BSA 27/94 (28.7%); BW 3/185 (1.6%)). At the other end of the educational spectrum, more BW patients had received a university or college education (BSA 33/94 (35.1%);

BW 82/185 (44.3%),  $p=0.0005$  for trend) (Appendix 6.2.16).

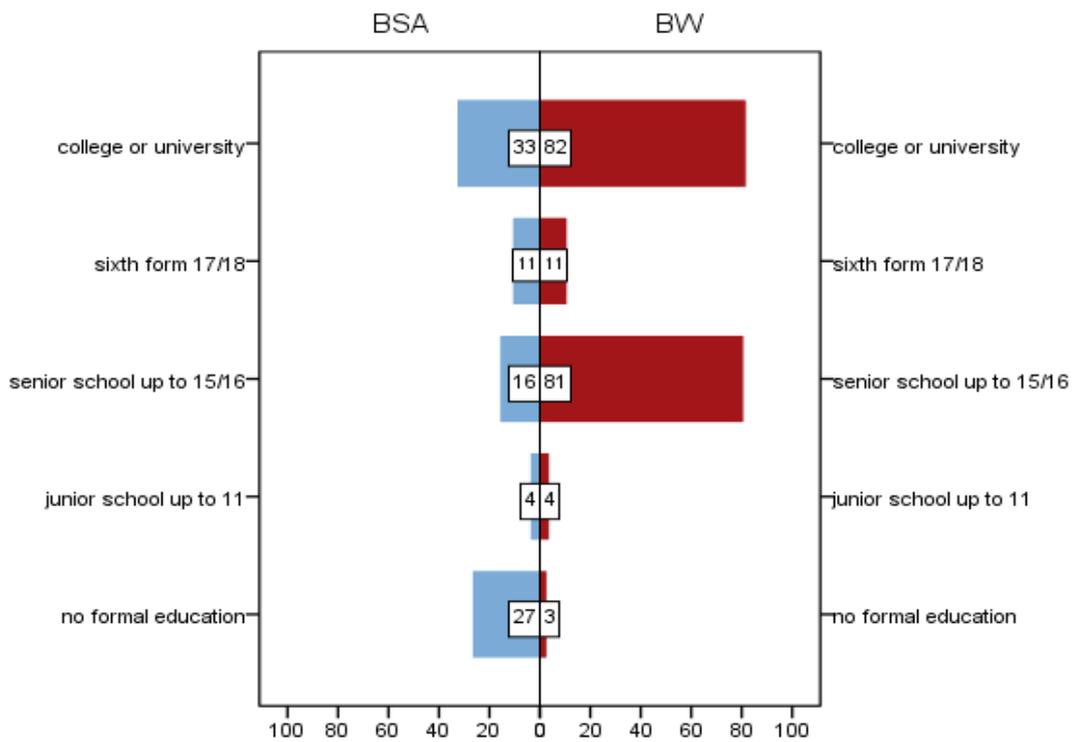


Fig 13 Educational attainment by ethnicity

Data on educational attainment was recoded into two groups with those patients reaching educational level of 15/16 removed. This created a 2x2 table representing groups at either end of educational attainment, the sample sizes being unbalanced. Those educated at the highest level had notably less depressive symptoms than those with either no formal education or only until up to the age of 11 (HADS D  $\geq 8$ , Lowest Ed. 14/30 (46.7%); Highest Ed. 18/97 (18.6%)  $p=0.004$ ; PHQ-9  $\geq 10$ ; Lowest Ed. 12/28 (42.9%); Highest Ed. 18/91(19.8%)  $p=0.027$ ). Those with education at sixth form or above were less likely to report symptoms of anxiety via HADS A  $\geq 8$  (Lowest Ed. 18/30 (60%); Highest Ed. 37/97(38.1%)  $p=0.057$ ) although both groups had similar results

using AnxT (Lowest Ed. 15/27 (55.6%); Highest Ed. 52/96 (54.2%)  $p=1.0$ ).

These results should be treated with caution given the analysis is oversimplified and the educational systems of India and the UK are different (Appendix 6.2.17-18).

### Interval between diagnoses to completion of first questionnaire (IDcFQ)

The median time from diagnosis to completion of the first questionnaire was 7 weeks (IQR 5,8). BW patients returned the questionnaire sooner than BSA patients (BSA Md 8 weeks, IQR 7,10,  $n=94$ ; BW Md 6 weeks (IQR 5,8)  $n=185$ , (Fig 14).

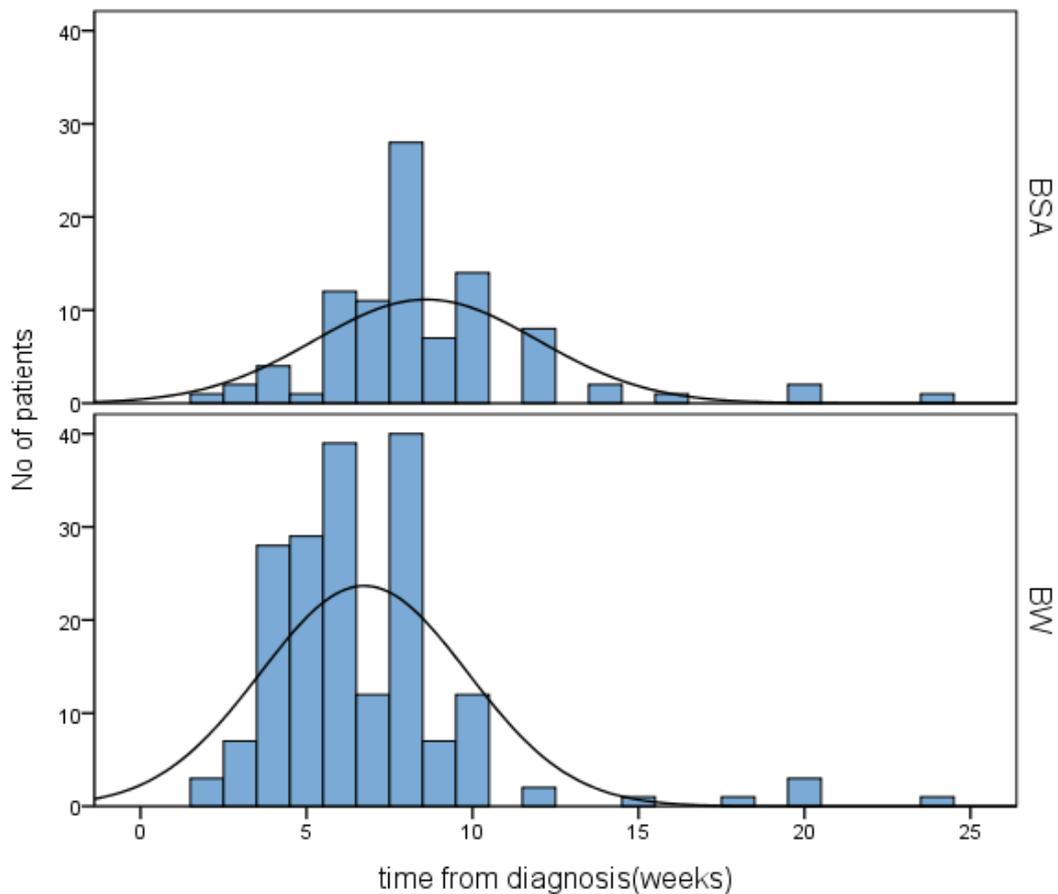


Fig 14 Time from diagnosis to completion of first questionnaire by ethnic group

Among BSA patients there was a weak positive correlation between TDcDQ and anxiety (HADS A) with a longer interval being associated with lower anxiety (Spearman's Rank Order Correlation  $n=94$ ,  $\rho=.220$ ,  $p=0.033$ ). This was not observed among BW patients as a trend ( $\rho=0.58$ ,  $p=0.431$ ). These results were not replicated using the AnxT ( $n=182$ ,  $\rho=0.012$ ,  $p=0.871$ ).

There were ethnic differences between TDcDQ and depression. A longer time gap was associated with lower depression for BSA patients (HADS D:  $n=94$ ,  $\rho=.208$ ,  $p=0.044$ ). There was no trend among BW patients (HADS D:  $n=185$ ,  $\rho=-.001$ ,  $p=0.988$ ) or via the DepT ( $p=0.915$ ) (Appendix 6.2.19 – 6.2.20).

### **Religion**

The majority of BSA patients described themselves as Hindu (53.2%) reflecting the large number of people whose self-identity is associated with India where Hinduism is the predominant religion. The next most common group was Muslim (25.5%). Of interest is that 100% BSA patients affiliated themselves with a religion in contrast to 81.6% of BW patients. With the small number of Muslim patients it was not possible to detect whether religion influenced the degree of psychological morbidity (Appendix 6.2.21).

### **6.3 Longitudinal change in anxiety and depression**

The longitudinal changes in anxiety and depression are reported for one sample and between ethnic groups. Five assessment tools were used to analyse data from the first questionnaire (baseline) the aim being to establish whether the tools indicated similar trends. Individual indicators of depression

via PHQ-9 are considered and the influence of socio-economic deprivation reported.

### **Longitudinal depression in one sample**

Just under one quarter of study participants were struggling with depressive symptoms at baseline via HADS D  $\geq 8$  and PHQ-9  $\geq 10$  (22.9% and 24% respectively). A higher figure of 34.7% was generated via DepT  $\geq 4$ . Moderate to severe depression affected 8.9% (PHQ9  $\geq 15$ ) and 2.3% had severe symptoms (PHQ-9  $\geq 20$ ). Using the higher HADS D threshold of  $\geq 11$  to denote 'moderate to severe' depressive symptoms, the figure was 12.2%. (Appendix Fig 15 & Appendix 6.3.1). At baseline median depression for one sample (n=279) via HADS D was 4 (IQR 1, 7) range 0-20.

By three months, the percentage of patients with depression had not changed significantly (HADS-D  $\geq 8$ , 27.9%; PHQ-9  $\geq 10$ , 27.6% and DepT  $\geq 4$ . 35.4%. 12% via PHQ-9  $\geq 15$  had 'moderate' symptoms of depression with HADS D  $\geq 11$  reported 11.4%. 4.8% were severely affected (PHQ-9  $\geq 20$ ).

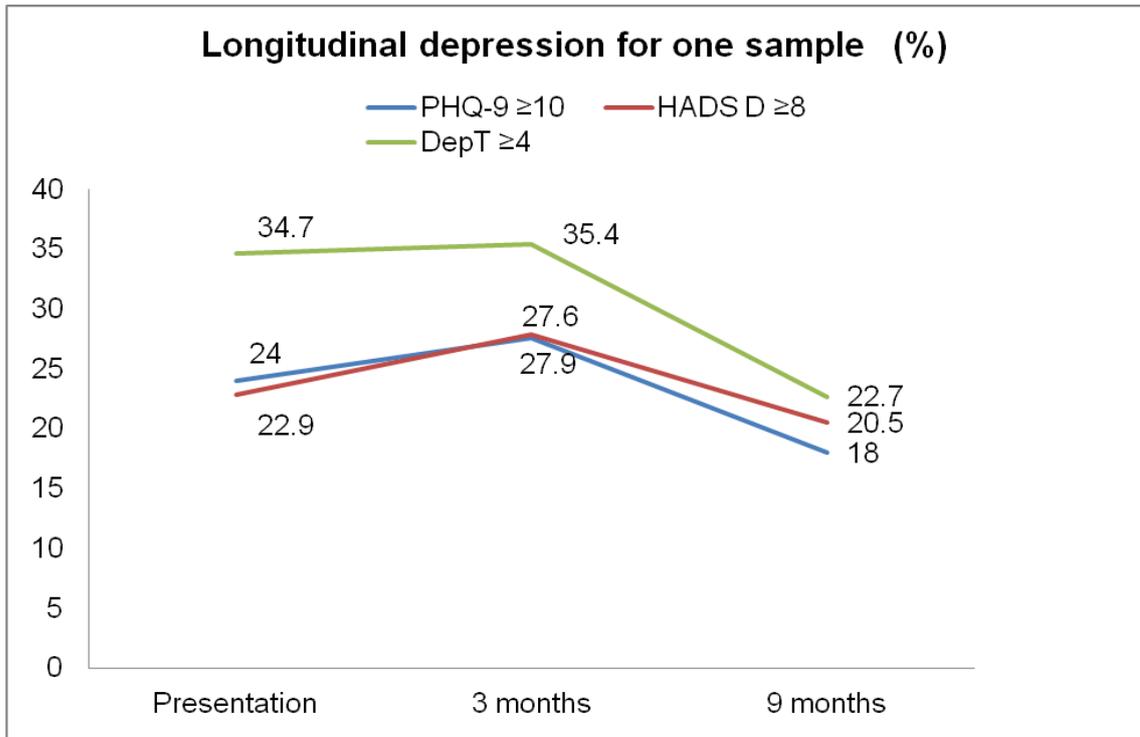


Fig 15

By nine months, the proportion with depression had slightly decreased although approximately one fifth of patients were still suffering (HADS-D  $\geq 8$  20.5%; PHQ-9  $\geq 10$  17.5% and DepT 22.7%). Those with moderate depressive symptoms accounted for 7.2% (PHQ-9  $\geq 15$ ) and 14% (HADS  $\geq 11$ ) with severe depressive symptoms affecting 2.8% (PHQ-9  $\geq 20$ ).

### Longitudinal anxiety in one sample

A far higher proportion of patients felt anxious rather than depressed at baseline with similar results being reported via HADS A  $\geq 8$  and AnxT  $\geq 4$  (42.3% and 43% respectively) (Fig 16 and Appendix 6.3.2). Moderate to severe anxiety was experienced by 24% of patients (HADS  $\geq 11$ ). At this time the median score for anxiety via HADS A was 7 (IQR 3.5, 10) range 0-21. By three months these figures had fallen slightly to 36.8% via HADS A  $\geq 8$  but were higher via AnxT  $\geq 4$

at 48.9%. By nine months, approximately a third of patients remained anxious (HADS A $\geq$ 8 30.8%; AnxT 35.3%).

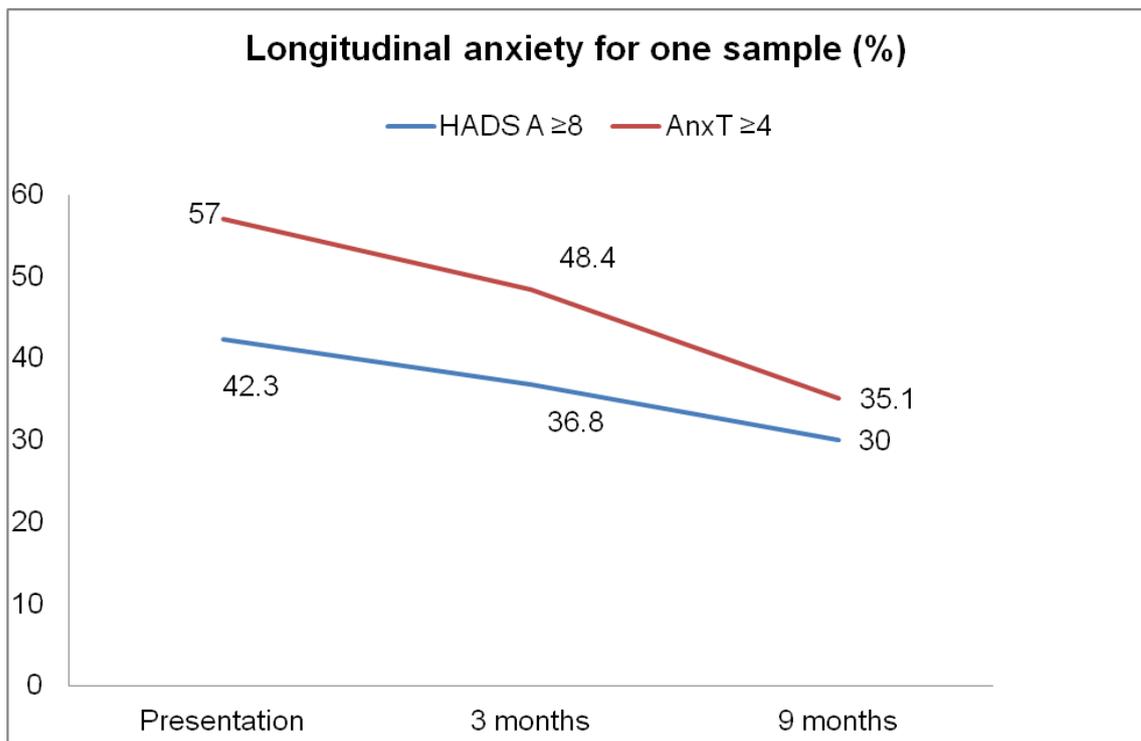


Fig 16

### Ethnic differences in anxiety and depression early after diagnosis

BSA patients experienced more psychological morbidity than BW patients early after their cancer diagnosis. Specifically over one third of BSA patients had depressive symptoms in contrast to just over one sixth of BW patients (HADS D  $\geq$ 8; BSA 33/94(35.1%); BW 31/185 (16.8%)  $p=0.001$ ). This was consistent with findings in a smaller sample via the PHQ-9  $\geq$ 10 ( $n= 258$ ; BSA 30/85 (35.3%); BW 32/173 18.3%  $p=0.005$ ) (Fig 17). Similarly with a higher HADS threshold ( $\geq$ 11), identifying those with more severe depressive symptoms, BSA patients were also over-represented (BSA 23/94 (24.5%); BW, 11/185 (5.9%)  $p=0.0001$ ). Figures for depression were significantly higher ( $\chi^2$ ) using the DepT

than via HADS-D or PHQ-9 using the aforementioned threshold scores (Fig 18 & Appendix 6.3.3).

Further analysis confirms the vulnerability of BSA patients to developing depressive symptoms. The median depression score via HADS D was higher than for BW (BSA n=94, Md 5 (IQR 2,10) range 0-20; BW n=185, Md 3 (IQR1,6) range 0-19). There was a significant ethnic difference with p (2-tailed) =0.0005. MW Tests concurred (Appendix 6.3.5).

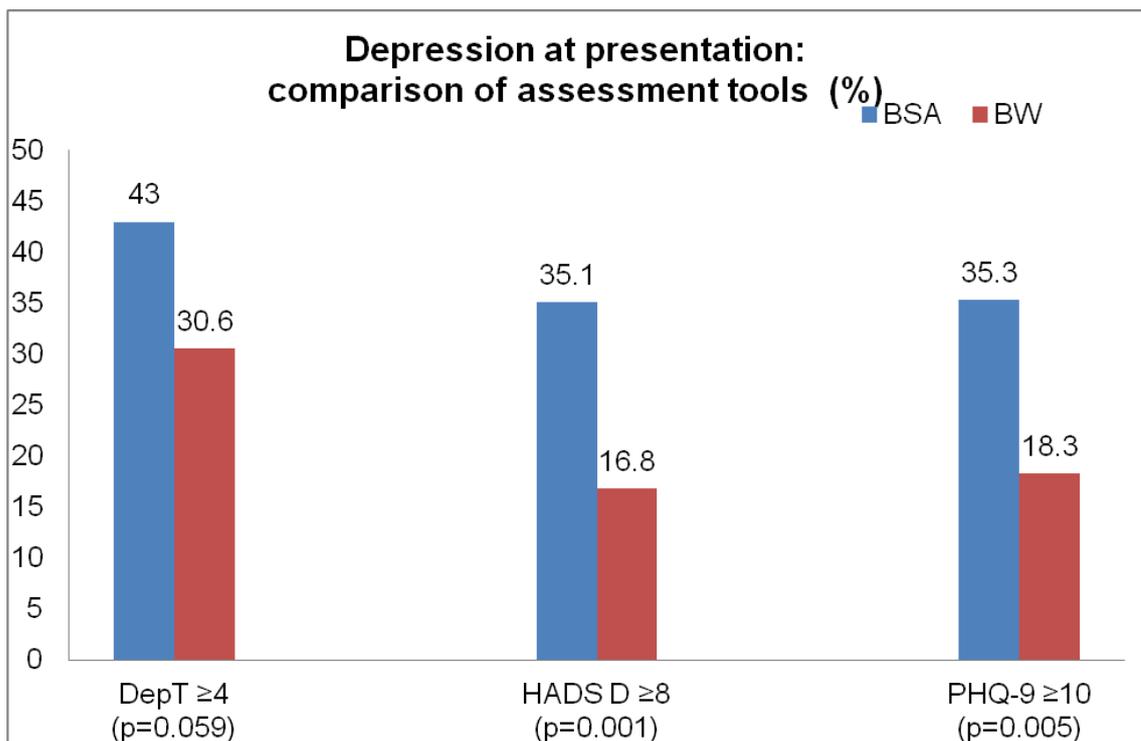


Fig 17

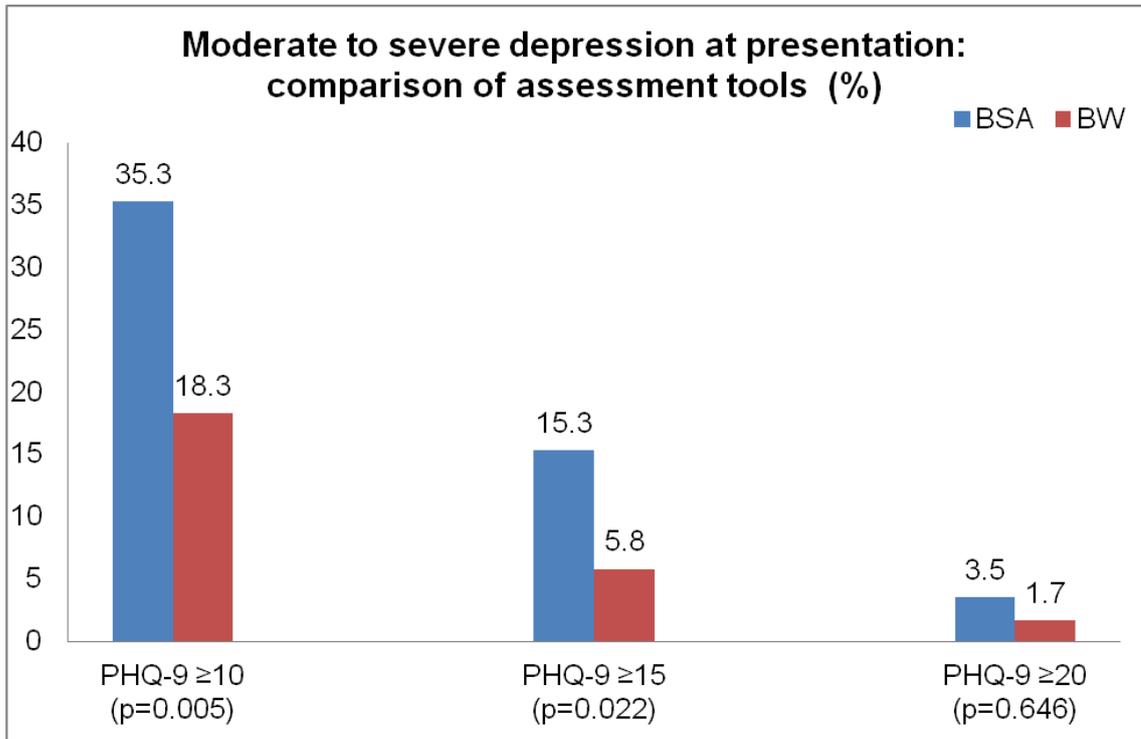


Fig 18

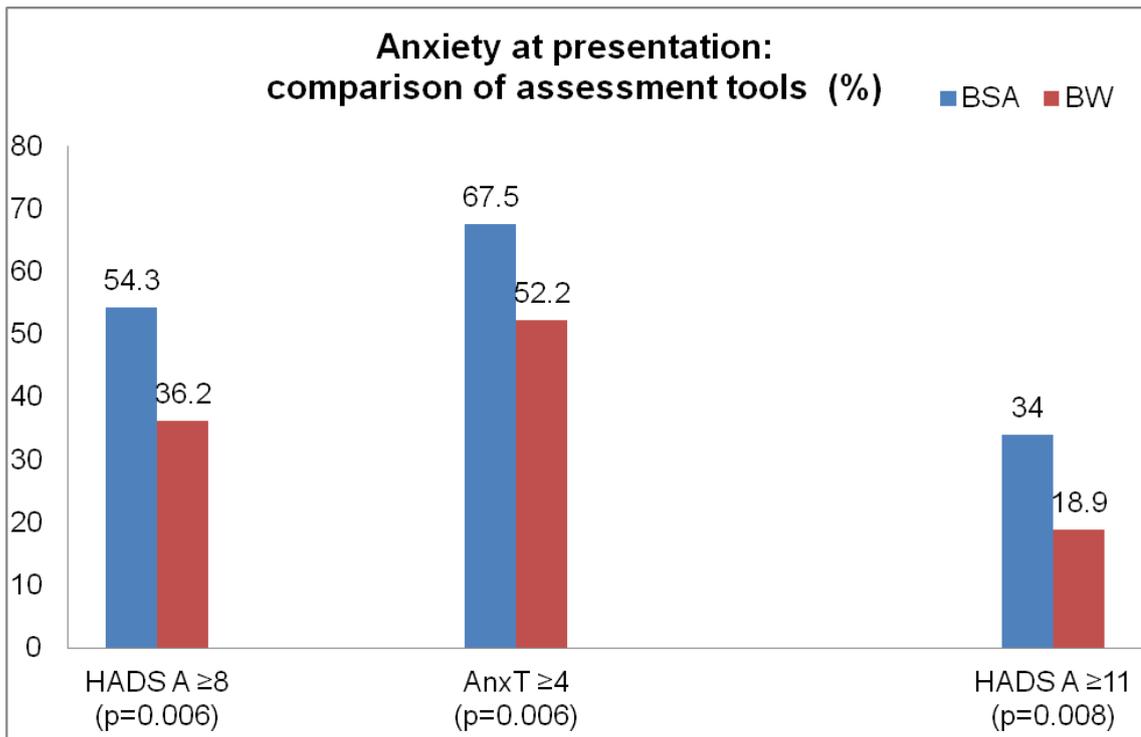


Fig 19

Following the trends in depressive symptoms more BSA patients than BW patients were anxious via HADS A  $\geq 8$ ; (BSA 51/94 54.3%; BW 67/185 36.2 %  $p=0.006$ ) (Fig 19 & Appendix 3 6.3.4) and  $\geq 11$  (BSA 32/94 34%; BW 35/185 18.9%  $p=0.008$ ). These findings were confirmed when comparing median scores via HADS A (BSA Md 8 (IQR 4, 9) range 0-19; BW 6 (IQR 3, 9) range 0-21. The difference was significant ( $p=0.019$ ) (Appendix 6.3.5).

### **Longitudinal ethnic trends in depression**

All assessments for depressive symptoms indicated how much more vulnerable BSA patients were when compared to BW patients over time. HADS  $\geq 8$  and PHQ-9  $\geq 10$  suggested significantly higher rates of depressive symptoms among BSA patients than BW patients across the nine month study period (Fig 20-21). There seems to be a slight increase in symptoms at three months among both ethnic groups (see p 179). There was little sign of a significant decrease in depressive symptoms by nine months with the exception of BW patients via

DepT≥4 (Fig 23).

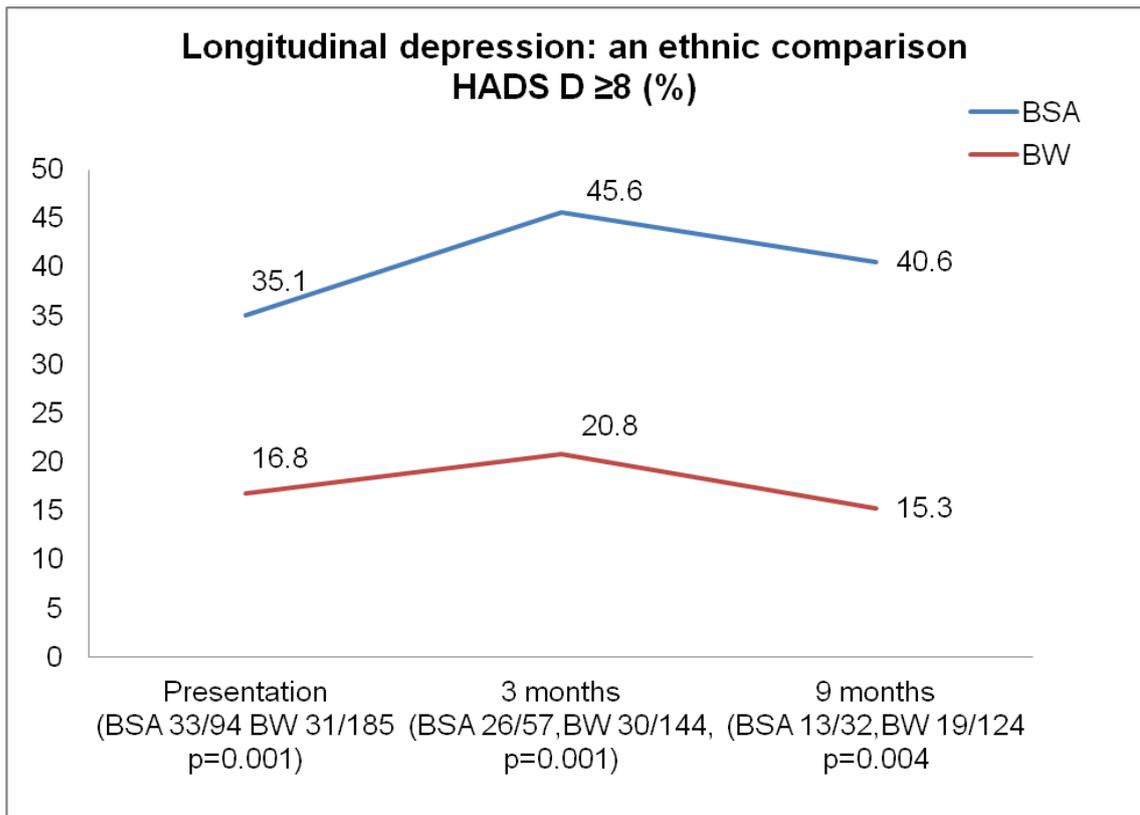


Fig 20

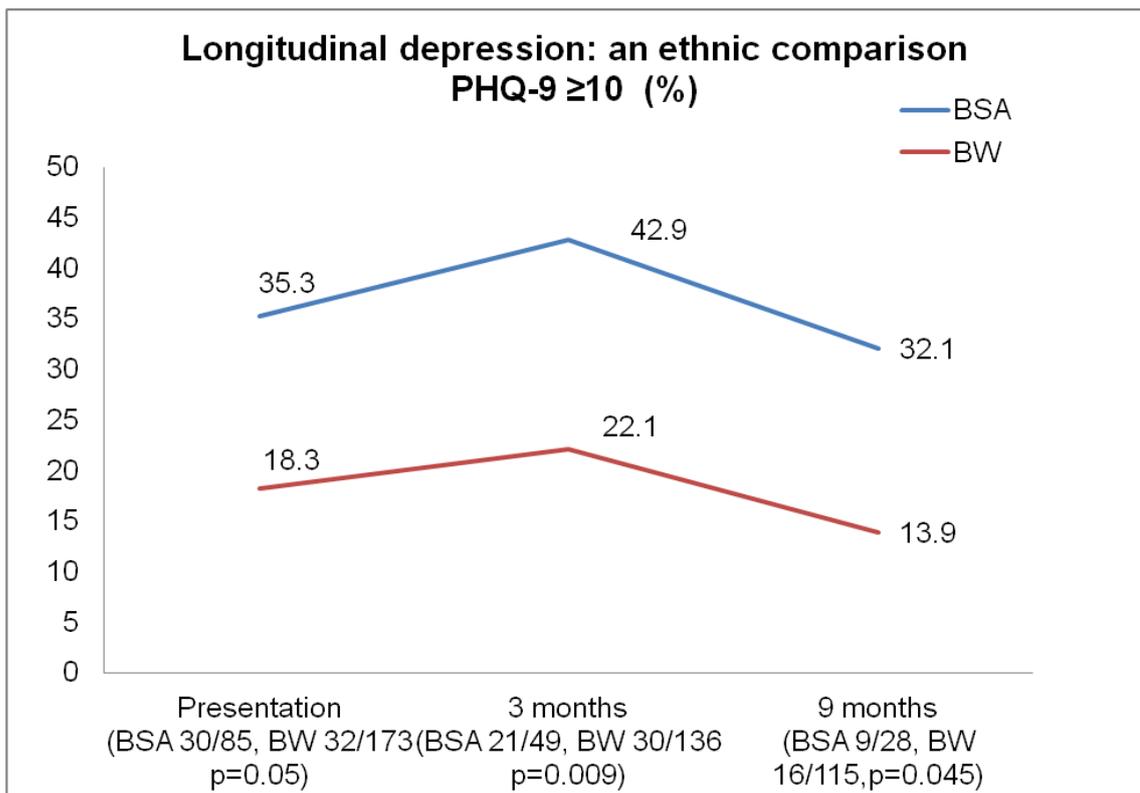


Fig 21

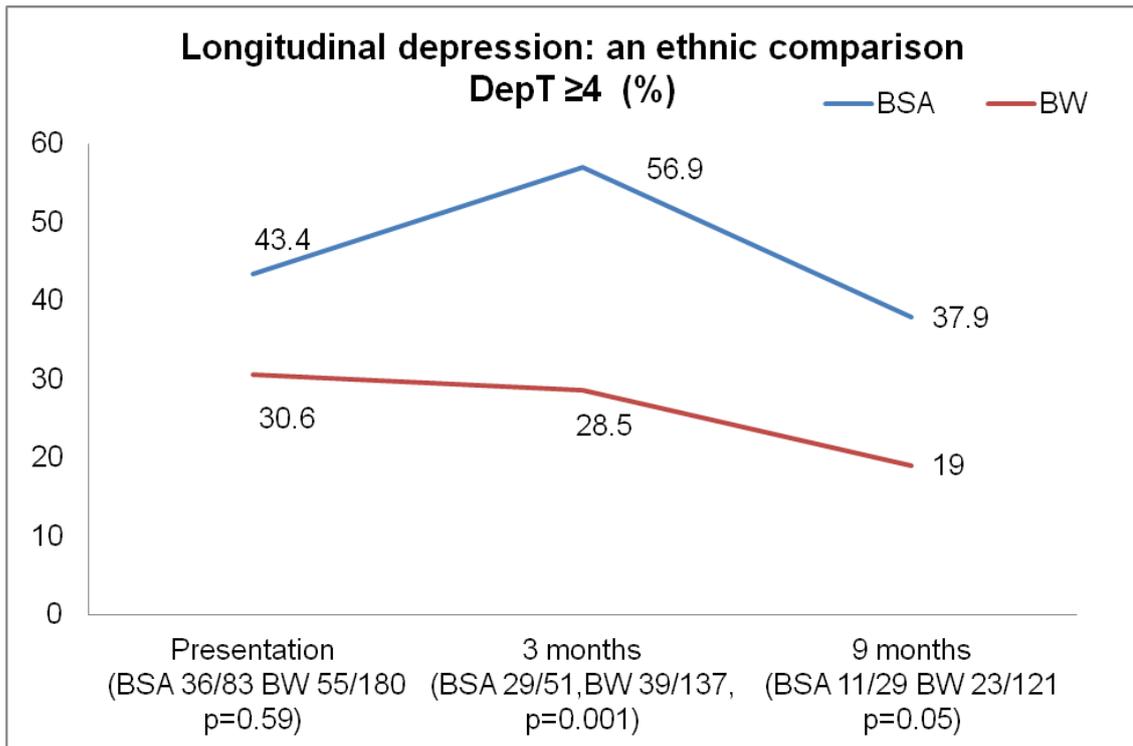


Fig 22

A higher proportion of BSA patients experienced moderate to severe depressive symptoms over time but regardless of assessment tool, ethnic differences in symptoms were not significant at these higher threshold scores, with the exception of HADS D  $\geq 11$  at baseline ( $p=0.0001$ ). The figures generated by these tools were dissimilar. For example, a consistent decrease in symptoms among BSA patient via HADS  $\geq 11$  was not reflected via PHQ-9  $\geq 15$  (Fig 23 & 24 Appendix 6.3.6). However, these figures should be treated with caution given the small number of people affected by the end of the study period. For example, at nine months 3 BSA and 7 BW patients had depressive scores  $\geq 15$  via HADS D.

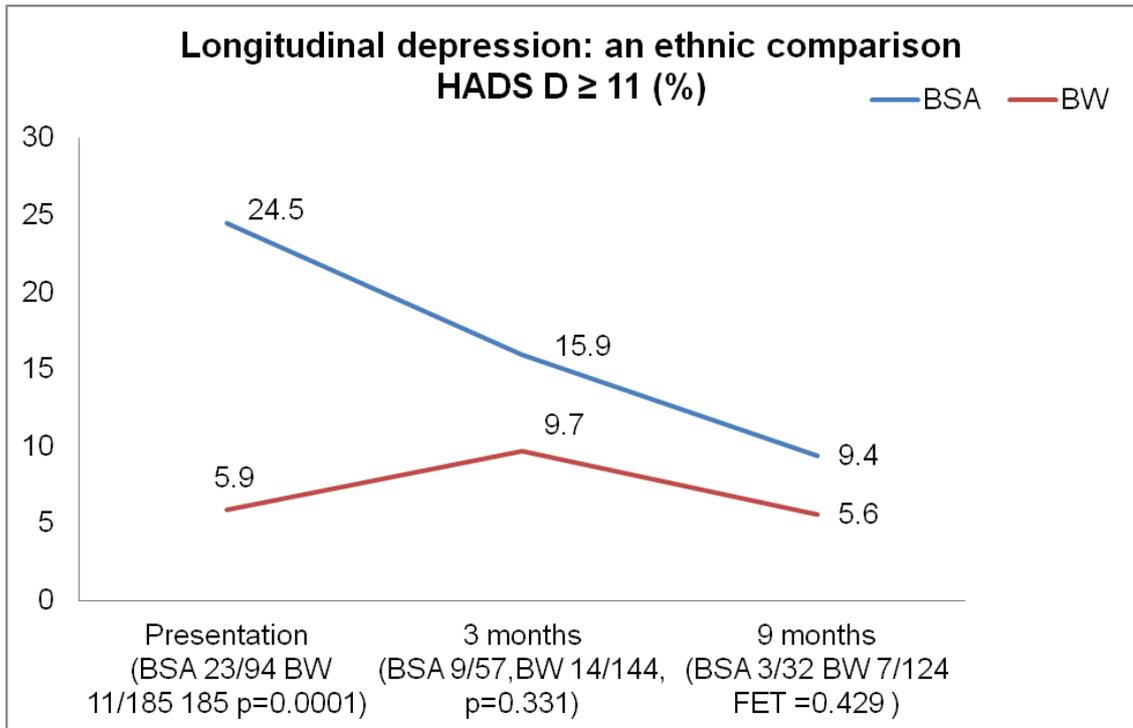


Fig 23

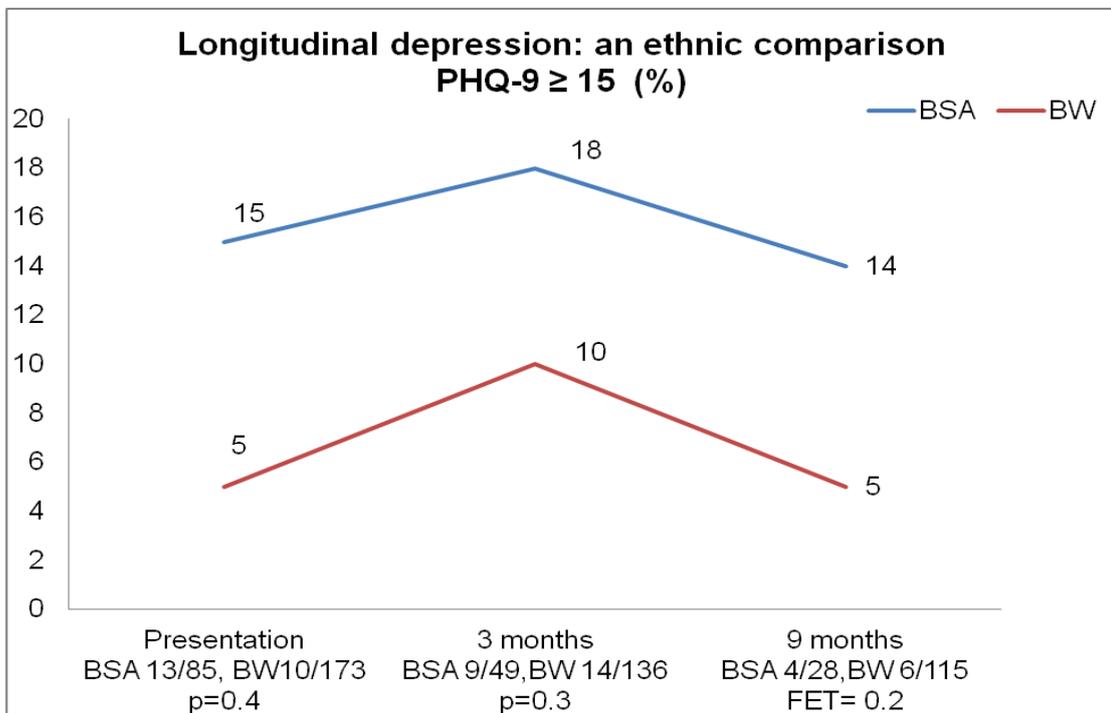


Fig 24

### Longitudinal ethnic trends in anxiety

Rates of anxiety appeared to subside slowly and consistently for both ethnic groups over time but higher levels of anxiety remained among BSA patients at three months (HADS A  $\geq 8$   $p=0.04$ ) and at nine months ( $p=0.254$ ) although by then the statistical significance of the difference had gone. The AnxT $\geq 4$  echoed this trend (3 months ( $p=0.13$ ), 9 months ( $p=0.17$ )) (Fig 25& 26).

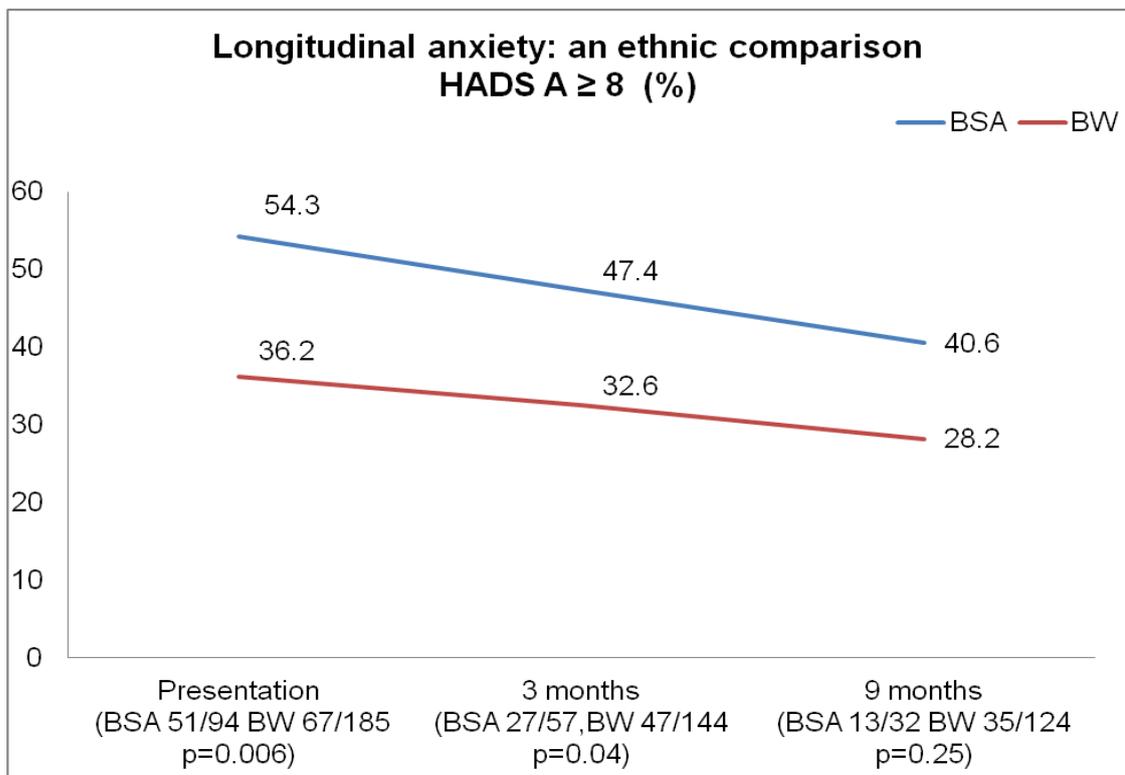


Fig 25

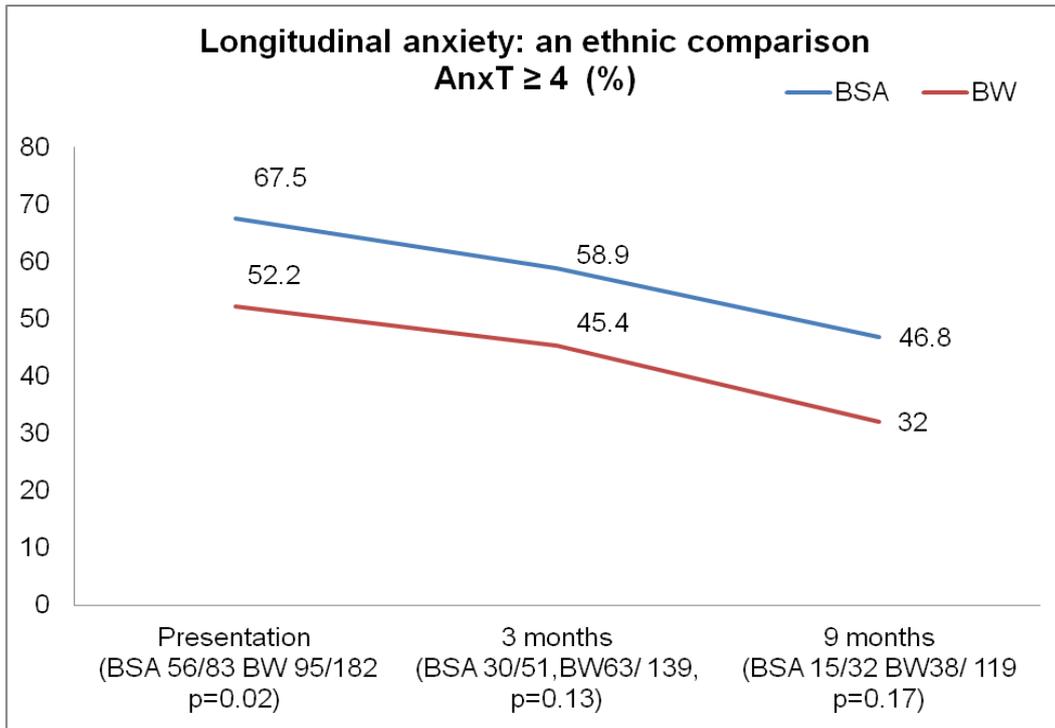


Fig 26

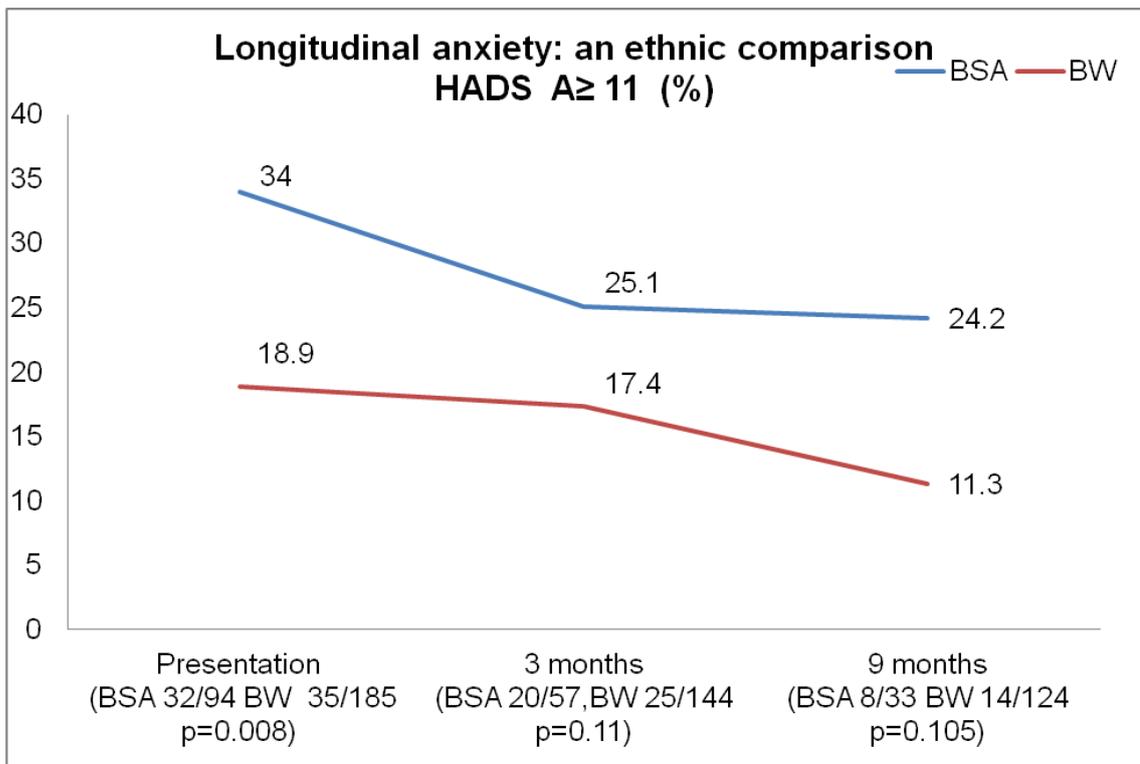


Fig 27

At the higher threshold score for HADS A  $\geq 11$  the pattern was not dissimilar to the lower threshold ( $\geq 8$ ) with a modest reduction in severe anxiety by nine months (Fig 27).

### Longitudinal distress by ethnicity

Distress describes feelings and behaviours which can be antecedent to anxiety or depression. The Distress Thermometer (ET)  $\geq 4$  was analysed in association with ethnicity over the study period (Appendix 6.3.7 – 6.3.8). Consistent with trends in both anxiety and depression BSA patients were more likely to be distressed than BW patients at baseline (Fig 28).

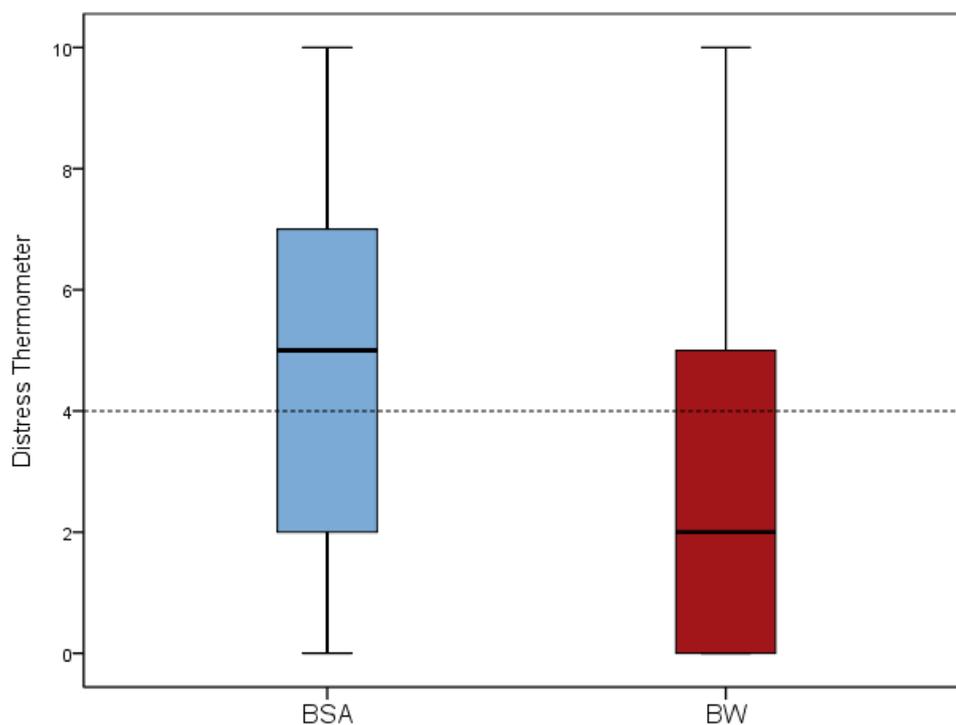


Fig 28: An ethnic comparison of distress at baseline

This difference continued over time but with a gradual decrease among both groups. Nevertheless 5/30 (50%) of BSA patients and 29/119 (24.4%) BW

patients remained distressed at nine months (Fig 29).

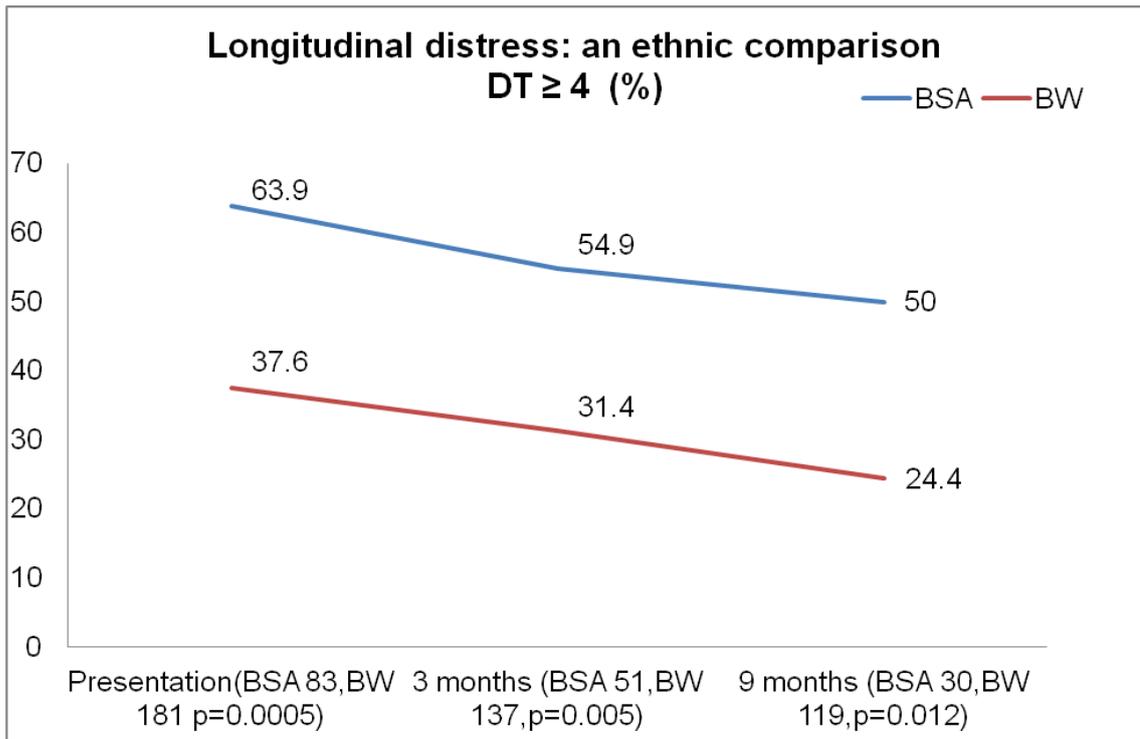


Fig 29

(see also 6.11 Longitudinal 'problems' causing distress )

### Longitudinal changes in anxiety and depression within ethnic groups

Among BW patients there was a fall in mean scores for both anxiety (HADS A  $p=0.0005$ ) and depression (HADS D  $p=0.024$ ) via Friedman tests. A fall in depression scores was also observed among BSA patients ( $p=0.018$ ) although the significance of this latter result is limited given the small sample size ( $n=32$ ) (Appendix 6.3.9).

## 6.4 The influence of socio-economic deprivation

Socio-economic deprivation is closely associated with being a member of an ethnic minority. It was important therefore to assess the extent to which

deprivation influenced the strength of the relationship between ethnicity and anxiety and depression.

It was previously reported that BSA patients were notably more socio-economically deprived than BW patients in this sample. Although this was a strong association (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 (Ppmc) ( $r$ ) with Partial Correlation calculations via HADS D ( $r = -.274$ ;  $p=0.0005$ ) partial correlation ( $-.235$ ,  $p=0.001$ ) and via PHQ-9 ( $r = -.251$ ,  $p=0.0005$ ) partial correlation ( $-.158$ ,  $p=0.011$ ). Deprivation only slightly influenced an increase in depressive symptoms.

There was a weak association between ethnicity and anxiety (HADS A  $r = -.147$   $p=0.014$ ). Although deprivation influenced the strength of that relationship to the extent that it became weak (partial correlation  $-.093$   $p=0.123$ ), the difference in the correlations was minimal. This corresponded with AnxT results ( $-.087$   $p=0.158$ ) partial correlation ( $-.083$ ,  $p=0.179$ ). To summarise, a patient's ethnicity was a stronger influence than deprivation on the incidence of anxiety and depression in this study (Appendix 6.4.1).

## **6.5 Indicators of depression (PHQ-9)**

Among BSA patients 'feeling tired or having little energy over the previous two weeks' was the strongest indicator of depressive symptoms over time (baseline 44/84 (52%), 3 months 24/50 (48%), 9 months 12/27 (44%). Disruption of

sleeping patterns was the second strongest (34.4%), followed by eating habits. (33%) However by three months a poor appetite (or overeating) had become more of a problem for 42.8% of BSA patients and it remained a strong indicator at nine months for 32%.

The same three indicators were relevant to BW patients but proportionally fewer patients had problems. At baseline, disturbances in sleep patterns troubled 30/87 (34.4%) of patients followed by changes in eating habits (33%). Fatigue affected 41/173 (23%) at baseline but the patients' suffering increased at three months 56/141 (39.7%). It remained as top indicator for depression among BW patients although the percentage of people affected fell 34/111 (30.6%) (Figs 30-32 & Appendices 6.5.1-6.5.2). These findings are consistent with the finding that both 'fatigue' and 'sleep' were among the top five causes of distress for both ethnic groups at baseline via the DT.

#### Key to Figures 30-32

1	Little interest or pleasure in doing things
2	Feeling down, depressed or hopeless
3	Trouble falling or staying asleep or sleeping too much
4	Feeling tired or having little energy
5	Poor appetite or overeating
6	Feeling bad about yourself – or that you are a failure or have let yourself or your family down
7	Trouble concentrating on things such as reading the newspaper or watching television
8	Moving or speaking so slowly that other people could have noticed. Or the opposite, being so fidgety or restless that you are moving around a lot more than usual
9	Thoughts that you would be better off dead or of hurting yourself in some way

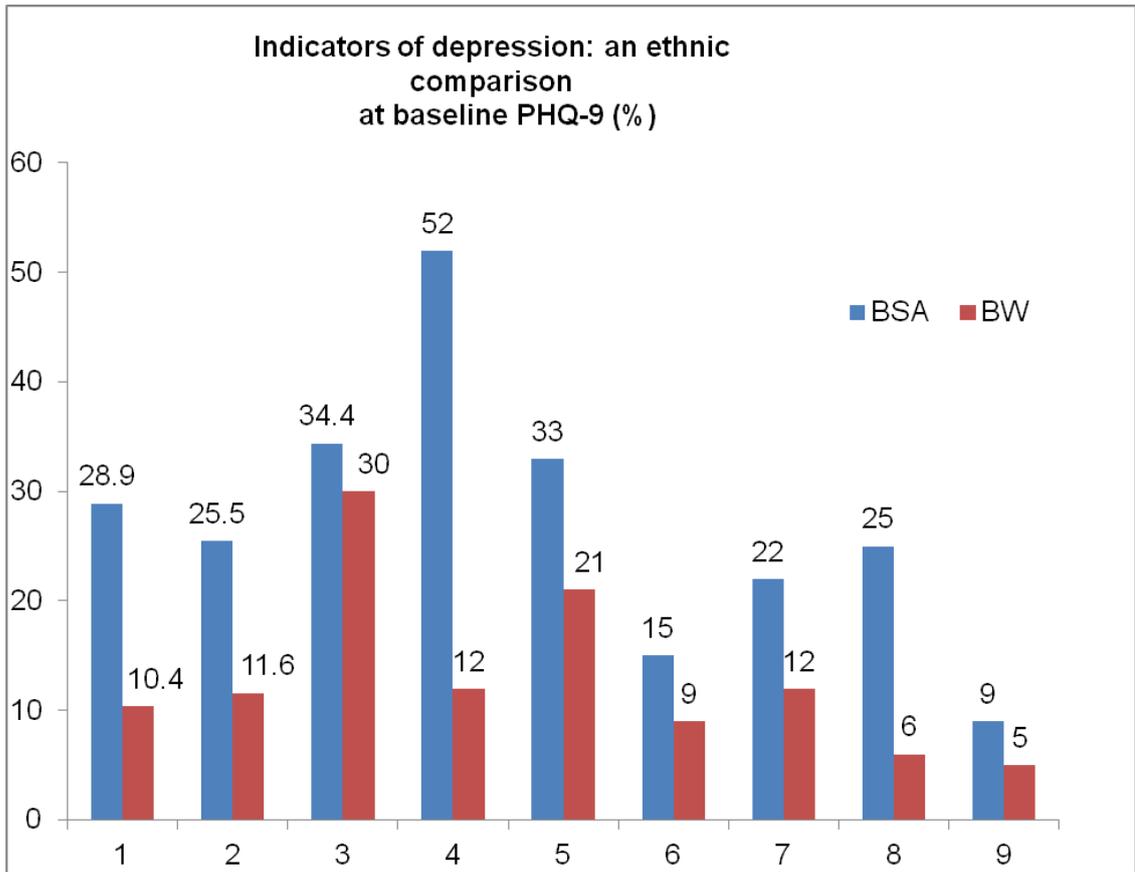


Fig 30

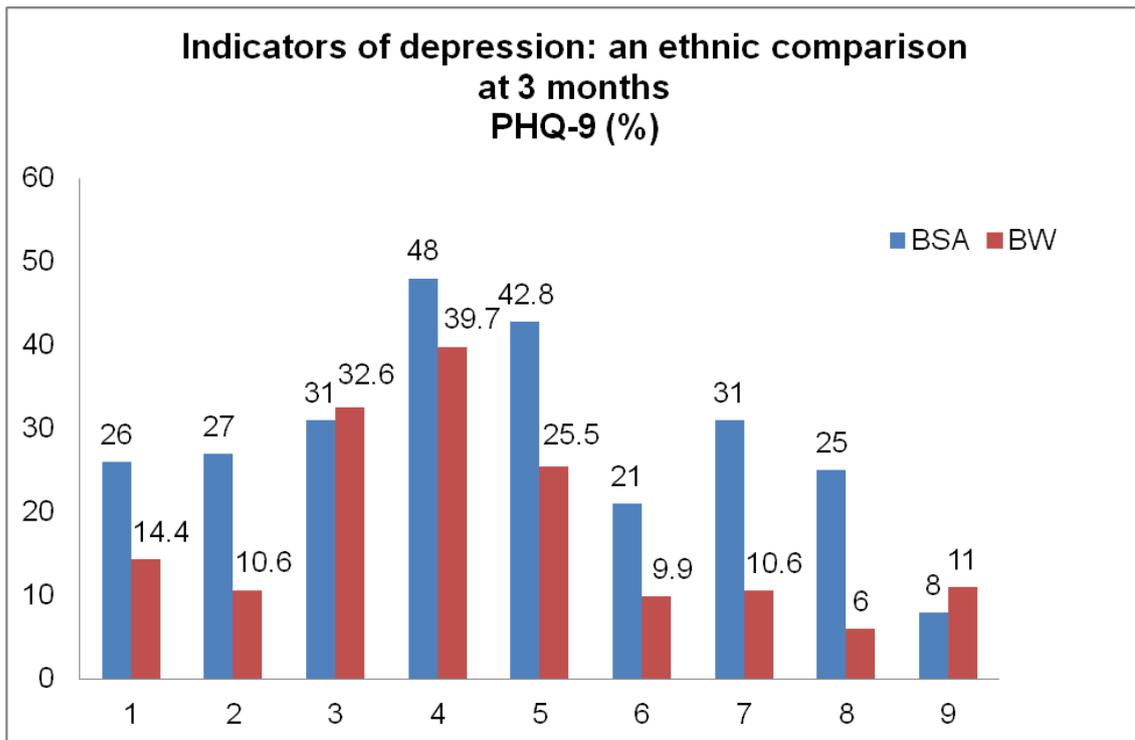


Fig 31

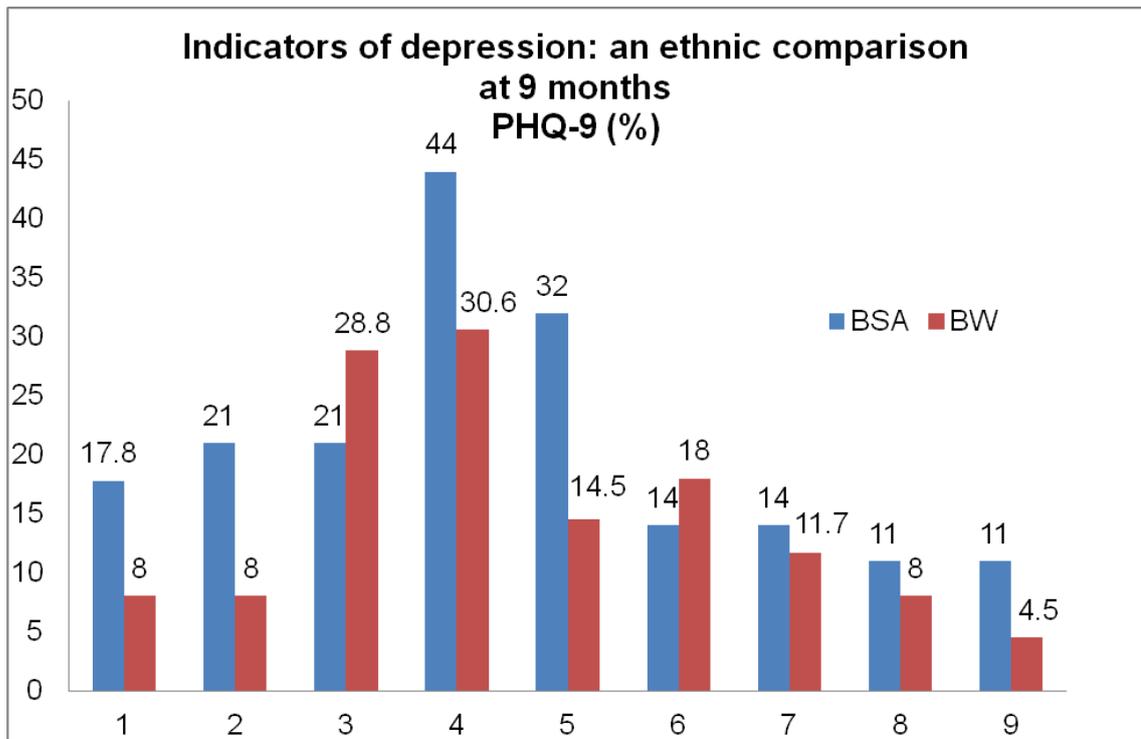


Fig 32

The widest ethnic differences were at baseline when BSA patients reported more problems with 'moving slower or faster' than BW patients (BSA 21/83 (25%) v BW 11/171 (6%),  $p=0.0005$ ), 'feeling tired or having little energy' (BSA 44/84 (52%) v BW 41/173 (23%),  $p=0.002$ ) and finding 'little interest and pleasure in doing things' (BSA 24/83 (28.9%) v BW 18/172 (10.4%)  $p=0.003$ ). Similar to other results in this study, BSA patients felt significantly more depressed or hopeless than BW, the difference being maintained until the three month point (baseline  $p=0.02$ , 3 months  $p=0.03$ ). Other indicators did not show strong ethnic differences in symptoms of depression (Appendices 6.5.1).

### Suicidal ideation

The vast majority of study participants did not experience suicidal thoughts. Suicidal ideation was explored via the PHQ-9 indicator "Over the last two weeks

how often have you been bothered by thoughts that you would be better off dead or hurting yourself in some way?" At baseline a total of 16 /253 people (6.2%) had suicidal thoughts. This included five people who were seriously affected having such thoughts every day. The total figure increased to 20/183 (10.9%) at three months before falling to 8/141 (5.6%) by nine months.

Somewhat surprisingly, given the higher levels of anxiety and depression among BSA patients, it was BW patients who appeared to be at slightly greater risk. 6/136 (11.7%) expressing suicidal ideation at three months in contrast to BSA with 4/47 (8.5%) (Appendix 6.5.2). Caution should be taken when considering the significance of ethnic differences given the small number of people affected.

## **6.6 Coping strategies and psychological outcomes**

Our pilot studies showed some patients used potentially maladaptive coping mechanisms which were associated with increased levels of anxiety and depression. We examined the coping strategies of both ethnic groups in some detail to detect whether those findings were replicated and to examine longitudinal patterns of coping.

The extent to which patients used each strategy and how its use changed longitudinally is described. In addition, using data from the first questionnaire, the associations between each strategy and anxiety and depression is reported. A comprehensive record of all results for chapter 6.6 is in appendices, 6.6.1 - 6.6.10.

## 6.61 Longitudinal trends in helplessness/hopelessness

*“it’s an awful thing to happen....feeling hopeless”*

BSA patient at baseline (x16)

Although the majority of patients did not experience helplessness/hopelessness, of those who did at baseline, more were likely to be BSA (MW: BSA Md 15(12:19), n=91; BW Md 12(10:16), n=183, U5755, Z=-4.178 p=0.0005 r=0.25) (Appendix 6.6.1). For example, more BSA patients agreed with the indicator “I feel completely at a loss about what to do” (BSA 31/94 (33%); BW 23/185 (12.4%) p=0.0005). There was no gender difference in any helplessness/hopelessness indicators with the exception of ‘I can’t cope’ where more females agreed than males (females 31/190 (16.3%) males 5/89 (5.6%) p=0.02). Longitudinally BSA patients reported higher levels of helplessness/helplessness than BW patients at three months (p=0.04) and at nine months although by that time the ethnic gap had narrowed (p=0.13) (Fig 33 & Appendix 6.6.3).

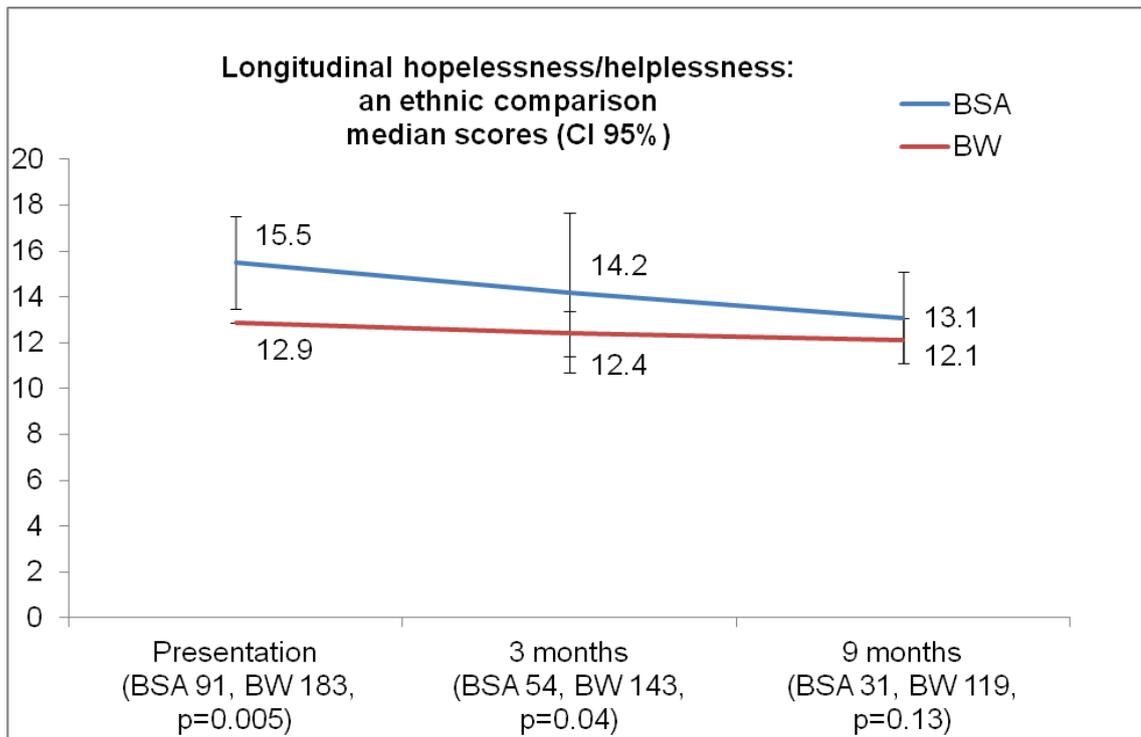


Fig: 33

Helplessness/hopelessness is sometimes considered to be a substitute for depression so it was not surprising that across the study period more patients who felt helplessness/hopelessness, acknowledged depressive symptoms (MW PHQ-9  $\geq 10$ ; Not depressed Md 12(10:15.5), n=193; Depressed Md 17(13:21), n=62, U 2969, Z=-5.987, p=0.0005, r=0.37). These findings were similar to results via HADS D $\geq 8$  (p=0.0005) and DepT (p=0.0005)(Appendix 6.6.4-6.6.6). At diagnosis those who felt helplessness/hopelessness were 1.3 times as likely to be depressed via HADS D 7v8 (OR 1.305 CI 1.21-1.4, p=0.0005). Helplessness/hopelessness predicted between 19.7-29.9% of the variance in depression.

There was a medium strength difference in median scores across all assessment tools for depression using the Cohen criteria 1988 (HADS D

$r=0.42$ ; DepT  $r = 0.41$ ). At three and nine months those who felt helplessness/hopelessness continued to be more at risk of depressive symptoms with strong effect sizes (3 months  $r=0.5$ ,  $p=0.0005$ , 9 months  $r=0.34$ ,  $p=0.0005$ ).

Helplessness/hopelessness were similarly associated with anxiety (MW: HADS A  $\geq 8$ , Not anxious Md 12(9:15),  $n=158$  Anxious Md 16(13:19),  $n=116$ ,  $U=4479$ ,  $Z=-7.255$ ,  $p=0.0005$ ,  $r=0.43$ ). The effect size maintained its strength. This result was supported the AnxT $\geq 4$  ( $p=0.0005$ ) (Appendix 6.6.7-8). Those helpless or hopeless were 1.3 times more likely to be anxious via HADS A (OR 1.3 CI 1.17-1.3). The maladaptive coping strategy predicted between 18-25% of the variance in anxiety. The risk of being anxious when feeling helpless or hopeless persisted across the study period.

## **6.62 Longitudinal trends in 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 x125

More BSA patients were fatalistic than BW patients although this was largely due to a spiritual response, "I've put myself in the hands of God" (BSA 71/94 (75.5%); BW 60/185 (32.4%)  $p=0.0005$ ). Although BSA patients continued to be more fatalistic there was a gradual decrease in its use among both groups by nine months (Appendix 6.6.1). For example proportionally fewer BSA patients devolved control to God (3 months 36/56 (64.3) 9 months

18/31(58.1%). The BW trend was static (3 months 51/143 (35.6%) and 9 months 42/119 (35.3%) (Fig 34 & Appendix 6.6.1).

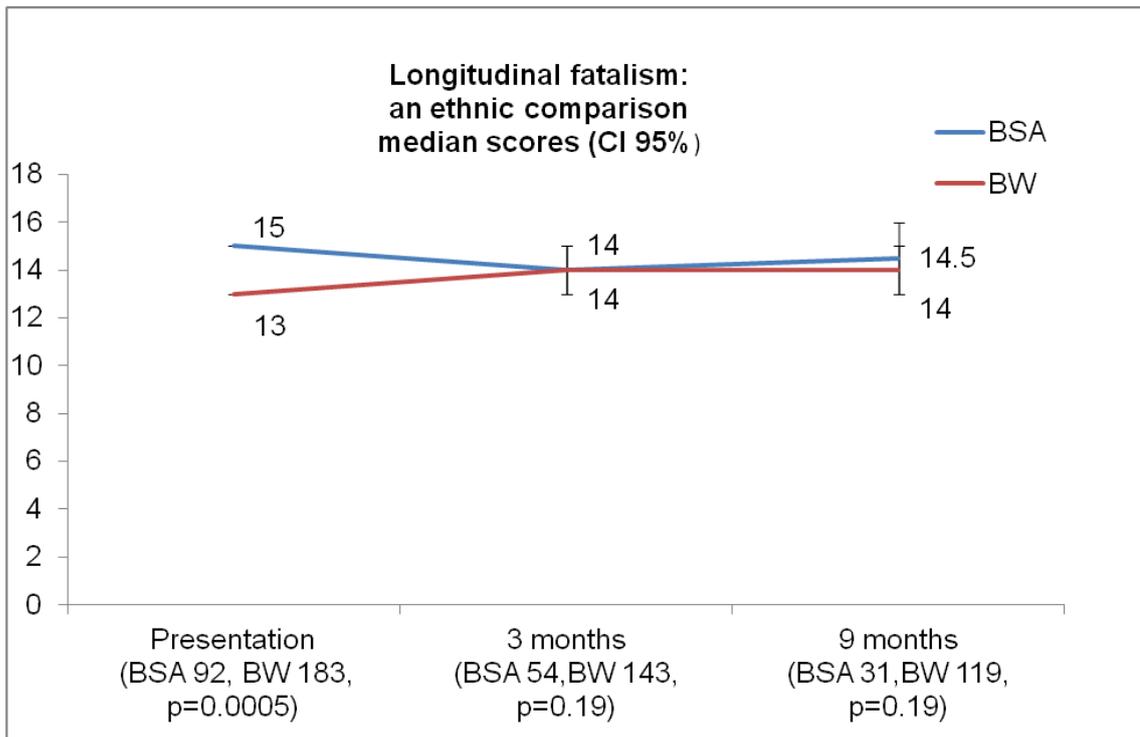


Fig 34

Although fatalism was not present in the majority of patients, those who were affected appeared to be at greater risk of depressive symptoms at baseline although the effect size was small (MW: PHQ-9 Not depressed Md 14(12:16), n=205; Depressed Md 15(13:17), n=53, U 4740.5, Z=-2.474, p=0.013, r 0.15).

This finding was supported by HADS D (MW: Not depressed Md 14(12:16), n=211 Depressed Md 15(13:17), n=64, U 5609.5, Z=-2.062 p=0.04 r 0.12).

There was however less convergence with the DepT although the trend was similar (p= 0.101). As a single variable, 'fatalism' was not a strong predictor of depression via HADS D for this sample (p=0.07).

By three months there was no significant difference in rates of fatalism between those depressed and those not (PHQ-9  $p=0.15$ ; HADS D  $p=0.23$ ). This remained the case at nine months (PHQ-9  $p=0.15$ ; HADS D  $p=0.65$ ) (Appendices 6.6.4-6.6.6).

Cancer fatalism was linked to higher rates of anxiety (MW: HADS A, Not anxious Md 14,  $n=158$ ; Anxious Md 15,  $n=117$ , U 7603  $Z=-2.53$   $p=0.01$ ,  $r=0.15$ ). The AnxT echoed this trend but was statistically insignificant ( $p=0.164$ ). Longitudinally this difference was not in evidence (HADS A 3 months  $p=0.09$ , 9 months  $p=0.7$ ) (Appendix 6.6.7-6.6.8).

### **6.63 Longitudinal trends in 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 118

Initially BSA patients were far more likely to use cognitive avoidance (mini mac) to cope than BW patients. (MW: BSA (Md 12(10:13),  $n=90$ ) (BW Md 10(8:12)  $n=182$ ), U=5404,  $Z=-4.608$   $p=0.0005$ ,  $r=0.28$ ). For example, “I deliberately push all thoughts of cancer out of my mind” (BSA 61/93 (65.6%); BW 63/185 (34.4%),  $p=0.0005$ ). (Appendix 6.6.1) Although a similar trend was observed with indicators of ‘avoidance’ in the CIDQ questionnaire, the difference was not as great (MW; BSA Md 6(4:6)  $n=86$ ; BW Md 5(4:7)  $n=167$ , U=6160  $Z=-1.866$   $p=0.06$   $r=0.11$ ). Longitudinally there was a trend for BSA patients to use cognitive avoidance to manage illness more than BW patients (Fig 35 & Appendix 6.6.3).

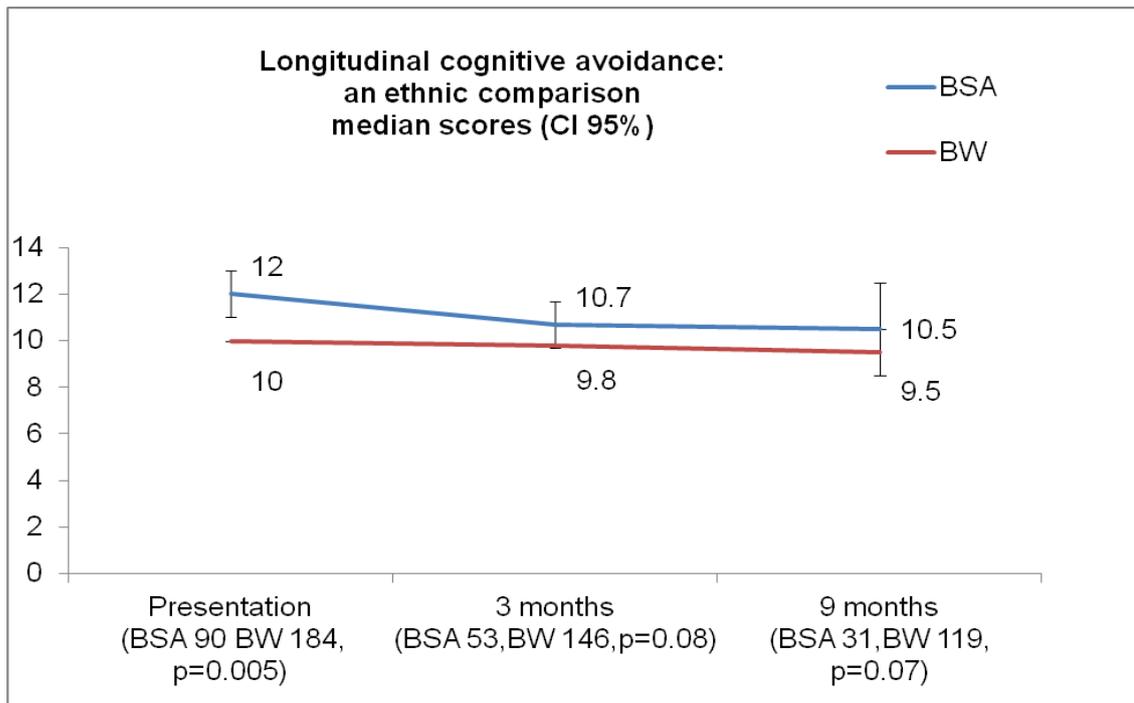


Fig 35

The initial decrease in the use of cognitive avoidance among BSA patients was particularly observed in one indicator, 'Not thinking about it helps me cope' (baseline 57 (61.3%), 3 months 32 (58.2%), 9 months 14 (45.2%)).

As one sample patients who used cognitive avoidance at baseline was associated with developing depressive symptoms, for example MW: PHQ-9 Not depressed Md 10(9:12), n=192 Depressed Md 11(10:13) n=61 U 4518.5 Z= -2.712 p=0.007, r=0.16 (Appendix 6.6.4-6.6.6). However, as a single variable it predicted only 4.6-7% of the variance in depression scores via HADS D.

Longitudinally there was less difference in use of cognitive avoidance between those depressed and not (PHQ-9; 3 months p=0.418, 9 months p= 0.059). A similar trend was seen via HADS D.

Using the indicators of 'avoidance' via CIDQ, the association with depression was also observed via PHQ-9 and HADS D at baseline. (MW: PHQ-9; Not depressed Md 5, (4:7) n=178, Depressed Md 7(4:8) n=58, U 3670, Z=-3.332, p=0.001, r -0.21);(MW HADS D; Not depressed Md 5(4:7) n=195; Depressed Md 7(5:9) n=58 U 3404, Z=-4.636, r=0.29, p=0.0005). The DepT displayed a weaker association but the trend was the same (p=0.002). Longitudinally the risk of depression when avoiding the reality of cancer remained at three months via PHQ-9 p=0.04 but not by nine months, (p=0.23).

Anxiety was associated with cognitive avoidance. For example, MW HADS A; Not anxious Md 10, n=157; Anxious Md 11, n=115, U=6731, Z=-3.618, p=0.0005, r=0.22. The AnxT concurred, p=0.002. Over time those using avoidance were more likely to be anxious (HADS A 3 months p=0.02, 9 months p=0.03) (Appendix 6.6.7-8).

#### **6.64 Longitudinal trends in 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 X103*

Being preoccupied with anxiety affected both ethnic groups across the total scores for all indicators with a negligible difference between them (MW; BSA Md 22 n=93; BW Md 21 n=183, U 7956, Z=-0.855, p=0.38, r=0.05)(Fig 36).

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%)  $p=0.048$  (Appendix 6.6.1). It appears paradoxical that BSA patients appeared to self-report greater anxiety via a single indicator (BSA 46/94 (48.9%) BW 60/185 (32.4%)  $p=0.011$ ).

Longitudinally there remained little ethnic difference in patients who were preoccupied with anxiety (3 months  $p=0.751$ , 9 months  $p=0.926$ ) (Appendix 6.6.3).

Those preoccupied with anxiety in one sample were at greater risk of becoming depressed (MW: PHQ-9 Not depressed Md 20(17:23)  $n=194$ ; depressed Md 24.5 (21:27)  $n=62$  U 3119  $Z=-5.987$   $p=0.0005$   $r=.37$ . Over time the risk of depression remained (PHQ-9 3 months  $p=0.0005$ , 9 months  $p=0.0005$ ). These results were supported by HADS D (Appendix 6.6.4-6.6.6). Those patients who engaged in anxiety preoccupation were 1.25 times more likely to be depressed (CI 1.16-1.34  $p=0.0005$ ) and it predicted between 16-24% of the variance in depression via HADS D 7v8.

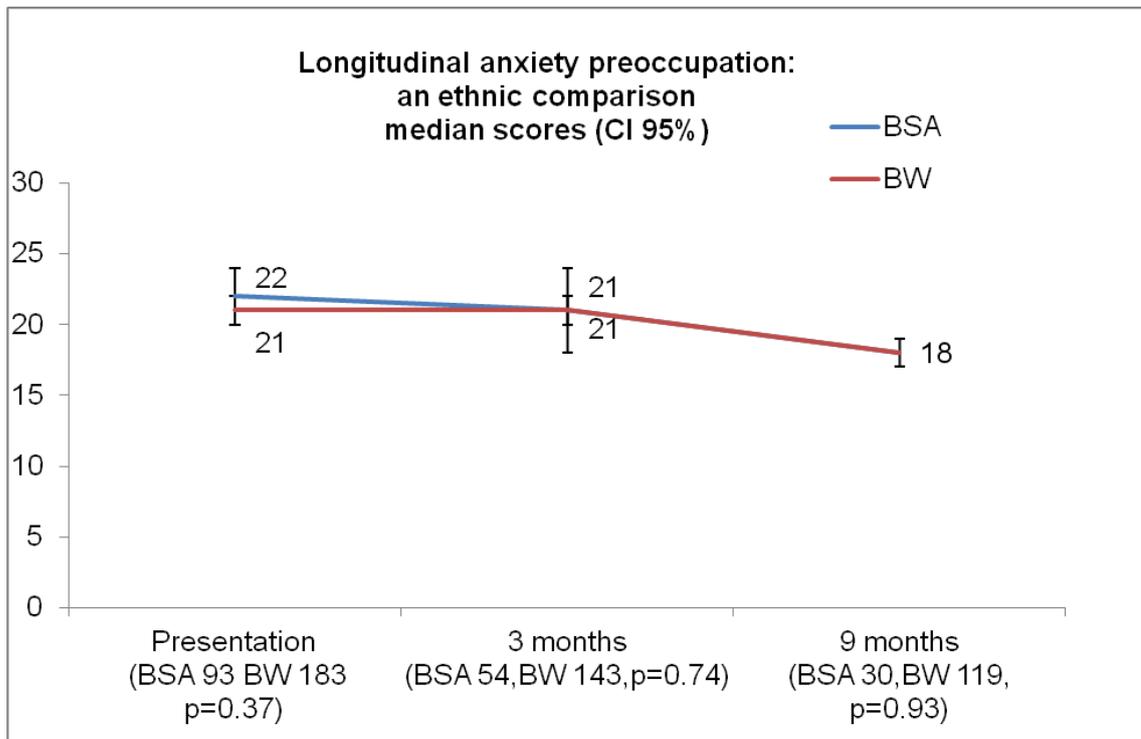


Fig 36

Given the overlap of phenomena between anxiety preoccupation (the strategy) and anxiety (the outcome) it was not surprising that there was also a strong association between them (HADS A  $r=0.63$ ,  $p=0.0005$ ). It remained so across the study period with a strong effect size (Appendix 6.6.7-8).

### 6.65 Longitudinal trends in denial

*"I'm not ill"*

Written on top of an uncompleted BIPQ by BW patient (127) having chemotherapy for breast cancer following surgery.

*"...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 (311) at nine months

Roy (2005) suggested that local BSA patients used denial to a greater extent than BW patients. We considered whether this was replicated in a different sample of patients.

The vast majority of patients did not use denial as a means of coping. However, of those who did, BSA patients were over-represented longitudinally although the gap was only significant at baseline and not well illustrated via median scores ( $p=0.001$ ). (Fig 37)

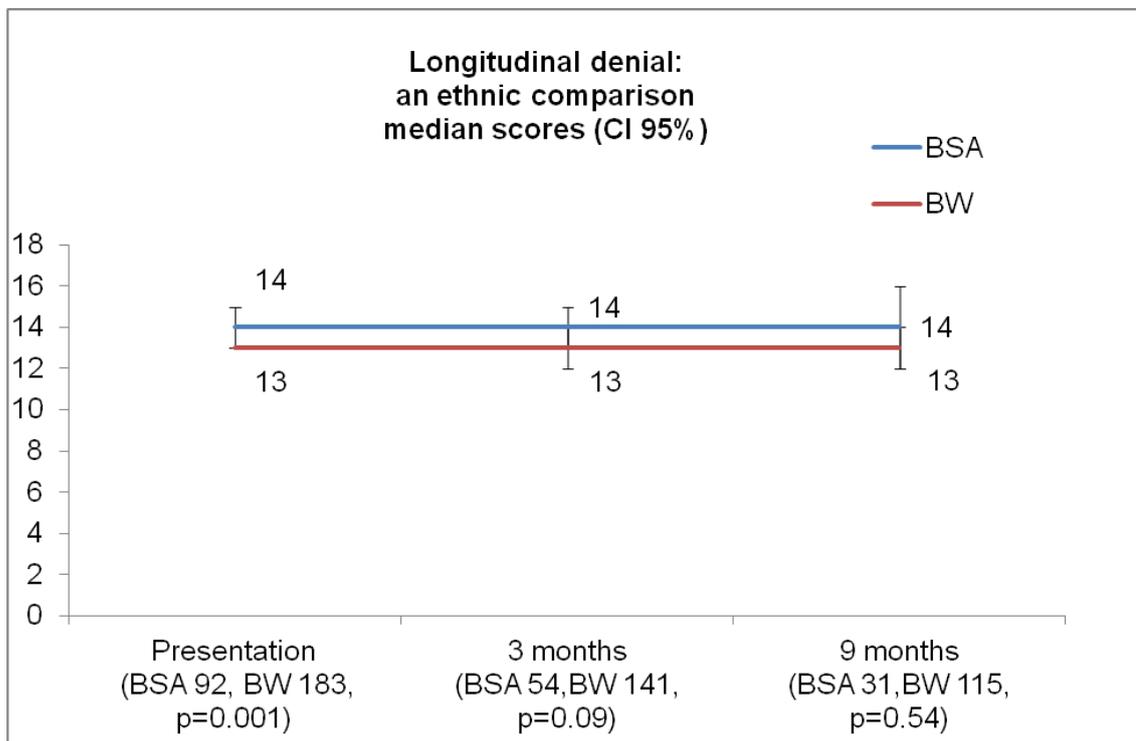


Fig 37

There was no association between denial and depression via PHQ-9 ( $p= 0.12$ ) or HADS D ( $p=0.9$ ) and this did not change longitudinally. Nor was there an association with anxiety over time (HADS A baseline  $p=0.59$ , 3 months  $p= 0.14$  9 months  $p=0.86$ ) (Appendix 6.6.4-6.6.8). In Roy's study the MAC indicator "I

don't really believe I have cancer" was highlighted as a measure of denial and was an indicator in the CIDQ. To facilitate comparisons with the pilot findings analysis of this single indicator was repeated.

**"I don't really believe I have cancer"**

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 in all agreed with this statement 'sometimes' (BSA 12 (52.2%); BW 11 (47.8%)). Longitudinally fewer BSA appeared to use denial to cope although an ethnic difference remained (Fig 38 & Appendix 6.6.10).

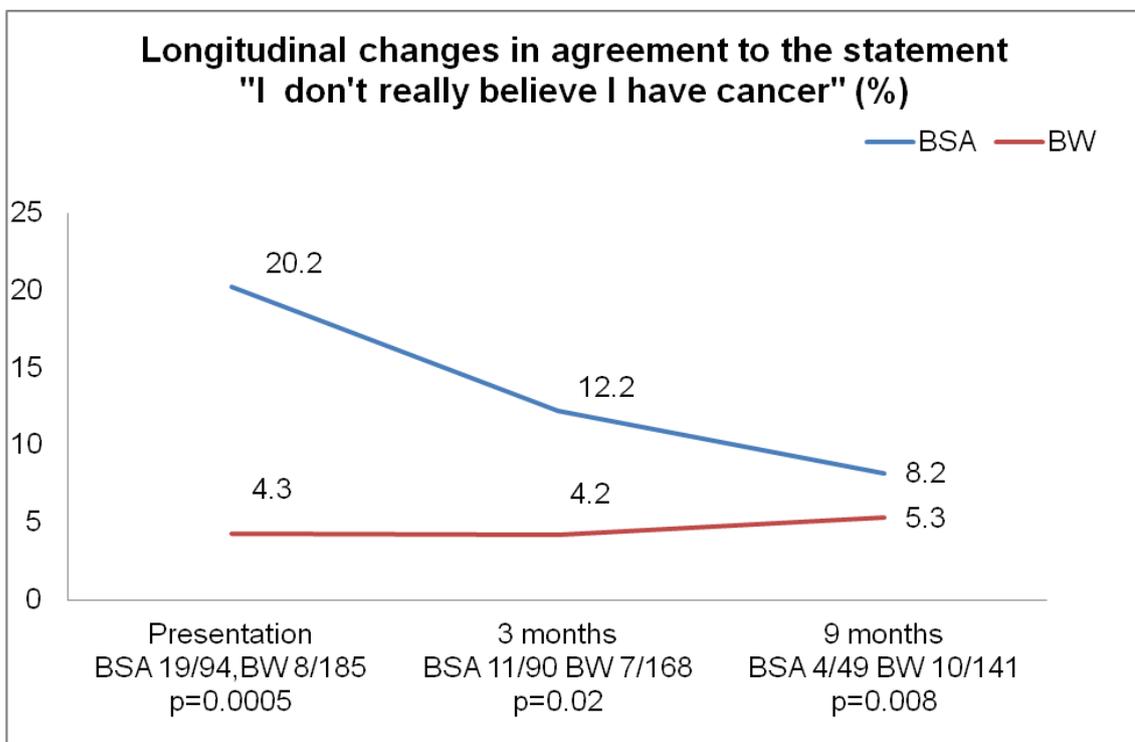


Fig 38

When considering gender differences, more women used denial than men. Of the 19 BSA patients who initially denied their diagnosis 14 were women with

five out of eight BW patients being women although this was not statistically significant. This trend was confirmed by Spearman's rank order tests (BSA rho 0.117 p=0.26, BW rho 0.014 p=0.85) (Table 7).

Although the numbers of people expressing denial were very low in both ethnic groups, there was a strong trend towards BSA being more likely to be anxious and depressed as illustrated below (Fig 39).

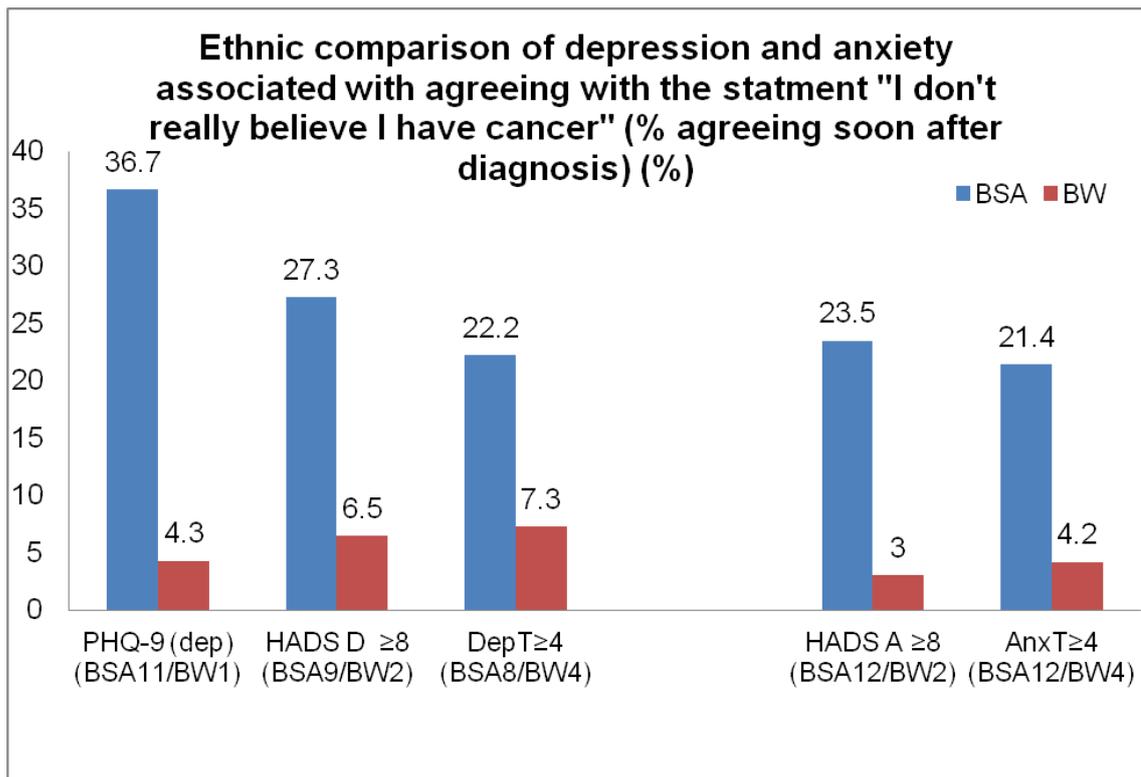


Fig 39

As one sample there was a correlation between this indicator of denial and depression with HADS D (rho 0.162 p=0.007) but not within separate ethnic groups. Using denial to cope was clearly not helpful. Over time fewer patients denied their diagnosis as a means of coping in either ethnic group (Appendix 6.2.2).

**Table 7 Correlations between: “I do not really believe I have cancer” and anxiety and depression at baseline**

Continuous scores		N=	Spearman Rho	P value
HADS A	BSA	94	0.120	0.250
	BW	185	0.004	0.956
	One Sample	279	0.076	0.205
HADS D	BSA	94	0.167	0.107
	BW	185	0.068	0.361
	One Sample	279	0.162	0.007

### 6.66 Longitudinal trends in fighting spirit

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

BW patient (172)

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

BW (354)

A large number of patients in both ethnic groups approached their illness with a ‘fighting spirit’. For example, “I am determined to beat this disease” (BSA 85/93 (91.4%); BW 170/185 (91.9%)  $p=1.0$ ) (Appendix 6.6.1). Of interest was the decrease in BSA patients being ...’determined to beat this disease’ between baseline and nine months later 24/31(77.4%). This was more than among BW patients (nine months 101/119 (84.9%) (Appendix 6.6.3).

There was little ethnic difference across the indicators for fighting spirit; for example, at baseline median scores were the same (MW: BSA Md 13 (11:14)  $n=92$ ); (BW Md 13 (11:14)  $n=183$ ),  $U 7973.5$ ,  $Z=-0.722$   $p=0.47$   $r=0.04$ ) (Fig 40).

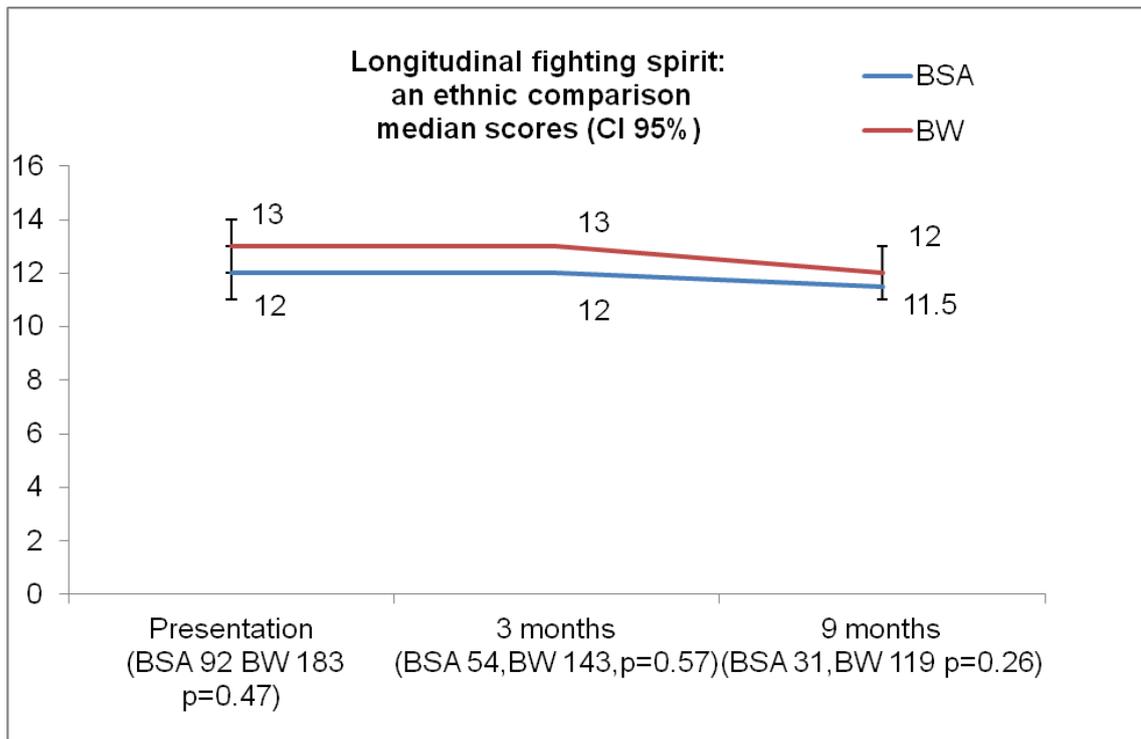


Fig 40

The decrease in the scores for fighting spirit among BW patients over the research period was significant (Friedman Test: BW n=108 1) 2.17 2)2.04 3)1.79,  $p=0.006$  but this was not the case among BSA patients although the sample across was small (n=28) (Appendix 6.6.9).

No consistent association was found between fighting spirit and either the presence or absence of psychological morbidity across the study period as one sample. The direction of the relationship was observed when comparing mean rank scores across assessment tools at baseline indicating that fighting spirit was associated with an absence of depression. (MW: PHQ-9; Depressed 121.08; Not depressed 130.87  $p=0.359$ , HADS D: Depressed 134.95; Not depressed 138.95  $p=0.713$ , and DepT Depressed 132.79; Not depressed 130.53  $p=0.817$ ). However this lacked statistical power. For example, HADS D

MW Depressed Md13 (12,14) Not depressed (Md13 (112,14) U 5554 Z= -.916  
p=0.36 r=-0.05. This tendency was observed longitudinally (Appendix 6.6.4-  
6.6.6).

A fighting spirit was not associated with more or less anxiety in this sample.  
(HADS A Not Anxious, Md 13 (IQR 11,14) n=159, anxious Md13 (IQR11,14)  
n=116 U 9071.5 Z = -.234 p=0.81 r=0.01) (Appendix 6.6.7- 8).

### **6.67 Information**

The information indicators in the CIDQ questionnaire are useful individually,  
being relevant to standards relating to information giving. For example, the vast  
majority of patients felt that they ...”had been given plenty of information about  
cancer” (agree 230/278 (83%) disagree 38(13.7%) sometimes 9(3%) (Appendix  
6.6.2). There was a negligible ethnic difference (BSA 76/93 (81.7%; BW  
154/185 (83.2%) p=0.776). Questions about whether the information was  
excessive or focused enough on the individual’s agenda were not asked.

Most people felt that they had been clearly told their diagnosis (255/279 (91%);  
however, of those who felt that they had not been told, more were BSA patients,  
(BSA 12/94 (12.8%); BW 8/185 (4.3%) p=0.034) (Appendix 6.6.2).

### **6.68 Longitudinal changes in coping within ethnic groups**

There was little evidence of a dramatic change in the use of coping strategies  
*within* either ethnic group across the nine month study period via Friedman  
tests. Only two results, both relating to BW patients, were of interest. There

was a significant fall in the use of anxiety preoccupation ( $p=0.0005$ ) this being similar to the fall in anxiety as a health outcome observed among BW patients via the same test ( $p= 0.0005$ ) (Appendix 6.6.9). The overlap of these phenomena has previously been referred to.

There was also a reduction in the use of a fighting spirit among BW patients ( $p=0.006$ ). Seen alongside the aforementioned results in anxiety preoccupation and anxiety as an outcome, this may be attributed to patients not needing to generate this mechanism to cope as much by nine months. It would be an over-simplification to suggest that the use of coping strategies did not change among BSA patients given the small sample sizes for the Friedman tests. For example, samples ranged from 26 to 29 patients.

## **6.7 Predictors of anxiety and depression**

This section presents selected results from models predicting anxiety and depression. Logistic regression analyses via  $HADS \geq 8$  were performed to create models for each ethnic group and for one sample from first questionnaire data.

### **Demographic predictors of anxiety and depression**

Demographic factors were weak predictors of anxiety and depression in this study with no model having a predictive power of over 10% of the variance in either health outcome. Only one model produced results of interest.

Previously it was noted that when analysing BSA patient data, those born in India tended to have some different views to those born in African States. For example, more people born in the Indian sub-continent believed that “people outside the family should not be told that I have cancer”. This prompted an enquiry into possible differences in psychological morbidity based on place of birth amongst BSA patients.

Although the model examining the association between place of birth and anxiety was not quite statistically significant  $\chi^2(1, N=81)=3.497, p=0.06$ , it did suggest that as a trend BSA patients born in India were 2.375 times more likely to be anxious than those born in Africa. Nevertheless, the model was weak explaining between 4.2% (Cox & Snell R Square) and 5.6 % (Nagelkerke R Square) of the variance in anxiety status and correctly classified 60.5% of cases (51.9% as constant) (Appendix 6.7.1).

### **Predictors of anxiety and depression from coping strategies and demographic factors**

Two models for each ethnic group were created when identifying predictors of anxiety and depression. The first was generated after entering all variables of interest. The second was restricted to coping strategies and demographic factors.

### **Predictors of anxiety and depression**

There were few surprises to report which was disappointing given the time spent on this aspect of the study. As a consequence, only a brief account of findings is reported here with a complete record of models relegated to

appendices. Predictors of anxiety included higher levels of distress (DT) Depression HADS D/ DepT. and helplessness/hopelessness constantly featured in models predicting anxiety for one sample and for both ethnic groups. Helplessness/hopelessness and anxiety preoccupation were the strongest predictors of depression (Appendix 6.7.2-6.7.9). Generally, predictive modelling did not generate results which would aid the identification of those most likely to be at risk of becoming anxious or depressed.

## **6. 8 Cancer beliefs**

This study considered beliefs about the nature of cancer and whether there were ethnic differences. Beliefs of patients recently diagnosed with cancer and the associations with anxiety and depression are reported. Data is presented for the whole sample and by ethnic group (Appendix 6.8.1- 2).

It was reassuring that the vast majority of this sample (232/279, 83.2%) believed cancer to be curable; however, there were significantly more BSA patients (BSA 10/94 (10.6%) v BW 5/185 (2.7%)  $p=0.001$ ) among the small number who did not. Overall 93.3% believed that early cancer in one part of the body is often curable and it is encouraging that 88.9% agreed that screening can find early signs of cancer. It is of some concern, however, that BSA patients were less likely to agree about the effectiveness of screening, (BSA 76/94 (80.9%), BW 172/185 (93%)). Although this was statistically insignificant (FET 1.0), the trend across three categories (disagree, no view and agree) showed a higher 'no view' among BSA patients than BW patients possibly

indicating antipathy among some when it came to undergoing screening (BSA 18 (19.1%), BW 11 (5.9%)).

Approximately 20% of both ethnic groups (BSA 18/94 (19.1%), BW 38/185 (20.5%) believed “treatment, especially surgery, can often cause the cancer to spread”. Overall 83/278 (29.8%) participants believed that “alternative therapies *are* as good as surgery, radiotherapy or chemotherapy” as treatment of cancer. If those holding ‘no view’ were included, the figure would reach 169/279 (61%). More than the expected number of BSA agreed than was expected (BSA Observed 36, Expected 28.1; BW observed 47, expected 54.9) contrasting with less than expected, among BW patients (Observed 47, Expected 54.9). With the traditional use of Ayurvedia it is perhaps not surprising that significantly more BSA believed in alternative treatment (BSA 38.3% v 25.5% BW  $p=0.0001$ ).

Cancer is still associated with stigma in some cultures and may be the reason why more BSA than BW agreed that “people outside the family should not be told I have cancer” (BSA 25/94 (26.6%); BW 10/185 (5.4%)  $p=0.0001$ ), although the majority of both groups disagreed. Similarly more BSA avoided talking to strangers about their diagnosis (CIDQ indicator: BSA 44/93 (47.3%); BW 67/185 (36.2%),  $p=0.034$ ). There was a significant difference in the need for privacy/secretcy between two subgroups within the BSA sample. Those ‘double’ migratory families, who originated in the Indian sub-continent and arrived in the UK having migrated to Africa first, were significantly less likely to agree with the need for secretcy than those migrating directly from the Indian sub-continent

(African migrants 3/ 31 (9.7%);ISC 18/50 (36%) p=0.015) (Fig 41).

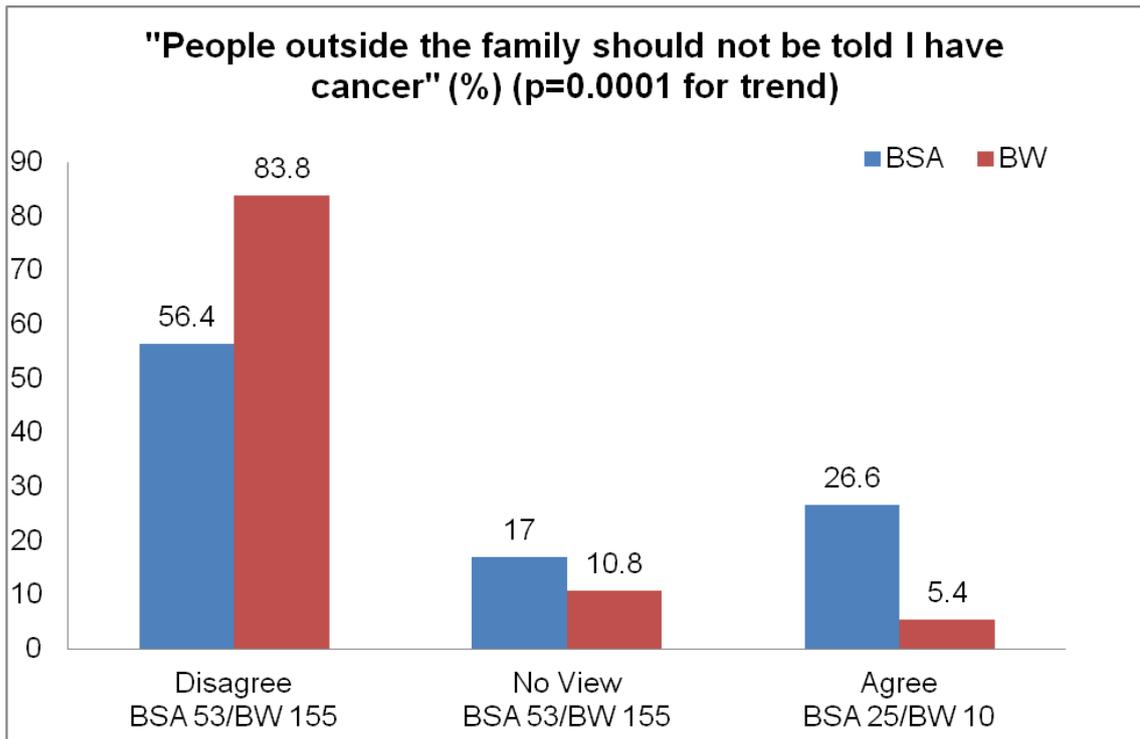


Fig 41

Beliefs about the causes of cancer were considered (Figs 42, 43 & 44). Overall 241/279 (86.4%) of patients believed cancer is caused by smoking including all of those diagnosed with lung or head and neck cancers, diagnoses closely associated with smoking. Of the few who disagreed there were more BSA patients than BW patients 8/94(8.5) v 6/185 (3.2%) p=0.026). More BSA than BW patients 12/94(12.8%) v12/185 (6.3%) expressed 'no view' about the relevance of smoking.

When asked whether diet, being overweight or lack of exercise could be causative of cancer, this sample may have lacked knowledge with few significant differences in the opinions of either BW or BSA patients. 19.4%, 26.2% and 33.3% did not agree that diet, being overweight, and lack of exercise

respectively, were causes of cancer. They are contributing factors in the incidence of some cancers. The distinction between a direct and indirect cause of cancer was not clear enough in the question and may be the reason why there were a high number of patients with no views (diet 35.1%, overweight 41.2% and lack of exercise 44.8%).

Pollution was believed by many (63.1%) to be a cause of cancer with 28% holding no view. Less (43%) felt occupation was a causative factor (with 36.2% having no view). The myth that stress causes cancer persists in a large minority of people 123/279 (44%) with more BSA patients agreeing with this proposition (BSA 51/94 (54.3%) v BW 72/185 (38.9%)  $p=0.028$ ). Of note is the confusion about the relationship between injury and cancer with a wide distribution of views as one sample (disagree 30.1%, no view 44% and agree 25.4%). Very few people believed cancer to be contagious, able to spread from person to person. No BW patients believed this with 10 patients (5.4%) expressing 'no view'. This compared to 4 (4.3%) BSA patients who believed cancer was contagious with 12 (12.8%) having no view ( $p=0.001$ ).

It is important not to overstate the belief in supernatural influences as causes of cancer in BSA patients as the majority did not hold this belief. For example, most disagreed with the statement "cancer is a form of punishment for wrongdoing" (disagree 68.1%, no view 20.2%, agree 11.7%). Yet given the stronger cultural belief in the supernatural in South Asian populations, significantly more BSA than BW patients appeared to believe there was supernatural involvement in the causation of cancer albeit amongst a small

minority. A highly statistical difference in views ( $p=0.0001$ ) exists across all 4 items relating to the supernatural (Appendix 6.8.2).

One BSA patient wrote cancer is...

*“an Act of God. A reprimand..to obey God’s commandments “ x101*

Another commented,

*“Having cancer means ‘warning’. Amber light. God’s name (prayers) wills, knowledge, deeds, that’s all one needs to concentrate on. You have to find out where you’ve come from and why”*

Written in Gujarati, BSA x73

### **Associations between cancer beliefs and anxiety and depression**

Although all the cancer beliefs were analysed for associations between anxiety and depression via the HADS, those reported and tabulated were restricted to the few with statistical significance (Appendix 6.8.3).

The belief that cancer was due to fate (karma) and nothing could be done to prevent it, was associated with higher rates of depression among BSA patients via HADS D  $\leq 7$  24/61 (39.3%) v  $\geq 8$  17/33 (51.5%)  $p=0.025$  for trend. It was not associated with anxiety. This was the only belief associated with depressive symptoms of statistical significance for the BSA patient sample. The sole cancer belief associated with higher anxiety among the few BSA patients was agreeing that cancer was punishment for wrongdoing via HADS A  $\leq 7$  1/43 (2.3% v  $\geq 8$  10/51 19.6%  $p=0.034$ ). The sample size was however very small.

Among BW patients, those who were depressed were more likely to agree that cancer was caused by stress ( $\leq 7$  52/154 (33.8%) v  $\geq 8$  20/31 (64.5%)  $p=0.006$  for trend). It was associated with greater anxiety via HADS A, which is unsurprising given the strong connections between stress, anxiety and depression, ( $\leq 7$  37/118 (31.4%) v  $\geq 8$  35/67 (52.2%)  $p=0.018$ ).

Those BW patients who were not depressed were more likely to disagree that cancer was punishment from God ( $\leq 7$  145/154 (94.2%) v  $\geq 8$  25/31 (80.6%)  $p=0.031$ ) or for wrongdoing ( $\leq 7$  145/154 (92.2%) v  $\geq 8$  24/31 (77.4%)  $p=0.007$ ).

No one agreed with the second statement although those with depressive symptoms appeared to sit on the fence expressing 'no view'. The same beliefs indicated a similar association with anxiety (Appendix 6.8.2). The majority of BW patients did not believe cancer was 'due to karma (fate) or that nothing could be done about it'. However, of those who did, more had symptoms of anxiety ( $\leq 7$  13/118 (11%) v  $\geq 8$  16/67 (23.9%)  $p=0.001$  for trend).

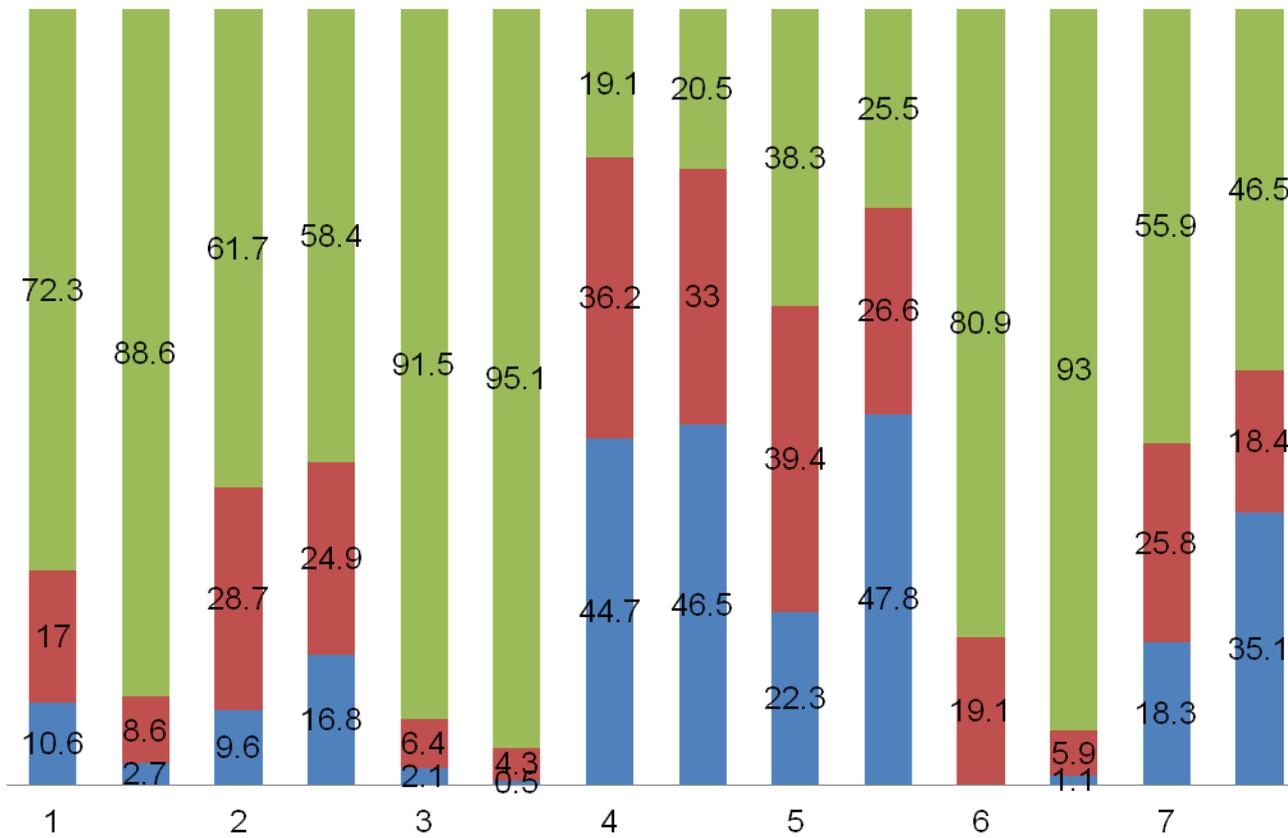
### **Cancer beliefs: predictors of anxiety and depression**

The recognition of cancer beliefs that strongly predict psychological morbidity are of clinical value; however, those of statistical significance in this study were weak. For example, among BSA patients "treatment especially surgery can often cause cancer to spread" predicted only 8.8% of the variance in depression scores and 14.5% of the variance in anxiety scores. There was no predictor of depression among BW patients and the belief that "Cancer is caused by fate (karma) and there is nothing can be done to prevent it" ( $p=0.006$ ) only explained 4.6% of the variance in anxiety scores (Appendix 6.8.4).

### Cancer beliefs (1)

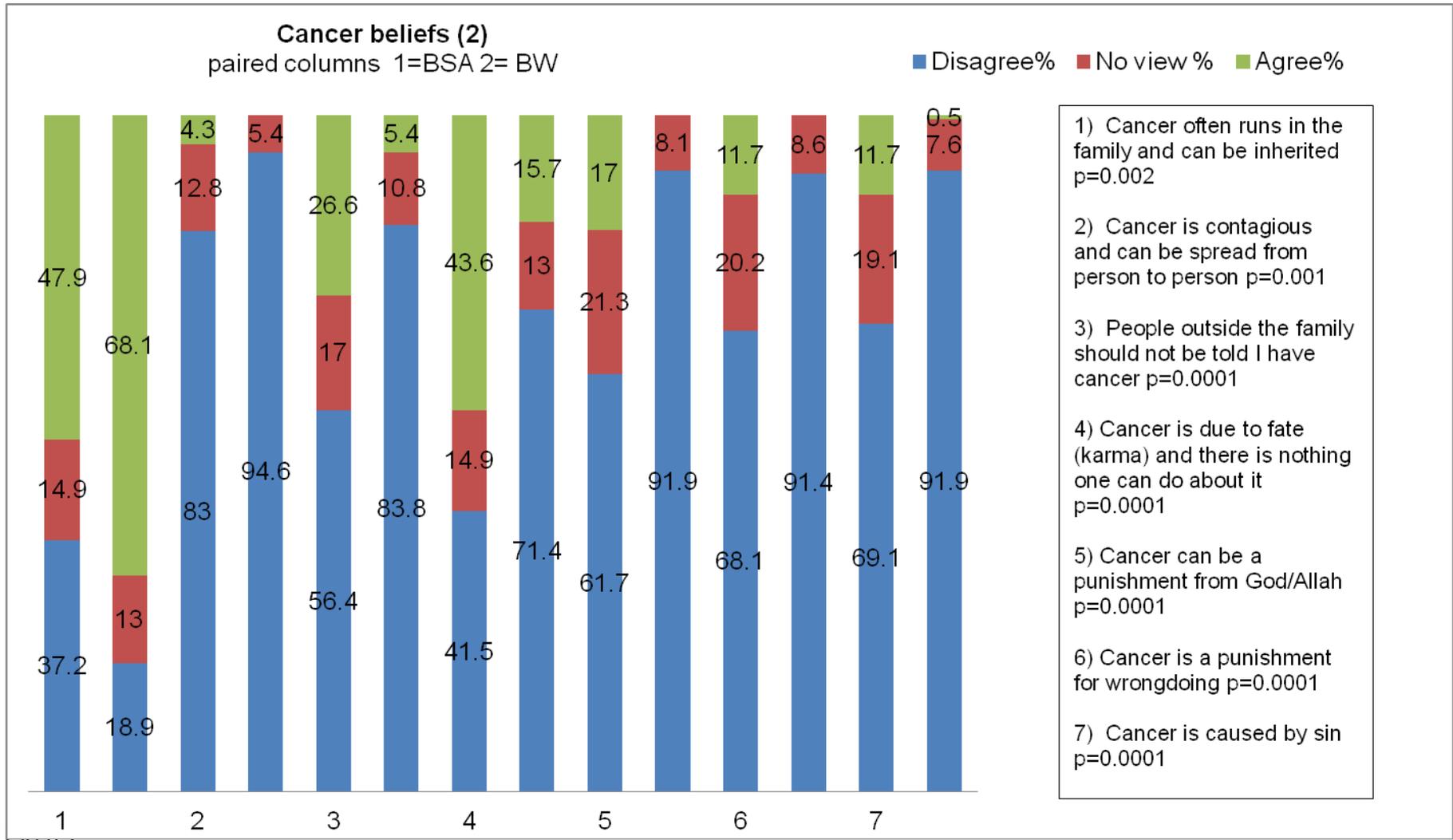
paired columns 1= BSA 2=BW

Disagree% No view % Agree%



- 1) Cancer is curable  
p=0.001
- 2) Cancer with spread...is incurable  
p=0.26
- 3) Early cancer in one part of the body is often curable  
p=0.35
- 4) Treatment especially surgery can often cause cancer to spread  
p=0.86
- 5) Alternative treatments are as effective as surgery radiotherapy and chemotherapy  
p=0.0001
- 6) It is possible to find cancer at a very early stage by screening...  
p=0.002
- 7) The causes of cancer are unknown  
p=0.013

Fig 42



- 1) Cancer often runs in the family and can be inherited  
p=0.002
- 2) Cancer is contagious and can be spread from person to person  
p=0.001
- 3) People outside the family should not be told I have cancer  
p=0.0001
- 4) Cancer is due to fate (karma) and there is nothing one can do about it  
p=0.0001
- 5) Cancer can be a punishment from God/Allah  
p=0.0001
- 6) Cancer is a punishment for wrongdoing  
p=0.0001
- 7) Cancer is caused by sin  
p=0.0001

Fig 43

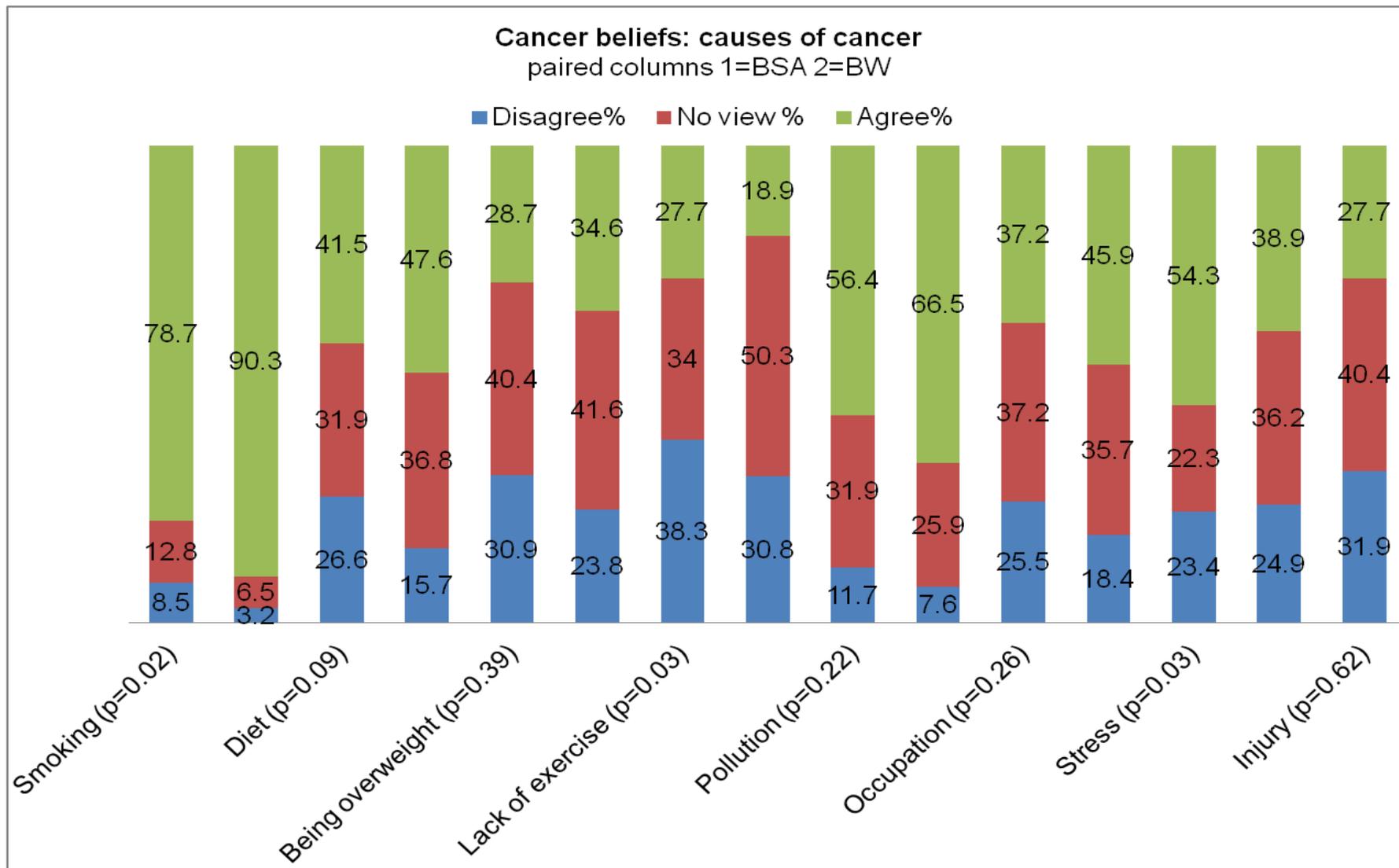


Fig 44

## 6.9 Patient/physician trust

*“(I) have great faith in the doctors and nurses that I have met during the initial examination and this gave me much hope” BW (192)*

*“I have put my trust in the doctors and nurses that are treating me and hope that everything is done in the best interest for me and my health”*

BSA (x66)

In all five domains of trust, doctors in the LCC were given high scores from both BW and BSA cancer patients (Appendix 6.9.1). 260/269 (96.7%) patients agreed with the statement measuring global trust, ‘overall I am satisfied with the medical care I have received’. There may be slightly less trust in the National Health Service as an organisation although trust was still remarkably high. 25 (9.3%) (N= 268) agreed with the statement ‘I am concerned that the NHS will not give me the best possible care’. When split by ethnicity 12/90 (13.3%) BSAs and 13/178 (7.3%) BW patients agreed; 62 (68.9%) BSA and 153 (86%) BW patients disagreed. Disregarding the 28 who held ‘no view’, there was a statistical difference between the ethnic groups with less trust in the institution among BSA patients ( $p= 0.05$ ).

*“All treatment options should be explained so that no doubt is left in the mind that the NHS doctors are looking at all optional medications/press and news talking of limitations to costs and you don’t know if this is hindering care/treatment....”*

BSA (x27)

*“I am concerned that the NHS will NOT give me the best care. ... based on the unavailability of the drugs e.g postcode lottery”*

*BW (289)*

There was a high degree of trust in local hospital doctors in both ethnic groups (Fig 45 & 46). When analysed as one sample 94.4% (n=272) completely trusted their hospital doctor. Furthermore, there was confidence that hospital doctors would give the best possible treatment, responses indicating no significant difference ethnically (BSA 89 (96.7%), BW 169( 94.8%) FET p=1.0). There is also a high degree of trust in GPs (all patients 80.2%, BSA 78%, BW 81.4%. Of the small minority who appeared to lack trust, BSA indicated less trust in their GP than BW; BSA 12/91 (13.2%), BW 9/177 (5.1%) excluding the no view (FET =0.033).

Confidentiality is an important domain of trust and a core element of the physician/patient relationship. 90.3% of 269 agreed with the statement “The hospital doctor will not give my medical history to others without my permission”. Approximately 10% expressed various degrees of mistrust, with 21(7.8%) being unsure expressing ‘no view’ and 5 (1.9%) had no trust. Given the low numbers, when analysing ethnic differences one can only observe the trend that more BW are insecure (no view) about the fact that their private information would be kept private (17/178 (9.5%) than BSAs 4/91(4.4%), and there is little ethnic difference in those lacking trust, BSA 2 (2.2%): BW 3 (1.7%).

Honesty is a core element of trust inside and outside the therapeutic relationship. 90.3% (n=268) of patients regarded their hospital doctors as being honest with them.

One patient wrote,

*“Doctors and consultant were forthright in giving their opinions, progress reports....,predictions. Honesty from them was essential for me. I believe we can cope with the truth not with lies”* BW (160)

Hospital doctors were perceived to be both caring and competent. 95.6% (n=270) agreed that, ‘the hospital doctors always listen to my concerns’ and 93.3% (n=269) that ‘hospital doctors do their best to help me’ (261/269 (97%). The small minority who lacked trust (8/269), and who had more symptoms of depression, (7/269; HADS D  $\geq$ 8), were less sure that doctors always listen to their concerns (HADS D  $\geq$ 8, 7 (5.5%)) and in a 2x2 table with ‘no view’ scores removed, this remained significant (FET=0.027). Finally, trust in competence, assessed by 4 items, was extremely high. The main indicator was ‘The hospital doctors are very competent and caring’. 95.6% of 270 patients strongly agreed or agreed with this statement, there being no significant difference between ethnic groups (p= 0.978 for trend) (Fig 45 & 46).

### **Patient preferences**

More subtle indicators of trust are observed in the preferences patients have for their patient/physician relationship (Appendix 6.9.2 & Fig 47). In terms of

decision-making 96.3% (n=268) preferred 'involvement' with the doctor in making 'important decisions'.

*"I am positive ...have a good sense of humour and will be guided by the doctors and nurses though will also make up my own mind having fully discussed matters with family"* BW (198)

There was no significant ethnic difference (BSA 96%, BW 96.3%). Far less, but still the majority, preferred 'my doctors to decide what is best for me' 178/264 (67.4%). Again, ethnic differences were insignificant (BSA 61/89 (68.5%); BW 117/175 (66.9%)  $p=0.079$ ). The trend, however, was towards BW patients preferring more control ( $p=0.009$ ).

We asked whether there was a preference for the gender of the doctor to be the same as the patient, given published evidence that within ethnic minorities there was reluctance to be medically examined by doctors of the opposite sex (Ahmad et al. 1989; Ahmad et al. 1991). Just over half of patients appeared unconcerned by this issue with 54.5% (n=268) disagreeing with the statement 'I prefer to see a doctor of the same sex (gender) as me' and 35.8% expressing no preference either way. A minority in both ethnic groups agreed with the statement with significantly higher numbers of BSA patients preferring to do so (BSA 18 (20%), BW 8 (4.4%) trend  $p=0.0001$ ). As one sample the preference for a doctor of the same sex was stronger among women than men (female 24/183 13.1%, male 2 /85 (2.4%) trend  $p=0.012$ ). The majority of these women were BSA. There was a trend towards those patients who were depressed having a higher preference for seeing a doctor of the same sex (HADS-D  $\leq 7$  4 (2.8%), HADS D  $\geq 8$  22 17.5%,  $p=0.0001$ ).

Preferences regarding who should impart sensitive information were explored. As one sample, only 11.9% (n=269) preferred 'to hear sensitive information from someone of a similar religion or background to me' and in both ethnic groups many patients expressed no preference either way (BSA 28 (30.8%), BW 70(39.3%)). There are however important ethnic variations. More BSA agreed with the statement than BW patients (n=171; BSA 24 (26.4%), BW 8 (4.5%) p=0.0001 for trend).

In this study, similar to that found in a pilot study, more BSA patients preferred the GP to be the communicator of sensitive information (BSA (52/94 (49.5%) v BW 30/177 (16.9%) trend p=0.0001. This did not affect the high levels of trust in the GP.

### **Predictors of trust**

165 out of 271 patients indicated trust in one or more questions. Whether trust was associated with preferences or items in other questionnaires was considered. When entered together in a logistic regression analysis those with low understanding of their illness (BIPQ p=0.011) and those who didn't find value in having treatment (CIDQ), were less likely to trust (p=0.0005). The strongest predictor of trust concerned the confidential nature of the patient/physician relationship (p=0.0005). Those who agreed with the statement 'The hospital doctors will not give my medical history to others without my permission' were more likely to trust the patient/physician relationship (p=0.0005). In addition, those who felt that the illness unduly affected their lives were less likely to trust (BIPQ p=0.005) (Appendix 6.9.3)

### **Patient/physician trust: associations with anxiety and depression**

Among BW patients those who were anxious were more strongly associated with preferring to hear sensitive information from their GP ( $p=0.029$  for trend) and being concerned that the NHS would not give them the best treatment ( $p=0.005$  for trend. This second indicator was also associated with depressive symptoms among BW patients ( $p=0.029$ ). BSA patients who were anxious were more likely to prefer to see a doctor of the same sex as themselves ( $p=0.005$ ).

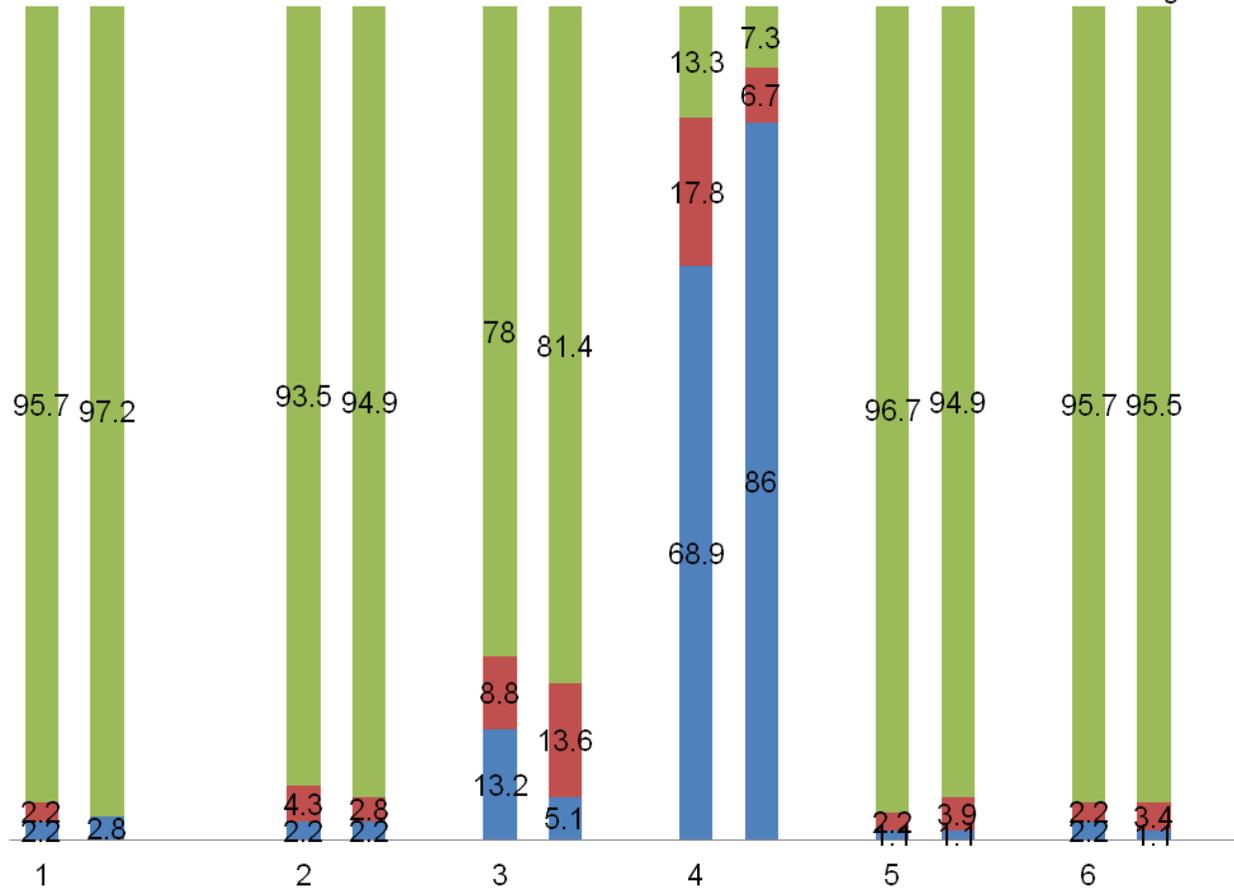
There were no significant associations between BSA and depressive symptoms while BW patients, who experienced symptoms of depression, were more concerned that hospital doctors might not give them the best treatment ( $0.008$ )(Appendix 6.9.4)

All indicators of trust were entered as potential predictors of anxiety and depression via logistic regression modelling but they did not form part of the 'best fit' model generated (see p 158).

### Patient/physician trust: an ethnic comparison

Paired columns 1=BSA 2=BW

■ % Disagree % ■ % No View % ■ % Agree %



- 1) Overall I am satisfied with the medical care I have received (global trust) p=0.014
- 2) I completely trust my hospital doctor (global trust) p=0.8
- 3) I completely trust my general practitioner p=0.04
- 4) I am concerned that the NHS will NOT give me the best treatment p=0.003
- 5) The hospital doctors always give me the best treatment (competence) p=0.75
- 6) The hospital doctors are very competent and careful (competence) p=0.69

Fig 45

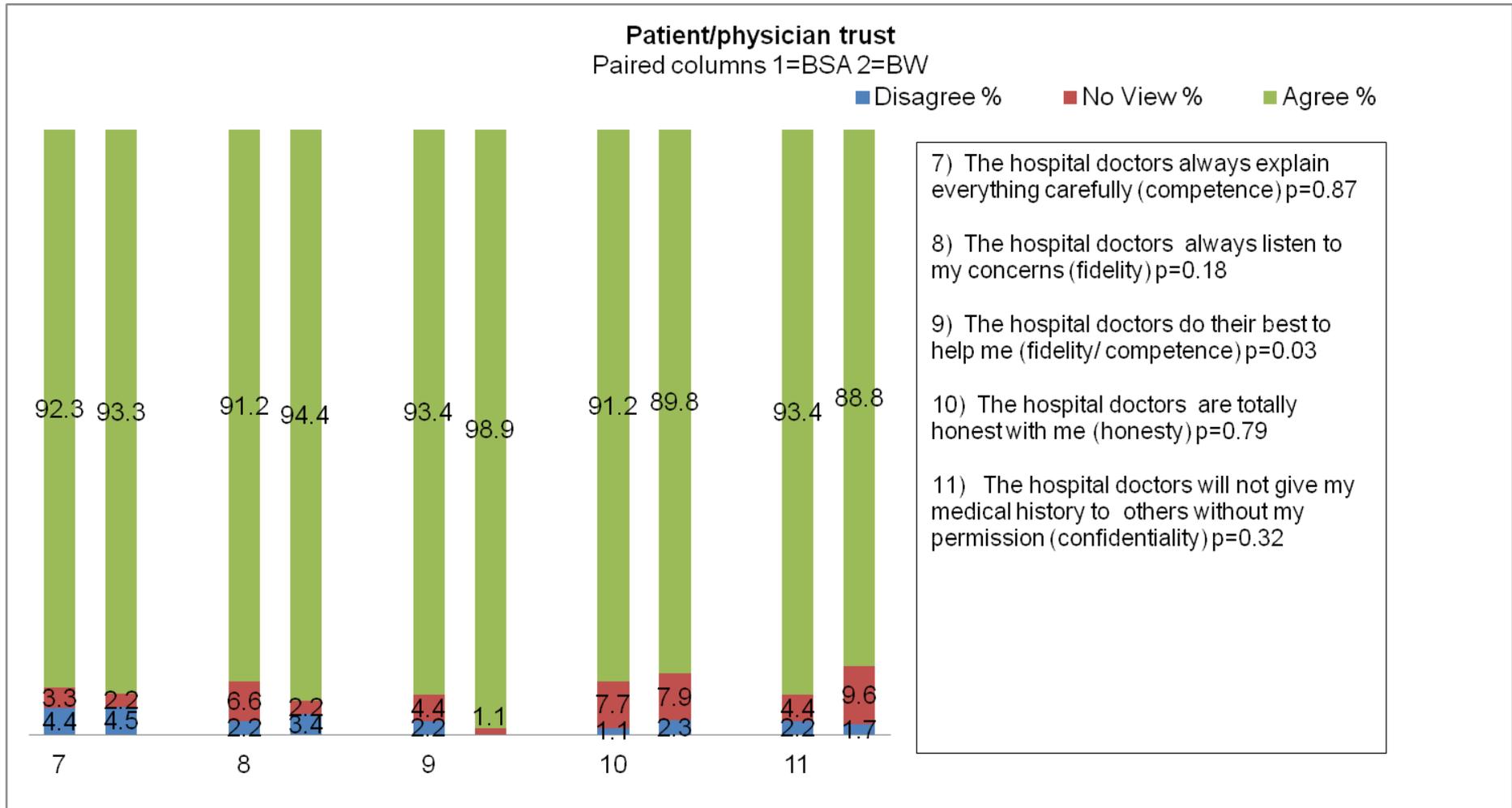


Fig 46

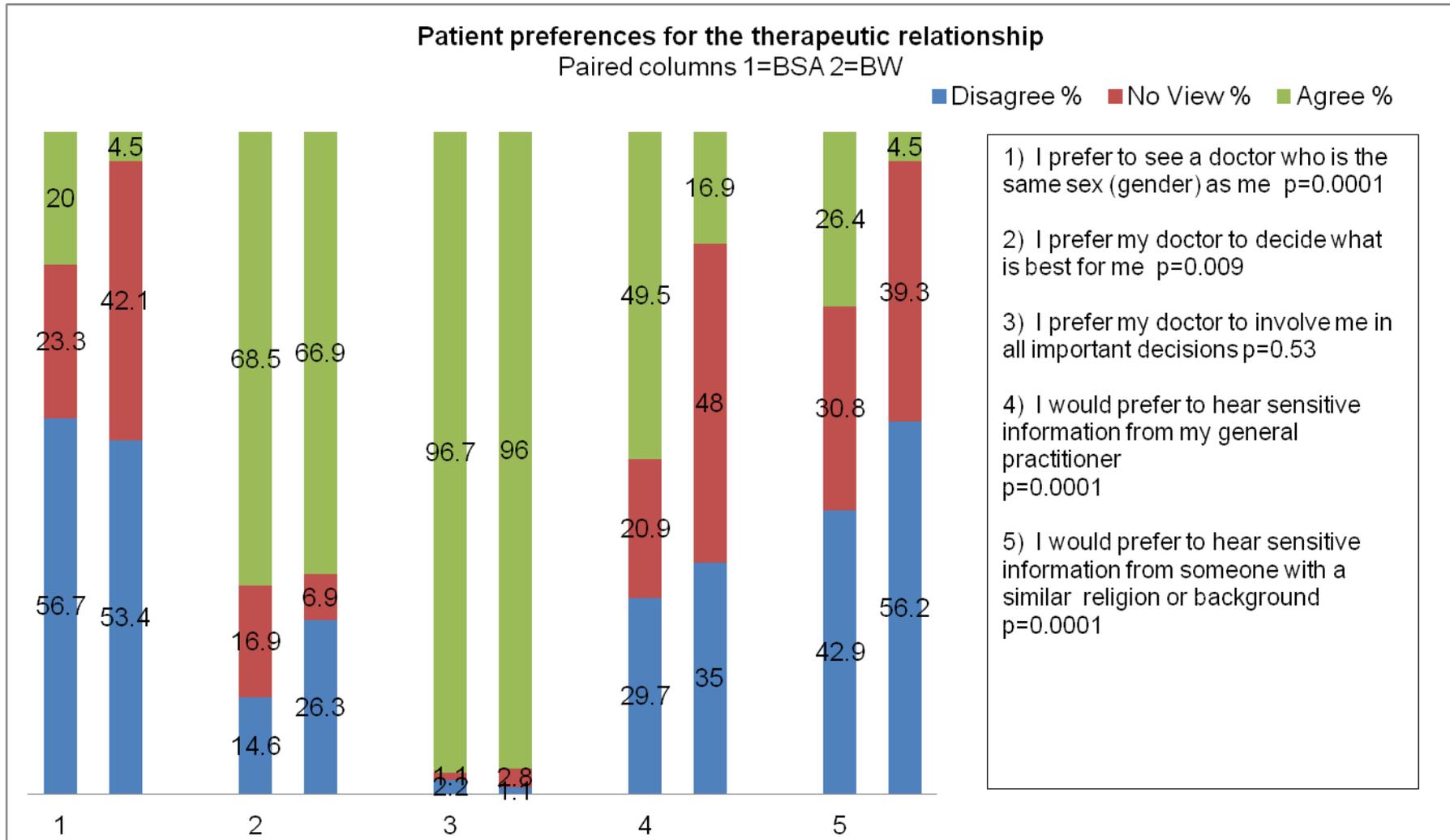


Fig 47

## 6.10 Longitudinal representations of cancer (BIPQ)

The cognitive and emotional representations of illness were explored via the BIPQ to identify issues of clinical significance.

Cancer was perceived differently by the two ethnic groups. The disease and its treatment appeared to have a greater impact on the lives of BSA than BW patients at each point of contact. The widest difference in response to the question "How much does your illness affect your life" was at baseline as the different median scores indicate (MW:BSA, BIPQ Md 7 (4,9): BW BIPQ Md 5(2,7), MW Z= -4.224, p= 0.0005). This trend was still present, although less so, three months later (BSA BIPQ Md 7(IQR4.5-8.5); BW Md 5(IQR 2,7) MW:Z= -3.325, p=0.001). By nine months, however, the ethnic difference was far less (BSA Md 5 (3,7) BW Md 3 (1.5,5); MW: Z=-1.744, p=0.081) (Appendix 6.10.1& 2). The effect on the lives of BSA patients appeared steady across the study period (Freidman test p =0.234). In contrast there was a steady decrease in the impact of cancer on the lives of BW patients (p=0.009).

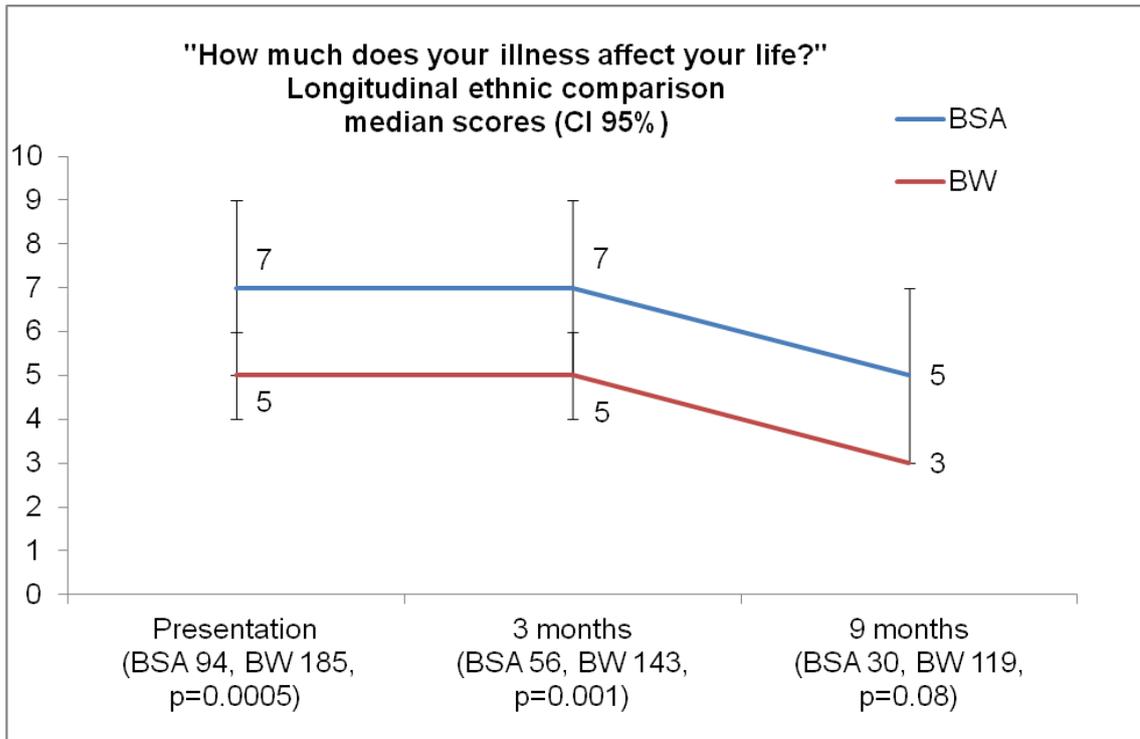


Fig 48

There was more 'worry' about the cancer spreading among BSA patients than BW patients initially (BSA Md 6 (3,9); BW Md 5 (3,7)  $p=0.012$ ); however, the worry was not excessively high for either group. The ethnic difference remained at three months ( $p=0.023$ ) but not by nine months ( $p=0.329$ ) Fig 49). Over time this particular concern did not decline among BSA patients (Friedman  $p=0.724$ ) in contrast to BW patients whose concern had lessened by three months before levelling at nine months ( $p=0.001$ ) (Appendix 6.10.4).

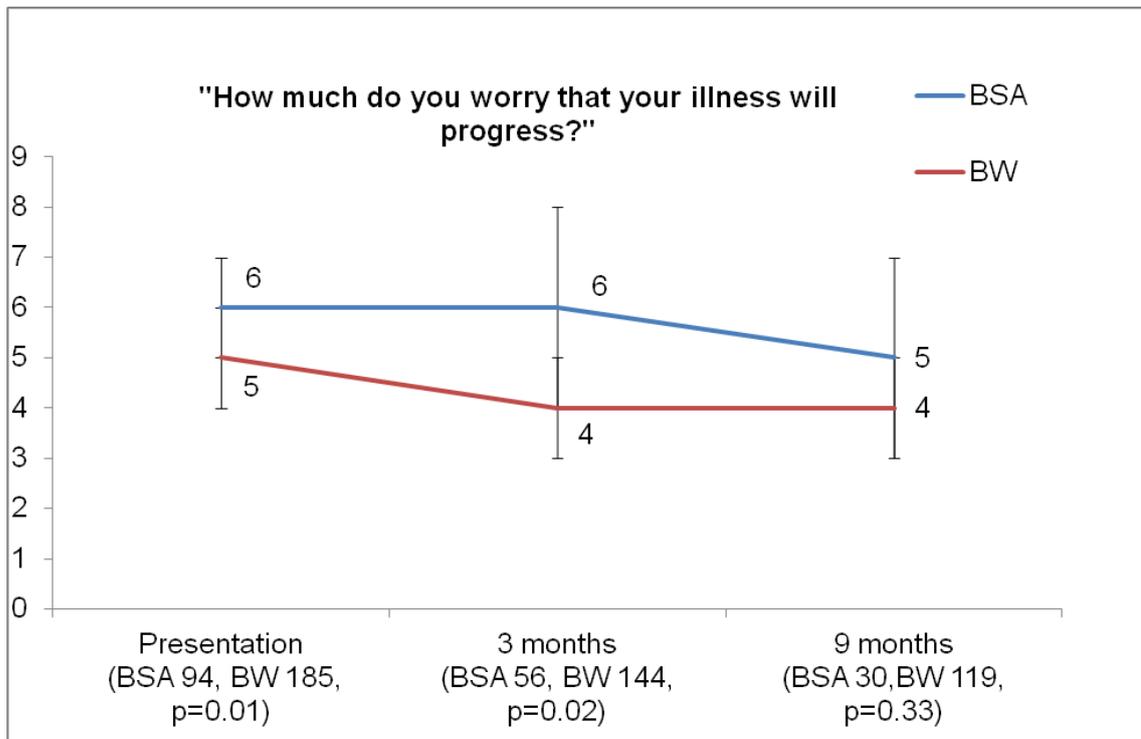


Fig 49

BSA patients experienced more symptoms of illness than BW at each point of contact with the widest difference at baseline (BSA Md 5 (2,8); BW Md 2(1,5) MW:  $Z = -3.262$   $p = 0.0005$ ) (Fig 49). Both groups report an increase in symptoms three months later, but the difference between them was less (BSA Md 6 (3,8); BW Md 4 (2,5.5) MW  $Z = -3.262$   $p = 0.001$ ). At nine months both mean rank scores had fallen although BW patients still reported less symptoms of illness. (BSA Md 4 (1,6) BW (Md 2 (1,5): MW  $Z = -1.569$   $p = 0.117$ ). It was difficult to draw conclusions from Friedman test results In the case of the BSA patients findings are limited by the small sample by nine months (BSA  $n = 28$  mean rank (baseline) 2.0 (3 months) 2.29 (9 months) 1.71,  $p = 0.083$ ). Among BW patients there was an increase in symptoms corresponding to undergoing treatments before declining by the end of the study period. (FT (1) 1.79 (2) 2.32

(3)1.89 p=0.0005).

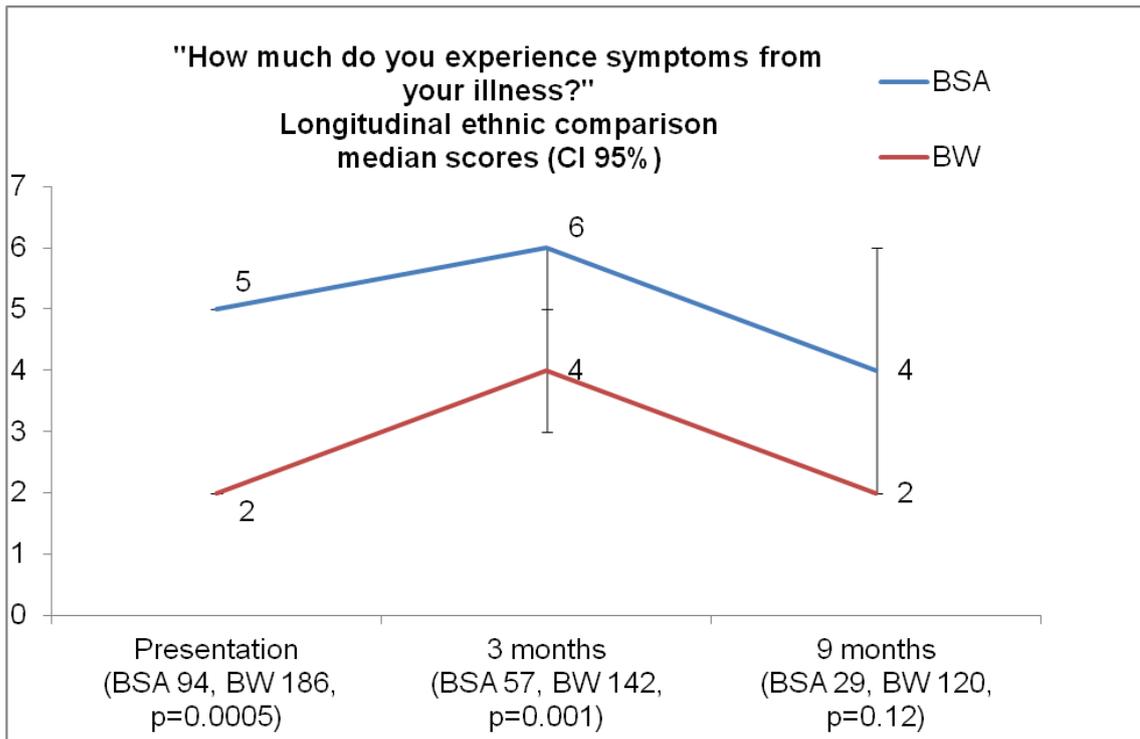


Fig 50

Interestingly, in spite of the burden of symptoms, confidence that treatment might help increased in both groups at three months (BSA Md 4(2,6); BW Md 4 (1.5,6) MW Z= -2.925, p= 0.0003) (BSA Md 8 (8,9) BW Md 8 (6,10); MW p 0.471). There was little ethnic difference from then on (9 months MW p=0.316)(Fig 51).

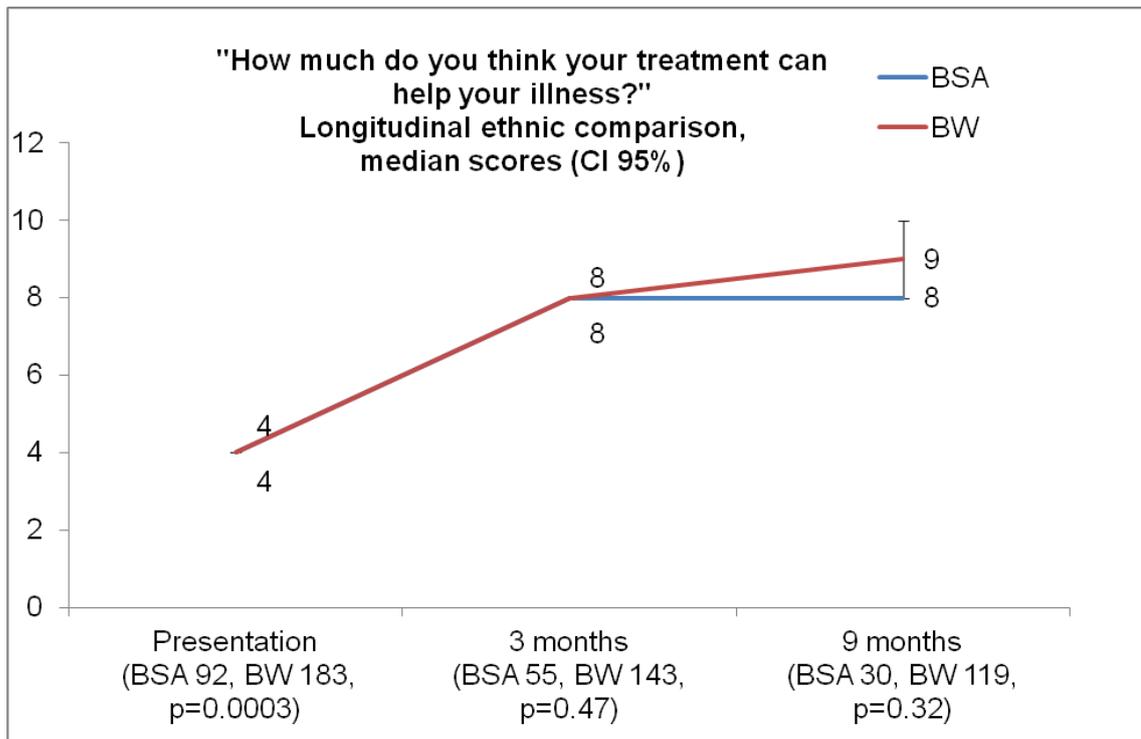


Fig 51

The emotional impact of cancer was markedly more pronounced among BSA patients across the study period (baseline p=0.002 3 months p=0.001 9 months p=0.005). This lessened for both ethnic groups as time passed. Friedman tests for both groups were insignificant (BSA p=0.422; BW p=0.072).

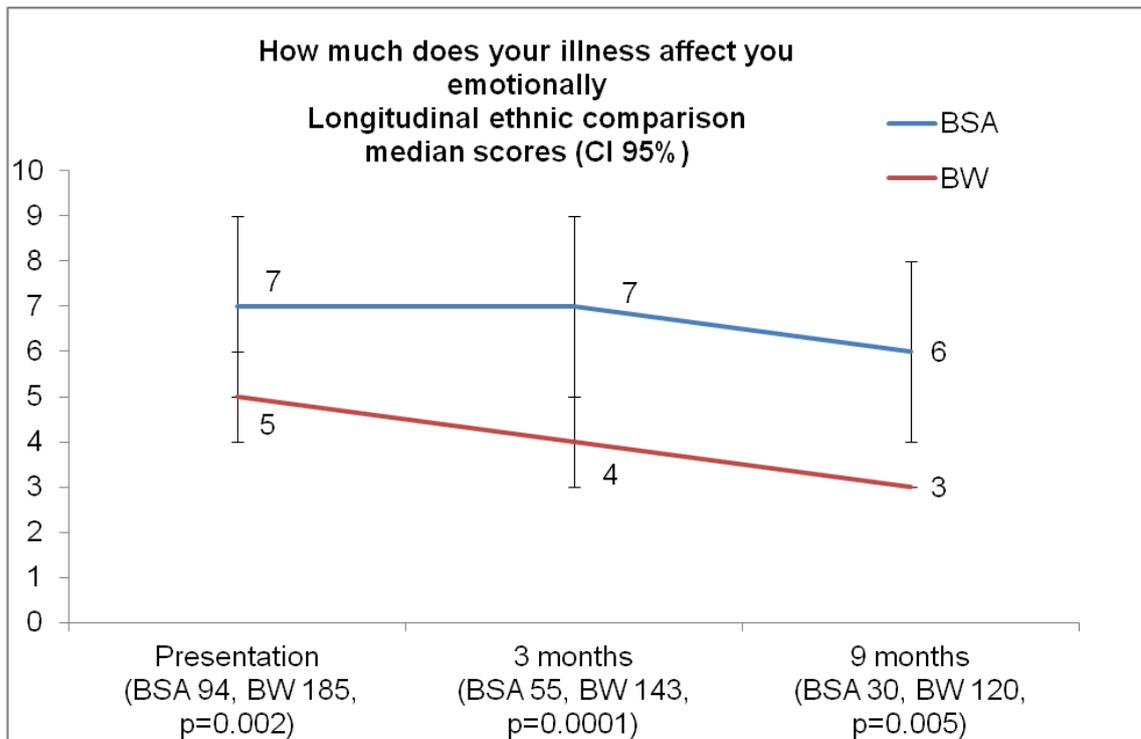


Fig 52

Initially there appears to be a paradox between the higher emotional impact of cancer felt among BSA patients and their greater sense of control over the illness at three months in comparison to BW patients (BSA Md 5 (IQR 3,7.5): BW Md 4(IQR 1,6) MW p=0.009) (Fig 52&53). Although the median scores of BSA patients remained higher than BW at interview 1 and three, the differences were small.

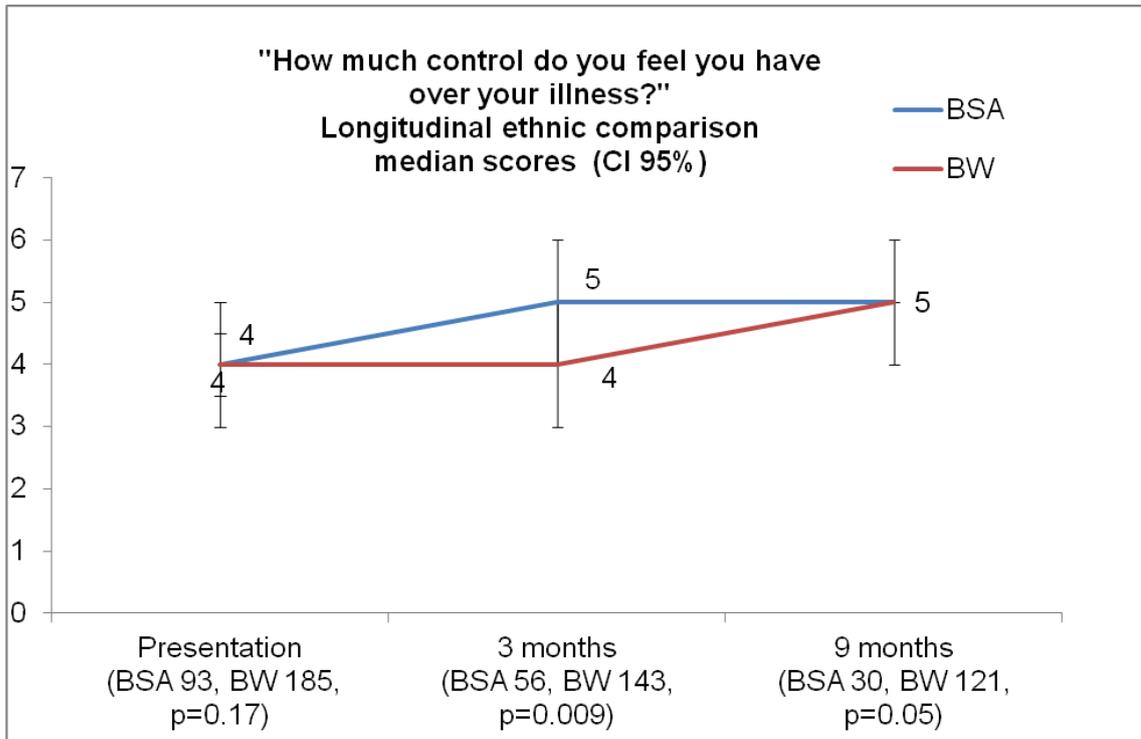


Fig 53

Within each ethnic group there was a similar pattern of change in scores with a sense of control increasing steadily.

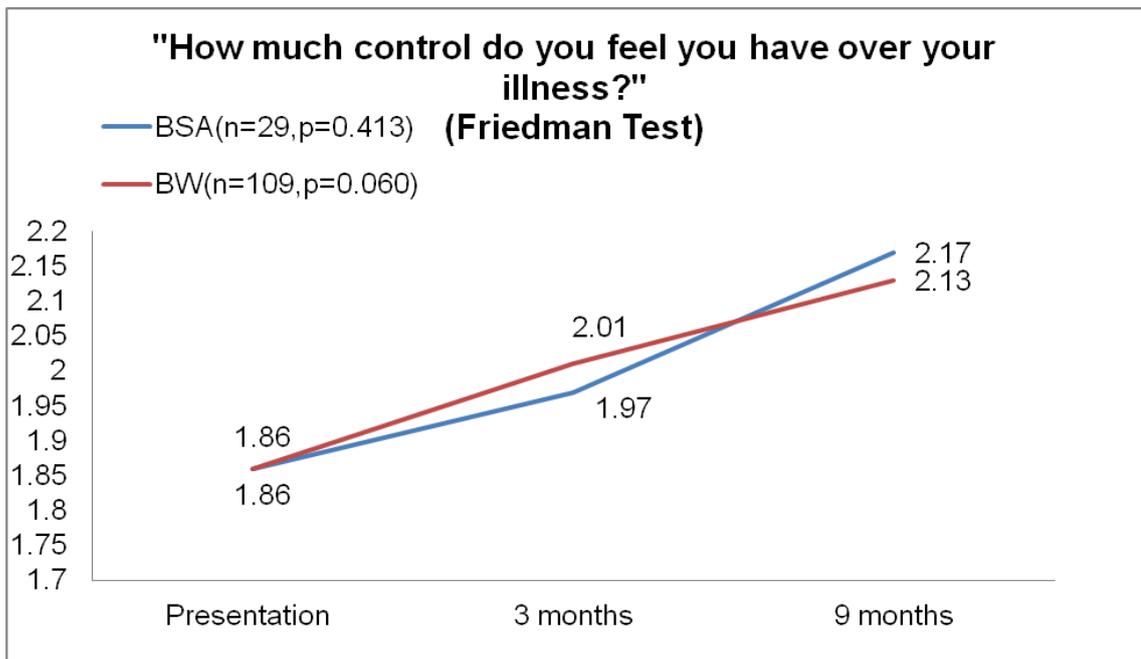


Fig 54

Surprisingly, given the potential barriers of language and literacy among some BSA's, there was little difference in the understanding of the illness within the ethnic groups across the study period (Fig 55). There was a gradual increase in understanding among BW longitudinally but the change was small. Friedman (baseline) 1.91 (3 months) 1.98 (9 months) 2.11  $p=0.197$ . Among BSA patients, after an initial increase in 'understanding' at three months, there was a downward trend by nine months but again the difference was small (Friedman (baseline) 1.86 (3 months) 2.16 (9 months) 1.98  $p=0.460$ ).

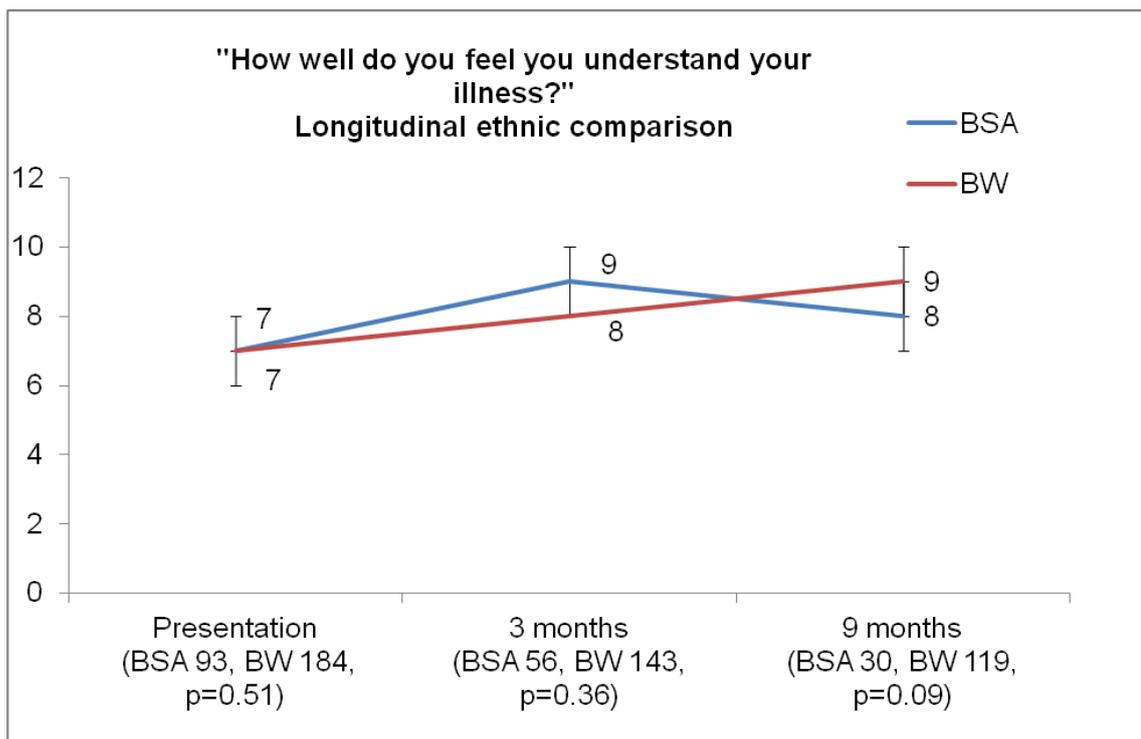


Fig 55

To summarise, the impact of cancer affected BSA patients more than BW. The former experienced more symptoms, worried more about disease progression and their diagnosis had a higher emotional impact than on BW patients. Consequently one might expect this to lower the feeling of control over the

disease; however, BSA patients consistently felt more control than BW patients at three months. There was also little difference in the understanding of disease between the two groups. Finally, in both groups the belief that treatment was helpful increased at a time when the impact of symptoms was high.

### **6.11 Longitudinal 'problems' which caused distress**

Ethnic differences in the causes of distress persisted across the study period through analysis of the 'problem checklist associated with the Distress Thermometer (ET) (Appendix 6.11.1-6.11.3). 70 patients (27%, n=260) acknowledged 'depression' as a cause of distress at baseline (Appendix 6.11.1-6.11.3). A higher percentage of BSA patients acknowledged depressive symptoms (BSA (35.6%); BW (22.5%) p=0.036). This ethnic gap largely remained at three months (BSA 38.2%; BW 23.7% p=0.065) before the depressive symptoms eased among BSA being similar to those of BW patients at nine months (BSA 26.7% BW 22.9% p=0.84).

Other psychological symptoms showed minimal ethnic differences; however, the following were all among the most frequently mentioned at baseline for patients as one sample group; worry (n=268, 60%), fears (n=264, 56%), nervousness (n=265, 52%) and sadness (n=262,40%). The trend was towards a greater ethnic gap after three months with BSA appearing to worry more but not significantly so (BSA 54.8% BW 37.8%, p= 0.131)(Fig 56).

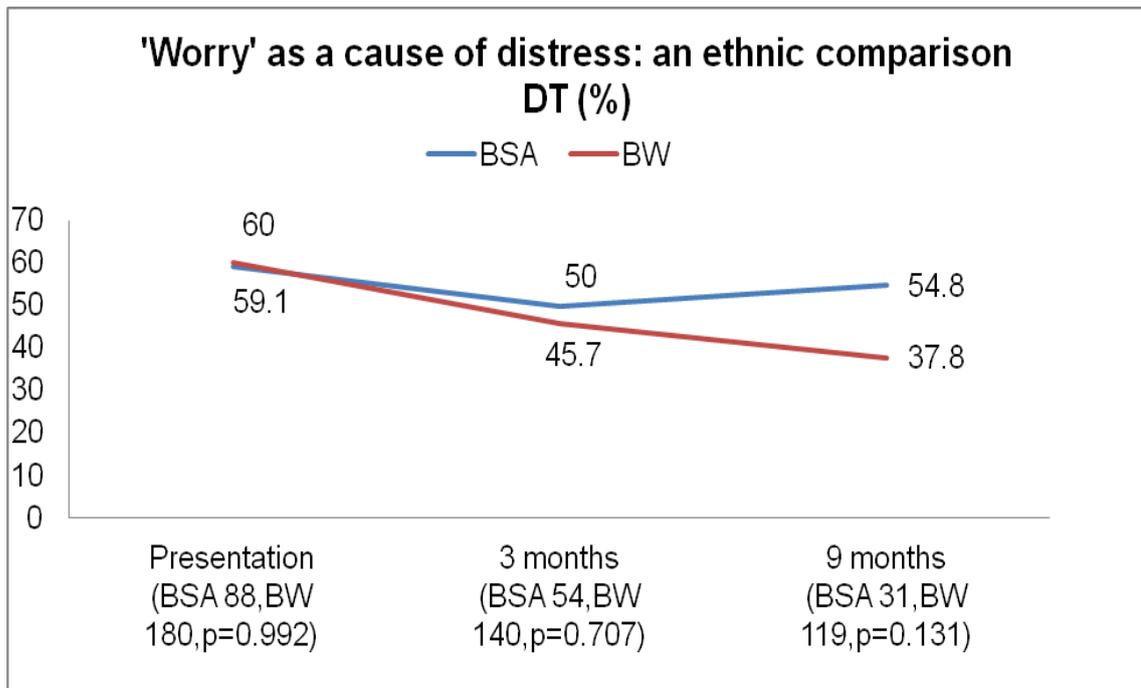


Fig 56

### Spirituality

It was within spirituality that the largest difference between the ethnic groups was observed. The majority of both groups did *not* find 'relating to God' to be a problem (baseline: (BSA 57 (67.1%); BW 163 (93.1%)). However, among the minority, BSA patients were far more likely to feel distress. (BSA 28(32.9%) BW 12(6.9%)  $p=0.0001$ ). When comparing mean rank scores the gap was clearer (MW: BSA 153.32; BW 119.41,  $Z= -5.458$ ,  $p=0.0001$ ). Although 32% of BSA were distressed by their relationship with God, only 11(13.3%) regarded 'loss of faith' distressing – again higher than among BW patients ( $p=0.013$ ). There were longitudinal changes. Of note was a decrease in the percentage of BSA patients being distressed 'relating to God' (20.8%) although there was little

difference in loss of faith at that point (14.5%) (Fig 57&58).

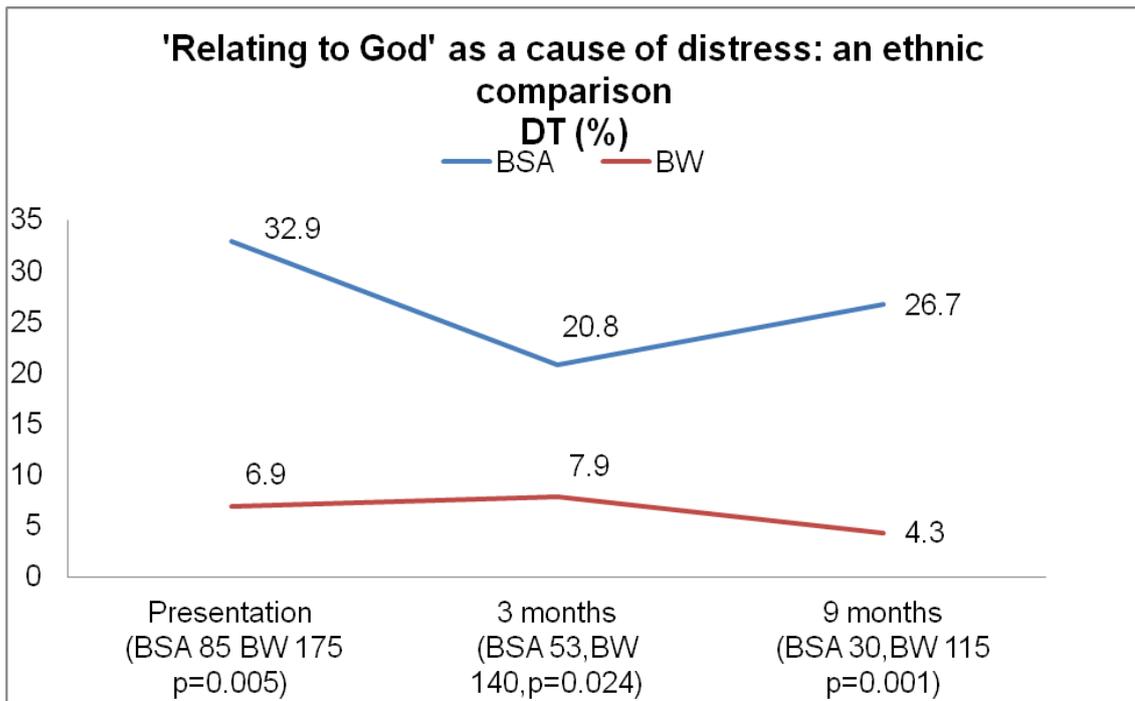


Fig 57

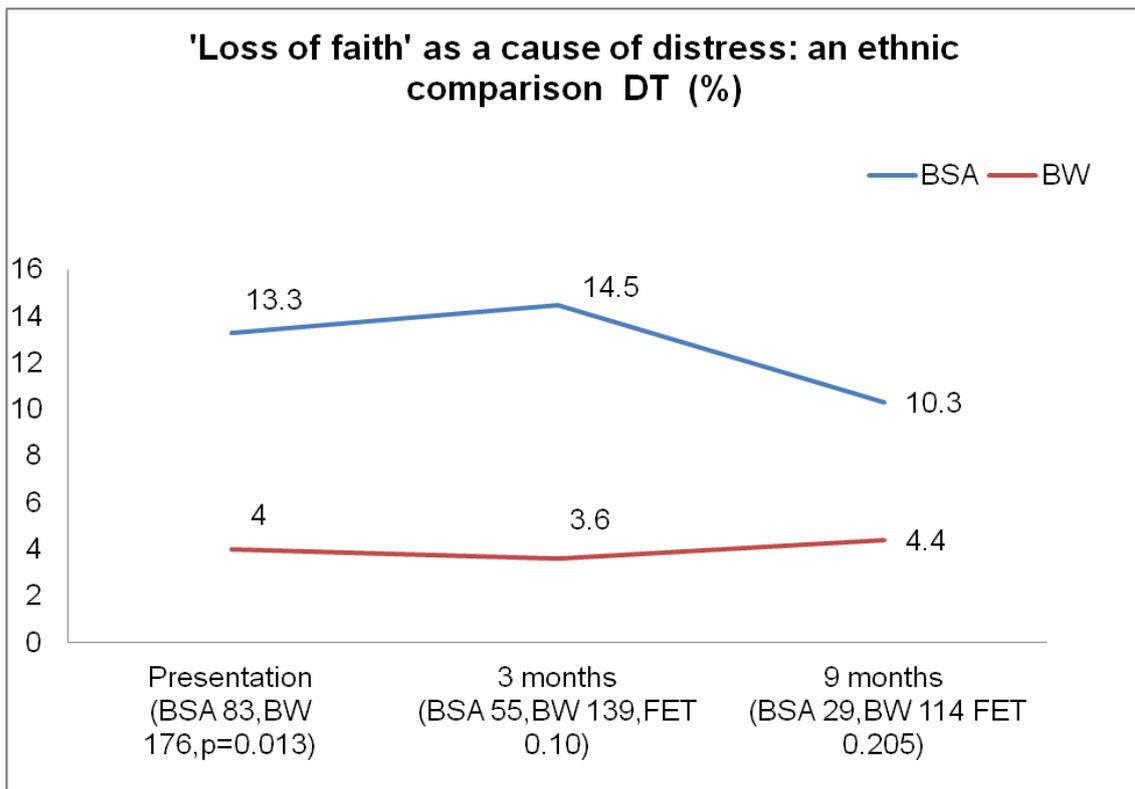


Fig 58

## Physical symptoms

It was apparent, both from a response to a BIPQ indicator and the DT Checklist, that 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 baseline. For example, pain (BSA 51/83(58%): BW 59/180(32.8%)  $p=0.0001$ ) (Fig 59) mouth sores (BSA 21/88(24.1%) BW 12 /179 (6.7%)  $p=0.0001$ (Fig 60) and fevers (BSA 18/87 (20.7%); BW 5/177 (2.8%)  $p=0.0001$ ) (Appendix 6.11.1). At three months, higher percentages of BSA patients reported pain, mouth sores, nausea (Fig 61), skin, washing and dressing and getting around (Fig 62) as causes for distress than among BW patients (see appendices 6.11.1).

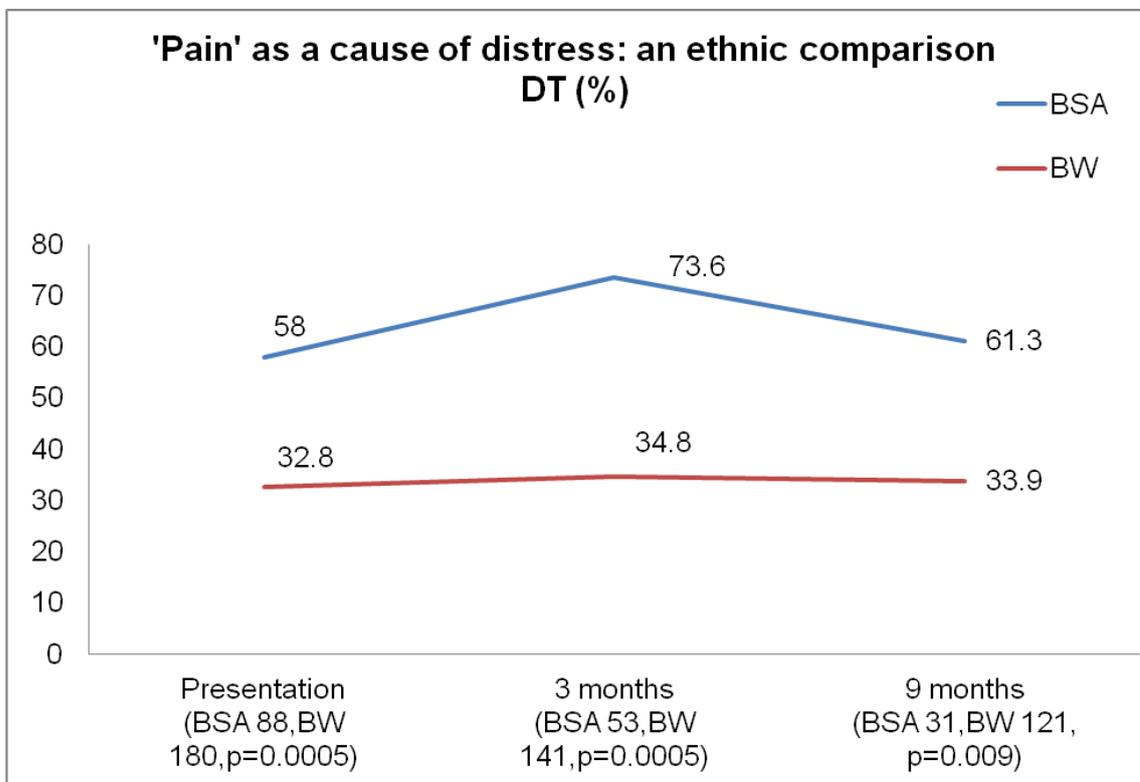


Fig 59

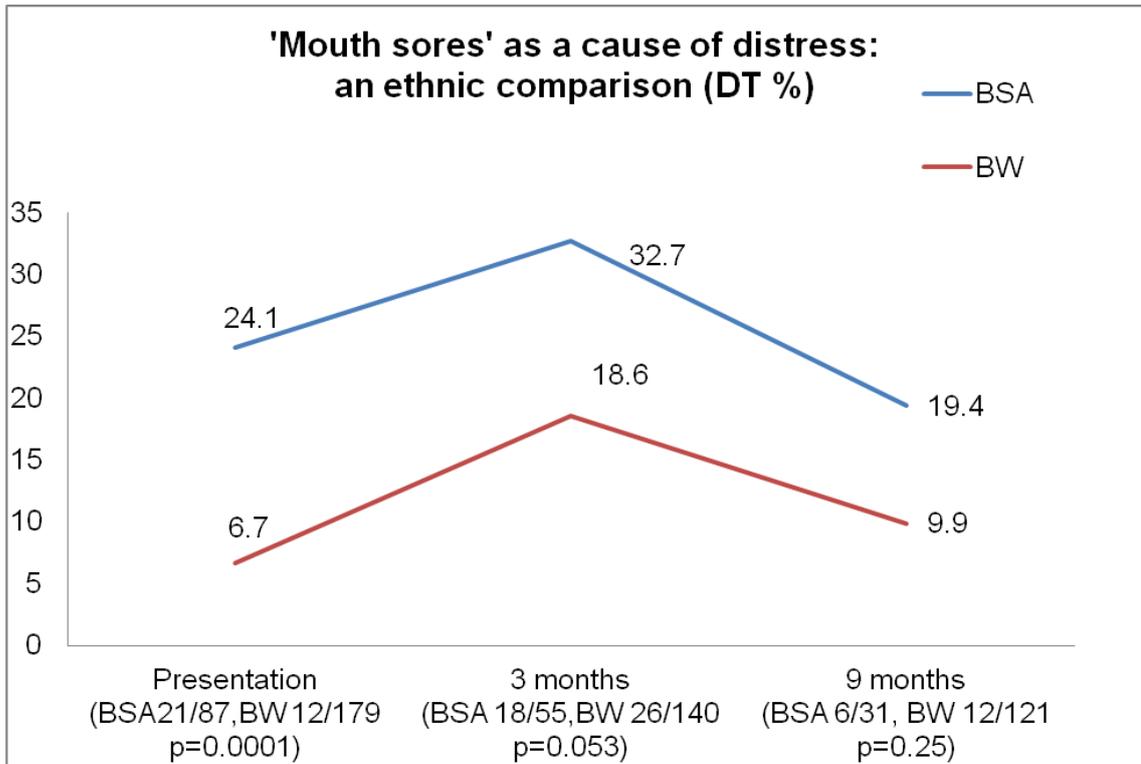


Fig 60

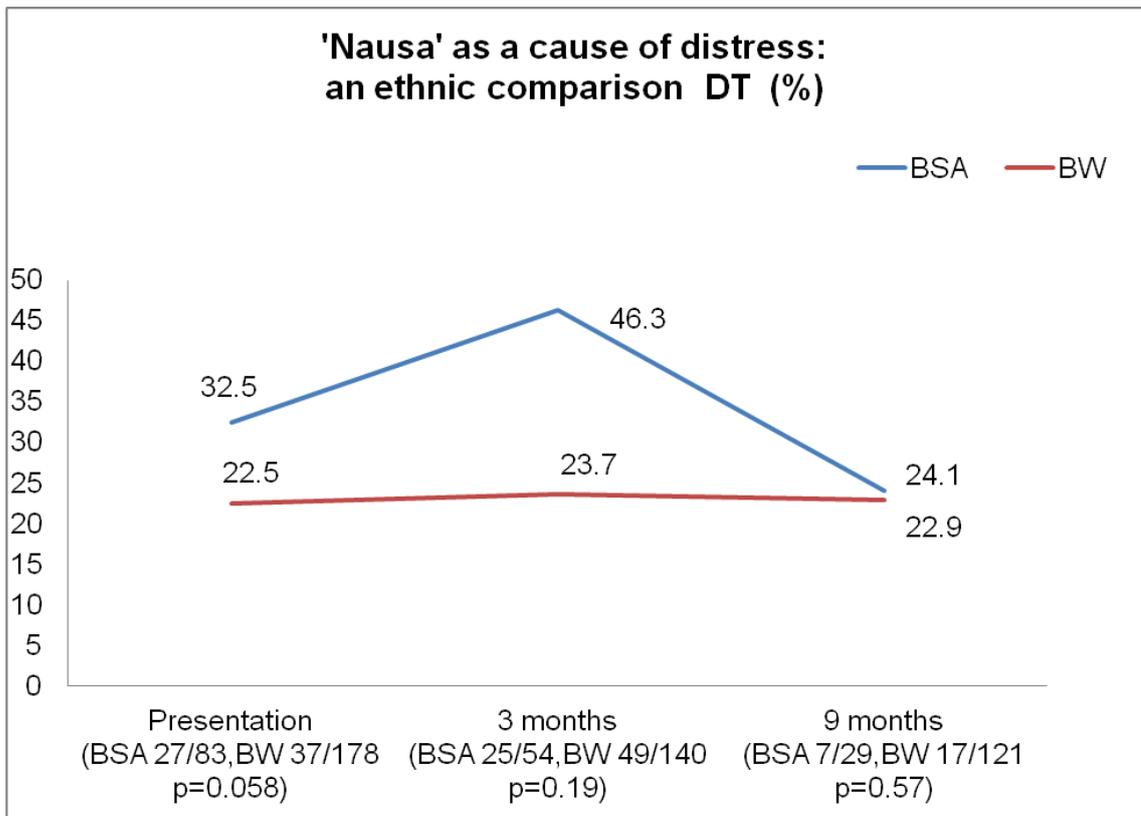


Fig 61

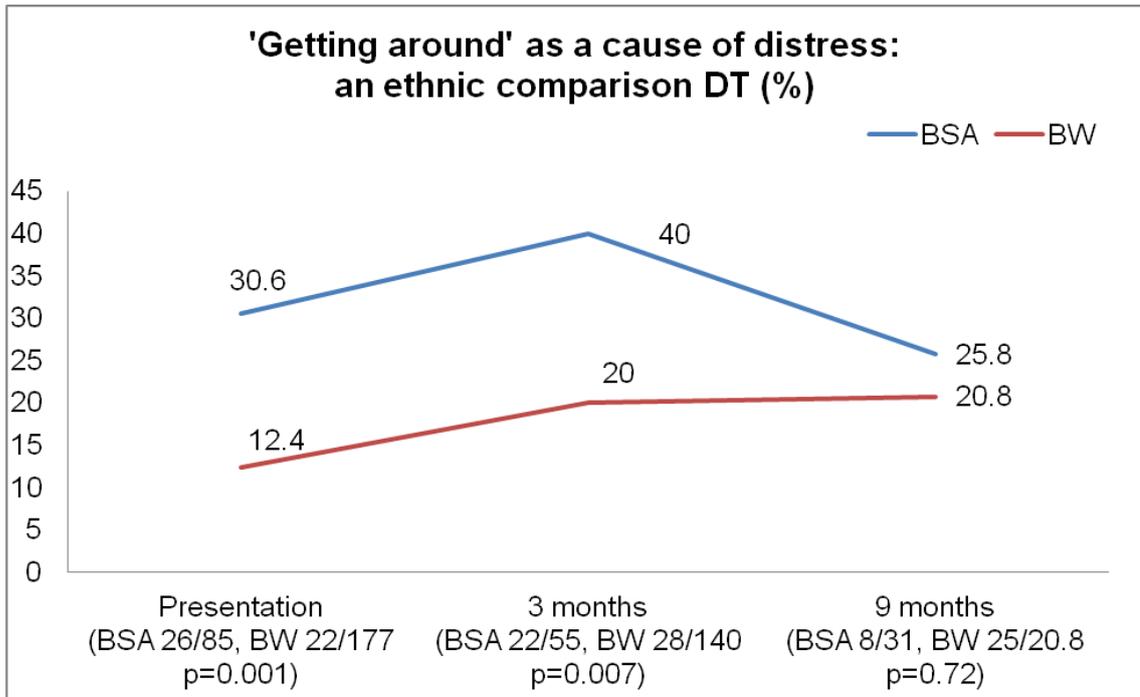


Fig 62

At baseline, fatigue affected 51% as one sample, increased to 66.3% at three months and fell to 52.3% at nine months (Fig 63). There was little variation in reports of fatigue among BSA longitudinally when comparing mean scores ( $p=0.148$  for trend). In contrast more BW patients felt fatigue at three months ( $X^2$  for trend  $p=0.006$ ). It affected both ethnic groups with little difference between them at three months (BSA 49 (57%) BW 84 (47.7%)  $p=0.742$ ) or at nine months (BSA 18(60%) BW 61 (50.4%)  $p=0.461$ ) Fig 60 and (Lord et al. (in press 2013)).

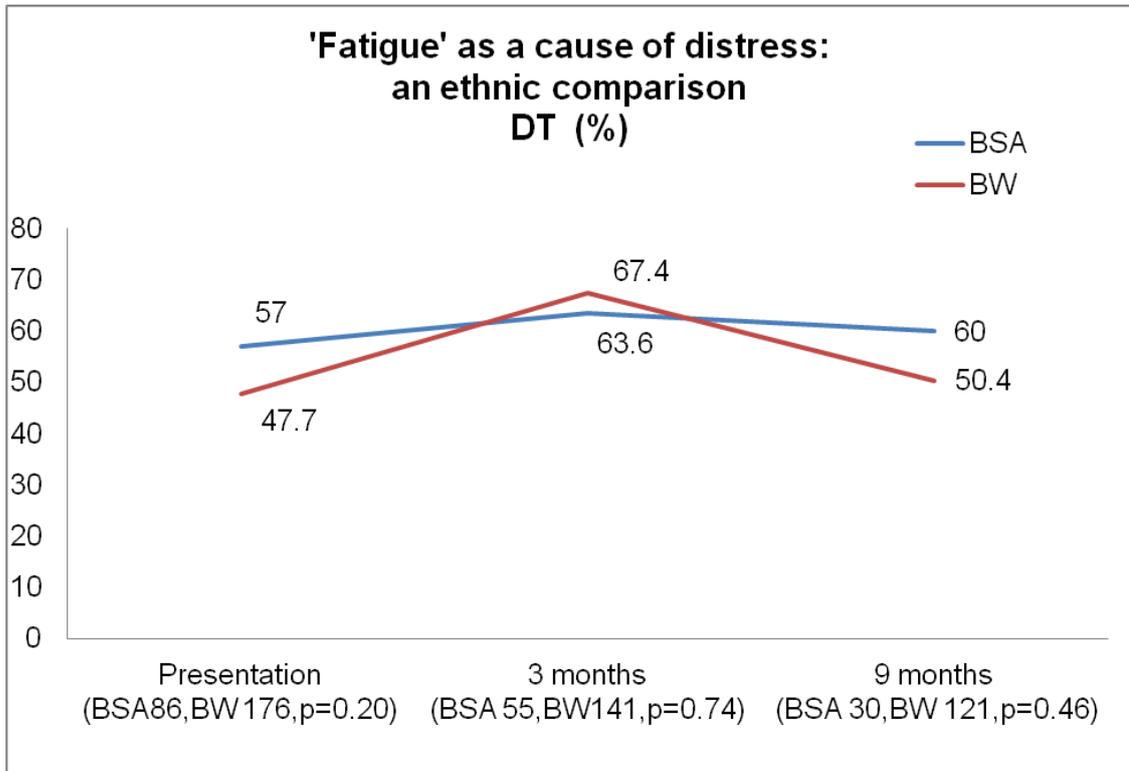


Fig 63

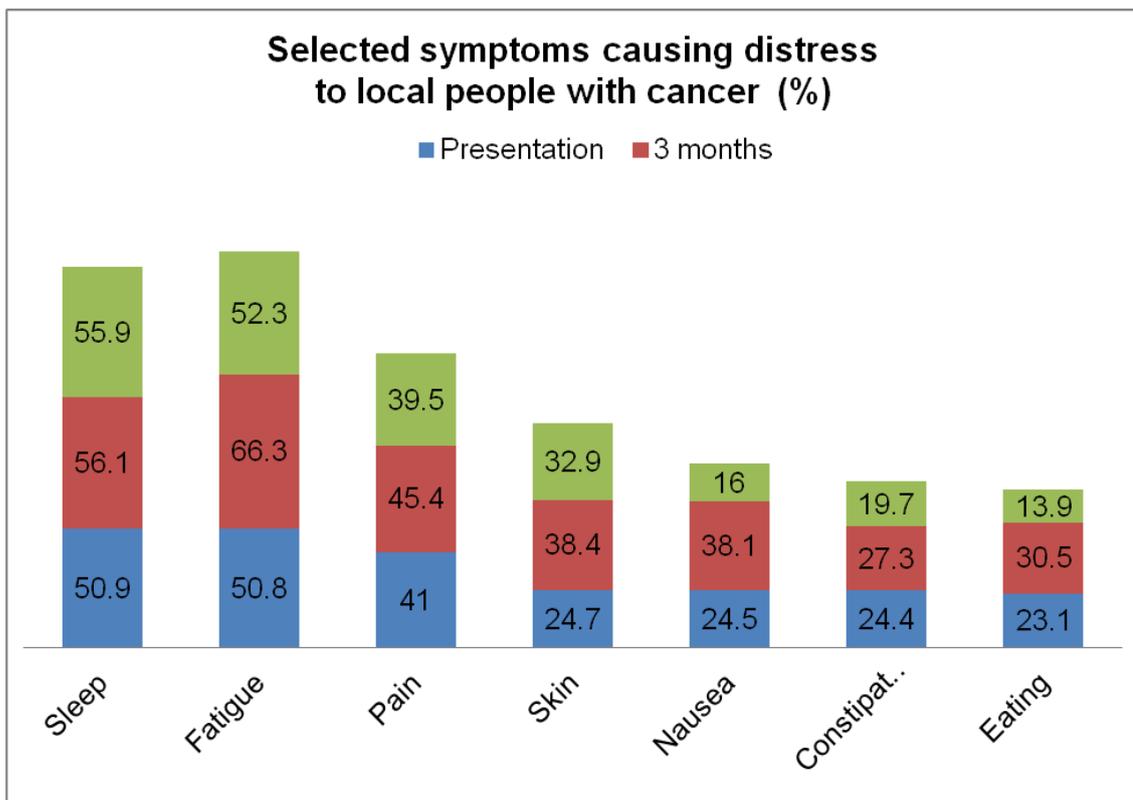


Fig 64

## **Socio-economic factors**

Socio-economic factors caused distress and may reflect the finding that deprivation was more prevalent among BSA patients in this study. For example, although 90.6% of the patients had no problem with housing, more BSA patients were concerned (BSA 21.4%; BW 3.9%  $p=0.0001$ ). Worries about insurance showed a similar difference (BSA 15.3%; BW 6.1%  $p=0.016$ ). Initially there was no ethnic difference in transportation difficulties ( $p=0.776$ ) although 15% of the whole sample described this as a problem. By three months, this problem had increased particularly among BSA patients (BSA 20.4% v BW 7.1%  $p=0.015$ ). The difference had subsided by the end of the study ( $p=0.23$ ). Childcare was not a dominant issue affecting only 15 patients. This is probably relating to the average age of the sample being over 59 when the majority of offspring would be adult. The results would probably be different amongst a younger cohort of patients. 94.3% did not have a problem but of those who did, more were BSA (BSA 11(13.1%); BW 4 (2.2%) FET 0.001).

## **Predictors of distress**

Distress is antecedent to the development of anxiety and depression. It is therefore potentially valuable to identify any physical or psychological predictors of distress which have implications for clinical practice.

## **Physical predictors of distress**

Mouth sores, sleep problems, and 'getting around' were the top physical causes of distress among cancer patients soon after diagnosis in one sample (Appendix 6.11.3). 'Getting around' might refer not just to being mobile around

one's home but being able to get to the shops and participate in social events. The predictive model was summarised as  $X^2(3, n= 253) = 37.161, p=0.0005$ . The most influential cause of distress was 'mouth sores' associated with high levels of pain and eating problems. There are several causative mechanisms implicated in mouth sore development and to date, in spite of international efforts to generate evidence-based clinical guidelines for prevention and treatment, there remains a lack of clarity (Keefe et al. 2007). With the large cohort of patients receiving anthracyclines in this sample, the reporting of mouth ulcers may be disproportionately high and results may be different in a more evenly distributed cross section of cancer patients. The odds ratio indicated that those with mouth sores were over six times more likely to report distress than those who did not. Those with sleep problems were twice as likely to report distress as were those who were losing their independence by having difficulty with mobility and access'. Sleep disturbances are a reliable symptom of depression (American Psychiatric Association, 1994).

### **Ethnic differences in causes of distress**

Mouth sores caused great distress across both groups but there were differences too. Among BW patients sleep problems were most distressing. Concerns about one's partner provided the next strongest contribution to the BW patient model. Together variables predicted between 11.3% and 15.5% of the variation in distress with the model being significant, BW:  $X^2(4, n= 171) = 20.547, p=0.0005$ .

Physical problems appeared to cause greater distress among BSA patients than BW patients echoing results from analysis of the BIPQ. Only two factors, 'getting around' and 'mouth sores', formed a model which predicted between 22.8 and 31.2% of the variation in distress in this patient group. BSA who had difficulty getting around were over 11 times more likely to be distressed (odds ratio 11.316) although this was not a major issue among BW patients. Conversely 'concerns for partner' were not a significant cause of distress among BSA patients but was an issue for some BW patients. The model summary for BSA physical predictors was  $X^2(2, n=79) = 20.469, p=0.0005$ .

### **Psychological predictors of distress**

Psychological factors were much stronger predictors of distress than physical symptoms. As one sample a model of four symptoms predicted 34.3 and 45.8% of the variation in distress.  $X^2(4, n=243) = 101.984, p=0.0005$ . The most influential single factor was 'relating to God'. Patients with this concern were over five times more likely to be distressed (odds ratio: 5.6).

This factor did not feature as a predictor for distress among BW patients. Instead 'depression', 'fears', 'nervousness' and 'sadness' predicted between 33.7% and 46% of distress,  $X^2(4, n=170) = 69.844, p=0.0005$ . Those feeling depressed were over seven times more likely to be distressed (odd ratio 7.17) and patients feeling nervous the odd ratio was 3.3.

Two psychological factors, 'sadness' and 'relating to God', produced the best model for BSA patients predicting between 35.3% and 48.2% of the distress,

$X^2(2, n=76) = 33.042, p=0.0005$ ). Those feeling sad were almost 16 times more likely to be distressed. Spiritual distress appeared influential among BSA patients. As a single variable it had a Wald value of 9.144,  $p=0.002$ , far more than for BW patients (Wald 4.059  $p=0.44$ ). This suggests a higher influence of supernatural beliefs in coping with cancer among BSA patients.

### **6.12 The need for help**

We investigated who most wanted help via the 'help thermometer'. 'Help' may take the form of access to information, spiritual support or forms of psychological care. Our aim was to establish whether those most distressed expressed a greater or lesser need for help than those not distressed as one sample and then cross culturally.

Overall 39.6% of all patients expressed a need for help soon after diagnosis. This figure fell slightly by three months (32.3%) and again at nine months (21.5%).

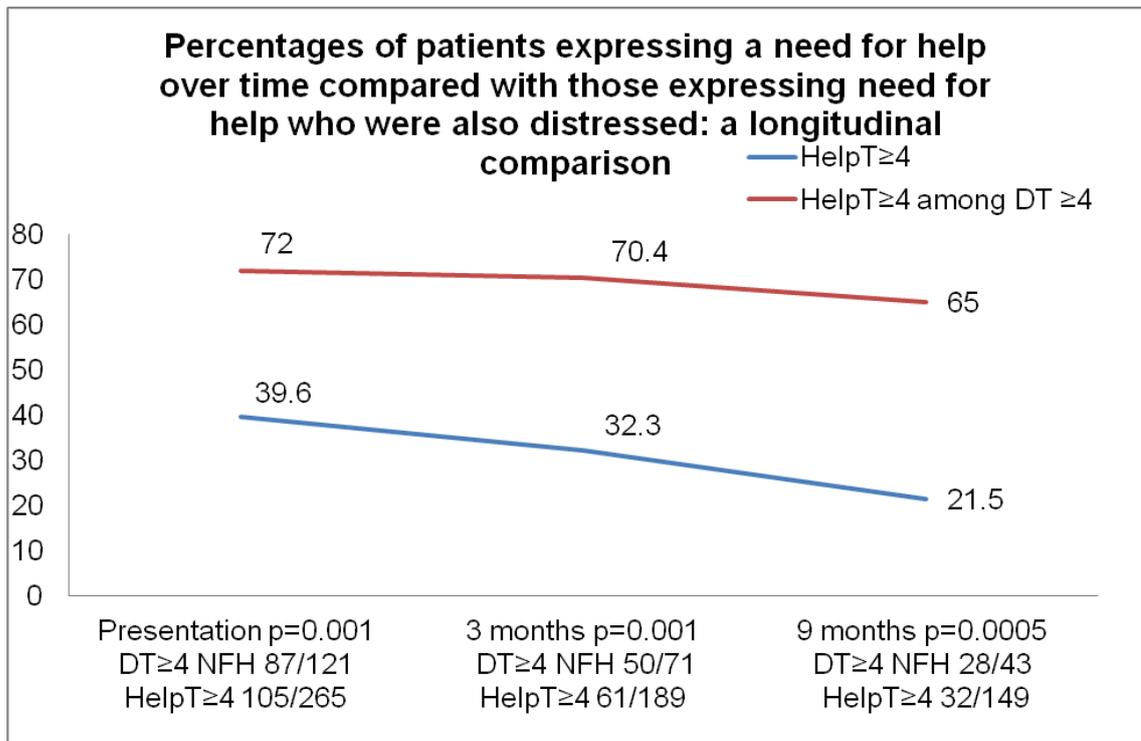


Fig 65

Far more patients, who had high levels of distress, expressed a need for help across the study period (DT ≥ 4). 87 (71%) did so soon after diagnosis (HelpT ≥ 4 among DT ≥ 4) in comparison to 39.6% of the total sample via the HelpT ≥ 4 (p=0.0001). This first figure remained steady at three months 50/71 (70.4%) with the statistical difference between the groups remaining (p=0.0001). It fell slightly to 28/43 (65%) at nine months (p=0.0001) (Fig 65).

Among those most distressed, more BSA than BW patients wanted help until nine months (baseline p=0.005, 3 months p=0.003, 9 months p=0.2) (Fig 66). One might expect, therefore, that a retrospective audit would detect

proportionally more referrals of BSA's for support.

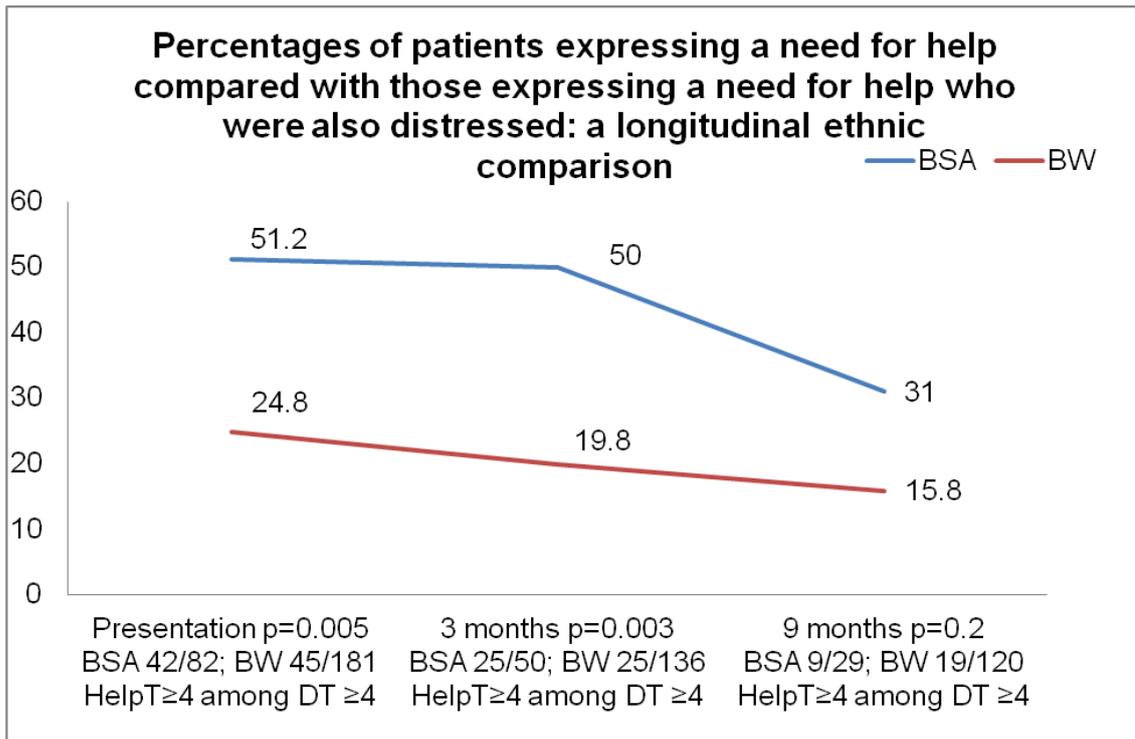


Fig 66

### 6.13 Retrospective audit

A retrospective audit was performed to detect whether there were any patterns of referral for psychological or psychiatric support or prescribing of anxiolytics/anti-depressants. The notes of 118 patients, who had completed all three questionnaires or the first and last questionnaires, were reviewed (BSA 23; BW 95).

In total 12/118 (10.1%) patients were referred for psychological support from either Psycho-Oncology or the hospital or community Palliative Care Teams. Of these 6 (5%) patients were referred to Psycho-Oncology. Unexpectedly there was no ethnic difference in the proportion of these referrals, (BSA 1(4.3%) BW 5 (5.3%) FET p=1.0). Three of these patients were also referred to palliative

care. Nine of 118 patients were referred to either the hospital (three) or community palliative care teams (six). There was no significant ethnic difference in patients referred (BSA 4(17.4%) BW 5(5.3%) FET  $p=0.071$ ). (One BSA patient referred to the community palliative care team also received 'counselling' via the GP practice).

There was no ethnic difference in the proportion of patients who were prescribed anxiolytics or anti-depressants (BSA 3(13%) BW 18 (18.9%)  $p=0.762$ . 21 (17.8%) patients received medication. A range of nine different medications were prescribed with benzodiazepines being the most commonly recorded (6). (One prescription was for anti-emetic purposes). Four of the six patients referred to psycho-oncology also received medication.

## **Section 7: Discussion**

### **7.1 Introduction**

The purpose of this study was to learn more about how newly diagnosed BSA and BW cancer patients coped in the months following presentation at a UK Cancer Centre. The aim was to detect any ethnic differences which placed individuals at greater risk of developing mental ill health. We considered how ethnic groups used maladaptive coping strategies and the extent to which their use was associated with symptoms of anxiety and depression over time. Ethnic differences in the experience of cancer and problems causing distress were explored. We asked whether cancer knowledge and beliefs differed cross culturally and if any had a detrimental effect on mental health. Trust in the patient/physician relationship was investigated and preferences for that relationship studied after postulating that mistrust might contribute to psychological distress. Our long term goal was to improve psychological support of both BSA and BW cancer patients by making recommendations to primary and secondary health care settings and for future directions for research.

### **7.2 Principal findings**

#### **Anxiety and depression**

Most patients of both ethnicities coped well when diagnosed with cancer but, supporting the main experimental hypothesis, proportionally more BSA cancer patients experienced symptoms of anxiety and depression than BW patients

soon after diagnosis. An ethnic difference in these symptoms persisted over a nine month period.

### **Coping strategies**

BSA cancer patients used maladaptive coping strategies more than BW patients at baseline and most were associated with higher rates of anxiety and depression. However ethnic differences had dissipated by three months with the exception of hopelessness/helplessness and cognitive avoidance. Correspondingly there were weaker associations with anxiety and depression at three and nine months. These findings partially support the hypothesis (p 77-8).

### **Cancer beliefs**

There were differences in the knowledge and beliefs about cancer cross culturally, supporting the hypothesis. There was a lack of awareness of several risk factors for cancer among study participants and some beliefs had a detrimental effect on the psychological wellbeing of a minority of individuals.

### **Patient/physician trust**

There were high levels of trust in the patient/physician relationship cross culturally.

BSA patients preferred to hear sensitive information from their GP.

There were ethnic differences in preferences for the patient/physician relationship which generally support the stated hypothesis, the exception being a similar ethnic wish for involvement in decision making.

### **Representations of cancer**

Cancer appeared to have a greater negative impact on the lives of BSA patients than BW patients although the former felt more control over their illness from three months post recruitment.

The ethnic difference in the 'experience of symptoms' over time was similar to the pattern of longitudinal depression. These findings confirm the hypothesis that there were ethnic differences in the representations of cancer.

### **Distress and the burden of symptoms**

There was little ethnic difference in distress caused by emotional symptoms.

Partially supporting the hypothesis that distress is experienced differently cross culturally, BSA patients reported more distress from a burden of physical 'problems' and socio-economic concerns than BW patients. The somatisation of distress by some BSA patients is consequently postulated.

Physical problems causing distress differed cross culturally and closely reflected the differences in longitudinal depression.

There was a high symptom burden among cancer patients with many being treatable.

BSA patients who were distressed were more likely to acknowledge the need for help than BW patients who were also distressed.

### **The influence of deprivation**

Although there was evidence of socio-economic causes for distress, deprivation was not a strong predictor of either anxiety or depression when compared to ethnicity.

### **Self-identity**

Self identity within this sample suggests that more BW patients felt 'English' than 'British'.

BSA patients tended to incorporate their country of origin into their self-identity more than their country of birth. There was a trend towards 'Britishness' within self-identity among BSA patients.

### **Recruitment and retention of participants**

Recruitment and retention of BSA study participants was difficult, reflecting a known phenomenon.

### **7.3 Ethnic differences in anxiety and depression soon after diagnosis (baseline)**

The vast majority of both ethnic groups adapted well when diagnosed with cancer and over time the numbers of patients doing so increased. However, as one sample, 22.9%, 24% and 34.7% of individuals self-reported symptoms of depression via HADS D $\geq$ 8, PHQ-9  $\geq$ 10, DepT $\geq$ 4 and 42.3% and 57% of patients felt anxiety via HADS A $\geq$ 8 and AnxT $\geq$ 4.

Symptoms of depression and anxiety were reported at higher rates among BSA patients than BW patients. Although all assessment tools demonstrated this, different percentages of patients were identified. Worryingly, BSA rates for depression were twice that of BW patients via two tools (BSA PHQ-9 35.3% HADS D $\geq$ 8 35.1%). This is a critical finding since this is almost six times higher than reported within the UK general population (6%). The depression rates for BW patients (PHQ-9 18.3%, HADS D $\geq$ 8 16.8%) were similar to those reported in a recent meta-analysis of cancer patients (16.3%), being approximately 2.5 times higher than in the general population (Mitchell et al. 2011a).

There was an ethnic difference in symptoms of anxiety with BSA patients at the higher end of ranges reported in two systematic reviews (HADS A $\geq$ 8, BSA 54.3%v BW 36.2% p=0.006) (van't Spijker et al. 1997, Spencer et al. 2010). Again these scores were far higher than in the general population (DSMIV 5-15%) (King et al. 2008).

These findings supported trends in other studies, notably a pilot study. Using HADS  $\geq 10$ , Roy (2005) reported BSA 20.7% v BW 10.4% ( $p=0.001$ ) had severe depressive symptoms. With a slightly higher threshold ( $\geq 11$ ) our study findings at baseline again pointed to an ethnic difference (BSA 34% v BW 18.9%  $p=0.008$ ). These concur with other reports which suggest that ethnic minority cancer patients experience more psychological distress than patients from host populations (Luckett et al. 2011; Carlson et al. 2004; Ashing-Giwa et al. 2007; Ell et al. 2005).

It is important to see these results in context. Ethnic minorities are heterogeneous. For example, although increased distress was reported among ethnic minority groups in a USA study, further analysis narrowed this to Hispanic cancer patients but not among other minority ethnic groups in the study (Luckett et al. 2011). Equally, there are variations in baseline common mental disorders in the UK among some BSA groups (Weich et al. 2004). Such variations in mental wellbeing prior to a diagnosis of cancer are likely to elevate the consequent reported rates of anxiety and depression once diagnosed.

In some situations South Asians with cancer appear more susceptible to anxiety and depression as an ethnic minority in Britain compared to those living as part of the host population in the Indian sub-continent. Rates of severe depression among local BSA patients were three times higher than those reported among Indian patients receiving curative treatments (7.6%) and twice as high when compared to Indians, most of whom were receiving chemotherapy for a cross section of cancers (16.2%) (Thomas et al. 2005; Pandey et al. 2006).

However, evidence was not consistent since, among patients receiving radiotherapy in Bangalore, depression rates were twice those of BSA patients using the same criteria (42%) (Chaturvedi et al. 1996b). Comparisons of anxiety symptoms followed the same trends HADS  $\geq 11$ , Thomas 8%; Pandey 15.4% and Chaturvedi HADS A  $\geq 7$ , 47%.

The extent to which the process of migration influenced BSA patients fell outside the main focus of this study but it remains an important area for research.

#### **7.4 Anxiety and depression in a single sample soon after diagnosis (baseline)**

As one sample the prevalence of depressive symptoms (HADS D  $\geq 8$  22.9%; PHQ-9  $\geq 10$  20.3%) were not inconsistent with a recent meta analysis (16.3%), (Mitchell et al. 2011a) and figures from the USA (15-25%) (National Cancer Institute, 2012). The rate was higher in our study when patients were asked if 'depression' caused distress via the DT  $\geq 4$  (27%). This was similar to other UK findings. 29% of patients post mastectomy and 22% post lumpectomy for breast cancer were depressed (Fallowfield et al. 1990). Of note is that in spite of HADS which omits physical symptoms of depression from the scale, figures for depression were very similar to PHQ-9 which included them.

Single sample levels of anxiety soon after diagnosis (HADS A  $\geq 8$  42.3%) were virtually the same as those reported among post operative women with early stages of breast cancer (42%) (Fallowfield et al. 1990). It was also similar with

those reported by a UK cancer study (48%) (Stark & House, 2000) although at the higher end of other ranges reported (van't Spijker et al. 1997) 0.9-49%; (Spencer et al. 2010) (6-34%).

## **7.5 Longitudinal ethnic differences in anxiety and depression**

The vulnerability to symptoms of anxiety and depression observed among BSA patients at baseline persisted across the study period via assessment tools inclusive of borderline symptoms. Anxiety decreased slowly, steadily and in parallel via both tools suggesting many individuals began to adapt to their diagnosis and to the impact it was having on their lives. However the percentage of anxious patients was still far higher at nine months than among the general public (HADS A $\geq$ 8 BSA 40.6%; BW 28.2%  $p=0.25$ ) (DSMIV 5-15%) (King et al. 2008). Cessation of treatment may leave a paradoxical void in the lives of some who found treatment, despite its side effects, reassuring (Hewitt et al. 2006). Anecdotally this is observed among patients with prostate cancer who, over 7- 8 weeks of daily treatment, can form a trusting relationship with the radiographers. For others, living with uncertainty and fear of disease recurrence may continue to affect psychological stability.

Analysing data at three points in time risks overlooking subtle variations in levels of distress which ebb and flow. However there are logical reasons why depressive symptoms increase at three months (HADS D $\geq$ 8,  $n=186$ , 27.9%, baseline 22.9%). Some individuals may struggle more by that time due to the side-effects of treatment, and the impact on their lives. Certainly some physical problems caused more people distress via the DT  $\geq$ 4 at three month than at

other times; pain (45.4%), fatigue (66.3%), sleep disturbances (56.1%), skin (38.4%), nausea (38.1%) and eating (30.5%) (Appendix 6.11.1).

The increase in depressive symptoms at three months did not wholly echo the findings of Heim et al. (1997) where symptoms had eased for many by four months. Equally there are reports of depression rates among breast cancer patients falling steadily over time (Burgess et al. 2005, Harrington et al. 2010). With a large cohort of patients with breast cancer in this study, reference was made to longitudinal breast cancer studies. A gradual fall in anxiety and depression was reported among early breast cancer patients assessed postoperatively at three and 12 months (Fallowfield et al. 1990). This was also observed in depressive symptoms over six months (Ford et al. 1995) and in both symptoms over a five year period (Burgess et al. 2005). However, with only a modest decrease in symptoms of anxiety and less so of depression by nine months in this study, it is unclear whether these symptoms would continue to dissipate in a similar trend. The numbers of participants with other types of cancer are too few to analyse and caution should be taken not to assume trends are the same across cancer types.

Studies of longitudinal cancer related anxiety and depression comparing ethnic minority and host populations are elusive. One recent USA publication did point to ethnic minorities (as well as the young, female and mother of children) experiencing higher levels of anxiety among 167 outpatients receiving radiotherapy; however, the vast majority of the sample were white and the

purpose of the research was other than contrasting host and ethnic minority anxiety levels (Dunn et al. 2012).

## **7.6 The influence of deprivation on anxiety and depression**

Local BSA patients were on average twice as deprived as BW patients reflecting a national trend for ethnic minorities to be twice as likely to be living in low income households as White people (Singleton et al. 2001). Surprisingly, deprivation was not a strong predictor for either anxiety or depression in our study. As a single variable, 'deprivation' did not contribute to logistic regression models predicting either. Ethnicity was more influential.

There was, however, an association between deprivation and distress (DT). Affluent patients from Leicester and its county were less distressed. This association, although weak, became more significant over time. Oddly as a trend this was seen among BSA patients but not BW patients. Although the expectation was that those more deprived would be more distressed, there was no evidence of this. This doesn't follow international findings which links socio-economic deprivation with higher incidence of depression and anxiety (Wilson et al. 1999, Ostler et al. 2001, Lorant et al. 2003). For example, among ethnic minority patients with breast cancer in the USA, low incomes correlated with greater anxiety (Ell et al. 2005). It remains unclear whether a USA study is relevant to UK cancer patients, given the self-reliant culture for accessing medical care in the USA. There, people on low incomes or unemployed are

more likely to feel troubled about finding funds to pay for life prolonging treatments.

There were ethnic differences in socio-economic causes of distress although they affected a minority of patients. For example, more BSA patients were distressed by the issue of housing soon after diagnosis ( $p=0.0001$ ). Worries about insurance differed too, although it is unclear whether this was about deprivation ( $p=0.016$ ). Was distress caused by difficulty in acquiring holiday insurance or by not being able to afford car insurance, the first being a luxury, the second possibly being critical to accessing hospital services? This finding possibly points to an ethnic economic gulf.

Certainly 'transportation', and this probably includes local parking issues at the Leicester Royal Infirmary, caused distress to 40 (15%) recently diagnosed patients. This figure fell slowly over time but BSA patients struggled with the issue more than BW patients, significantly so in the middle phase of the study period (20.4%), a time when patients were most likely to be attending hospital regularly for treatment. There must be a concern that this may influence decision making about treatment and subsequent adherence to treatment particularly among poorer families. The issue of hospital parking costs is acknowledged nationally and prompted the charity Macmillan Cancer Support to campaign on the issue.

Although deprivation was not a major influence in this study, there remains concern among researchers that the complex relationship between socio-

economic deprivation and membership of an ethnic minority places undue emphasis on the influence of ethnicity on health outcomes (Nazroo, 2003) (Lannin et al. 1998). Socio-demographic factors such as income status should be considered as possible reasons for poorer health outcomes - not just 'ethnicity' because of the overlap of phenomena. In addition ethnic groups should be considered separately to avoid overlooking distinct ethnic differences.

## **7.7 Associations between selected demographic factors and psychological morbidity**

### **Educational attainment**

BW patients were generally better educated than BSA patients although the latter were largely multi lingual in contrast to BW patients. The difference reflected both the compulsory education up to age of 14 in the UK from the Fisher's Education Act, 1918, (Great Britain,1918) and up to 15 in the Education Act 1944 (Great Britain,1944) and the lack of educational opportunities in the Indian sub-continent particularly in past decades. Compulsory education between the age of six and 14 came into law in India in 2009 through The Right of Children to Free and Compulsory Education Act. Adherence is yet to be universal (Indian Consitution,2009).

As one sample, the more educated experienced less anxiety and depression, though these findings need to be treated with caution. For example, patients may self-report inflated educational attainment. In addition, with the educational systems of India and the UK being different, making comparisons is unreliable.

The option to select 'college/university' may include both academic qualifications and workplace apprenticeships.

### **Gender and age**

Although being female is a known risk factor for both anxiety and depression there are inconsistent findings in the oncology population (Burgess et al. 2005). Our results reflect this with insufficient evidence to suggest a strong association between gender and either outcome. Neither was there evidence associating age with psychological outcomes. There was only a tentative suggestion that older BW patients were less anxious and less depressed.

### **Treatment intent**

One might expect higher anxiety and depression among those receiving palliative care as patients contemplate the end of life. However there was little difference longitudinally reflecting findings of a meta analysis (Mitchell et al. 2011a) although another publication states that there are consistent findings and that those with advanced cancer are at greater risk of anxiety and depression (Holland et al. 2010). We found that a higher percentage of patients receiving radical treatment felt anxiety at nine months (HADS A). As previously reported it may be that treatment has the paradoxical effect of being both stressful and reassuring. One limitation to these findings is the difficulty in defining 'palliative intent' since it includes those with a prognosis of weeks and those with a life expectancy in terms of years. Prognosis may affect mood and is a probable factor in the difference in rates of anxiety and depression based on cancer type.

### **Cancer type**

Our findings reflect the trend for prostate patients to have low levels of depressive symptoms in contrast to those with lung cancer (Montazeri et al. 1998; Massie, 2004). Those with prostate cancer may believe it to be a long term condition. In addition, given that it is more prevalent among older men, it may be one of a number of co-morbidities and not necessarily the most life threatening. The sample of patients with lung cancer was unfortunately insufficient to detect whether there was an increase in longitudinal depressive symptoms as published in studies by Montazeri or Hopwood (Montazeri et al. 1998, Hopwood & Stephens, 2000).

### **Time since diagnosis**

There was no ethnic difference in the speed at which patients were seen at their first appointment as gauged via the hospital appointment system, however BSA were significantly slower to return the first questionnaire than BW patients. Possible reasons include cultural avoidance, mistrust of research and communications barriers. The longer time delay equated to lower scores for depression among BSA and a trend towards lower scores for anxiety. One might conclude that a degree of psychological adaptation was taking place as time passed.

## **7.8 Ethnic differences in the use of coping strategies and associations with anxiety and depression**

To understand more about why BSA patients were more psychologically vulnerable we investigated whether there were ethnic differences in the use of coping strategies.

### **Helplessness/hopelessness**

Locally, BSA patients were more likely to adopt a helpless/hopeless attitude than BW patients. This was observed consistently across all Mini MAC indicators soon after diagnosis and supports the findings of Roy in the local population (Asians: 53.1% v Caucasians: 42.2%,  $p=0.005$ ) (Roy et al. 2005, Roy 2004). BSA continued to feel more helpless and hopeless than BW over time, although the difference became negligible by nine months.

This strategy was strongly associated with symptoms of both anxiety and depression among both ethnic groups via all assessment tools. The associations remained consistently strong longitudinally, and helplessness/hopelessness featured strongly as a predictor of both anxiety and depression in several regression models at baseline. Patients who felt helpless had an odds ratio of becoming anxious or depressed of 1.3 and 1.2 respectively, which followed the trend, if not the strength, reported among over 1300 Australian cancer patients (OR 2.7; 2.7) (Boyes et al. 2011). This is consistent with a strong body of global empiric research, for example in Japan, Canada, across European countries, the USA and Australia (Akechi et al.

2004, Lo et al. 2010, Grassi et al. 2010);Brothers & Andersen, 2009; Schou et al. 2004;Osborne et al, 2003; Johansson et al, 2011).

The longitudinal patterns of this coping strategy were not identical to the trend in depressive symptoms. This supports the theories of Beck and Abramson who consider there is a clear distinction between the two although they have a close association (Beck et al. 1985; Abramson et al. 1989).

When considering what factors may contribute to the association between helplessness /hopelessness and anxiety and depression, some cancer beliefs appear influential as one sample. For example, believing that 'cancer is a punishment from God/Allah' was associated with depression ( $\rho = -.377$ ,  $n=274$   $p=0.0005$ ) as was the belief that it was a 'punishment for wrongdoing' ( $\rho = -.349$   $n=274$   $p=0.0005$ ). This suggests that some supernatural beliefs may be interpreted negatively (see 7.9). Greater understanding of the influence of supernatural beliefs may focus spiritual support to them.

Of some concern for UK oncology centres is that higher helplessness/hopelessness is associated with agreeing with the statement 'I am concerned that the NHS will NOT give me the best treatment' ( $\rho = -.259$ ,  $n=264$   $p=0.0005$ ). A lack of confidence in the ability of the NHS to give optimal treatment contributed to negative feelings in some patients. Politicians and health care professionals should not underestimate the impact of mistrust.

To date there is little research referring specifically to associations between cancer, ethnic minorities and hopelessness. Other terms such as distress and quality of life are used, which makes comparisons with other research findings problematic.

### **Cognitive avoidance**

Cognitive avoidance, a domain of denial, was used by BSA patients far more than among BW patients, at least initially. Of interest is that 'situational avoidance' was the second most common means of coping commented upon in a review of two palliative care studies among cancer patients in Southern India. 33.3% used it to cope (Pandey, 2004). Our study suggests that BSA patients also tended to use this method of coping. Nevertheless, there was a consistent decrease in its use among local BSA patients with 17% less patients finding that 'not thinking about cancer helped them cope' by the end of the study period. This was steeper than among BW patients (5%). Possibly by three months some patients consciously or unconsciously had turned to other means of coping.

This strategy may not be confined to coping with illness since it is commonly referred to as being a cultural norm among South Asian peoples. In educational resources instructing foreign business communities, there are references to the need to be aware that, faced with disagreement, it is normal for an Indian to be reluctant to say 'no' since it is regarded as impolite. Being vague and lacking commitment or giving a reply the individual thinks one wants to hear are more commonly used strategies of avoidance (Butler 2012; World Business Culture,

2012). Cognitive and behavioural avoidance were observed not just as a coping strategy in this study but in the processes of recruiting and retaining BSA patients as study participants.

Avoidance is associated with higher rates of depression and distress among cancer patients although the associations with anxiety are less clear cut (Livneh, 2009). Our findings pointed to higher levels of depressive symptoms as one sample but this was only noteworthy at baseline. In contrast there was a consistent and significant association between cognitive avoidance and higher rates of anxiety across the study period.

One indicator of cognitive avoidance in the Mini MAC scale is the use of distraction. One might argue that this is not necessarily maladaptive in certain circumstances. When it is impossible for a patient to influence their situation such as while waiting for diagnostic test results, it is not unreasonable to avoid pointless ruminating by distracting oneself.

### **Fatalism**

The greater use of fatalism by BSA study participants than the host population supports findings among other South Asian populations (Roy et al. 2005; Dein 2004; Randhawa & Owens, 2004; Chattoo et al. 2002; Gurm et al. 2008) and among African Americans (Morgan et al, 2008). In this study its use among BSA patients appeared to decline quickly, more so than BW patients, but there was little ethnic difference in its use as a means of coping at nine months.

Reasons for the initial decrease in fatalism remain unclear. Of note is the 17%

decrease over nine months in those 'placing themselves in the hands of God', which was the strongest indicator of fatalism.

For some reason proportionally fewer BSA patients devolved responsibility to God for their wellbeing by three months. The hospital experience may have been less negative than anticipated, encouraging the fatalistic to participate actively in their care. Harmful misconceptions about cancer may have been corrected when patients were exposed to the hospital environment. The patient/physician relationship may have been beneficial. (There were high levels of trust among study participants). Some patients may have been able to reframe thinking positively through spiritual coping or through positive thinking and endurance (Pargament et al. 2004; Bolam et al. 2003). Unfortunately data about changes in cancer beliefs and patient/physician trust were not collected to consider this.

Cancer fatalism was associated with higher rates of both anxiety and depression which supports research from India (Kishore et al. 2008, Chaturvedi et al. 1996a) and lower adherence to screening services in the UK (Szczepura, et al. 2008; Miles et al, 2011). Associations were less strong at three and nine months corresponding to a decrease in fatalism.

### **Anxiety preoccupation**

BSA patients self-reported higher levels of anxiety as a health outcome via HADS A and AnxT and of 'feeling anxious' via one indicator of the Mini MAC.

However, other indicators suggest that BW patients used anxiety preoccupation as a strategy slightly more than BSA patients, although there was a negligible difference between ethnicities ( $p=0.376$ ) findings which reflected Roy's study ( $p=0.147$ ) (Roy 2004). There is arguably a contradiction between using anxiety preoccupation in which the individual focuses attention on the problem and cognitive avoidance/denial which is designed to protect by blocking such thoughts. BSA may not use anxiety preoccupation as a coping strategy being more accustomed to using strategies such as cognitive avoidance instead. As with other coping strategies, it remains unclear how many patients of either ethnic group, has a pre-existing trait of anxiety preoccupation.

As a single sample anxiety preoccupation was strongly associated with depression across the study period. Patients, who used it, had an odds ratio(OR) of 1.24 times the risk of being depressed via HADS D, although this is somewhat less than the OR of 4.6 among a large sample of Australian patients (Boyes et al. 2011). Our findings support others among a variety of nationalities and body site cancers (Johansson et al. 2011; Watson et al. 1991; Lampic et al. 1994; Nordin & Glimelius 1998; Grassi et al. 2004; Akechi et al. 2001; Kangas et al. 2007).

## **Denial**

Since the mid 1990's, highlighted by the work of people like Rob Buckman, there has been a gradual acceptance that doctors should inform patients of their diagnosis in contrast to past use of misleading euphemisms or colluding with relatives to keep the patient uninformed, in the belief that this was a more

compassionate approach (Buckman, 1992). All study participants had been informed of their diagnosis but 18% denied this at baseline. Our findings corroborated those of Roy. In the pilot study BSA patients were more likely to use denial to cope at baseline via the MAC question, 'I don't really believe I have cancer' (BSA 48.2%; BW 31.3%,  $p=0.019$ ). In the current study the percentage of people doing so was less but the ethnic trend was the same (BSA 20.2%; BW 4.3%,  $p=0.0001$ ). Some answered more cautiously stating they agreed 'sometimes'. (There was no option to have 'no view'). Perhaps some local patients found it was helpful to use denial at times to avoid being emotionally overwhelmed. This may not necessarily be harmful if of short term use (Lazarus 1981). The local ethnic difference supports the findings when comparing cancer patients living in Mumbai and London in a 2007 review of denial in cancer patients (Vos & de Haes, 2007; Chakravorty et al. 1993). The decrease in denial over time echoed findings in the USA where the percentage of cancer patients using denial fell from between 15 and 5% to 4% six months later (Cannon et al. 2004). Local BSA patients continued to use denial more than BW patients longitudinally although the ethnic difference narrowed. Similar to patterns of fatalism and avoidance, there was a steeper decrease in denial among BSA patients initially, the causes of which remain unclear.

Denial has been strongly associated with higher rates of depression and lower anxiety (Deimling et al. 2006; Chakravorty et al. 1993; Livneh, 2009), and an analysis of the single indicator 'I don't really believe I have cancer' showed that BSA patients who denied were more likely to report symptoms of anxiety and depression longitudinally. However when analysing all indicators of denial via

CIDQ this was not confirmed. It is likely that this can be explained by the fact that the scale is not validated. For example 'I may get better from this treatment' is one indicator of denial in CIDQ but this may be an entirely realistic belief given that a large percentage of participants were having treatment with curative intent.

### **Fighting spirit**

Similar to Roy's findings, this study showed no significant ethnic difference at any point during the nine month period although BW patients consistently used the coping strategy more than BSA patients (baseline  $p=0.470$  3 months  $p=0.563$  9 months  $p=0.265$ ) (Roy, 2004). Nevertheless the majority of both ethnic groups continued to use this adaptive coping strategy.

Having a fighting spirit only weakly predicted lower depressive symptoms as one sample, although this was the consistent pattern across assessment tools. The results therefore followed the trend in a recent systematic review of the concept (O'Brien & Moorey, 2010).

Longitudinally, BW patients used fighting spirit less. There was a 14% drop in its use between baseline and nine months compared to a fall of 8% among BSA patients. This could point to it being no longer needed in the light of an effective disease response to treatment, but conversely lower usage could point to patients with poorer prognoses becoming disheartened by deteriorating health (Bjorck et al, 1999). Longitudinal research based on cancer prognoses may generate a clearer use of fighting spirit, although there was no difference in the

use of fighting spirit between those with palliative versus curative intent among our patients who represented a cross section of cancers ( $p=0.266$  for trend).

## **Summary**

Initially BSA patients use maladaptive coping strategies more than BW patients and their use was strongly associated with anxiety and depression but at three months there was a decrease in use of these strategies, particularly among BSA patients. In spite of this the rates of depression remained high and the ethnic differences persisted implying that additional factors to the use of maladaptive coping strategies were influential in causing depression.

## **7.9 Spiritual coping**

Spirituality is strong in cultures within the Indian sub-continent and religion has played a prominent role in national politics within that region. Spiritual coping was not the main focus of this study but findings point to it being of relevance when explaining the variations in the use of coping strategies among BSA patients. Locally 100% of BSA patients affiliated themselves to a religion in contrast to 81.6% BW patients, although these figures do not distinguish between those who regularly attended religious services, those who didn't but had spiritual beliefs, and those who reported their religion as a default position. A minority of study patients appeared to interpret spiritual beliefs negatively. There is a modestly strong association between fatalism and the belief among some local BSA patients that 'cancer is due to fate (karma) and there is nothing I can do to prevent it' ( $\rho = -.212$   $n=92$   $p=0.042$ ). The belief was a minor predictor of anxiety for BSA patients too. Furthermore, of the minority of both

groups who were distressed by their relationship with God via the DT, proportionally more were BSA (baseline BSA 28 (32.9%) v BW 12 (6.9%)  $p=0.005$ ). Over time the percentage of distressed BSA patients fluctuated (3 months 11(20.8%) 9 months 8 (26.7%). This should be considered alongside the finding that fewer BSA patients 'placed themselves in the hands of God' as a means of coping over time as previously reported. As an indicator of fatalism, this suggests the psychological devolution of personal responsibility to God is a maladaptive way of coping; however, for the devout, trust in God may well be a core way of coping. Clearly a relationship with God/Allah is an important influence on psychological equilibrium for some.

The ethnic difference was marked. Only one BW patient viewed cancer as a punishment for sin and none as a punishment for wrongdoing or from God/Allah. In contrast more BSA patients regarded cancer as punishment 9(11.7%). The views of BW patients are consistent with other studies (Bussing et al, 2005). For example, only 3% of 387 German cancer patients (81% had breast cancer) viewed their illness as a punishment although the ethnic mix of the German series was not listed.

Of particular relevance to this study is that 46% of Indian cancer patients used religion as their main means of coping (Pandey, 2004). This suggests that further research into BSA coping is required. Do spiritual beliefs for example explain, at least in part, why local BSA patients felt more control over their disease than BW patients in spite of the greater emotional and physical impact on their lives? It may also contribute to the steep fall in maladaptive coping in

the initial months after diagnosis. Conversely, is it implicated in higher helplessness/hopelessness scores with consequent risk of greater anxiety and depression? Are UK cancer support services overlooking the impact of a coping strategy which, if understood better, could assist in the reduction of ethnic differences in anxiety and depression through spiritual support? A recent study among older American ethnic minority women with breast cancer suggests that the assumption that a belief in divine control is automatically fatalistic should be critically appraised (Umezawa et al. 2012). They found that divine control was positively related to acceptance and negatively related to avoidant coping.

#### **7.10 Ethnic differences in the burden of symptoms**

A key finding in this study was the similarity between longitudinal ethnic differences in the experience of 'symptoms' (BIPQ/DT) and the longitudinal ethnic difference in depression (HADS D/ PHQ-9). BSA patients appeared to experience far higher rates of physical symptoms particularly pain, mouth sores, nausea and problems getting around (DT) than BW patients.

The association was not restricted to BSA patients since crucially mouth sores, sleep disturbances and difficulty 'getting around' formed a predictive model for depression for the whole sample. Some physical problems such as sleep disturbances and fatigue both of which affected over 50% of patients in this study, are acknowledged indicators of depression within DSM IV criteria (Spitzer et al. 1999). This shows just how much the symptom burden from cancer and side effects of treatments can impact on the emotional stability for

some patients and supports Lazarus's theory that when assessing how an individual is coping, one must consider the environmental context, not just their personality traits.

Given the far higher levels of anxiety and depression among BSA patients, the absence of an ethnic difference in the 'emotion' indicators via the DT checklist initially appears counter intuitive. Similar rates of worry, fears, nervousness and sadness were the leading causes of distress cross culturally. A number of factors may explain this.

### **Somatisation**

BSA patients may tend to present physical symptoms of an emotional condition, termed somatisation. In 15 out of 19 physical or socio-economic concerns (DT checklist), BSA patients reported greater distress than BW patients. This concurs with previous research among BSA patients in general practice consultations (Bhui et al. 2004) and among other ethnic minorities in relation to other host populations (Ghods et al. 2008; Das et al. 2006; Poureslami et al. 2011). Somatisation is, however, not confined to ethnic minorities since increased fatigue, sleep disturbances and changes in appetite were strong somatic indicators of depression via PHQ-9 for both groups.

Self-reported pain illustrates how distress may be somatised. It was of concern to find that 58% of BSA and 33% BW patients reported pain at baseline, rising significantly among BSA patients three months later (73.6%) although not among BW patients (34.5%). Indeed this ethnic difference was detected in a

London sample of cancer patients where 36% of South Asians v 23% of the total sample felt that hospital staff did not help them all the time with their pain. This ethnic difference was also seen in the proportion of South Asian cancer patients reporting pain 'all or most of the time', being twice the average (16% v 36%) (National Audit Office, 2005).

It is unlikely that these reports refer exclusively to physically induced pain. 'Total pain' is a condition commonly referred to in cancer and palliative care to describe four dimensions of pain, physical, social, spiritual and psychological. Factors combine so that the individual can feel overwhelmed with problems. Cecily Saunders termed this 'total pain' reflecting the negative holistic impact of cancer on one's life (Saunders, 1967). It is acknowledged that psychological factors play a modest but significant role in the intensity of pain (Syrjala & Chapko, 1995). In a recent article which reported an analysis of this dataset, the significance of somatic and non-somatic symptoms was considered. One conclusion was that most somatic symptoms were influential when diagnosing depression and they should be factored into any psycho-oncology assessment (Mitchell et al. 2012).

With higher rates of anxiety and depression observed among our BSA patients, logically there should be a equally higher referral rate to psycho-oncology and support services but this was not found ( $p=0.07$ ). Likewise one might expect a higher number of patients referred to palliative care teams for symptom control advice. If somatisation is overlooked in the clinical setting there is a danger that medication will be prescribed to control what is perceived to be a purely

physical symptom leaving psychologically distressed patients undetected and untreated. Reports of physical symptoms, particularly among BSA patients require a more holistic assessment if distress, from whatever source, is to be alleviated.

### **Communication barriers**

Somatisation is not the sole theory for the higher physical symptom burden among ethnic minorities. Poor language and literacy skills may be implicated since both are required to comply with symptom management and treatment regimens. For example, all local hospital medicine labels are by default written in English. Being unable to comprehend instructions may lead to erroneous or non-adherence to symptom control medication. Among Vietnamese (n= 25) and Chinese American (n=72) breast cancer survivors, low proficiency in English was significantly associated with symptom distress (p=0.002) (Yi et al, 2011). In addition, levels of depression in migrants were the same as in the host population when the former spoke fluent English pointing to the increased vulnerability of those who lack proficiency in the host language (Nazroo, 1997).

Concern about poorer health outcomes among newcomers to Canada prompted a recent study among Chinese, Latino, Punjabi and Iranian immigrants with asthma. The language barrier, difficulty in accessing information in their mother tongue and doubts about whether the health care system was culturally competent were themes given for poorer control of the condition. In particular reservations were expressed about the quality of

patient / physician communication due to language and cultural barriers. In this qualitative study dislike of the inhaler, perceived side effects of medications and fear of addiction were some reasons expressed which risked compromising adherence to prescribed medical management of asthma with consequent poorer health outcomes (Poureslami et al. 2011). Such barriers may explain why there was a preference for a doctor of the same background or religion among our BSA cohort.

Studies considering ethnic perceptions of pain point to the need to consider the symptom within the context of cultural beliefs and values if culturally sensitive pain control is to be achieved. For example, stoic pain behaviour due to a belief that pain was testing one's faith was associated with Asian Americans which risks health professionals erroneously believing patients were pain free (Shavers, 2010). This risks under-prescribing of analgesia. These factors are unlikely to be restricted to pain and may be a contributing factor in the increased physical symptoms experienced among Leicester-based BSA patients.

### **Influence of Ayurvedia**

With trust in Ayurvedia some BSA patients may prefer to use it to treat the side effects of disease and treatments rather than conventional symptom control measures. Reluctance to adhere to prescribed medication such as anti-emetics cannot be ruled out as a reason for a higher symptom burden. One wonders whether this was influential among 62% of 50 Chinese Americans with cancer who self-reported analgesic use which health professionals deemed inadequate (Edrington et al. 2010). This theory is supported by the pragmatic approach to

managing illness observed in Indian patients (Kohli & Dalal 1998; Dalal, 2000). What is acknowledged is that there may be ambivalence towards western medicine among ethnic minorities (Department of Health, 2007), and that local trust in Ayurvedia reflects the beliefs among lay BSA people approached in shops in Watford, Harrow and Leicester (Jobanputra & Furnham, 2005).

Did a combination of these factors, over and above pre-existing maladaptive coping traits, cause local BSA patients a heavier symptom burden? If confirmed through more focused studies, an awareness of the importance of identifying somatic symptoms, a patient's proficiency in English, and a greater appreciation of the meaning and expression of symptoms among health professionals could trigger more culturally sensitive symptom control measures. A lower symptom burden may be the result, with the potential to reduce rates of distress, anxiety and depression.

### **7.11 Understanding cancer**

A lack of health literacy risks poorer health outcomes and poorer use of health care services so it was appropriate to consider the extent to which patients understood their illness (Berkman et al. 2011; Bostock & Steptoe, 2012).

There was little ethnic difference in how well all patients felt they understood cancer. This initially appears at odds with the barriers of language and literacy evident among our BSA sample. One could take this at face value giving credit to both the ability of patients with communication barriers to overcome them in their desire for understanding and to those who provide the information meeting diverse needs. However, this does not tally with Muthu Kumar's findings that local Asian patients were less likely than BW patients to agree to the statement

'I want as much information as possible' (BW 93.1v BSA 77.5%  $p=0.001$ ) although clearly the majority of both groups agreed.

Another possible explanation is that a difference in comprehension remained but, because of a greater tendency to use cognitive avoidance and for a minority, reservations about biomedical treatments, BSA patients were acknowledging that they had as much information as they required, this being less than comprehensive. Importantly, a greater understanding by the patient of their illness was a predictor of trust in this sample (Appendix 6.9.3). Of concern however, is that in London more South Asians, than a cross section of Londoners, did not understand their diagnosis (SA 32%; Londoners 19%), or treatment options (SA 45%; Londoners 33%) (Department of Health, 2000). If this is a reflection of the population of Leicester it requires local attention.

### **7.12 The need for help**

Of distressed patients, BSA's expressed a greater need for help than BW patients but as previously noted there was no correspondingly increased referral rate of the former for psychological support. This may be because most studies suggest that a minority of people want clinical help (Mitchell et al, 2011b) or that there is an under-identification of those who do. Among UK ethnic minorities barriers to seeking help for symptoms of cancer varied by gender with women identifying emotional barriers while men pointed to practical barriers (Waller et al. 2009). If 'clinical' help is not wanted the question remains just what help is required? Given the support (information, self-help, access to

benefits advice etc,) this question needs to be asked of each patient along the cancer pathway.

### **7.13 Cancer beliefs**

A positive finding is that a large majority of BSA and BW patients believed cancer is curable. This is in line with figures published by Cancer Research UK which stated that 'half of people diagnosed with cancer ..... survive their disease for more than five years' (Cancer Research UK, 2009). However, the current study shows the need for further public education with regard to cancer treatment. About 20% of both BSA and BW patients believed treatment, especially surgery, causes the disease to spread throughout the body. This myth seems to be commonly held in the USA, especially among Black Americans and can be a reason for late diagnosis or declining treatment. In a study of breast cancer patients in eastern Carolina (30% African-Americans) 56% of late-stage compared with 30% of early-stage patients held the misconception that 'air causes a cancer to grow faster'. 62% of late stage and 53% of early-stage patients believed that 'surgery caused the cancer to grow faster' (Lannin et al. 1998). In a telephone survey conducted by the American Cancer Society of 957 people thought to be typical of the continental US adult population in telephone households, 40.8% agreed with the statement 'treating cancer with surgery can cause it to spread throughout the body' (Gansler et al. 2005).

Belief in these misconceptions can lead cancer patients to refuse potentially life-saving treatment. In a study of 626 consecutive Veterans Affairs lung cancer

patients (61% African-American and 29% White), 38% believed air exposure caused the cancer to spread. This was the reason given by 19% of African-American patients for refusing surgery (Margolis et al. 2003). Whether this belief led to late diagnosis or declining treatment locally is unknown. The opinion that 'treatment especially surgery causes the disease to spread throughout the body' was held equally by a minority (20%) of BSA and BW patients, but was highly significantly associated with anxiety ( $p=0.01$ ) or depression ( $p=0.02$ ) in BSA patients.

Overall, 29.9% regarded alternative treatments as effective as surgery, radiotherapy and chemotherapy and this was especially true of BSA patients. 47.8% agreed and 26.6% expressed no view. Although we have no supportive evidence, the use of alternative medicine may have delayed diagnosis and treatment in some of our BSA patients, as Gujarati first and second generation immigrants (including those in Leicester) have high confidence in alternative medicine and its practitioners (Jobanputra & Furnham, 2005). One wonders whether the finding in a Pakistan cancer study that 75% of patients used homeopathic treatments before seeing an oncologist is the case locally (Kumar et al. 2010).

Women from ethnic minority subgroups are less likely to participate in cervical screening programmes (Bahl 1996; Abdullahi et al. 2009). The majority of both BSA (80.9%) and BW (93%) patients agreed that 'it is possible to find cancer at a very early stage by tests like cervical smears'. The major difference between

the two groups was the number expressing 'no view' (BSA 19.1%; BW 5.9%). Perhaps this is another area that requires further educational effort.

The concept that smoking can cause cancer was understood by most of our patients, but it was not clear if this influenced smoking habits. There is evidence that more BSA men under 50 years smoke in Leicester than BW men (Smith et al. 2003a). By and large the lack of knowledge of risk factors such as obesity, diet and lack of exercise is similar to other UK studies (Redeker et al. 2009; Sanderson et al. 2009) and in the USA (Wold et al. 2005). In common with these studies, our patients overestimated the importance of stress and environmental pollution. Almost a quarter of both local BSA and BW patients ascribed injury as a cause of cancer and this is exactly in line with the findings of Cartwright and Martin over half a century ago (Cartwright & Martin, 1958).

It was of interest to note that there was a stronger belief among BSA patients that people outside the family should not be told that the patient has cancer (26.6% v 5.4%  $p=0.001$ ). Although fewer BSA patients than BW patients believed that heritable factors can cause cancer (47.9% v 68.1%) it did form part of a weak predictive model for anxiety among BSA patients. A small minority of BSA patients believed that cancer was contagious (4.2%) with 12% with 'no view'. These beliefs may contribute to understanding why there was a need for family secrecy. Previous research has shown that among some BSA populations serious conditions such as cancer can be seen as a social blight on a family and its future prospects, inviting blame and isolation (Bottorff et al. 1998, Johnson et al. 1999; Department of Health, 2009). The significant

difference in attitude towards this belief is noted between those migrating from the Indian sub-continent via Africa and those migrating directly from the sub-continent with the former holding the belief more strongly. This divergence of views shows the heterogeneous nature of any migrant population.

Some beliefs did have associations with anxiety and depression but the sample sizes were rather small. This resulted in only weak predictors of psychological morbidities which were of minimal clinical importance. Nevertheless clinicians should remain vigilant since some beliefs were harmful for a few patients in both ethnic groups. There was a large sample difference between patients who had high levels of anxiety and depression and those without. It is unclear whether a larger BSA sample, would strengthen findings.

Our results show there is a continued need for education about the causes of cancer among both BW and BSA patients. There is a need to concentrate on knowledge about cancer reduction strategies (smoking, diet, weight and exercise) and also to correct inaccurate beliefs about the importance of pollution, stress and trauma as causes of cancer. The belief that properly conducted surgery can disseminate cancer may lead to undue anxiety and may delay effective treatment, as may the initial preference for treatment via alternative therapies.

#### **7.14 Patient/physician trust**

We postulated that BSA patients trusted doctors less than BW patients and that this would influence how they coped. Except for one small study of trust among

cancer patients who used complementary medicine, there have been no other quantitative studies of trust between cancer patients and doctors in the UK. A recent review highlighted the need for more studies regarding trust in cancer clinicians (Hillen et al. 2011). Trust in both hospital and community doctors and the NHS in general was very high among both BSA and BW patients who entered the study and we assume their views are similar to other Leicestershire patients. Our results are not inconsistent with the views of the British public overall.

The British Medical Association has regularly commissioned the polling agency MORI to examine trust in doctors. The public were asked whether they trusted a variety of professions and occupations to tell the truth. In spite of adverse publicity, such as the Bristol 'baby' and Alder Hey scandals, in 2003 the number of people who felt that doctors told the truth was over 90%. Respondents with experience of the NHS were more likely to say they thought doctors were doing their job very well (Ford et al. 2008). An international team (van der Schee et al. 2007) showed significantly higher trust in family physicians, hospital specialists and nurses in England and Wales compared with Holland and Germany. In one question our study has shown there may be slightly less trust in the NHS as an organisation. This is consistent with the findings of Calnan and Sanford, 2004 who suggested that any mistrust in the health service in the UK is centred on the way the organisation is financed and organised rather than the individuals within the system.

This study points towards less trust in the NHS among BSA than BW patients ( $p=0.003$ ). Underlying reasons were not clearly identified. Mistrust was not related to gender or to the belief that alternative treatments were as effective as conventional treatments. Neither was it related to the need to keep knowledge of cancer within the family. Further investigation is needed.

Overall there was little difference in the trust in hospital doctors between BW and BSA patients. This did not reflect the results of a patient survey in which patients from ethnic minorities were more likely to have negative experiences of doctors and nurses patients (Department of Health, 2000).

Most of the research looking at the levels of trust within racial groups in the past has been carried out in the USA. Some studies have suggested that Asian Americans (Vietnamese, Korean and Chinese Americans) have significantly less trust in doctors compared with either Latinos or non-Hispanic Whites; 71.6% of non-Hispanic Whites surveyed had a greater degree of trust in doctors compared with 55% of South Asian patients (Ngo-Metzger et al. 2004). Similar results were reported in a study in San Francisco, where a large number of patients in a primary care health maintenance organisation were interviewed. Asians rated physician performance significantly less favourably than did Whites (Murray-Garcia et al. 2000).

There was slightly less trust in GPs among BSA than BW patients ( $p=0.04$ ). However the difference was minimal affecting 12 BSA patients and 9 BW patients and its significance should not be overstated since there was a

preference among BSA patients to receiving sensitive information from the GP ( $p=0.0001$ ). This is supported by the fact that 81.9% were registered with a GP from a BSA background. Patients may prioritise the need to gain an understanding about their condition, treatment options and use of medications in their mother tongue and in a culturally sensitive manner. Of particular relevance is that, at least in this sample, a better understanding by the patient of their illness was a predictor of trust. A warning to health care professionals lies in the finding from the 2011/12 National Cancer Patient Experience Survey that ethnic minorities reported a less positive experience than White patients due in part to problems with communication (Department of Health, 2012).

For this sample population, partnership seems to be the preferred patient/physician relationship. Patients may balance the need for expert knowledge with the need for personal control, with BW patients tending towards being less content to defer decision making to the doctor ( $p=0.009$ ). The necessity to 'own' the treatment decision as a means of coping may explain this. However of note is that Black and minority ethnic communities felt less likely to feel involved in decisions about their cancer care (Cancer Research UK, 2006). It is of some concern that 10% of patients questioned whether hospital doctors would keep medical information confidential. There was however no ethnic difference in concern expressed. National publicity about breaches of the Data Protection Act by health professionals in the NHS (Information Commissioner's Office, 2010) may explain the concern. Analysis of those expressing concerns found associations with anxiety and depression, but the figures were too small to be able to draw meaningful conclusions.

As discussed previously, significantly more BSA patients wanted to hear sensitive information from a doctor of a similar background and/or from the GP. There was, however, a difference, albeit small, in the high degree of trust in the GP between BW and BSA patients with less trust expressed by the latter. Local BSA hospital staff suggested that knowledge of cancer within some BSA families may be interpreted as having a detrimental effect on the patient's family honour and should be hidden. Is there concern, be it groundless, among a minority of BSA patients that their GP may convey this information to other people as expressed by ethnic minority patients in Newham? If so, and it was not proven in this patient group, it is worrying that there is any concern at all. This is an area for future enquiry.

Nevertheless trust in both local hospital and primary care doctors was truly very high by international standards. This may be partially influenced by the fact that financial considerations have only a limited impact among the dealings of doctors and the general public. In spite of adverse publicity about perceived rationing of cancer drugs, the vast majority of our patients believed that hospital doctors will always give them the best treatment. The rising costs of medical care have been shown to erode trust in doctors in the USA (Cunningham 2009). Patients in American communities with relatively large uninsured populations are also less likely to trust their physician (Pagan et al, 2007). As we enter an era of austerity it is vital to preserve this very high level of trust among cancer patients.

The fact that some BSA patients prefer to receive sensitive information from their GP or someone from a similar religion or background needs to be recognised. There is much more to learn about the benefits of a closer clinical partnership between hospital doctors and GPs in helping patients with cancer cope.

### **7.15 Self-identity of study participants**

We took the opportunity to consider whether the views of study participants reflected national trends in self-identity.

The national shift among the English White population to feel more English than British was observed locally. However since the 2001 census only allowed the option to describe oneself as British rather than English it is not possible to report trends accurately. These statistics are reported for comparison with other future studies.

In contrast, among patients who included their adopted country in their sense of ethnicity, feeling British had more meaning than feeling English. The application for a 'British' rather than 'English' passport as a means of permanent residence in the UK is vital to those wishing to migrate permanently to the UK and may be a factor in this trend. The belief, expressed by a London focus group, may resonate locally (p 7).

Recently the 'Understanding Society' Report found that minority ethnic groups expressed stronger 'British' identity than British White people (McFall, 2012). In

particular, Muslims from a Pakistani background, contrary to expectations, asserted a stronger association to Britain than BW people. However it is unclear whether the trend for people in England to be moving their identity from Britain to England, was taken into account.

Anecdotally when asking BSA colleagues who were born in African countries why patients did not include a reference to their birth place in their sense of identity, they referred to retaining closer links with extended family members who remained in the Indian sub-continent. It was pointed out to the author that there was often an exodus of entire families and communities from Africa leaving no family attachments there. The memory of the distress and 'shame' attached to a forced deportation was cited by one as a reason to reject an association with their country of birth.

Of particular interest is a shift from feeling 'Asian', which was reported in a local study 17 years ago where 60% (n=147) BSA general practice patients referred to themselves inclusive of the word 'Asian' (Pringle & Rothera, 1995). Only 10% did so in this study. Our findings support the theory that ethnic self-identity is a fluid concept (Bhopal et al. 1991) regardless of place of birth among both White and South Asian people within our sample.

## **Section 8: Limitations**

### **8.1 Study limitations**

This study encountered a number of methodological and recruitment based limitations which are listed below.

Excepting the PHQ-9, assessment tools are not validated in Gujarati. Although the 'back- translation' method was used, mistranslation of some terms cannot be excluded, risking errors in patient responses.

In addition to using well established and validated tools, unvalidated questionnaires were included. The CiDQ used a coding system which lacked statistical rigour. In hindsight the COPE scale (Carver, 1989) or the Brief COPE (Carver ,1997) would have been more appropriate. Of lesser concern was the 'Trust and Cancer Beliefs questionnaires' which, although unvalidated, were analysed simply.

The Mini MAC scale was used in contrast to the MAC questionnaire in a pilot study. The authors of the former scale viewed it as a 'new measurement of adjustment' rather than a shortened version of the MAC (Watson et al. 1994). The mismatch limited opportunities to compare patients' use of coping strategies with those of Roy.

The ethnic samples were unequal but they were sufficient to produce results of statistical significance. This was a convenient sample rather than representative of a set number of patients across types of cancer. For example,

40% had breast cancer so the results are arguably skewed towards their experience of coping.

There is an ethnic difference in the time from diagnosis to first questionnaire with BSA patients taking on average a longer period of time returning the data. This could have skewed results slightly but the extent to which this affected findings is unclear.

It is likely that the rates of anxiety and depression are under-reported. Anecdotally those who were most distressed on baseline at the LCC often did not feel able to participate in the study.

Although tools assessing symptoms of anxiety and depression reflect similar trends, the number of people with this symptom burden varies between tools. From a clinical perspective some patients will be given a false negative or false positive assessment of being at risk depending on the tool in use.

Recruitment and retention of BSA patients was difficult and retention at nine months was low among BSA patients which limits the significance of findings at that time.

Information about cancer beliefs and information relating to the patient /physician relationship were acquired once only. The psychological impact of changes in beliefs from exposure to cancer services and contact with hospital personnel was not investigated.

The influence of religious coping was largely omitted from this study although it was the top coping strategy among a study of Indian cancer patients and was referred to in the UK Empiric study. It may have played a larger role in how BSA coped than was identified.

BIPQ Item nine asked patients to rank three causes for their illness. This was not completed well and was omitted from analysis.

We were unable to differentiate between patients who had pre existing mental health issues and those for whom anxiety and depression was triggered by cancer.

Our study findings may have relevance to other BSA populations but caution should be taken not to assume they are homogeneous since subtle differences were identified based on place of birth within this BSA sample.

Given the variations in baseline levels of CMD within BSA populations, it is important to recall that participants largely represented BSA Hindus from India and Africa and therefore is not representative of patients from Pakistan or Bangladesh.

The analysis correcting the relationship between ethnicity and psychological morbidities with socio economic deprivation was based on one statistic which is simplistic.

## **8.2 Recruitment and retention**

Recruitment and retention of BSA patients to this study was a challenge and was the subject of a paper (Symonds et al, 2012). The local experience is reported and possible reasons explored with reference to other publications.

Recruitment to cancer trials has increased in the UK from less than 3.5% in 2001 to 12% (Stead et al. 2011) but, despite the emphasis on a 'duty' to ensure 'adequate' representation of ethnic minorities in clinical research by the Research Governance Framework, 2001, comprehensive information on accrual of ethnic minorities to cancer research is not currently available (Department of Health, 2001) partly due to under-reporting of ethnic representation in research publications. A case study from the University College London Hospital Trust found that recruitment levels into clinical trials were 30% less for minority ethnic patients compared to White cancer patients after adjusting for disease, age and gender (Godden et al. 2010).

Failure to enter certain population groups into clinical trials is inequitable with respect to outcomes (Djulfbegovic et al. 2009) but it is also important in that absence of specific population subsets could have implications regarding the safety and efficacy of the trial regimen especially if it includes new drugs (Hussain-Gambles et al, 2006). Equally under-representation of ethnic minorities in psycho-oncology studies risks under-detection of distress and consequent inequality of access to support services.

In this study the number of patients approached to participate was not recorded. The proportion of BSA patients needed to provide statistically valid findings was far higher than among BW due to proportionally more BW patients being registered. Accrual of BSA patients was going to be slower which risks giving the impression that it was more difficult to recruit from this population. Certainly there were similar percentages of both BSA and BW patients who consented to take part and then completed the first questionnaire (BSA 52.5% v BW 56.2%), but greater efforts were required to acquire this data from BSA patients to achieve this figure. Subjectively all recruiting staff reported great difficulty in recruiting BSA patients.

It is in the retention of participants that the ethnic difference is most apparent. Far fewer BSA patients completed all questionnaires (BSA 34% v BW 63%) despite efforts to follow up BSA 'non returns'.

### **Barriers to recruitment**

Many barriers to participation exist, especially in minority populations (Wells & Zebrack 2008; Ford et al. 2008; Shah et al. 2010). Examples include concerns about efficacy and safety of trials, fear of additional financial costs, concern about randomization, trial burden, breaches of confidentiality, dependency issues and cultural barriers. It has recently been estimated that less than 5% of US cancer patients are enrolled into trials and ethnic minorities plus individuals of low socio-economic status are less likely to be trial participants (Ford et al. 2008). What is uncertain is how many patients are explicitly offered participation. The very low uptake of trials is widely accepted as an

unsatisfactory situation. This was recognised by the American Society of Clinical Oncology which embarked on an intensive campaign to increase participation of racially and ethnically diverse populations into cancer clinical trials (Goss et al. 2009).

### **Human factors negatively influencing the recruitment of ethnic minority patients**

Local experience points to factors such as stress, denial, avoidant behaviour, consent reversal by family decision and travel to countries of origin as reasons for poor recruitment and retention of study patients (Table 7). For example 64% of the 85 BSA patients who withdrew after giving consent, used forms of avoidant behaviour to do so.

**Table 8 Reasons given for withdrawal from study after consent**

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

Of interest is that some BSAs recruited to the study decided to return to their country of origin either on a temporary or permanent basis at some point of the cancer trajectory. Five were known to have travelled abroad, effectively withdrawing from the study, but several more reported to staff their intention to do so or had returned from a recent trip. Whether this decision had a detrimental effect on treatment timetables and disease response is unknown.

Anecdotally several local women, both BW and BSA who had undergone surgery for breast cancer and were to have adjuvant chemotherapy and radiotherapy, considered themselves already cured and therefore felt they fell outside the remit of this study. This may represent the use of positive reframing or denial as a means of coping. Alternatively information exchange between health care professionals and patients may have been overly optimistic. Recruiters reported that a few BSA patients felt that they did not have cancer as a reason for non participation despite their presence in an oncology clinic and with a record of the diagnosis being given. Whether this was an example of denial or the detrimental effects of the language barrier is unclear.

Trust in the patient/physician relationship may have influenced our local experience of recruitment. In the initial pilot studies patients were invited to take part by a senior male doctor who was part of the treatment team. Recruitment was easier in these studies, although by no means straightforward, possibly helped in part by a symbiotic relationship based on patient/physician trust. In contrast in this study, attempts to recruit patients by persons of perceived lesser hierarchical status (senior nurses and radiographers) were less successful.

The relationship between patients and their doctors is crucial to the success of recruitment into clinical research. The most frequently quoted barrier to minority accrual to cancer related trials is mistrust of research and the medical system (Ford et al. 2008; Ross et al. 1999; Hussain-Gambles et al. 2004). In a recent meta-analysis of seven qualitative studies among Indians resident in Singapore, the USA and in India, mistrust of researchers was regarded as a significant barrier by 26% of participants (Shah et al. 2010). Practices in the Indian sub-continent may have coloured the views of Indian and Pakistani patients in the UK. The perceived poor reputation of research methods in parts of the Indian sub-continent, where consent might not be sought or where the vulnerable populations may be exploited, may have led to non-participation of British South Asians in UK studies (Hussain-Gambles et al, 2006). Mistrust may become a more prominent issue given the increase in outsourcing of multi-national clinical trials to countries within the Indian sub-continent.

In the United States, studies based on survey questionnaires and focus groups suggested that various historical factors, such as the infamous Tuskegee syphilis observation study, have undermined trust in medical research among minority groups (Bates & Harris, 2004).

Locally ethnic minority patients appear to have a considerable amount of trust in their general practitioners. Although it remains to be tested a greater partnership role between the hospital and GPs may increase trial recruitment.

## **Trial design factors negatively influencing the recruitment of ethnic minority patients**

Modern design and practice in clinical trials may foster poor accrual. For example, in the western world, there is a normal statutory requirement for consent to be given by the individual concerned, and the individual within the trial is the focus of the information delivery and the consent process. In contrast, within BSA communities the decision to take part in a clinical trial may be a collective decision taken by the family rather than the individual. That decision may be influenced by socio-economic factors, as ethnic minorities in many western societies have a lower average family income than the majority population. Loss of income or travel costs incurred by more hospital visits may be factors that inhibit participation as research. In addition, ethnic perceptions of cancer, death, treatments and the associated stigma of this disease can have an impact on choices regarding treatment and participation in trials (Symonds et al. 2012).

Research Ethics Committees require all information to be translated into the language of the likely participants. The provision of information relies on literacy skills of the participant and their family. Problems with this approach have been seen within the University Hospitals of Leicester, particularly with Gujarati speaking patients who often cannot read the Gujarati translations as this is largely a spoken language. Many have English reading skills but for some this may be inadequate to understand research concepts such as randomisation and the need for written consent. The use of a translator may help but technical words may have no direct translation into Indian languages

risking misunderstanding and there is the risk of omissions, additions, and the loss of neutrality in the translation process.

International studies have shown that the regulatory setting of many clinical trials is a deterrent to participation, with the emphasis on written consent, closed questions and form filling (Sood et al. 2009). Elements of the research process have been found to be disrespectful, for example where the mother tongue is predominantly a spoken language being required to sign a consent form may imply a lack of trust in one's spoken word (Sheikh, 2006). A request for a signature on a form which may be perceived as a written contract may cause offence. Within some South Asian populations the cancer diagnosis is a stigma which may affect decision making (Lord et al. 2011).

Cancer is not the only illness associated with stigmatisation in BSA patients. Rooney and colleagues found it was a barrier to asthma research participation among BSA patients in London and Edinburgh (Rooney et al. 2011).

The expectation of the local Ethnic Committee is that the information given to the patient is heavily based on consent and information sheets required for randomised control trials. In particular, a section entitled "what if something goes wrong" caused many to be confused and wary. Stating the ratio of each population to be recruited was misunderstood by some, with two prospective participants, one BSA and one BW, wrongly believing the difference was racially inappropriate. In hindsight statistical details were unnecessary.

Although it is erroneous to believe that being involved in clinical trials and cancer research is automatically of benefit to the individual, it remains important that the needs of ethnic minorities are known and accommodated in cancer treatment and care. Local experience suggests that greater involvement of BSA patients in cancer research may be achieved by working more closely with local GPs - a similar recommendation to that made previously in a larger study (Hussain-Gambles et al, 2006). Closer liaison with the local Ethics Committees to enable the use of more culturally sensitive methods of recruitment while still enforcing rigorous ethical standards may improve patient participation. Finally greater user involvement in cancer services by representatives of the local ethnic minority populations may also lessen any feelings of mistrust.

## **Section 9: Conclusion**

This study explored how newly diagnosed cancer patients coped in the months following their diagnosis. Since some individuals develop mental health disorders as a consequence of their diagnosis, this is clinically important. This study confirms evidence among other populations that there was greater psychological morbidity among minority BSA patients, the majority of whom have Indian ancestry, compared to patients from the host population. The greater use of potentially maladaptive coping strategies among BSA patients soon after diagnosis, the apparent heavier burden of symptoms and the affect of cancer myths and misconceptions, contributed to the ethnic divide in coping. The main findings were summarised in chapter 7.2.

## **Section 10: Recommendations**

Participation of patient representatives from all major ethnic groups in any reconfiguration of local patient services is advised if cancer services are to provide ethnically sensitive and tailored care.

Specifically clinical assessments along the cancer pathway need to consider the patient within their ethnic and social context to understand the impact of cancer and patient preferences for care. For example, since more local patients from South Asian ancestry appear to prefer closer liaison between hospital doctors and the GP, establishing personal preferences early should trigger a 'communication' protocol. Ideally patient and GP should be represented in its design. This may also foster improved representation of this ethnic minority in clinical trials based on patient trust. Likewise when a language barrier exists a patient should be considered to be potentially psychologically vulnerable due to isolation. The presence of an interpreter at each key clinical meeting should be triggered automatically, rather than rely on a request.

Psychological assessments, as part of established medical management along the cancer pathway, are recommended. It should take into account the somatisation of distress if vulnerable patients, from whatever ethnicity, are to receive prompt support.

A better appreciation and focus on alleviating the heavy symptom burden experienced by many patients should be central to medical and nursing management.

Future research into the role of spiritual coping is desirable particularly involving populations where spiritual beliefs are frequently central. It is an increasingly neglected aspect of patient care with chaplaincy teams in UK hospitals under threat, arguably due to an under appreciation of their role in supporting patients. Better evidence of its value within cancer care may provide more focused care in liaison with community based spiritual services. One area for enquiry is that some Mini MAC statements are considered indicators of cancer fatalism, a maladaptive coping strategy but they can also be interpreted as an adaptive spiritual coping.

It would be of interest to explore why some local BSA patients, who initially used more maladaptive coping strategies than BW patients, appeared to adapt more quickly than the host population. A follow up qualitative study may generate themes which could give direction to devising strategies to reduce distress earlier along the cancer pathway.

There is currently a dearth of empirical evidence about whether there are ethnic differences in survival time based on an increased risk of anxiety and depression among BSA patients. A longitudinal quantitative study may provide greater insight.

It would be valuable to determine the extent to which the findings of this study are replicated in other UK South Asian populations. Given that the term 'BSA' is an umbrella term for several diverse populations this is by no means a certainty. Findings could help shape improvements in future services by

incorporating evidence based recommendations to accommodate the needs of these specific minority groups.

Closer liaison with hospital ethics committees is needed to ensure recruitment methods are sensitive to patients of any ethnicity while preserving rigorous adherence to ethical standards. Adopting Hussain-Gambles' 2006 recommendations to improve the participation of BSA patients in research proposals and methodologies is advised. Furthermore there is a need to identify and develop validated assessment tools sensitive to the needs of ethnic minorities. This may improve rates of patient participation in research and also enable better cross-study analysis.

The prevalence of harmful myths and misconceptions about cancer can be undermined by educational programmes targeted towards the general public via the department of health. Health professionals too, require greater awareness of this issue if harmful beliefs are to be corrected.

Finally re analysis of this database with socio economic deprivation as the core variable instead of ethnicity has merit since it would provide the opportunity to identify the extent to which coping is influenced by the degree of deprivation regardless of ethnicity. If deprivation was the more powerful variable it would add weight to the recommendations of The Marmot Report (2010) that tackling social injustice is the more effective policy to resolving health inequalities than focusing purely on ethnic inequalities

### **Concluding statement**

Previously under researched, this study offers additional insight into how a UK ethnic minority population copes with cancer. It highlights how BSA patients in an East Midland city and local county are at increased risk of developing psychological morbidities due to an interaction between the use of maladaptive coping strategies and a combination of environmental factors. Directions for future research and implications for clinical practice are suggested which may assist in reducing ethnic inequalities in some cancer outcomes.

## **Appendix 1: Supporting statistics**

### 6.2.1: Distribution of age, gender and deprivation

		Kolmogorov-Smirnov Statistic	Df	Sig.
<b>Age</b>	BSA	.053	94	0.200
	BW	.064	185	0.062
<b>Gender</b>	Male	.452	89	0.0005
	Female	.411	190	0.0005
<b>Deprivation</b>	BSA	.165	94	0.0005
	BW	.175	185	0.0005

### 6.2.2: Age, ethnicity and psychological morbidity

		n=	Spearman rho	2-tailed Sig.
<b>PHQ-9</b>	BSA	85	-.081	0.463
	BW	173	-.229	0.002
<b>HADS D</b>	BSA	94	.051	0.62
	BW	185	-.160	0.03
<b>DepT</b>	BSA	84	-.166	0.131
	BW	185	-.159	0.033
<b>HADS A</b>	BSA	94	-.051	0.627
	BW	185	-.266	0.0005
<b>AnxT</b>	BSA	83	-.098	0.380
	BW	182	-.279	0.0005

### 6.2.3: Rates of anxiety and depression by gender

		n=	≤9	% within symptom	≥10	% within symptom	χ <sup>2</sup>
<b>PHQ-9</b>	Male	85	68	80	17	20	0.364
	Female	173	128	74	45	26	
			≤7		≥8		
<b>HADS D</b>	Male	89	71	79.8	18	20.2	0.558
	Female	190	144	75.8	46	24.2	
			≤3		≥4		
<b>DepT</b>	Male	85	60	70.6	25	29.4	0.265
	Female	177	111	62.7	66	37.3	
			≤7		≥8		
<b>HADS A</b>	Male	89	59	66.3	30	33.7	0.063
	Female	190	102	53.7	88	46.3	
			≤3		≥4		
<b>AnxT</b>	Male	87	48	55.2	39	25.8	0.008
	Female	178	66	37.1	112	62.9	

#### 6.2.4: Gender: associations with anxiety and depression at baseline

Mann Whitney U Test		n=	Mean Rank Score	Md (IQR)	U	Z	r	sig.
<b>PHQ-9</b>	M	85	113.90	4(2:7)	6026.5	-2.363	0.14	0.018
	F	173	137.16	5(2:9.5)				
<b>HADS D</b>	M	89	134.80	3(1:6)	7992.5	-.740	0.044	0.459
	F	190	142.43	4(1:7)				
<b>DepT</b>	M	86	120.82	1(0:4)	6649.5	-1.781	0.109	0.075
	F	178	138.14	2(0:5)				
<b>HADS A</b>	M	89	123.75	6(2:9)	7009	-2.308	0.138	0.021
	F	190	147.61	7(4:11)				
<b>AnxT</b>	M	87	110.49	3(1:6)	5785	-3.359	0.206	0.001
	F	178	144.00	5(2:8)				

#### 6.2.5: Median scores for anxiety and depression by gender within ethnic groups via Mann Whitney U Tests

	HADS D	n=	Md (IQR)	range	p-value
<b>BSA</b>	Male	25	4(2.5:9)	0-20	
	Female	69	5(2:11)	0-18	0.589
<b>BW</b>	Male	64	3(1:6)	0-19	
	Female	121	3(1:6)	0-18	0.884
	<b>HADS A</b>				
<b>BSA</b>	Male	25	6(2:13)	0-19	
	Female	69	8(5:12)	0-19	0.123
<b>BW</b>	Male	64	6(3:9)	0-21	
	Female	121	7(3:10)	0-20	0.181

### 6.2.6: Anxiety and depression by gender within ethnic group at baseline

		n=	Male	% within gender	Female	% within gender	X <sup>2</sup>
<b>PHQ-9 9v10</b>							
BSA	ND	55	18	75	37	60.7	
	D	30	6	25	24	39.3	0.32
BW	ND	141	50	82	91	81.3	
	D	32	11	18	21	18.8	1.0
<b>HADS D 7v8</b>							
BSA	ND	61	17	68	44	63.8	
	D	33	8	32	25	36.2	0.892
BW	ND	154	54	84.4	100	82.6	
	D	31	10	15.6	21	17.4	0.926
<b>DepT 3v4</b>							
BSA	ND	47	14	63.6	33	54.1	
	D	36	8	36.4	28	45.9	0.601
BW	ND	124	46	73	78	67.2	
	D	55	17	27	38	32.8	0.529
<b>HADS A 7v8</b>							
BSA	NA	43	15	60	28	40.6	
	A	51	10	40	41	59.4	0.151
BW	NA	118	44	68.8	74	61.2	
	A	67	20	31.3	47	38.8	0.389
<b>AnxT 3v4</b>							
BSA	NA	27	10	43.5	17	28.3	
	A	56	13	56.5	43	71.7	0.291
BW	NA	87	38	59.4	49	41.5	
	A	95	26	40.6	69	58.5	0.032

### 6.2.7: Diagnoses with median scores for anxiety and depression

		n	Median (IQR)	range
<b>HADS D</b>	Breast cancer	114	3(1:7)	0-18
	Gynaecological	34	5(2:7)	0-17
	Colorectal	45	3(2:6)	0-18
	Lung	19	5(3:7)	1-20
	Prostate	23	1(0:5)	0-19
<b>HADS A</b>	Breast cancer	114	7(4:7)	0-20
	Gynaecological	34	8(5:11)	0-18
	Colorectal	45	6(4:11)	0-21
	Lung	19	6(4:9)	1-19
	Prostate	23	6(2:7.5)	0-19

### 6.2.8: Treatment intent for one sample and by ethnicity

Time	Treatment intent	One sample n= (%)	BSA	BW	X <sup>2</sup>
Baseline	Sample	279	94	185	0.96
	Radical Palliative	188 (67.4) 91 (32.6)	64 (68.1) 30 (31.9)	124 (67.4) 61 (33)	
3 months	Sample	204	51	138	0.47
	Radical Palliative	136(66) 68 (33.3)	40 (80) 16 (32)	96 (66.6) 52 (37.6)	
9 months	Sample	147	31	116	0.29
	Radical Palliative	105 (71.4) 42 (28.2)	25 (80.6) 6 (19)	80 (68) 36 (31)	

### 6.2.9: Influence of 'treatment intent' on symptoms of depression

PHQ-9 9v10			n=	≤9	%	≥10	% within symptom	X <sup>2</sup>
Baseline	Rad		173	137	79.2	36	20.8	0.116
	Pall		85	59	69.4	26	30.6	
3 months	Rad		124	86	69.4	38	30.6	0.246
	Pall		61	48	78.7	13	21.3	
9 months	Rad		102	85	83.3	17	16.7	0.872
	Pall		41	33	80.5	8	19.5	
<b>HADS D 7v8</b>				<b>≤7</b>	<b>%</b>	<b>≥8</b>		
Baseline	Rad		188	151	80.3	37	19.7	0.088
	Pall		91	64	70.3	27	29.7	
3 months	Rad		136	96	70.6	40	29.4	0.588
	Pall		65	49	75.4	16	24.6	
9 months	Rad		111	88	79.3	23	20.7	1.0
	Pall		45	36	80	9	20	
<b>DepT 3v4</b>				<b>≤3</b>		<b>≥4</b>		
Baseline	Rad		176	119	67.6	57	32.4	0.316
	Pall		86	52	60.5	34	39.5	
3 months	Rad		126	79	62.7	47	37.3	0.765
	Pall		62	41	66.1	21	33.9	
9 months	Rad		107	81	75.7	26	24.3	0.638
	Pall		42	34	81	8	19	

### 6.2.10: Influence of 'treatment intent' on symptoms of anxiety

HADS A 7v8			N=	≤7	% within symptom	≥8	% within symptom	X <sup>2</sup>
	Baseline	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
<b>AnxT 3v4</b>				<b>≤3</b>		<b>≥4</b>		
	Baseline	Rad	178	75	42.1	103	57.9	
		Pall	87	39	44.8	48	55.2	0.777
	3 months	Rad	128	62	48.4	66	51.6	
		Pall	62	35	56.5	27	43.5	0.378
	9 months	Rad	108	67	62	41	38	
		Pall	42	30	71.4	12	28.6	0.373

### 6.2.11: Participants place of birth

Place of birth	BSA=94	%	BW=185	%
UK (incl. British Forces Overseas)	12	12.9	182	98.4
Africa	31	33.3		
Indian Sub Continent	50	53.8		
Missing	1	1.06		
USA			1	0.54
Republic of Ireland			2	1.08

### 6.2.12: BSA place of birth and associations with anxiety and depression

	n=		UK	%	ISC	% within POB	Africa	% within POB	X <sup>2</sup>
PHQ-9 9 v 10	54	≤9	5	9.3	29	53.7	20	37	0.740
	25	≥10	4	13.3	17	56.7	9	30	
HADS D 7v8	39	≤7	4	10.3	18	46.2	17	43.6	0.201
	54	≥8	8	14.8	32	59.3	14	25.9	
DepT	47	≤3	4	8.5	24	51.1	19	40.5	0.128
	36	≥4	7	19.4	21	58.3	8	22.2	
HADS A 7v8	43	≤7	4	9.3	20	46.5	19	44.2	0.110
	50	≥8	8	16	30	60	12	24	
AnxT.3v4	27	≤3	1	3.7	15	55.6	11	40.7	0.165
	55	≥4	10	18.2	29	52.7	16	29.1	

### 6.2.13: BSA place of birth, excluding those born in the UK

	n=		ISC	%within POB	Africa	%within POB	p value $\chi^2$
<b>PHQ-9</b>	74	≤9	28	62.2	21	70	0.656
		≥10	17	37.8	9	30	
<b>HADS D</b>	81	≤7	31	62	23	74.2	0.374
		≥8	19	38	8	25.8	
<b>DepT</b>	71	≤3	24	54.5	19	70.4	0.283
		≥4	20	45.5	8	29.6	
<b>HADS A</b>	81	≤7	20	40	19	61.3	
		≥8	30	60	12	38.7	
<b>AnxT</b>	71	≤3	15	34.1	11	40.7	0.756
		≥4	29	65.9	16	59.3	

### 6.2.14: Distribution of deprivation scores by ethnicity/ and Mann Whitney U Test

	n=	Mean Rank	Md (IQR)	U	Z	r	Sig.
<b>BSA</b>	94	83.19	6.5(4,10)	3354.5	-8.402	.503	0.0005
<b>BW</b>	185	168.87	16 (11,18)				

### 6.2.15: Deprivation and psychological morbidities

Continuous Scores		n=	Spearman rho	2 tailed sig.
<b>PHQ-9</b>	BSA	85	-.250	0.021
	BW	173	-.080	0.296
<b>HADS D</b>	BSA	94	-.093	0.372
	BW	185	-.075	0.308
<b>DepT</b>	BSA	84	.027	0.807
	BW	180	-.105	0.161
<b>HADS A</b>	BSA	94	-.123	0.238
	BW	185	-.010	0.891
<b>AnxT</b>	BSA	83	.121	0.275
	BW	182	.059	0.427

**6.2.16: Deprivation and psychological morbidity (collapsed variable)**

	n=		1 to 6	% within dep.	7 to 14	% within dep.	15 to 20	% within dep.	X <sup>2</sup> for Trend
<b>PHQ-9</b>	≤9	196	42	21.4	59	30.1	95	48.5	
	≥10	62	20	32.3	24	38.7	18	29	0.022
<b>HADS D</b>	≤7	215	45	65.2	72	78.3	98	83.1	
	≥8	64	24	34.8	20	21.7	20	16.9	0.22
<b>DepT</b>	≤3	171	36	21.1	55	64	80	69.6	
	≥4	91	25	41	31	36	35	38.5	0.359
<b>HADS A</b>	≤ 7	161	34	21.1	52	32.3	75	46.6	
	≥8	118	35	29.7	40	33.9	43	36.4	0.156
<b>AnxT</b>	≤3	114	29	48.3	34	38.6	51	43.6	
	≥4	151	31	51.7	54	61.4	66	56.4	0.497

**6.2.17: Educational attainment by ethnicity**

	n=	%	BSA	%	BW	%	X <sup>2</sup> for trend
No formal education	30	10.7	27	29.7	3	1.7	
Junior school (up to 11)	8	2.8	4	4.4	4	2.2	
Senior School (15-16)	97	34.7	16	17.8	81	44.8	
Sixth form (17-18)	22	7.8	11	12.1	11	6.1	
University or College	115	41.2	33	36.3	82	45.3	p=0.0005

**6.2.18: Relationship between educational attainment and psychological morbidity**

	n=		% within symptom		% within symptom	X <sup>2</sup>
<b>PHQ-9</b>	119	≤9		≥10		
No formal education or ≤11	28	16	57.1	12	42.9	
Sixth form and above	91	73	80.2	18	19.8	0.027
<b>HADS D</b>	127	≤7		≥8	%	
No formal education or ≥11	30	16	53.3	14	46.7	
Sixth form and above	97	79	81.4	18	18.6	0.004
<b>DepT</b>	122	≤3		≥4		
No formal education or ≥11	27	17	63	10	37	
Sixth form and above	95	65	68.4	30	31.6	0.764
<b>HADS A</b>	127	≤7		≥8	%	
No formal education or ≥11	30	12	40	18	60	
Sixth form and above	97	60	61.9	37	38.1	0.057
<b>AnxT</b>	123	≤3		≥4		
No formal education or ≥11	27	12	44.4	15	55.6	
Sixth form and above	96	44	45.8	52	54.2	1.0

**6.2.19: Distribution of scores by ethnicity: (TDcFQ) and Mann Whitney U test**

TDcFQ	Kolmorov-Smirnov	Mean Rank Scores	Md. (IQR)	U	Z	r	2 tailed sig.
BSA	0.199 (p=. 0.0005)	178.70	8 (7,10)	5057	-5.784	0.34	0.0005
BW	0.197 (p=0.0005)	120.34	6 (5,8)				

**6.2.20: Relationship between (TDcFQ) and anxiety and depression by ethnicity**

Continuous scores		n=	rho	2 tailed sig.
PHQ-9	BSA	85	-.322	0.003
	BW	173	-.042	0.580
HADS D	BSA	94	.208	0.044
	BW	185	-.001	0.988
DepT.	BSA	84	.113	0.307
	BW	180	.008	0.915
HADS A	BSA	94	.220	0.033
	BW	185	0.58	0.431
AnxT	BSA	83	.008	0.946
	BW	182	.012	0.871

### 6.2.21: Religious affiliation

Religion	Total (%)	BSA (%)	BW (%)
Christian	148 (53)	Nil	148 (80)
Muslim	24 (9)	24 (25.5)	Nil
Hindu	50 (18)	50 (53.2)	Nil
Sikh	16 (6)	16 (17)	Nil
Other	4 (1)	1 (1.06)	3 (1.6)
None	37 (13)	Nil	37 (18.4)

### 6.3.1: Longitudinal depression for one sample

PHQ-9 -sum indicators 1-9		Cut off score	n=	%
258	<b>Baseline</b>	≥10	62	24.0
		≥15	23	8.9
		≥20	6	2.3
184	<b>3 months</b>	≥10	50	27.6
		≥15	23	12.0
		≥20	9	4.8
38	<b>9 months</b>	≥10	24	17.5
		≥15	10	7.2
		≥20	4	2.8
<b>HADS D</b>				
279	<b>Baseline</b>	≥8	64	22.9
		≥11	34	12.2
		≥15	10	3.6
201	<b>3 months</b>	≥8	56	27.9
		≥11	23	11.4
		≥15	10	5.0
156	<b>9 months</b>	≥8	32	20.5
		≥11	22	14.0
		≥15	10	6.4
<b>DepT</b>				
262	<b>Baseline</b>	≥4	91	34.7
189	<b>3 months</b>	≥4	67	35.4
150	<b>9 months</b>	≥4	34	22.7

### 6.3.2: Longitudinal anxiety for one sample

HADS A		Cut off score	n=	%
279	<b>Baseline</b>	≥8	118	42.3
		≥11	67	24.0
		≥15	23	8.3
201	<b>3 months</b>	≥8	74	36.8
		≥11	45	22.4
		≥15	16	8.0
157	<b>9 months</b>	≥8	48	30.6
		≥11	22	14.0
		≥15	10	6.4
<b>AnxT</b>				
265	<b>Baseline</b>	≥4	151	57.0
190	<b>3 months</b>	≥4	92	48.4
151	<b>9 months</b>	≥4	53	35.1

### 6.3.3: Longitudinal incidence of depression by ethnic group

<b>PHQ 9</b>		<b>n=</b>	<b>≤9</b>	<b>%</b>	<b>≥10</b>	<b>%</b>	<b>χ<sup>2</sup></b>
BSA	Baseline	85	55	64.7	30	35.3	
BW		173	141	81.5	32	18.3	0.05
BSA	3 months	49	28	57.1	21	42.9	
BW		136	106	77.9	30	22.1	0.009
BSA	9 months	28	19	67.9	9	32.1	
BW		115	99	86.1	16	13.9	0.045
<b>HADS D</b>		<b>n=</b>	<b>≤7</b>	<b>%</b>	<b>≥8</b>	<b>%</b>	
BSA	Baseline	94	61	64.9	33	35.1	
BW		185	154	83.2	31	16.8	0.001
BSA	3 months	57	31	54.4	26	45.6	
BW		144	114	79.2	30	20.8	0.001
BSA	9 months	32	19	59.4	13	40.6	
BW		124	105	84.7	19	15.3	0.004
<b>DepT</b>		<b>n=</b>	<b>≤3</b>	<b>%</b>	<b>≥4</b>	<b>%</b>	
BSA	Baseline	83	47	56.5	36	43.4	
BW		180	125	69.4	55	30.6	0.59
BSA	3 months	51	22	43.1	29	56.9	
BW		137	98	71.5	39	28.5	0.001
BSA	9 months	29	18	62.1	11	37.9	
BW		121	98	81	23	19	0.052

### 6.3.4: Longitudinal incidence of anxiety by ethnic group

<b>HADS A</b>		<b>n=</b>	<b>≤7</b>	<b>%</b>	<b>≥8</b>	<b>%</b>	
BSA	Baseline	94	43	45.7	51	54.3	
BW		185	118	63.8	67	36.2	0.006
BSA	3 months	57	30	52.6	27	47.4	
BW		144	97	67.4	47	32.6	0.074
BSA	9 months	32	19	59.4	13	40.6	
BW		124	89	71.8	35	28.2	0.254
<b>AnxT</b>		<b>n=</b>	<b>≤3</b>	<b>%</b>	<b>≥4</b>	<b>%</b>	
BSA	Baseline	83	27	32.5	56	67.5	
BW		182	87	47.8	95	52.2	0.02
BSA	3 months	51	21	41.1	30	58.9	
BW		139	76	54.6	63	45.4	0.13
BSA	9 months	32	17	53.2	15	46.8	
BW		119	81	68	38	32	0.17

### 6.3.5: Comparative assessments of anxiety and depression by ethnicity

Mann Whitney U Test			n=	Mean Rank Score	Md	U	Z	r	Sig.
PHQ-9	Pres.	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	Pres.	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	Pres.	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	Pres.	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	Pres.	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

**6.3.6: Depressive symptoms at 3 threshold scores using PHQ-9**

<b>PHQ-9</b>		<b>N=</b>	<b>≥10</b>	<b>%</b>	<b>X<sup>2</sup></b>
BSA	Baseline	85	30	35.3	
BW		173	32	18	0.03
BSA	3 months	49	21	42	
BW		136	30	22	0.06
BSA	9 months	28	9	32	
BW		115	12	10	0.03
		<b>N=</b>	<b>≥15</b>		
BSA	Baseline	85	13	15	
BW		173	10	5	0.04
BSA	3 months	49	9	18	
BW		136	14	10	0.02
BSA	9 months	28	4	14	
BW		115	6	5	FET 0.2
		<b>N=</b>	<b>≥20</b>		
BSA	Baseline	85	3	3.5	
BW		173	3	1.7	FET 0.6
BSA	3 months	49	4	8	
BW		136	5	3.6	FET0.2
BSA	9 months	28	1	3.5	
BW		115	3	2.6	FET 1.0

**6.3.7: The distribution of DT scores for BSA and BW patients**

	<b>Mean</b>	<b>Kolmogorvo-Smirnov statistic</b>	<b>Df</b>	<b>2 tailed sig.</b>
BSA	4.88(.364)	.148	83	0.0005
BW	3.20 (.231)	.177	181	0.0005

**6.3.8: Longitudinal differences in distress (DT 3v4) by ethnicity**

		<b>sample</b>	<b>0-3</b>	<b>%</b>	<b>4+</b>	<b>%</b>	<b>X<sup>2</sup></b>
BSA	Baseline	83	30	36.1	53	63.9	
BW		181	113	62.4	68	37.6	0.0005
BSA	3 months	51	23	45.1	28	54.9	
BW		137	94	80.3	43	60.6	0.005
BSA	9 months	30	15	50	15	50	
BW		119	90	75.6	29	24.4	0.012

**6.3.9: Longitudinal trends of anxiety and depression within each ethnic group**

<b>Friedman Tests</b>		<b>Time interval</b>	<b>n=</b>	<b>Mean Rank Scores</b>	<b>Mean</b>	<b>X<sup>2</sup> (DF 2)</b>	<b>Sig</b>
HADS A Scores	BSA	1	33	1.88	6.12	2.150	.341
		2		2.20	7.97		
		3		1.92	6.61		
	BW	1	99	2.30	7.59	15.219	0.0005
		2		1.86	6.26		
		3		1.83	6.01		
HADS D Scores	BSA	1	32	1.63	3.75	8.088	0.018
		2		2.27	6.72		
		3		2.11	5.75		
	BW	1	99	1.98	4.39	7.497	0.024
		2		2.19	4.92		
		3		1.83	4.04		

**6.4.1: Relationship between ethnicity and anxiety and depression corrected for deprivation**

	<b>n=</b>	<b>Pearson product-moment correlation</b>	<b>p-value</b>	<b>n=</b>	<b>Correlation corrected for deprivation</b>	<b>2 tailed sig.</b>
PHQ-9	256	-.251	0.0005	255	-.158	0.011
HADS D	277	-.274	0.0005	276	-.235	0.0005
DepT	262	-.131	0.033	261	-.118	0.057
HADS A	277	-.147	0.014	276	-.093	0.123
AnxT	263	-.087	0.158	262	-0.083	0.179

### 6.5.1 PHQ-9: Indicators of depressive symptoms (1)

Indicator			n=		%	$\chi^2$
<b>Little interest or pleasure in doing things</b>						
	Present	BSA	83	24	28.9	
		BW	172	18	10.4	0.003
	3 months	BSA	46	12	26	
		BW	138	20	14.4	0.2
	9 months	BSA	28	5	17.8	
		BW	110	9	8	FET 0.1
<b>Feeling down, depressed or hopeless</b>						
	Present	BSA	86	22	25.5	
		BW	172	20	11.6	0.02
	3 months	BSA	48	13	27	
		BW	141	15	10.6	0.03
	9 months	BSA	28	5	17.8	
		BW	110	9	8	0.15
<b>Trouble falling or staying asleep or sleeping too much</b>						
	Present	BSA	87	30	34.4	
		BW	172	52	30	0.7
	3 months	BSA	48	15	31	
		BW	141	46	32.6	0.8
	9 months	BSA	28	6	21	
		BW	111	32	28.8	0.7
<b>Feeling tired or having little energy</b>						
	Present	BSA	84	44	52	
		BW	173	41	23	0.002
	3 months	BSA	50	24	48	
		BW	141	56	39.7	0.6
	9 months	BSA	27	12	44	
		BW	111	34	30.6	0.4
<b>Poor appetite or overeating</b>						
	Present	BSA	81	27	33	
		BW	170	36	21	0.15
	3 months	BSA	49	21	42.8	
		BW	141	36	25.5	0.14
	9 months	BSA	28	9	32	
		BW	110	16	14.5	0.14
<b>Feeling bad about yourself-or that you are a failure or have let yourself or your family down</b>						
	Present	BSA	85	13	15	
		BW	173	16	9	0.28
	3 months	BSA	47	10	21	
		BW	141	14	9.9	0.13
	9 months	BSA	28	4	14	
		BW	111	20	18	FET 1.0

**PHQ-9: Indicators of depressive symptoms (2)**

<b>Trouble concentrating on things such as reading the newspaper and watching television</b>						
			<b>n=</b>		<b>%</b>	<b>X<sup>2</sup></b>
	Present	BSA	86	19	22	
		BW	174	21	12	0.1
	3 months	BSA	48	15	31	
		BW	141	15	10.6	0.01
	9 months	BSA	28	4	14	
		BW	111	13	11.7	FET 0.7
<b>Moving so slowly that other people could have notice-or the opposite being so fidgety or restless that you are moving around a lot more than usual</b>						
	Present	BSA	83	21	25	
		BW	172	11	6	0.0005
	3 months	BSA	49	15	31	
		BW	141	15	10.6	0.07
	9 months	BSA	28	3	11	
		BW	111	9	8	FET 0.7
<b>Thoughts that you would be better off dead or of hurting yourself in some way</b>						
	Present	BSA	84	8	9	
		BW	171	8	5	0.2
	3 months	BSA	48	4	8	
		BW	141	16	11.3	0.7
	9 months	BSA	28	3	11	
		BW	111	5	4.5	FET 0.3

**6.5.2: Indicator for suicidal ideation (PHQ-9)**

		<b>N=</b>	<b>Not at all</b>	<b>Several days</b>	<b>More than half the days</b>	<b>Nearly every day</b>	<b>Total with suicidal thoughts (%)</b>	<b>X<sup>2</sup> for trend</b>
<b>Baseline</b>	Single sample	253	237	10	1	5	16(6.2)	
	BSA	82	74	4	1	3	8(9.7)	
	BW	171	163	6	0	2	8(4.6)	0.235
<b>3 months</b>	Single sample	183	163	17	2	1	20(10.9)	
	BSA	47	43	2	1	1	4(8.5)	
	BW	136	120	15	1	0	16(11.7)	0.152
<b>9 months</b>	Single sample	141	133	5	2	1	8(5.6)	
	BSA	27	24	2	0	1	3(11.1)	
	BW	114	109	3	2	0	5(4.3)	0.102

### 6.6.1 Mini MAC indicators for each coping style over 9 months (1)

Hopelessness/ Helplessness		n=	Does not apply to me	%	Applies to Me	%	X <sup>2</sup>
<b>I feel like giving up</b>							
Baseline	BSA	94	77	81.9	17	18.1	
	BW	185	177	95.7	8	4.3	0.0005
3 months	BSA	55	45	81.8	10	18.2	
	BW	143	127	88.8	16	11.2	0.285
9 months	BSA	31	28	90.3	3	9.7	
	BW	117	111	94.9	6	5.1	0.603
<b>I feel completely at a loss about what to do</b>							
Baseline	BSA	94	63	67	31	33	
	BW	185	162	87.6	23	12.4	0.0005
3 months	BSA	56	43	76.8	13	23.2	
	BW	143	125	87.4	18	12.6	0.101
9 months	BSA	31	27	87.1	4	12.9	
	BW	119	110	92.4	9	7.6	FET 0.471
<b>I can't handle it</b>							
Baseline	BSA	93	66	71	27	29	
	BW	185	161	87	24	13	0.002
3 months	BSA	54	42	77.8	12	22.2	
	BW	143	133	93	10	7	0.006
9 months	BSA	31	28	90.3	3	9.7	
	BW	119	106	89.1	13	10.9	1.0
<b>I feel that there is nothing I can do help myself</b>							
Baseline	BSA	93	67	72	26	28	
	BW	185	160	86.5	25	13.5	0.006
3 months	BSA	55	42	76.4	13	23.6	
	BW	143	128	89.5	15	10.5	0.032
9 months	BSA	31	29	93.5	2	6.5	
	BW	119	108	90.8	11	9.2	0.894
<b>I think this is the end of the world</b>							
Baseline	BSA	94	78	83	16	17	
	BW	185	175	94.6	10	5.4	0.003
3 months	BSA	56	43	76.8	13	23.2	
	BW	143	132	92.3	11	7.7	0.005
9 months	BSA	31	30	96.8	1	3.2	
	BW	119	112	94.1	7	5.9	FET 1.0

<b>Hopelessness/ Helplessness</b>		n=	<b>Does not apply to me</b>	<b>%</b>	<b>Applies to Me</b>	<b>%</b>	<b>X<sup>2</sup></b>
<b>I feel that life is hopeless</b>							
Baseline	BSA	94	77	81.9	17	18.1	
	BW	185	174	94.1	11	5.9	0.003
3 months	BSA	55	46	83.6	9	16.4	
	BW	143	134	93.7	9	6.3	0.053
9 months	BSA	31	29	93.5	2	6.5	
	BW	118	109	92.4	9	7.6	FET 1.0
<b>I can't cope</b>							
Baseline	BSA	94	71	75.5	23	24.5	
	BW	185	172	93	13	7	0.0005
3 months	BSA	55	45	81.8	10	18.2	
	BW	143	134	93.7	9	6.3	0.023
9 months	BSA	31	28	90.3	3	9.7	
	BW	119	106	89.1	13	10.9	FET 1.0
<b>I am not very hopeful about the future</b>							
Baseline	BSA	93	66	71	27	29	
	BW	185	152	82.2	33	17.8	0.047
3 months	BSA	55	39	70.9	16	29.1	
	BW	143	108	75.5	35	24.5	0.629
9 months	BSA	31	25	80.6	6	19.4	
	BW	119	92	77.3	27	22.7	0.876

<b>Cognitive Avoidance</b>		<b>n=</b>	<b>Does not apply to me</b>	<b>%</b>	<b>Applies to Me</b>	<b>%</b>	<b>X<sup>2</sup></b>
<b>I distract myself when cancer thoughts come into my head</b>							
Baseline	BSA	93	33	35.5	60	64.5	
	BW	185	77	41.6	108	58.4	0.391
3 months	BSA	55	21	38.2	34	61.8	
	BW	143	51	35.7	92	64.3	0.869
9 months	BSA	31	11	35.5	20	64.5	
	BW	119	54	45.4	65	54.6	0.431
<b>Not thinking about it helps me cope</b>							
Baseline	BSA	93	36	38.7	57	61.3	
	BW	185	106	57.3	79	42.7	0.005
3 months	BSA	55	23	41.8	32	58.2	
	BW	143	75	52.4	68	47.6	0.238
9 months	BSA	31	17	54.8	14	45.2	
	BW	119	75	63	44	37	0.531
<b>I make a positive effort not to think about my illness</b>							
Baseline	BSA	93	21	22.6	72	77.4	
	BW	184	76	41.3	108	58.7	0.003
3 months	BSA	54	15	27.8	39	72.2	
	BW	143	54	37.8	89	62.2	0.253
9 months	BSA	31	11	35.5	20	64.5	
	BW	119	52	43.7	67	56.3	0.535
<b>I deliberately push all thoughts of cancer out of my mind</b>							
Baseline	BSA	93	32	34.4	61	65.5	
	BW	185	122	65.9	63	34.4	0.0005
3 months	BSA	54	23	42.6	31	57.4	
	BW	143	85	59.4	58	40.6	0.05
9 months	BSA	31	11	35.5	20	64.5	
	BW	119	68	57.1	51	42.9	0.051

<b>Fatalism</b>		<b>n=</b>	<b>Does not apply to me</b>	<b>%</b>	<b>Applies to Me</b>	<b>%</b>	<b>X<sup>2</sup></b>
<b>At the moment I take one day at a time</b>							
Baseline	BSA	94	24	25.5	70	74.5	
	BW	185	66	35.7	119	64.3	0.115
3 months	BSA	55	25	45.5	30	54.5	
	BW	143	52	36.4	91	63.6	0.311
9 months	BSA	31	12	38.7	19	61.3	
	BW	120	60	50	60	50	0.357
<b>I've put myself in the hands of God</b>							
Baseline	BSA	94	23	24.5	71	75.5	
	BW	185	125	67.6	60	32.4	0.0005
3 months	BSA	56	20	35.7	36	64.3	
	BW	143	92	64.3	51	35.7	0.0005
9 months	BSA	31	13	41.9	18	58.1	
	BW	119	77	64.7	42	35.3	0.036
<b>I count my blessings</b>							
Baseline	BSA	94	22	23.7	71	76.3	
	BW	185	40	21.6	145	78.4	0.817
3 months	BSA	56	14	25	42	75	
	BW	143	23	16.1	120	83.9	0.211
9 months	BSA	30	9	30	21	70	
	BW	119	23	19.3	96	80.7	0.306
<b>I've had a good life, what's left is a bonus</b>							
Baseline	BSA	93	30	32.3	63	67.7	
	BW	185	79	42.7	106	57.3	0.12
3 months	BSA	55	23	41.8	32	58.2	
	BW	143	60	42	83	58	1.0
9 months	BSA	31	7	22.6	24	77.4	
	BW	119	45	37.8	74	62.2	0.169
<b>Since my cancer diagnosis I now realise how precious life is and I'm making the most of it</b>							
Baseline	BSA	93	12	12.9	81	87.1	
	BW	185	31	16.8	154	83.2	0.508
3 months	BSA	55	10	18.2	45	81.8	
	BW	143	18	12.6	125	87.4	0.433
9 months	BSA	31	6	19.4	25	80.6	
	BW	119	16	13.4	103	86.6	0.587

<b>Anxiety Preoccupation</b>		<b>n=</b>	<b>Does not apply to me</b>	<b>%</b>	<b>Applies to Me</b>	<b>%</b>	<b>X<sup>2</sup></b>
<b>I feel very angry about what has happened to me</b>							
Baseline	BSA	94	57	60.6	37	39.4	
	BW	185	126	68.1	59	31.9	0.268
3 months	BSA	55	34	61.8	21	38.2	
	BW	143	91	63.6	52	36.4	0.942
9 months	BSA	31	21	67.7	10	32.3	
	BW	119	88	73.9	31	26.1	FET 0.503
<b>It is a devastating feeling</b>							
Baseline	BSA	94	41	43.6	53	56.4	
	BW	185	97	52.4	88	47.6	0.206
3 months	BSA	55	30	54.5	25	45.5	
	BW	143	83	58	60	42	0.776
9 months	BSA	31	18	58.1	13	41.9	
	BW	119	82	68.9	37	31.1	0.354
<b>I worry about the cancer returning or getting worse</b>							
Baseline	BSA	94	28	29.8	66	70.2	
	BW	185	57	30.8	128	69.2	0.97
3 months	BSA	54	19	35.2	35	64.8	
	BW	143	40	28	103	72	0.417
9 months	BSA	31	11	35.5	20	64.5	
	BW	119	39	32.8	80	67.2	0.953
<b>I am apprehensive</b>							
Baseline	BSA	93	46	49.5	47	50.5	
	BW	185	50	27	135	73	0.0005
3 months	BSA	55	32	58.2	23	41.8	
	BW	143	56	39.2	87	60.8	0.024
9 months	BSA	29	21	72.4	8	27.6	
	BW	118	54	45.8	64	54.2	0.018
<b>I am upset about having cancer</b>							
Baseline	BSA	94	36	38.3	58	61.7	
	BW	185	36	19.5	149	80.5	0.001
3 months	BSA	56	23	41.1	33	58.9	
	BW	143	37	25.9	106	74.1	0.054
9 months	BSA	31	16	51.6	15	48.4	
	BW	119	56	47.1	63	52.9	0.802

<b>Anxiety preoccupation</b>		<b>n=</b>	<b>Does not apply to me</b>	<b>%</b>	<b>Applies to Me</b>	<b>%</b>	<b>X<sup>2</sup></b>
<b>I have difficulty in believing that this is happening to me</b>							
Baseline	BSA	93	29	31.2	64	68.8	
	BW	185	74	40	111	60	0.192
3 months	BSA	55	24	43.6	31	56.4	
	BW	143	62	43.4	81	56.6	1.0
9 months	BSA	31	15	48.4	16	51.6	
	BW	119	62	52.1	57	47.9	0.868
<b>I suffered great anxiety about it</b>							
Baseline	BSA	94	48	51.1	46	48.9	
	BW	185	125	67.6	60	32.4	0.011
3 months	BSA	55	29	52.7	26	47.3	
	BW	143	104	72.7	39	27.3	0.012
9 months	BSA	31	22	71	9	29	
	BW	119	85	71.4	34	28.6	1.0
<b>I am a little frightened</b>							
Baseline	BSA	94	29	30.9	65	69.1	
	BW	185	36	19.5	149	80.5	0.048
3 months	BSA	55	19	34.5	36	65.5	
	BW	143	45	31.5	98	68.5	0.806
9 months	BSA	31	11	35.5	20	64.5	
	BW	119	51	42.9	68	57.1	0.591

<b>Fighting Spirit</b>		<b>n=</b>	<b>Does not apply to me</b>	<b>%</b>	<b>Applies to Me</b>	<b>%</b>	<b>X<sup>2</sup></b>
<b>I see my illness as a challenge</b>							
Baseline	BSA	94	24	25.5	70	74.5	
	BW	185	46	24.9	139	75.1	1
3 months	BSA	55	17	30.9	38	69.1	
	BW	143	42	29.4	101	70.6	0.969
9 months	BSA	31	9	29	22	71	
	BW	119	44	37	75	63	0.540
<b>I try to fight the illness</b>							
Baseline	BSA	93	11	11.8	82	88.2	
	BW	185	24	13	161	87	0.936
3 months	BSA	56	9	16.1	47	83.9	
	BW	142	25	17.6	117	82.4	0.961
9 months	BSA	31	8	25.8	23	74.2	
	BW	118	28	23.7	90	76.3	0.996

<b>Fighting Spirit</b>		<b>n=</b>	<b>Does not apply to me</b>	<b>%</b>	<b>Applies to Me</b>	<b>%</b>	<b>χ<sup>2</sup></b>
<b>I am very optimistic</b>							
Baseline	BSA	93	20	21.5	73	78.5	
	BW	185	30	16.2	155	83.8	0.359
3 months	BSA	55	14	25.5	41	74.5	
	BW	143	22	15.4	121	84.6	0.150
9 months	BSA	30	9	30	21	70	
	BW	119	18	15.1	101	84.9	0.104
<b>I am determined to beat this disease</b>							
Baseline	BSA	93	8	8.6	85	91.4	
	BW	185	15	8.1	170	91.9	1
3 months	BSA	55	9	16.4	46	83.6	
	BW	143	13	9.1	130	90.9	0.224
9 months	BSA	31	7	22.6	24	77.4	
	BW	119	18	15.1	101	84.9	0.471

#### 6.6.2: CIDQ indicators for each coping style over 9 months

<b>Denial</b>		<b>n=</b>	<b>Disagree</b>	<b>%</b>	<b>Some times</b>	<b>%</b>	<b>Agree</b>	<b>%</b>	<b>χ<sup>2</sup></b>
<b>I keep health related issues to myself</b>									
Baseline	BSA	93	50	53.8	20	21.5	23	24.7	
	BW	185	105	56.8	62	33.5	18	9.7	0.002
3 months	BSA	56	25	44.6	19	33.9	11	19.6	
	BW	143	68	47.5	60	41.9	15	10.4	0.19
9 months	BSA	30	15	50	10	33	6	0.2	
	BW	115	51	44.3	46	39	18	15	0.7
<b>I think there has been a mistake in giving a diagnosis of cancer</b>									
Baseline	BSA	94	81	86.2	5	5.3	8	8.5	
	BW	185	173	93.5	7	3.8	5	2.7	0.07
3 months	BSA	55	51	92	0	0	4	0.07	
	BW	143	138	96.5	2	0.01	3	0.02	val.<5
9 months	BSA	31	28	90	0	0	3	9.6	
	BW	115	111	96.5	1	0.8	3	2.6	val<5
<b>I don't really believe I have cancer</b>									
Baseline	BSA	94	63	67	12	12.8	19	20.2	
	BW	185	166	89.7	11	5.9	8	4.3	0.0001
3 months	BSA	55	42	76.3	2	3.6	11	20	
	BW	143	126	88	10	6.9	7	4.8	0.003
9 months	BSA	31	22	70.9	6	19.3	3	9.6	
	BW	115	105	91.3	4	3.4	6	5.2	val<5

<b>Denial</b>		<b>n=</b>	<b>Disagree</b>	<b>%</b>	<b>Some times</b>	<b>%</b>	<b>Agree</b>	<b>%</b>	<b>X<sup>2</sup></b>
<b>I have difficulty in believing that this is happening to me</b>									
Baseline	BSA	92	26	28.3	8	8.7	58	63	
	BW	184	62	33.7	17	9.2	105	57.1	0.619
3 months	BSA	56	21	37.5	10	17.8	25	44.6	
	BW	143	46	32.1	53	37	44	30.7	0.02
9 months	BSA	31	12	38.7	9	29	10	32.2	
	BW	115	46	40	40	34.7	29	25.2	0.7
<b>I try not to dwell on my illness</b>									
Baseline	BSA	93	21	22.6	23	24.7	49	52.7	
	BW	185	18	9.7	26	14.1	141	76.2	0.0001
3 months	BSA	56	12	21.4	17	30.3	27	48.2	
	BW	142	10	7.0	20	14	112	78.8	0.0001
9 months	BSA	31	5	16.1	5	16.1	21	67.7	
	BW	118	11	9.3	12	10.1	95	80.5	0.31
<b>I cannot really see the point of having treatment</b>									
Baseline	BSA	93	77	82.8	3	3.2	13	14	
	BW	185	178	96.2	2	1.1	5	2.7	0.001
3 months	BSA	56	50	89.2	1	1.78	5	8.9	
	BW	143	131	91.6	8	5.6	4	2.8	val<5
9 months	BSA	31	30	96.7	0	0	1	3.2	
	BW	118	112	94.9	2	1.6	4	3.3	val<5
<b>I don't let myself get upset about my illness</b>									
Baseline	BSA	94	25	26.6	17	18.1	52	55.3	
	BW	185	35	18.9	53	28.6	97	52.4	0.101
3 months	BSA	55	14	25.4	17	30.9	24	43.6	
	BW	143	30	20.9	44	30.7	69	48.2	0.7
9 months	BSA	30	7	23.3	8	26.6	15	50	
	BW	117	16	13.6	25	21.3	76	64.9	0.27
<b>I may get better from this illness</b>									
Baseline	BSA	94	16	17	8	8.5	70	74.5	
	BW	185	22	11.9	13	7	150	81.1	0.421
3 months	BSA	57	5	8.7	7	12.2	45	78.9	
	BW	142	18	12.6	12	8.4	112	78.8	0.5
9 months	BSA	31	2	6.4	3	9.6	26	83.8	
	BW	114	15	13.1	5	4.3	94	82.4	val<5

<b>Avoidance</b>		<b>n=</b>	<b>Disagree</b>	<b>%</b>	<b>Some times</b>	<b>%</b>	<b>Agree</b>	<b>%</b>	<b>X<sup>2</sup></b>
<b>I avoid talking to strangers about my diagnosis</b>									
Baseline	BSA	93	31	33.3	18	19.4	44	47.3	
	BW	185	55	29.7	63	34.1	67	36.2	0.034
3 months	BSA	56	28	50	6	10.7	22	39.2	
	BW	143	73	51	25	17.4	45	31.4	0.3
9 months	BSA	31	12	38.7	5	16.1	14	45	
	BW	118	65	55	21	17.7	32	27.1	0.14
<b>I avoid discussing painful issues with some health professionals</b>									
Baseline	BSA	93	69	74.2	9	9.7	15	16.1	
	BW	184	156	84.8	14	7.6	14	7.6	0.065
3 months	BSA	56	43	76.7	6	10.7	7	12.5	
	BW	143	112	78.3	22	15.3	9	6.2	0.2
9 months	BSA	31	21	67.7	6	19.3	4	12.9	
	BW	118	91	77.1	11	9.3	16	13.5	val<5
<b>I pretend I do not have cancer</b>									
Baseline	BSA	94	64	68.1	17	18.1	13	13.8	
	BW	185	166	89.7	11	5.9	8	4.3	0.0001
3 months	BSA	56	41	73.2	3	5.3	12	21.4	
	BW	143	122	85.3	16	11.1	5	3.4	val<5
9 months	BSA	31	21	67.7	1	3.2	9	29	
	BW	143	122	85.3	16	11.1	5	3.4	val<5
<b>I do not like to meet other people with cancer</b>									
Baseline	BSA	93	70	75.3	13	14	10	10.8	
	BW	185	154	83.2	22	11.9	9	4.9	0.146
3 months	BSA	56	45	80.3	6	10.7	5	8.9	
	BW	143	122	85.3	17	11.8	4	2.7	0.17
9 months	BSA	31	22	70.9	5	16.1	4	12.9	
	BW	115	90	78.2	14	12.1	11	9.5	val<5
<b>I avoid reminders of cancer on TV, radio and newspapers</b>									
Baseline	BSA	93	67	72	13	14	13	14	
	BW	185	113	61.1	43	23.2	29	15.7	0.142
3 months	BSA	55	35	63.6	11	20	9	16.3	
	BW	143	82	57.3	40	27.9	21	14.6	0.5
9 months	BSA	31	19	61.2	6	19.3	6	19.3	
	BW	118	77	65.2	30	25.4	11	9.3	0.27

Information		n=	Disagree	%	Some times	%	Agree	%	$\chi^2$
<b>No one has clearly told me I have cancer</b>									
Baseline	BSA	94	81	86.2	1	1.1	12	12.8	
	BW	185	174	94.1	3	1.6	8	4.3	0.034
3 months	BSA	56	54	96.4	1	1.7	1	1.7	
	BW	143	134	93.7	1	0.6	8	5.5	val<5
9 months	BSA	31	30	96.7	0	0	1	3.2	
	BW	115	108	93.9	0	0	7	6	val<5
<b>I have been told my cancer is curable</b>									
Baseline	BSA	93	35	37.6	15	16.1	43	46.2	
	BW	185	85	45.9	35	18.9	54	35.1	0.2
3 months	BSA	55	19	34.5	2	3.6	34	61.8	
	BW	143	48	33.5	14	9.7	81	56.6	0.35
9 months	BSA	31	10	32.2	1	3.2	20	64.5	
	BW	118	45	38.1	8	6.7	65	55	0.5
<b>I have been given plenty of information about cancer</b>									
Baseline	BSA	93	13	14	4	4.3	76	81.7	
	BW	185	26	14.1	5	2.7	154	83.2	0.776
3 months	BSA	55	5	9	0	0	50	90.9	
	BW	143	13	9	7	4.8	123	86	val<5
9 months	BSA	118	9	7.6	2	1.7	107	90.6	
	BW	31	1	3.2	1	3.2	29	93.5	val<5

### 6.6.3: Longitudinal ethnic differences in coping strategies

Mann Whitney U Test			n=	MRS	Median (IQR)	U	Z	r	p-value
H/H	Pres	BSA	91	165.76	15(12:19)				
		BW	183	123.45	12(10:16)	5755	-4.178	0.25	0.0005
	3m	BSA	54	112.48	16((10:18)				
		BW	143	93.93	12(9:16)	3133	-2.056	0.12	0.04
	9m	BSA	31	85.92	13.5(11:15)				
		BW	119	72.79	11.5(9:16)	1521.5	-1.512	0.12	0.13
Cog. Avoid.	Pres	BSA	90	167.46	12(10:13)				
		BW	182	121.19	10(8:12)	5404	-4.608	0.28	0.0005
	3m	BSA	53	108.65	11(9:12)				
		BW	143	94.74	10(9:12)	3251.5	-1.537	0.10	0.124
	9m	BSA	31	88.08	11(8:12)				
		BW	119	72.22	10(8:12)	1454.5	-1.823	0.15	0.068
Fatalism	Pres	BSA	92	168.02	15(14:17)				
		BW	183	122.19	13(12:15)	5656	-4.464	0.27	0.0005
	3m	BSA	54	107.14	14(13:16)				
		BW	143	95.93	14(12:15)	3421.5	-1.239	0.08	0.215
	9m	BSA	30	84.32	14.5(13:17)				
		BW	119	72.65	14(12:15)	1505.5	-1.330	0.10	0.183
Anx. Preocc.	Pres	BSA	93	144.45	22(18:25)				
		BW	183	135.48	21(18:24)	7956	-.885	0.05	0.376
	3m	BSA	54	101.09	21(17:23.5)				
		BW	143	98.17	21(18:24)	3748	-.317	0.02	0.751
	9m	BSA	30	74.35	18(15:22)				
		BW	119	75.16	18(16:23)	1765.5	0.093	0.007	0.926
Fighting Spirit	Pres	BSA	92	133.17	13(11:14)				
		BW	183	140.43	13(11:14)	7973.5	-.722	0.04	0.470
	3m	BSA	54	95.21	12(11:14)				
		BW	143	100.43	12(11:14)	3656	0.579	0.04	0.563
	9m	BSA	31	67.81	12(10:14)				
		BW	119	77.50	11.5(11:14)	1606	-1.116	0.09	0.265

<b>Mann Whitney U Test</b>			<b>n=</b>	<b>MRS</b>	<b>Median (IQR)</b>	<b>U</b>	<b>Z</b>	<b>r</b>	<b>p-value</b>
Denial	Pres	BSA	92	160.96	15(13:17)				
		BW	183	126.46	13(11.5:15)	6306	-3.4314	0.20	0.001
	3m	BSA	54	108.71	14(12:15)				
		BW	141	93.90	13(12:15)	3228.5	-1.653	0.11	0.098
	9m	BSA	31	77.63	14(12:16)				
		BW	115	72.39	13(11:15)	1654.5	-.617	0.05	0.537
Avoidance	Pres	BSA	86	138.87	6(4:6)				
		BW	167	120.89	5(4:7)	6160	-1.866	0.11	0.062
	3m	BSA	50	108.71	6(4:7)				
		BW	141	93.90	5(4:7)	2648.5	-1.518	0.11	0.129
	9m	BSA	31	78.02	6(4:7)				
		BW	101	62.97	4.5(3:6)	1208.5	-1.931	0.16	0.054
Information	Pres	BSA	91	156.48	8(6:9)				
		BW	180	125.56	7(5:8)	6326	-3.100	0.18	0.002
	3m	BSA	55	105.46	7(6:8.5)				
		BW	139	94.35	7(5:8)	3284.5	-1.261	0.08	0.207
	9m	BSA	31	88.92	8(6:9)				
		BW	114	68.67	7(5:8)	1273.5	-2.408	0.19	0.016

#### 6.6.4 Longitudinal associations between coping strategies and depression via HADS D 7v8

Mann Whitney U Test HADS D 7v8			n=	MRS	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
Anxiety Preoccup	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

<b>Mann Whitney U Test HADS D 7v8</b>			<b>n=</b>	<b>MRS</b>	<b>Median (IQR)</b>	<b>U</b>	<b>Z</b>	<b>r</b>	<b>p-value</b>
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
Avoidance	Pres	ND	195	115.46	5(4:7)				
		D	58	165.81	7(5:9)	3404	-4.636	0.29	0.0005
	3m	ND	124	79.21	5(3.5:6)				
		D	50	108.05	6(2:8)	2072.5	-3.454	0.26	0.001
	9m	ND	100	63.87	5(3:6)				
		D	30	70.95	5(4:7)	1336.5	-.910	0.07	0.363
Information	Pres	ND	210	133.80	7(5:8)				
		D	61	143.57	7(5:8)	5943	-.869	0.05	0.385
	3m	ND	141	83.79	7(5:8)				
		D	53	99.56	7(5:9)	3627.5	-.317	0.02	0.751
	9m	ND	113	70.79	7(5:8)				
		D	30	76.55	7(6:9)	1558.5	-.685	0.05	0.493

### 6.6.5 Longitudinal associations between coping strategies and depression via PHQ-9 9 v10

Mann Whitney U Test (PHQ-9 9v10)			n=	MRS	Median (IQR)	U	Z	r	p-value
H/H	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. Avoid.	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
Fighting 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

<b>Mann Whitney U Test (PHQ-9 9v10)</b>			<b>n=</b>	<b>MRS</b>	<b>Median (IQR)</b>	<b>U</b>	<b>Z</b>	<b>r</b>	<b>p-value</b>
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
Avoidance	Pres	ND	178	110.12	5(4:7)				
		D	58	144.22	7(4:8)	3670	-3.332	-0.21	0.001
	3m	ND	112	75.19	5(4:7)				
		D	47	91.46	6(4:8)	2-93.5	-2.054	0.16	0.040
	9m	ND	100	60.17	5(3.5:6)				
			23	69.96	6(2:8)	967	-1.197	0.1	0.231
Information	Pres	ND	191	123.90	7(5:8)				
		D	61	134.66	7(6:8)	5328	-1.018	-0.06	0.309
	3m	ND	130	88.40	7(5.5:8)				
		D	49	94.26	7(6:8)	2976.5	-.685	0.05	0.493
	9m	ND	114	67.79	7(5:8)				
			23	75.02	7(5:9)	1172.5	-.807	0.06	0.420

### 6.6.6 Longitudinal associations between coping strategies and depression via DepT 3v4

Mann Whitney DepT 3v4			n=	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	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
Avoidance	Pres	ND	156	109.50	5(4:6)				
		D	86	143.27	6.5(4:8)	4835.5	-3.622	0.23	0.0005
	3m	ND	109	79.62	5(4:6)				
		D	67	102.94	7(4:8)	2684	-2.968	0.22	0.003
	9m	ND	108	63.95	5(3:6)				
		D	33	94.08	7(5:8)	1020.5	-3.739	0.31	0.0005
Information	Pres	ND	171	132.24	7(6:8)				
		D	89	127.16	7(5:8)	7312.5	-.523	0.03	0.601
	3m	ND	119	91.94	7(5:8)				
		D	67	96.28	7(5:8)	3800.5	-.593	0.04	0.593
	9m	ND	113	74.58	7(5:8)				
		D	33	69.80	7(5:8)	1742.5	-.580	0.04	0.562

6.6.7 Longitudinal associations between coping strategies and anxiety via HADS A 7v8

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	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
Avoidance	Pres	NA	101	103.53	5(3:6)				
		A	141	134.37	7(5:8)	5305.5	-3.407	0.21	0.001
	3m	NA	106	74.82	4(3:6)				
		A	68	107.27	6 (4:8)	2259.5	-4.191	0.3	0.0005
	9m	NA	86	59.09	4(3:6)				
		A	44	78.03	6(4:8)	1340.5	-2.735	0.23	0.006
Information	Pres	NA	160	133.67	7(5:8)				
		A	111	139.36	7(6:8)	8507	-.596	0.03	0.551
	3m	NA	124	93.04	7(5:8)				
		A	70	105.40	7(6:8)	3787	-1.494	0.1	0.135
	9m	NA	97	67.62	7(5:8)				
		A	46	81.23	7(6:9)	1806.5	-1.856	0.15	0.063

### 6.6.8 Longitudinal associations between coping strategies and anxiety at baseline

Mann Whitney AnxT 3v4			n	MRS	Md (IQR)	U	Z	r	p-value
H/H	Pres	NA	112	102.26	12(9:14.5)				
		A	150	153.33	15(11.5:18)	5125.5	-5.417	0.33	0.0005
	3m	NA	96	80.85	12(9:16)				
		A	92	108.74	15(11:17)	3106	-3.525	0.25	0.0005
	9m	NA	94	68.79	12(9:16)				
		A	53	83.25	13(11:16)	2001	-1.986	0.15	0.047
Cog. avoidance	Pres	NA	112	113.65	10(8:12)				
		A	148	143.25	11(9:12)	6401	-3.173	0.14	0.002
	3m	NA	95	94.99	10(9:12)				
		A	92	92.98	10(8.5:12)	4276	-.257	0.01	0.797
	9m	NA	94	72.98	10(8:11)				
		A	53	75.80	10(9:12)	2395.5	-.389	0.03	0.698
Fatalism	Pres	NA	112	124.01	14(12:16)				
		A	150	137.09	14(12:16)	7561	-1.391	0.08	0.164
	3m	NA	96	88.73	13(12:15)				
		A	92	100.52	14(12:16)	3862	-1.496	0.12	0.135
	9m	NA	94	72.21	13(12:16)				
		A	53	77.17	14(12:16)	2323	-.682	0.05	0.495
Anx. Preoccup.	Pres	NA	113	86.77	19(16:21)				
		A	150	166.08	24(21:26)	3363.5	-8.388	0.51	0.0005
	3m	NA	97	70.49	19(16:21)				
		A	92	120.84	24(20:26)	2084.5	-6.339	0.46	0.0005
	9m	NA	95	63.05	19(16:22)				
		A	53	95.02	23(21:26)	1430	-4.358	0.36	0.0005
Fighting Spirit		NA	113	128.32	13(11:14)				
		A	150	134.77	13(11.5:14)	8059	-.689	0.04	0.491
	3m	NA	97	93.78	12(11:15)				
		A	92	96.28	13(12:14)	4344	-.317	0.02	0.751
	9m	NA	95	63.05	13(12:16)				
		A	53	95.02	13(12:16)	2418.5	-.400	0.03	0.689

<b>Mann Whitney AnxT 3v4</b>			<b>n</b>	<b>MRS</b>	<b>Md (IQR)</b>	<b>U</b>	<b>Z</b>	<b>r</b>	<b>p-value</b>
Denial (CIDQ)		NA	114	132.46	13(12:15)				
		A	150	132.53	13.5(12:16)	8545.5	-0.007	0.0004	0.994
	3m	NA	97	90.29	13(12:15)				
		A	92	99.96	13(12:16)	4005.5	-1.222	0.09	0.222
	9m	NA	96	77.71	13(12:15)				
		A	53	69.73	13(11:15)	2264.5	-1.116	0.09	0.264
Avoidance		NA	101	103.53	5(3.5:6)				
		A	141	134.37	6(4:8)	5305.5	-3.407	0.21	0.001
	3m	NA	88	81.63	5(4:6)				
		A	89	96.29	6(4:8)	3267	-1.917	0.14	0.055
	9m	NA	88	68.27	5(4:7)				
		A	53	75.54	6(4:7)	2091.5	-1.033	0.08	0.302
Information		NA	114	137.45	7(6:8)				
		A	146	125.08	7(5:8)	7530	-1.335	0.08	0.182
	3m	NA	97	90.72	7(6:8)				
		A	90	97.53	7(6:8)	4047	-.872	0.06	0.383
	9m	NA	94	75.90	7(6:8)				
		A	52	69.16	7(5:8)	2218.5	-.937	0.07	0.349

### 6.6.9 Longitudinal coping strategies within each ethnic group

Freidman Tests		Time interval	N=	Mean Rank	X <sup>2</sup> (DF 2)	Sig
Hopelessness Helplessness	BSA	1 2 3	27	2.15 2.11 1.74	3.083	0.214
	BW	1 2 3	108	2.08 1.91 2.01	1.907	0.385
Cognitive Avoidance	BSA	1 2 3	27	2.13 1.87 2.00	1.167	0.558
	BW	1 2 3	110	2.01 2.03 1.96	.377	0.828
Fatalism	BSA	1 2 3	26	2.23 1.67 2.10	5.033	0.081
	BW	1 2 3	109	1.93 2.04 2.03	.914	0.633
Anxiety preoccupation	BSA	1 2 3	27	2.17 2.02 1.81	1.838	0.399
	BW	1 2 3	108	2.32 1.94 1.74	21.219	0.0005
Fighting Spirit	BSA	1 2 3	28	2.0 2.07 1.93	.344	0.842
	BW	1 2 3	108	2.17 2.04 1.79	10.141	0.006
Denial	BSA	1 2 3	29	2.17 2.09 1.74	3.365	.186
	BW	1 2 3	102	2.00 1.95 2.05	.552	.759
Avoidance	BSA	1 2 3	27	2.19 1.69 2.13	5.341	0.069
	BW	1 2 3	83	2.09 2.04 1.87	2.614	0.271
Information	BSA	1 2 2	29	2.07 1.97 1.97	0.247	0.884
	BW	1 2 3	99	2.11 1.92 1.97	2.263	0.322

**6.6.10: Longitudinal changes in denial (I don't really believe I have cancer)**

MW' I don't really believe...'		n=	Mean Rank Score	Md (IQR)	U	Z	r	p-value
Baseline.	BSA	82	112.34	1(0:2)	5809	-4.505	0.28	0.0005
	BW	174	136.11	1(0:1)				
3m	BSA	53	83.20	1(0:1)	2978.5	-3.217	0.23	0.001
	BW	133	97.61	1(0:1)				
9m	BSA	25	66.16	1(0:1)	1329	-1.235	0.10	0.217
	BW	114	70.84	1(0:0)				

**6.7.1: Place of birth as predictor of anxiety among BSA patients**

Place of Birth as a Predictor of Anxiety (HADS A ≥8) in 94 BSA patients							
1) Place of birth Africa/Indian Sub Continent 2) constant							
Goodness of fit test			Model Summary				
Chi square	Df	Sig	Likelihood	C&S R <sup>2</sup>	Nag R <sup>2</sup>	95% C.I for odds ratio (Exp (B))	
3.497	1	.061	108.682	.042	.056		
B	S.E	Wald	Df	Sig	Exp (B)	Lower	Upper
1) .865	.468	3.412	1	0.065	2.375	.949	5.947
Constant - .460	.369	1.553	1	.213	.632		

**6.7.2: Predictors of anxiety for one sample (all variables of interest)**

Predictors of anxiety using HADS A ≥8 in 261 patients (all variables of interest)							
1) DT 2) DepT. 3) H/H 4) constant							
Goodness of fit test			Model Summary				
Chi square	Df	Sig	Likelihood	C&S R <sup>2</sup>	Nag R <sup>2</sup>	95% C.I for odds ratio (Exp (B))	
116.291	3	.000	235.502	.360	.486		
B	S.E	Wald	Df	Sig	Exp (B)	Lower	Upper
1) .316	.069	21.141	1	.000	1.372	1.199	1.570
2) .142	.064	4.930	1	.026	1.152	1.017	1.306
3) .126	.044	8.155	1	.004	1.134	1.040	1.237
Const -3.860	.618	39.050	1	.000	.021		

**6.7.3: Predictors of anxiety for one sample (demographic and coping strategies only)**

<b>Predictors of anxiety using HADS A <math>\geq</math>8 in 261 patients (demographics and coping strategy variables only)</b>							
1) H/H 2) Avoidance. 3) Age 4) constant							
<b>Goodness of fit test</b>			<b>Model Summary</b>				
<b>Chi square</b>	<b>Df</b>	<b>Sig</b>	<b>Likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>		
67.066	3	.000	274.809 <sup>a</sup>	.234	.315	95% C.I for odds ratio (Exp (B))	
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>Df</b>	<b>Sig</b>	<b>Exp (B)</b>	<b>Lower</b>	<b>Upper</b>
1) .201	.039	27.052	1	.000	1.223	1.133	1.319
2) .203	.061	11.245	1	.001	1.225	1.088	1.380
3) -.026	.015	3.034	1	.082	.974	.946	1.003
Const. -2.765	1.052	6.910	1	.009	.063		

**6.7.4: Predictors of anxiety for BSA sample**

<b>Predictors of anxiety using HADS A <math>\geq</math>8 in 83 BSA patients (all variables of interest)</b>							
1) Depression (HADS D) 2) Distress (DT) 3) constant							
<b>Goodness of fit test</b>			<b>Model Summary</b>				
<b>Chi square</b>	<b>Df</b>	<b>Sig</b>	<b>Likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>		
45.583	2	.000	69.467 <sup>a</sup>	.423	.563	95% C.I for odds ratio (Exp (B))	
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>Df</b>	<b>Sig</b>	<b>Exp (B)</b>	<b>Lower</b>	<b>Upper</b>
1) .323	.089	13.113	1	.000	1.381	1.160	1.645
2) .258	.100	6.640	1	.010	1.294	1.064	1.574
Const.-3.026	.678	19.904	1	.000	.048		

### 6.7.5 Predictors of anxiety for BW sample

Predictors of anxiety using HADS A $\geq 8$ in 166 BW patients (demographics and coping strategies)							
1) H/H 2) avoidance 3) constant							
Goodness of fit test			Model Summary				
Chi square	Df	Sig	Likelihood	C&S R <sup>2</sup>	Nag R <sup>2</sup>		
49.715	2	.000	167.495 <sup>a</sup>	.259	.355	95% C.I for odds ratio (Exp (B))	
B	S.E	Wald	Df	Sig	Exp (B)	Lower	Upper
1) .227	.053	17.998	1	.000	1.255	1.130	1.393
2) .336	.081	17.058	1	.000	1.400	1.193	1.642
Const. -5.512	.917	36.123	1	.000	.004		

### 6.7.6 Predictors of depression for one sample

Predictors of depression using HADS D $\geq 8$ in 274 patients							
1) H/H 2) Anx. Preoccupation 3) ethnicity 4) Constant							
Goodness of fit test			Model Summary				
Chi square	Df	Sig	Likelihood	C&S R <sup>2</sup>	Nag R <sup>2</sup>		
71.691	3	0.0001	223.784	.230	.349	95% C.I for odds ratio (Exp (B))	
B	S.E	Wald	Df	Sig	Exp (B)	Lower	Upper
1) .167	.049	11.697	1	.001	1.182	1.074	1.301
2) .136	.045	9.047	1	.003	1.146	1.049	1.252
3) -.636	.353	3.240	1	.072	.530	.265	1.058
Const. 6.371	.985	41.799	1	.000	.002		

### 6.7.7 Predictors of depression for BSA sample

Predictors of depression using HADSD $\geq 8$ in 85 BSA patients							
1) Anx Preocc. 2) H/H 3) avoidance							
Goodness of fit test			Model Summary				
Chi square	Df	Sig	Likelihood	C&S R <sup>2</sup>	Nag R <sup>2</sup>		
23.968	3	.000	85.141 <sup>a</sup>	.246	.340	95% C.I for odds ratio (Exp (B))	
B	S.E	Wald	Df	Sig	Exp (B)	Lower	Upper
1) .136	.075	3.332	1	.068	1.146	.990	1.326
2) .171	.076	5.097	1	.024	1.187	1.023	1.377
3) -.103	.102	1.024	1	.312	.902	.739	1.102
Const -5.869	1.494	15.430	1	.000	.003		

### 6.7.8 Predictors of depression for BW sample

<b>Predictors of Depression (HADSD <math>\geq</math>8) in 166 BW patients</b>							
1) H/H 2) Anx. Preoccupation 3) avoidance 4) constant							
<b>Goodness of fit test</b>			<b>Model Summary</b>				
<b>Chi square</b>	<b>Df</b>	<b>Sig</b>	<b>Likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>	95% C.I for odds ratio (Exp (B))	
59.555	3	.000	91.099	.301	.505		
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>Df</b>	<b>Sig</b>	<b>Exp (B)</b>	<b>Lower</b>	<b>Upper</b>
1) .225	.086	6.873	1	.009	1.252	1.058	1.482
2) .172	.081	4.476	1	.034	1.188	1.013	1.393
3) .454	.119	14.456	1	.000	1.575	1.246	1.990
Const-11.700	2.057	32.356	1	.000	.000		

### 6.7.9: Distress and need for help as predictors for depression as one sample

<b>Distress and need for help as predictors of depression (HADS D <math>\geq</math>8) among 263 patients</b>							
1) DT 2) Need for Help T 3) constant							
<b>Goodness of fit test</b>			<b>Model Summary</b>				
<b>Chi square</b>	<b>Df</b>	<b>Sig</b>	<b>Likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>	95% C.I for odds ratio (Exp (B))	
69.565	2	.000	210.446	.232	.355		
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>Df</b>	<b>Sig</b>	<b>Exp (B)</b>	<b>Lower</b>	<b>Upper</b>
1) .292	.068	18.598	1	.000	1.339	1.173	1.529
2) .171	.060	8.145	1	.004	1.187	1.055	1.335
Const. -3.379	.398	71.920	1	.000	.034		

### 6.8.1 Cancer beliefs for one sample

Statement	n=	disagree	%	no view	%	agree	%
Cancer is curable	279	15	5.4	32	11.5	232	83.2
Cancer, with spread throughout the body, is incurable	279	40	14.3	73	26.2	166	59.5
Early cancer, in one part of the body, is often curable	279	3	1.1	14	5	262	93.9
Treatment, especially surgery, can often cause cancer to spread	279	128	45.9	95	34.1	56	20.1
Alternative treatments are as effective as surgery, radiotherapy or chemotherapy	278	109	39.2	86	30.9	83	29.9
It is possible to find cancer at a very early stage using tests like cervical smears	279	2	0.7	29	10.4	248	88.9
The causes of cancer are unknown	278	82	29.5	58	20.9	138	49.6
The following are causes of cancer....							
Smoking	279	14	5	24	8.6	241	86.4
Diet	279	54	19.4	98	35.1	127	45.5
Being overweight	279	73	26.2	115	41.2	91	32.6
Lack of exercise	279	93	33.3	125	44.8	61	21.9
Pollution	279	25	9	78	28	176	63.1
Occupation	279	58	20.8	101	36.2	120	43
Stress	279	68	24.4	88	31.5	123	44.1
Injury	279	84	30.1	124	44.4	71	25.4
Cancer often runs in the family and is inherited	279	70	25.1	38	13.6	171	61.3
Cancer is contagious and can spread from person to person	279	253	90.7	22	7.9	4	1.4
People outside the family should not be told I have cancer	279	208	74.6	36	12.9	35	12.5
Cancer is due to fate (karma) and nothing can be done to prevent it	279	171	61.3	38	13.8	70	25.1
Cancer can be punishment from God/Allah	279	228	81.7	35	12.5	16	5.7
Cancer is punishment for wrongdoing	279	233	83.5	35	12.5	11	3.9
Cancer is caused by sin	279	235	84.2	32	11.5	12	4.3

**Table 6.8.2 An ethnic comparison of cancer beliefs**

<b>Statement</b>		<b>N=</b>	<b>disagree</b>	<b>%</b>	<b>no view</b>	<b>%</b>	<b>agree</b>	<b>%</b>	<b>X<sup>2</sup> for trend</b>
Cancer is curable	BSA	94	10	10.6	16	17	68	72.3	0.001
	BW	185	5	2.7	16	8.6	164	88.6	
Cancer ,with spread throughout the body is incurable	BSA	94	9	9.6	27	28.7	58	61.7	0.258
	BW	185	31	16.8	46	24.9	108	58.4	
Early cancer in one part of the body is often curable	BSA	94	2	2.1	6	6.4	86	91.5	0.354
	BW	185	1	0.5	8	4.3	176	95.1	
Treatment especially surgery can often cause cancer to spread	BSA	94	42	44.7	34	36.2	18	19.1	0.864
	BW	185	86	46.5	61	33	38	20.5	
Alternative treatments are as effective as surgery, radiotherapy or chemotherapy	BSA	94	21	22.3	37	39.4	36	38.3	0.0001
	BW	184	88	47.8	49	26.6	47	25.5	
It is possible to find cancer at a very early stage using tests like cervical smears	BSA	94	0	0	18	19.1	76	80.9	0.002
	BW	185	2	1.1	11	5.9	172	93	
The causes of cancer are unknown	BSA	93	17	18.3	24	25.8	52	55.9	0.013
	BW	185	65	35.1	34	18.4	86	46.5	
The following area causes of cancer									
Smoking	BSA	94	8	8.5	12	12.8	74	78.7	0.026
	BW	185	6	3.2	12	6.5	167	90.3	
Diet	BSA	94	25	26.6	30	31.9	39	41.5	0.092
	BW	185	29	15.7	68	36.8	88	47.6	
Being overweight	BSA	94	29	30.9	38	40.4	27	28.7	0.393
	BW	185	44	23.8	77	41.6	64	34.6	
lack of exercise	BSA	94	36	38.3	32	34	26	27.7	0.032
	BW	185	57	30.8	93	50.3	35	18.9	

Statement		N=	disagree	%	no view	%	agree	%	X <sup>2</sup> for trend
Pollution	BSA	94	11	11.7	30	31.9	53	56.4	
	BW	185	14	7.6	48	25.9	123	66.5	0.224
Occupation	BSA	94	24	25.5	35	37.2	35	37.2	
	BW	185	34	18.4	66	35.7	85	45.9	0.262
Stress	BSA	94	22	23.4	21	22.3	51	54.3	
	BW	185	46	24.9	67	36.2	72	38.9	0.028
Injury	BSA	94	30	31.9	38	40.4	26	27.7	
	BW	185	54	29.2	86	46.5	45	24.3	0.625
Cancer often runs in the family and is inherited	BSA	94	35	37.2	14	14.9	45	47.9	
	BW	185	35	18.9	24	13	126	68.1	0.002
Cancer is contagious and can spread from person to person	BSA	94	78	83	12	12.8	4	4.3	
	BW	185	175	94.6	10	5.4	0	0	0.001
People outside the family should not be told I have cancer	BSA	94	53	56.4	16	17	25	26.6	
	BW	185	155	83.8	20	10.8	10	5.4	0.0001
Cancer is due to fate (karma) and nothing can be done to prevent it	BSA	94	39	41.5	14	14.9	41	43.6	
	BW	185	132	71.4	23	13	29	15.7	0.0001
Cancer can be punishment from God/Allah	BSA	94	58	61.7	20	21.3	16	17	
	BW	185	170	91.9	15	8.1	0	0	0.0001
Cancer is punishment for wrongdoing	BSA	94	64	68.1	19	20.2	11	11.7	
	BW	185	169	91.4	16	8.6	0	0	0.0001
Cancer is caused by sin	BSA	94	65	69.1	18	19.1	11	11.7	
	BW	185	170	91.9	14	7.6	1	0.5	0.0001

**6.8.3: Associations between cancer beliefs and anxiety and depression via HADS A and D (selected results of statistical significance reported)**

HADS D		n=	disagree	%	No view	%	agree	%	X <sup>2</sup> for trend
<b>BSA</b>									
Cancer is due to fate (karma) and nothing can be done to prevent it	≤7	61	31	50.8	6	9.8	24	39.3	
	≥8	33	8	24.2	8	24.2	17	51.5	0.025
<b>BW</b>									
Early cancer in one part of the body is often curable	≤7	154	0	0	8	5.2	146	94.8	
	≥8	31	1	3.2	0	0	30	96.8	0.037
Cancer is caused by stress	≤7	154	41	26.6	61	39.6	52	33.8	
	≥8	31	5	16.1	6	19.4	20	64.5	0.006
Cancer is punishment from God	≤7	154	145	94.2	9	5.8	0	0	
	≥8	31	25	80.6	6	19.4	0	0	0.031
Cancer is punishment for wrongdoing	≤7	154	145	94.2	9	5.4	0	0	
	≥8	31	24	77.4	7	22.6	0	0	0.007
<b>HADS A</b>									
<b>BSA</b>									
Cancer is punishment for wrongdoing	≤7	43	32	74.4	10	23.3	1	2.3	
	≥8	51	32	62.7	9	17.6	10	19.6	0.034
<b>BW</b>									
Cancer is caused by stress	≤7	118	34	28.8	47	39.8	37	31.4	
	≥8	67	12	17.9	20	29.9	35	52.2	0.018
Cancer is due to fate (karma) and nothing can be done to prevent it	≤7	118	95	80.5	10	8.5	13	11	
	≥8	67	37	55.2	14	20.9	16	23.9	0.001
Cancer is punishment from God	≤7	118	113	95.8	5	4.2	0	0	
	≥8	67	57	85.1	10	14.9	0	0	0.023
Cancer is punishment for wrongdoing	≤7	118	113	95.8	5	4.2	0	0	
	≥8	67	56	83.6	11	16.4	0	0	0.01

#### 6.8.4 Cancer beliefs which predict anxiety and depression via logistic regression

<b>Predictors of Anxiety (HADS A <math>\geq</math> 8 )in a BSA sample of 60 patients (cancer beliefs)</b>								
1) Treatment especially surgery can often cause cancer to spread								
2) Cancer can be inherited								
<b>Goodness of fit test</b>			<b>Model Summary</b>					
<b>Chi square</b>	<b>df</b>	<b>Sig</b>	<b>likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>	<b>95% C.I. for EXP (B)</b>		
8.763	2	0.013	66.59	0.145	0.197			
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>df</b>	<b>sig</b>	<b>Exp(B)</b>	<b>Lower</b>	<b>Upper</b>	
1)	1.431	0.678	4.458	1	0.035	4.184	1.108	15.799
2)	1.096	0.594	3.399	1	0.065	2.992	0.933	9.592
<b>Predictors of Anxiety (HADS A <math>\geq</math> 8 )in a BW sample of 160 patients (cancer beliefs)</b>								
Cancer is caused by fate (karma) and there is nothing one can do to change it								
<b>Goodness of fit test</b>			<b>Model Summary</b>					
<b>Chi square</b>	<b>df</b>	<b>Sig</b>	<b>likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>	<b>95% C.I. for EXP (B)</b>		
7.514	1	0.006	196.507	0.046	0.063			
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>df</b>	<b>sig</b>	<b>Exp(B)</b>	<b>Lower</b>	<b>Upper</b>	
1.151	0.421	7.481	1	0.006	3.16	1.386	7.208	
<b>Predictors of Depression (HADS D <math>\geq</math> 8 )in a BSA sample of 60 patients</b>								
Treatment especially surgery can often cause cancer to spread								
<b>Goodness of fit test</b>			<b>Model Summary</b>					
<b>Chi square</b>	<b>df</b>	<b>Sig</b>	<b>likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>	<b>95% C.I. for EXP (B)</b>		
5.531	1	0.019	74.349	0.088	0.12			
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>df</b>	<b>sig</b>	<b>Exp(B)</b>	<b>Lower</b>	<b>Upper</b>	
1.514	0.704	4.627	1	0.031	4.545	1.144	18.06	

### 6.9.1: Ethnic Comparison of trust in the patient physician relationship

Trust statement		n	disagree	expected	%	no view	expected	%	agree	expected	%	X <sup>2</sup> for trend
Overall I am satisfied with the medical care I have received (global trust)	BSA	92	2	2.4	2.2	2	0.7	2.2	88	88.9	95.7	0.136
	BW	179	5	4.6	2.8	0	1.3	0	174	173.1	97.2	
I completely trust my hospital doctor (global trust)	BSA	92	2	2	2.2	4	3.1	4.3	86	86.9	93.5	0.8
	BW	178	4	4	2.2	5	5.9	2.8	169	168.1	94.9	
I completely trust my general practitioner (GP)	BSA	91	12	7.1	13.2	8	10.9	8.8	71	73	78	0.044
	BW	177	9	13.9	5.1	24	21.1	13.6	144	142	81.4	
I am concerned that the NHS will NOT give me the best possible care	BSA	90	62	72.2	68.9	16	9.4	17.8	12	8.4	13.3	0.003
	BW	178	153	142.8	86	12	18.6	6.7	13	16.6	7.3	
The hospital doctors will always give me the best treatment (competence)	BSA	92	1	1	1.1	2	3.1	2.2	89	87.9	96.7	0.747
	BW	178	2	2	1.1	7	5.9	3.9	169	170.1	94.9	
The hospital doctors are very competent and careful (competence)	BSA	92	2	1.4	2.2	2	2.7	2.2	88	87.9	95.7	0.689
	BW	178	2	2.6	1.1	6	5.3	3.4	170	170.1	95.5	
The hospital doctors always explain everything carefully (competence)	BSA	91	4	4.1	4.4	3	2.4	3.3	84	84.6	92.3	0.877
	BW	178	8	7.9	4.5	4	4.6	2.2	166	165.4	93.3	
The hospital doctors always listen to my concerns (fidelity)	BSA	91	2	2.7	2.2	6	3.4	6.6	83	84.9	91.2	0.182
	BW	178	6	5.3	3.4	4	6.6	2.2	168	166.1	94.4	
The hospital doctors do their best to help me (fidelity/competence)	BSA	91	2	0.7	2.2	4	2	4.4	85	88.3	93.4	0.03
	BW	178	0	1.3	0	2	4	1.1	176	172.7	98.9	
The hospital doctors are totally honest with me (honesty)	BSA	91	1	1.7	1.1	7	7.1	7.7	83	82.2	91.2	0.798
	BW	177	4	3.3	2.3	14	13.9	7.9	159	159.8	89.8	

<b>Trust statement</b>		<b>n</b>	<b>disagree</b>	<b>expected</b>	<b>%</b>	<b>no view</b>	<b>expected</b>	<b>%</b>	<b>agree</b>	<b>expected</b>	<b>%</b>	<b>X<sup>2</sup> for trend</b>
The hospital doctors will not give my medical history to others without my permission (confidentiality)	BSA	91	2	1.7	2.2	4	7.1	4.4	85	82.2	93.4	
	BW	178	3	3.3	1.7	17	13.9	9.6	158	160	88.8	0.32

### 6.9.2: Ethnic comparison of preferences for the therapeutic relationship

Trust statement		n	Disagree	Expected	%	No View	Expected	%	Agree	Expected	%	X <sup>2</sup> for trend
I prefer to see a doctor who is the same sex (gender) as me	BSA	90	51	49	56.7	21	32.2	23.3	18	8.7	20	
	BW	178	95	97	53.4	75	63.8	42.1	8	17.3	4.5	0.0001
I prefer my doctors to decide what is best for me	BSA	89	13	19.9	14.6	15	9.1	16.9	61	60	68.5	
	BW	175	46	39.1	26.3	12	17.9	6.9	117	118	66.9	0.009
I prefer my doctors to involve me in all important decisions	BSA	91	2	1.4	2.2	1	2	1.1	88	87.6	96.7	
	BW	177	2	2.6	1.1	5	4	2.8	170	170.4	96	0.532
I would prefer to hear sensitive information from my general practitioner (GP)	BSA	91	27	30.2	29.7	19	35.3	20.9	45	25.5	49.5	
	BW	177	62	58.8	35	85	68.7	48	30	49.5	16.9	0.0001
I would prefer to hear sensitive information from someone of a similar religion or background to me	BSA	91	39	47	42.9	28	33.2	30.8	24	10.8	26.4	
	BW	178	100	92	56.2	70	64.8	39.3	8	21.2	4.5	0.0001

### 6.9.3 Predictors of trust using logistic regression

<b>Model A: Including 'Confidentiality'</b>							
1) My doctors will not give my medical history to others without my permission							
<b>Goodness of fit test</b>			<b>Model Summary</b>				
<b>Chi square</b>	<b>df</b>	<b>sig</b>	<b>likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>	<b>95% C.I. for EXP (B)</b>	
66.840	4	0.0005	292.119	.220	.299		
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>Df</b>	<b>sig</b>	<b>Exp (B)</b>	<b>Lower</b>	<b>Upper</b>
-1.018	.291	12.230	1	0.0005	.361	.204	.639
<b>Model B: Excluding 'Confidentiality'</b>							
1) I cannot really see the point in having treatment (CIDQ)							
2) How much does your illness affect your life? (BIPQ)							
3) How well do you understand your illness? (BIPQ)							
<b>Goodness of fit test</b>			<b>Model Summary</b>				
<b>Chi square</b>	<b>df</b>	<b>sig</b>	<b>likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>	<b>95% C.I. for EXP (B)</b>	
29.800	3	0.0005	331.943	.104	.142		
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>Df</b>	<b>sig</b>	<b>Exp (B)</b>	<b>Lower</b>	<b>Upper</b>
1) -3.92	.154	6.460	1	0.011	.676	.500	.914
2) -.162	.046	12.527	1	0.0005	.850	.777	.930
3) .131	.051	6.514	1	0.011	1.140	1.031	1.261

6.9.4: **Associations between Trust indicators and anxiety and depression via HADS A and D** (selected results of statistical significance reported)

HADS D		n=	disagree	%	No view	%	agree	%	X <sup>2</sup> for trend
<b>BW</b>									
The hospital doctors will always give the best treatment	≤7	178	1	0.7	3	2.0	143	97.3	
	≥8	31	1	3.2	4	12.9	26	83.9	0.008
The hospital doctors do their best to help me stress	≤7	147	0	0	0	0	147	100	
	≥8	31	2	6.5	0	0	29	93.5	0.031
I prefer to see a doctor of the same sex as me	≤7	147	85	57.8	57	38.8	5	3.4	
	≥8	31	10	32.3	18	58.1	3	9.7	0.022
I am concerned that the NHS will not give me the best care	≤7	147	131	89.1	8	5.4	8	5.4	
	≥8	31	22	71	4	12.9	5	16.1	0.029
<b>HADS A</b>									
<b>BSA</b>									
I prefer to see a doctor of the same sex as me	≤7	40	28	70	10	25	2	5.0	
	≥8	50	23	46	11	22	16	32	0.005
<b>BW</b>									
I prefer to hear sensitive information from my GP	≤7	112	39	34.8	60	53.6	13	11.6	
	≥8	65	23	35.4	25	38.5	17	26.2	0.029
I am concerned that the NHW will not give me the best care	≤7	113	106	93.8	3	2.7	4	3.5	
	≥8	65	47	72.3	9	13.8	9	13.8	0.0005

### 6.10.1 Distribution of data for indicators of BIPQ

Tests for distribution		Ethnic group	Skewness	Kolmogorov-Smirnov		
				Statistic	Df	2 tailed Sig.
Indicators						
How much does your illness affect your life?	Present.	BSA	-.314 (.249)	.155	94	0.0001
		BW	.175 (.179)	.112	185	0.0001
	3 months	BSA	-.510(.319)	.162	56	0.001
		BW	.168(.203)	.118	143	0.0001
	9 months	BSA	-.210(.427)	.152	30	0.076
		BW	.421(.221)	.114	119	0.001
How much are you worried your illness will progress?	Present.	BSA	-.383 (.249)	.119	94	0.002
		BW	.148 (.179)	.120	185	0.0001
	3 months	BSA	-.384(.249)	.119	94	0.002
		BW	.148(.179)	.120	184	0.0001
	9 months	BSA	-.103(.427)	.131	30	.200
		BW	.274(.222)	.127	119	0.001
How much control do you feel you have over your illness?	Present.	BSA	.169(.250)	.091	93	.057
		BW	.395(.179)	.133	185	0.0001
	3 months	BSA	-.152(.319)	.098	56	0.200
		BW	.249(.203)	.110	143	0.0001
	9 months	BSA	-.126(.427)	.188	30	0.008
		BW	.158(.220)	.118	121	0.0001
How much do you think your treatment can help your illness?	Present.	BSA	-1.375(.251)	.242	92	0.0001
		BW	-1.786(.180)	.220	183	0.0001
	3 months	BSA	-1.418(.322)	.264	55	0.0001
		BW	-.842(.203)	.172	143	0.0001
	9 months	BSA	-1.514(.427)	.277	30	0.0001
		BW	-1.683(.222)	.219	119	0.0001
How much do you experience symptoms from your illness?	Present	BSA	-.089(.249)	.118	94	0.003
		BW	.649(.178)	.169	186	0.0001
	3 months	BSA	-.307(.316)	.144	57	0.005
		BW	.318(.203)	.096	142	0.003
	9 months	BSA	.104(.434)	.166	29	.040
		BW	.787(.221)	.168	120	0.0001
How concerned are you about your illness?	Present.	BSA	-.955(.249)	.224	94	0.0001
		BW	-.701(.179)	.159	185	0.0001
	3 months	BSA	-.864(.322)	.175	55	0.0001
		BW	-.327(.203)	.146	143	0.0001
	9 months	BSA	-.630(.427)	.215	30	0.001
		BW	.029 (.221)	.101	120	0.004

Tests for distribution		Ethnic group	Skewness	Kolmogorov-Smirnov		
				Statistic	Df	2 tailed Sig.
Indicators						
How well do you understand your illness?	Present.	BSA BW	-.931(.250) -.989(.179)	.147 .182	93 184	0.0001 0.0001
	3 months	BSA BW	-1.350(.319) -1.271(.203)	.222 .167	56 143	0.0001 0.0001
	9 months	BSA BW	-1.466(.427) 2.375(.222)	.184 .200	30 119	0.011 .0001
How much does your illness affect you emotionally?	Present.	BSA BW	-.588(.249) .101(.179)	.160 .127	94 185	0.0001 0.0001
	3 months	BSA BW	-.582(.322) .229(.203)	.197 .139	55 143	0.0001 0.0001
	9 months	BSA BW	-.281(.427) .457(.221)	.106 .136	30 120	.200 0.0001

**6.10.2: Longitudinal ethnic comparison of cognitive and emotional representations of cancer (Mann Whitney U Tests)**

			n=	MRS	Md. (IQR)	U	Z	Sig
How much does your illness affect your life								
	Pres.	BSA	94	168.47	7(4:9)	6019	-4.224	0.0005
		BW	185	125.54	5(2:7)			
	3m	BSA	56	121.57	7(4.5:8.5)	2796	-3.325	0.001
		BW	143	91.55	5(2:7)			
	9m	BSA	30	87.78	5(3:7)	1431.5	-1.744	0.081
		BW	119	72.43	3(1.5:5)			
How much are you worried your illness will progress								
	Pres.	BSA	94	156.98	6(3:9)	7098.5	-2.521	0.012
		BW	185	131.37	5(3:7)			
	3m	BSA	56	114.76	6(4:8)	3177.5	-2.275	0.023
		BW	144	94.22	4(2:6.5)			
	9m	BSA	30	82.38	5(2:7)	1593.5	-.976	0.329
		BW	119	73.78	4(1:7)			
How much control do you feel you have over your illness								
	Pres.	BSA	93	149.19	6(3:9)	7831	-1.366	0.172
		BW	185	135.33	5(3:7)			
	3m	BSA	56	116.86	5(3:7.5)	3060	-2.602	0.009
		BW	143	93.40	4(1:6)			
	9m	BSA	30	89.33	5(4:8)	1385	-1.968	0.049
		BW	121	72.04	5(2:7)			
How much do you think your treatment can help your illness								
	Pres.	BSA	92	120.05	4(2:6)	6794	-2.925	0.003
		BW	183	149.28	4(1.5:6)			
	3m	BSA	55	104.14	8(8:9)	3677.5	-.720	0.471
		BW	143	97.72	8(6:10)			
	9m	BSA	30	68.17	8(7:10)	1580	-1.003	0.316
		BW	119	76.72	9(7:10)			
How much do you experience symptoms from your illness								
	Pres.	BSA	94	177.1	5(2:8)	5114	-5.624	0.0005
		BW	186	120.29	2(1:5)			
	3m	BSA	57	121.15	6(3:8)	2819.5	-3.262	0.001
		BW	142	91.72	4(2:5.5)			
	9m	BSA	29	86.53	4(1:6)	1469	-1.569	0.117
		BW	120	72.72	2(1:5)			
How concerned are you about your illness								
	Pres.	BSA	94	149.12	8(5:10)	7837.5	-1.366	0.172
		BW	185	135.36	7.5(5:10)			
	3m	BSA	55	112.06	8(5:9)	3241.5	-1.929	0.054
		BW	143	94.67	7(3.5:8)			
	9m	BSA	30	87.47	8(6:9)	1441	-1.696	0.090
		BW	120	72.51	9(7:10)			
How well do you feel you understand your illness								
	Pres.	BSA	93	135.6	7(6:9)	8281.5	-0.68	0.511
		BW	184	142.24	8(6:9)			
	3m	BSA	56	105.82	9(7:10)	3678	-.910	0.363
		BW	143	97.72	8(7:10)			
	9m	BSA	30	63.88	8(6:9)	1451.5	-1.685	0.092
		BW	119	78.40	9(7:10)			

			<b>n=</b>	<b>MRS</b>	<b>Md. (IQR)</b>	<b>U</b>	<b>Z</b>	<b>Sig</b>
How much does your illness affect you emotionally								
	Pres.	BSA BW	94 185	161.12 129.27	7(4:9) 5(2:7)	6710	-3.132	0.002
	3m	BSA BW	55 143	123.07 90.43	7(3.5:9) 4(2:7)	2636	-3.608	0.0001
	9m	BSA BW	30 120	95.48 70.50	6(3:8) 3(1:6)	1200.5	-2.831	0.005

#### 6.10.4 Longitudinal trends in representations of cancer within ethnic group

Friedman Tests			Interview	Mean Rank	Chi <sup>2</sup> (DF 2)	Sig
How much does your illness affect your life?	BSA	29	1	2.10	2.902	.234
			2	2.14		
			3	1.76		
	BW	108	1	2.12	9.534	0.009
			2	2.10		
			3	1.78		
How much are you worried your illness will progress?	BSA	29	1	2.02	.646	.724
			2	2.09		
			3	1.90		
	BW	109	1	2.27	14.804	0.001
			2	1.86		
			3	1.87		
How much control do you feel you have over your illness?	BSA	29	1	1.86	1.768	.413
			2	1.97		
			3	2.17		
	BW	109	1	1.86	5.626	0.060
			2	2.01		
			3	2.13		
How much do you think your treatment can help your illness?	BSA	28	1	1.93	1.727	.422
			2	2.18		
			3	1.89		
	BW	107	1	2.14	5.273	0.072
			2	1.91		
			3	1.94		
How much do you experience symptoms from your illness?	BSA	28	1	2.0	4.971	0.083
			2	2.29		
			3	1.71		
	BW	109	1	1.79	22.264	0.0005
			2	2.32		
			3	1.89		
How concerned are you about your illness?	BSA	28	1	2.11	.800	.670
			2	2.0		
			3	1.89		
	BW	109	1	2.40	45.553	0.0005
			2	2.0		
			3	1.6		
How well do you feel you understand your illness?	BSA	29	1	1.86	1.553	.460
			2	2.16		
			3	1.98		
	BW	108	1	1.91	3.252	.197
			2	1.98		
			3	2.11		
How much does your illness affect you emotionally?	BSA	28	1	1.88	1.210	.546
			2	2.12		
			3	2.0		
	BW	109	1	2.34	28.373	0.0005
			2	1.92		
			3	1.73		

**6.11.1: Longitudinal ethnic comparison of causes of distress**

<b>Problem</b>			<b>n=</b>	<b>No</b>	<b>%</b>	<b>Yes</b>	<b>%</b>	<b>X<sup>2</sup></b>
Housing	Baseline	BSA	84	66	79	18	21.4	
		BW	181	174	96	7	3.9	0.0001
	3 months	BSA	53	45	84.9	8	15.1	
		BW	141	139	98.6	2	1.4	0.001
	9 months	BSA	31	26	83.9	5	16.1	
		BW	121	119	98.3	2	1.7	FET 0.004
Insurance	Baseline	BSA	85	72	85	13	15.3	
		BW	179	168	94	11	6.1	0.029
	3 months	BSA	53	45	84.9	8	15.1	
		BW	143	143	100	0	0	0.0001
	9 months	BSA	31	27	87.1	4	12.9	
		BW	120	115	95.8	5	4.2	FET 0.086
Work/School	Baseline	BSA	86	73	85	13	15.1	
		BW	179	158	88	21	11.7	0.565
	3 months	BSA	54	45	83.3	9	16.7	
		BW	142	125	88	17	12	0.529
	9 months	BSA	30	25	83.3	5	16.7	
		BW	120	105	87.5	15	12.5	0.764
Transportation	Baseline	BSA	84	70	83	14	16.7	
		BW	180	154	86	26	14.4	0.776
	3 months	BSA	54	43	79.6	11	20.4	
		BW	141	131	92.9	10	7.1	0.016
	9 months	BSA	30	26	86.7	4	13.3	
		BW	119	112	94.1	7	5.9	FET 0.233
Childcare	Baseline	BSA	84	73	87	11	13.1	
		BW	179	175	98	4	2.2	FET 0.001
	3 months	BSA	54	51	94.4	3	5.6	
		BW	143	141	98.6	2	1.4	FET 0.128
	9 months	BSA	29	26	89.7	3	10.3	
		BW	120	119	99.2	1	0.8	FET 0.023
Dealing with partner	Baseline	BSA	86	75	87	11	12.8	
		BW	178	157	88	21	11.8	0.976
	3 months	BSA	55	48	87.3	7	12.7	
		BW	142	126	88.7	16	11.3	0.969
	9 months	BSA	31	25	80.6	6	19.4	
		BW	118	106	89.8	12	10.2	.277
Dealing with children	Baseline	BSA	86	73	85	13	15.1	
		BW	179	157	88	22	12.3	0.658
	3 months	BSA	54	45	83.3	9	16.7	
		BW	139	122	87.8	17	12.2	0.565
	9 months	BSA	31	25	80.6	6	19.4	
		BW	118	112	94.9	6	5.1	0.026



<b>Problem</b>			<b>n=</b>	<b>No</b>	<b>%</b>	<b>Yes</b>	<b>%</b>	<b>X<sup>2</sup></b>
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
Fatigue	Baseline	BSA	86	37	43	49	57	
		BW	176	92	52	84	47.7	0.202
	3 months	BSA	55	20	35.4	35	63.6	
		BW	141	46	32.6	95	67.4	0.742
	9 months	BSA	30	12	40	18	60	
		BW	121	60	49.6	61	50.4	0.461
Sleep	Baseline	BSA	87	40	46	47	54	
		BW	180	91	51	89	49.4	0.568
	3 months	BSA	56	21	37.5	35	62.5	
		BW	140	65	46.4	75	53.6	0.328
	9 months	BSA	31	10	32.3	21	67.7	
		BW	121	57	47.1	64	52.9	0.199
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
Breathing	Baseline	BSA	86	65	76	21	24.4	
		BW	178	154	87	24	13.5	0.041
	3 months	BSA	54	43	79.6	11	20.4	
		BW	139	116	83.5	23	16.5	0.678
	9 months	BSA	31	26	83.9	5	16.1	
		BW	119	102	85.7	17	14.3	1.0
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
Eating	Baseline	BSA	86	56	66	29	33.7	
		BW	178	146	82	32	18	0.007
	3 months	BSA	55	37	67.3	18	32.7	
		BW	142	100	70.4	42	29.6	0.796
	9 months	BSA	31	25	80.6	6	19.4	
		BW	120	105	97.5	15	12.5	0.489

<b>Problem</b>			<b>n=</b>	<b>No</b>	<b>%</b>	<b>Yes</b>	<b>%</b>	<b>X<sup>2</sup></b>
indigestion	Baseline	BSA	87	61	70	26	29.9	
		BW	179	153	86	26	14.5	0.005
	3 months	BSA	55	34	61.8	21	38.2	
		BW	139	98	70.5	41	29.5	0.318
	9 months	BSA	31	20	64.5	11	35.5	
		BW	121	100	82.6	21	17.4	0.050
Constipation	Baseline	BSA	85	54	64	31	36.5	
		BW	177	144	81	33	18.6	0.003
	3 months	BSA	55	40	72.7	15	27.3	
		BW	139	101	72.7	38	27.3	1.0
	9 months	BSA	31	25	80.6	6	19.4	
		BW	121	97	80.2	24	19.8	1.0
Diarrhoea	Baseline	BSA	85	66	78	19	22.4	
		BW	177	158	89	19	10.7	0.021
	3 months	BSA	55	41	74.5	14	25.5	
		BW	141	102	72.3	39	27.7	0.894
	9 months	BSA	30	25	83.3	5	16.7	
		BW	120	103	85.8	17	14.2	0.954
Urination	Baseline	BSA	86	64	74	22	25.6	
		BW	177	157	89	20	11.3	0.005
	3 months	BSA	54	41	75.9	13	24.1	
		BW	139	110	79.1	29	20.9	0.771
	9 months	BSA	31	25	80.6	6	19.4	
		BW	119	107	89.9	12	10.1	0.269
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
Nose	Baseline	BSA	87	67	77	20	23	
		BW	175	160	91	15	8.6	0.002
	3 months	BSA	54	34	63	20	37	
		BW	139	107	77	32	23	0.074
	9 months	BSA	30	31	70	9	30	
		BW	121	105	86.8	16	13.2	0.053
Tingling sensation	Baseline	BSA	87	55	63	32	36.8	
		BW	175	154	88	21	12	0.0001
	3 months	BSA	54	28	51.9	26	48.1	
		BW	141	97	68	44	31.2	0.041
	9 months	BSA	31	23	74.2	8	25.8	
		BW	121	76	62.8	45	37.2	0.329

<b>Problem</b>			<b>n=</b>	<b>No</b>	<b>%</b>	<b>Yes</b>	<b>%</b>	<b>X<sup>2</sup></b>
Swollen Feeling	Baseline	BSA	87	58	67	29	33.3	
		BW	176	159	90	17	9.7	0.0001
	3 months	BSA	56	35	62.5	21	37.5	
		BW	138	109	79	29	21	0.028
	9 months	BSA	31	20	64.5	11	35.5	
		BW	121	99	81.8	22	18.2	0.066
Sexual	Baseline	BSA	84	76	91	8	9.5	
		BW	173	157	91	16	9.2	1.0
	3 months	BSA	50	42	84	8	16	
		BW	140	122	87.1	18	12.9	0.752
	9 months	BSA	31	29	93.5	2	6.5	
		BW	121	109	90.1	12	9.9	FET 0.736

### 6.11.2 Longitudinal causes of distress in a single sample

<b>Cause of distress (DT)</b>		<b>sample</b>	<b>No</b>	<b>%</b>	<b>Yes</b>	<b>%</b>
Worry	Present.	268	108	40.3	160	59.7
	3 m	194	103	53.1	91	46.9
	9 m	150	88	58.7	62	41.3
Fears	Present.	264	115	43.6	149	56.4
	3 m	194	112	57.7	81	41.8
	9 m	149	88	59.1	61	40.9
Nervousness	Present.	265	127	47.9	138	52.1
	3 m	194	133	68.6	61	31.4
	9 m	149	100	67.1	49	32.9
Sleep	Present.	267	131	49.1	136	50.9
	3 m	196	86	43.9	110	56.1
	9 m	152	67	44.1	85	55.9
Fatigue	Present.	262	129	49.2	133	50.8
	3 m	196	66	33.7	130	66.3
	9 m	151	72	47.7	79	52.3
Pain	Present.	268	158	59	110	41
	3 m	194	106	54.6	88	45.4
	9 m	152	92	60.5	60	39.5
Sadness	Present.	262	152	60	70	40
	3 m	193	118	61.1	75	38.9
	9 m	150	100	66.7	50	33.3
Depression	Present.	260	190	73.1	70	26.9
	3 m	194	140	72.2	54	27.8
	9 m	148	113	76.4	35	23.6
Skin	Present.	263	198	75.3	65	24.7
	3 m	198	122	61.6	76	38.4
	9 m	152	102	67.1	50	32.9

<b>Cause of distress (DT)</b>		<b>sample</b>	<b>No</b>	<b>%</b>	<b>Yes</b>	<b>%</b>
Nausea	Present.	261	197	75.5	64	24.5
	3 m	194	120	61.9	74	38.1
	9 m	150	126	84	24	16
Constipation	Present.	262	198	75.6	64	24.4
	3 m	194	141	72.7	53	27.3
	9 m	152	122	80.3	30	19.7
Eating	Present.	264	203	76.9	61	23.1
	3 m	197	137	69.5	60	30.5
	9 m	151	130	86.1	21	13.9
Tingling sensation	Present.	262	209	79.8	53	20.2
	3 m	195	125	64.1	70	35.9
	9 m	152	99	65.1	53	34.9
Indigestion	Present.	266	214	80.5	52	19.5
	3 m	194	132	68	62	32
	9 m	152	120	78.9	32	21.1
Getting around	Present.	262	214	81.7	48	18.3
	3 m	195	145	74.4	50	25.6
	9 m	151	118	78.1	33	21.9
Swollen Feeling	Present.	263	217	82.5	46	17.5
	3 m	194	144	74.2	50	25.8
	9 m	152	119	78.3	33	21.7
Breathing	Present.	264	219	83	45	17
	3 m	193	159	82.4	34	17.6
	9 m	150	128	85.3	22	14.7
Urination	Present.	263	221	84	42	16
	3 m	193	151	78.2	42	21.8
	9 m	150	132	88	18	12
Relating to God	Present.	260	220	84.6	40	15.4
	3 m	193	171	88.6	22	11.4
	9 m	145	132	91	13	9
Transportation	Present.	264	224	84.8	40	15.2
	3 m	195	174	89.2	21	10.8
	9 m	149	138	92.6	11	7.4
Diarrhoea	Present.	262	224	85.5	38	14.5
	3 m	196	143	73	53	27
	9 m	150	128	85.3	22	14.7
Nose	Present.	262	227	86.6	35	13.4
	3 m	193	141	73.1	52	26.9
	9 m	151	126	83.4	25	16.6

<b>Cause of distress (DT)</b>		<b>sample</b>	<b>No</b>	<b>%</b>	<b>Yes</b>	<b>%</b>
Bathing and dressing	Present.	264	229	86.7	35	13.3
	3 m	195	171	87.7	24	12.3
	9 m	151	129	85.4	22	14.6
Dealing with children	Present.	265	230	86.8	35	13.2
	3 m	193	167	86.5	26	13.5
	9 m	149	137	91.9	12	8.1
Work/School	Present.	265	231	87.2	34	12.8
	3 m	196	170	86.7	26	13.3
	9 m	150	130	86.7	20	13.3
Mouth sores	Present.	266	233	87.6	33	12.4
	3 m	195	151	77.4	44	22.6
	9 m	152	134	88.2	18	11.8
Dealing with partner	Present.	264	232	87.9	32	12.1
	3 m	197	174	88.3	23	11.7
	9 m	149	131	87.9	18	12.1
Housing	Present.	265	240	90.6	25	9.4
	3 m	194	188	95.9	8	4.1
	9 m	152	145	95.4	7	4.6
Sexual	Present.	257	233	90.7	24	9.3
	3 m	190	164	86.3	26	13.7
	9 m	152	138	90.8	14	9.2
Insurance	Present.	264	240	90.9	24	9.1
	3 m	196	188	95.9	8	4.1
	9 m	151	142	94	9	6
Fevers	Present.	264	241	91.3	23	8.7
	3 m	193	169	87.6	24	12.4
	9 m	150	134	89.3	16	10.7
Loss of faith	Present.	259	241	93.1	18	6.9
	3 m	194	181	93.3	13	6.7
	9 m	143	135	94.4	8	5.6
Childcare	Present.	263	248	94.3	15	5.7
	3 m	197	192	97.5	5	2.5
	9 m	149	145	97.3	4	2.7

**6.1.13 Predictors of distress for a single sample and for ethnic groups using logistic regression**

<b>Demographic Predictors of Distress for 264 patients</b>							
1) Time since diagnosis 2) Age 3) Gender , Constant							
<b>Goodness of fit test</b>			<b>Model Summary</b>				
<b>Chi square</b>	<b>Df</b>	<b>Sig</b>	<b>Likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>	95% C.I for odds ratio (Exp (B))	
20.905	3	.0005	343.241 <sup>a</sup>	.076	.102		
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>Df</b>	<b>Sig</b>	<b>Exp (B)</b>	<b>Lower</b>	<b>Upper</b>
1) .153	.047	10.817	1	.001	1.165	1.064	1.277
2) -.025	.013	3.797	1	.051	.975	.951	1.000
3) .612	.289	4.492	1	.034	1.845	1.047	3.250
-.210	.895	.055	1	.815	.811		

<b>Psychosocial Predictors of Distress Among 243 Patients</b>							
1) Sadness 2) Nervousness 3) Depression 4) Relating to God 5) constant							
<b>Goodness of fit test</b>			<b>Model Summary</b>				
<b>Chi<sup>2</sup></b>	<b>Df</b>	<b>Sig</b>	<b>Likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>	95% C.I for odds ratio (Exp (B))	
101.984	4	0.0005	232.705	.343	.458		
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>Df</b>	<b>Sig</b>	<b>Exp (B)</b>	<b>Lower</b>	<b>Upper</b>
1) 1.063	.347	9.371	1	.002	2.895	1.466	5.718
2) 1.131	.338	11.229	1	.001	3.100	1.599	6.009
3) 1.614	.434	13.805	1	.000	5.024	2.144	11.773
4) 1.723	.504	11.686	1	.001	5.603	2.086	15.052
-1.848	.268	47.620	1	.000	.158		

<b>Psychological Predictors of Distress Among 170 BW Patients</b>							
1) Depression (HADS D) 2) Fears 3) Nervousness 4) Sadness Constant							
<b>Goodness of fit test</b>			<b>Model Summary</b>				
<b>Chi<sup>2</sup></b>	<b>Df</b>	<b>Sig</b>	<b>Likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>		
69.844	4	0.0005	154.308	.337	.460	95% C.I for odds ratio (Exp (B))	
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>Df</b>	<b>Sig</b>	<b>Exp (B)</b>	<b>Lower</b>	<b>Upper</b>
1) 1.971	.519	14.398	1	.000	7.177	2.593	19.864
2) 1.198	.456	6.911	1	.009	3.312	1.356	8.089
3) .891	.422	4.455	1	.035	2.437	1.066	5.575
4) .823	.421	3.823	1	.051	2.278	.998	5.198
-7.431	1.101	45.574	1	.000	.001		

<b>Psychological Predictors of Distress Among 76 BSA Patients</b>							
1) Sadness 2) Relating to God, Constant							
<b>Goodness of fit test</b>			<b>Model Summary</b>				
<b>Chi<sup>2</sup></b>	<b>Df</b>	<b>Sig</b>	<b>Likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>		
33.042	2	0.0005	66.991	.353	.482	95% C.I for odds ratio (Exp (B))	
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>Df</b>	<b>Sig</b>	<b>Exp (B)</b>	<b>Lower</b>	<b>Upper</b>
1) 2.771	.714	15.059	1	.0005	15.968	3.940	64.714
2) 1.971	.749	6.929	1	.008	7.180	1.654	31.159
3) -5.692	1.372	17.198	1	.0005	.003		

<b>Symptoms which predicted distress in 253 patients</b>							
1) Mouth sores 2) Sleep 3) Getting around							
<b>Goodness of fit test</b>			<b>Model Summary</b>				
<b>Chi square</b>	<b>Df</b>	<b>Sig</b>	<b>Likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>		
37.161	3	0.0005	311.478	.137	.183	95% C.I for odds ratio (Exp (B))	
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>Df</b>	<b>Sig</b>	<b>Exp (B)</b>	<b>Lower</b>	<b>Upper</b>
1) 1.879	.573	10.753	1	.001	6.550	2.130	20.143
2) .763	.273	7.782	1	.005	2.144	1.255	3.664
3) .930	.372	6.264	1	.012	2.535	1.224	5.253
-.190	.205	19.746	1	.000	.403		

<b>Predictors of Distress for 171 BW patients</b>							
1) Dealing with partner 2) fatigue 3) sleep 4) mouth sores , constant							
<b>Goodness of fit test</b>			<b>Model Summary</b>				
<b>Chi square</b>	<b>Df</b>	<b>Sig</b>	<b>Likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>	95% C.I for odds ratio (Exp (B))	
20.547	4	0.0005	204.526	.113	.155		
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>Df</b>	<b>Sig</b>	<b>Exp (B)</b>	<b>Lower</b>	<b>Upper</b>
1) .895	.547	2.670	1	.102	2.446	.837	7.153
2) .654	.353	3.440	1	.064	1.924	.964	3.841
3) .720	.348	4.286	1	.038	2.057	1.039	4.073
4) 1.458	.846	2.972	1	.085	4.298	.819	22.559
-5.142	1.195	18.505	1	.000	.006		

<b>Predictors of Distress in 79 BSA Patients</b>							
1) Getting around 2) Mouth sores Constant							
<b>Goodness of fit test</b>			<b>Model Summary</b>				
<b>Chi square</b>	<b>Df</b>	<b>Sig</b>	<b>Likelihood</b>	<b>C&amp;S R<sup>2</sup></b>	<b>Nag R<sup>2</sup></b>	95% C.I for odds ratio (Exp (B))	
20.469	2	0.0005	83.399	.228	.312		
<b>B</b>	<b>S.E</b>	<b>Wald</b>	<b>Df</b>	<b>Sig</b>	<b>Exp (B)</b>	<b>Lower</b>	<b>Upper</b>
1) 2.426	.800	9.199	1	.002	11.316	2.359	54.278
2) 1.856	.825	5.056	1	.025	6.399	1.269	32.263
-4.567.	1.361	11.259	1	.001	.010		

## **Appendix 2: Questionnaires in English and Gujarati**

(Original is on three pages)

Patient Study Number

Please help us to understand your knowledge of the causes of cancer and results of treatment

**Cancer Beliefs**

	Agree Strongly	Agree	No View	Disagree	Strongly Disagree
Cancer is curable					
Cancer, with spread throughout the body, is incurable					
Early cancer, in one part of the body, is often curable					
Treatment, especially surgery, can often cause the cancer to spread					
Alternative treatments are as effective as surgery, radiotherapy or chemotherapy					
It is possible to find cancer at a very early stage by screening using tests like cervical smears					
The causes of cancer are unknown					

**Causes of Cancer**

The following are causes of cancer	Agree Strongly	Agree	No View	Disagree	Strongly Disagree
Smoking					
Diet					
Being overweight					
Lack of exercise					
Pollution					
Occupation					
Stress					
Injury					

Patient Study Number

Agree Strongly    Agree    No View    Disagree    Strongly Disagree

Cancer often runs in the family and is inherited					
Cancer is contagious and can spread from person to person					
People outside the family should not be told I have cancer					
Cancer is due to fate (karma) and nothing can be done to prevent it					
Cancer can be a punishment from God/Allah					
Cancer is punishment for wrong doing					
Cancer is caused by sin					

**Trust in Doctors**

Please rate your confidence in the care from your hospital and hospital staff in relation to your current illness. Your answers will be treated anonymously & will not cause any problems with your medical care.

	Agree Strongly	Agree	No View	Disagree	Strongly Disagree
Overall, I am satisfied with the medical care I have received					
I completely trust my hospital doctors					
The hospital doctors will always give me the best treatment					
The hospital doctors are very competent and careful					

Patient Study Number

Agree Strongly    Agree    No View    Disagree    Strongly Disagree

The hospital doctors always explain everything carefully					
The hospital doctors always listen to my concerns					
The hospital doctors do their best to help me					
The hospital doctors are totally honest with me					
The hospital doctors will not give my medical history to others without my permission					
I prefer to see a doctor who is the same sex (gender) as me					
I prefer my doctors to decide what is best for me					
I prefer my doctors to involve me in all important decisions					
I completely trust my general practitioner (GP)					
I would prefer to hear sensitive information from my general practitioner (GP)					
I would prefer to hear sensitive information from someone of a similar religion or background to me					
I am concerned that the NHS will NOT give me the best possible care					

# (original is on three pages)

GUJARATI

દર્દી અભ્યાસ નંબર Patient Study No

મોરખાની કઠીને કેન્સર થવાના કારણો અને તેની સારવારના પરિણામો વિશે તમારી કેટલી જાણકારી છે તે સમજવામાં અમને મદદ કરો

કેન્સર વિશેની માન્યતાઓ Cancer Beliefs

	નિહિતપણે સમજવા	સમજવા કોઈ અભિપ્રાય નથી	નાસંમત	નિહિતપણે અસમજવા
કેન્સરનો ઉપચાર છે				
કેન્સર, જે આખા શરીરમાં ફેલાય છે તેનો ઉપચાર નથી				
કોરોનાનું કેન્સર, શરીરના માત્ર એક ભાગમાં થવું હોય તેનો મોટાભાગે ઉપચાર કરી શકાય છે.				
સારવાર, ખાસ કરીને સર્જની કેન્સર ફેલાવાનું ધુમ્પકને કારણે અને છે.				
કૌશલ્ય સારવાર ખુબ સર્જની, યોગ્યભેદવાળી કે કેમોથેરાપી જેટલીજ અસરકારક હોય છે.				
સાંકેતિક સર્જની જેવી ટ્રેડ(તપાસ) કરવાથી કેન્સર પ્રાથમિક તબક્કે જ પારની થાય છે.				
કેન્સર થવાના કારણોની જાણકારી નથી				

કેન્સર થવાના કારણો Causes of Cancer

કેન્સર થવાના કારણો નીચે મુજબ છે	નિહિતપણે સમજવા	સમજવા કોઈ અભિપ્રાય નથી	નાસંમત	નિહિતપણે અસમજવા
ધુમ્પકન (સીગરેટ) Smoking				
ખોરાક (ડાયટ) Diet				
વજન વધારવાથી (ઓવરવેઇટ) Being overweight				
કસરત નો અભાવ Lack of exercise				
ધૂળ/દૂધ/પ્રદુષણ Pollution				
કાર્યભી Occupation				
ભાગ્ય/ઠગણી (સ્ટ્રેસ) Stress				
ઘાત Injury				

Cancer Beliefs Questionnaire V3 31/01/08

દર્દી અભ્યાસ નંબર Patient Study No

	નિહિતપણે સમજવા	સમજવા કોઈ અભિપ્રાય નથી	નાસંમત	નિહિતપણે અસમજવા
કેન્સર સામાન્યતઃ કુટુંબમાં થાય છે અને તે વારસાગત છે				
કેન્સર એ પી રોગ છે અને તે એક અસ્પષ્ટી ગીટ્ટ અસ્પષ્ટી ફેલાઈ શકે				
મને કેન્સર છે તે મારા કુટુંબીજનો વિચાર્ય જીવનને ના કંઈવું ભેદભે.				
કેન્સર નવોમ(કેન્સર) કારણે છે અને તેને વિચારવા કંઈ કરી ના શકાય				
કેન્સર જનમાન/અશ્કાર નરુથી અપાયેલ સ્વભાવે છે				
કેન્સર મોટું કરવાની સમજ છે				
ખાવ કરવાથી કેન્સર થવું છે				

ડોક્ટરોમાં વિશ્વાસ Trust in Doctors

તમારી હાલની (નિમત્તી માટે તમારી ધોરણવધ અને ધોરણવધના કર્મચારી સભ્યો(સ્ટાફ)સંબંધી તમારી કેટલી વિશ્વાસ છે તે મોરખાની કઠીને જણાવો. તમારા જવાબો નવામી રીતે વાપરવામાં આવશે અને તેનાથી તમારી સારવારમાં કોઈ તકલીફ નહીં પડે.

	નિહિતપણે સમજવા	સમજવા કોઈ અભિપ્રાય નથી	નાસંમત	નિહિતપણે અસમજવા
મને મરીલ તમીલી સારવારથી યું સંતુષ્ટ છે.				
મારા ધોરણવધના ડોક્ટરો ખર મને પૂરું જાણે છે				
ધોરણવધના ડોક્ટરો મને અંધારા ઉત્તમ સારવાર આપે.				
ધોરણવધના ડોક્ટરો પ્રશ્નો કાવજી કરનાર અને મોનુ છે.				

Cancer Beliefs Questionnaire V3 31/01/08

દર્દી અભ્યાસ નંબર Patient Study No

	નિહિતપણે સમજવા	સમજવા કોઈ અભિપ્રાય નથી	નાસંમત	નિહિતપણે અસમજવા
ધોરણવધના ડોક્ટરો તમીલી જાણત પ્રશ્નો કાવજી સમજાવે છે.				
ધોરણવધના ડોક્ટરો અંધારા મારી વિના વિશે સંજ્ઞા છે.				
ધોરણવધના ડોક્ટરો મને મદદ કરવાની ઉત્તમ કોશિશ કરે છે.				
ધોરણવધના ડોક્ટરો મારી સાથે સંપૂર્ણપણે પ્રમાણિત છે.				
ધોરણવધના ડોક્ટરો મારા તમીલી ઉત્તમસારની વિગતો મારી મંજૂરી વિના ગીજાને નહીં આપે.				
જે ડોક્ટર સારની અભિ(ધોરણ)ના ધોરણ તેમની પાસે જવાનું યું પસંદ કરે				
મારા માટે ઉત્તમ સુ છે તે ડોક્ટરો નહીં કરે તે મને પસંદ છે.				
જ્યાં માનવના નિર્ણયો લેવામાં મારા ડોક્ટરો મારી સમાવેશ કરે તેનું મને પસંદ છે.				
યું મારા જાણી(જનરલ પ્રેક્ટીસનર) પર સંપૂર્ણ વિશ્વાસ રાખું છું				
યું મારા જનરલ પ્રેક્ટીસનર (જાણી) પાસેથી કોઈપણ સારવેદનીય માહિતી સંભાળવાનું પસંદ કરે				
યું મારા જાણી જ સરના વખે કે સામાજિક પરિસ્થિતિ ધરાવતી અભિ પાસેથી સારવેદનીય જાણ સંભાળવાનું પસંદ કરે.				
એન.એચ.એસ મને કાવજી તેટલી ઉત્તમ વિગત નહીં આપે તેની મને ફિડર છે.				

Translated by Ujala Resource Centre Tel: (0116) 265 4747 2008 03D

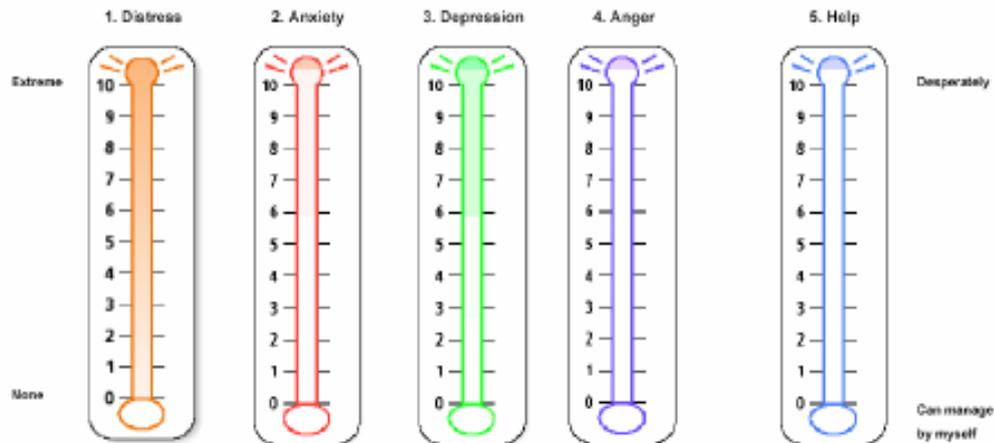
Cancer Beliefs Questionnaire V3 31/01/08

## Emotion Thermometers (Inc. Distress Thermometer)

In the first four columns, please circle the number that best describes how much emotional upset you have been experiencing in the past week, including today.  
In the last column please indicate how much you need help for these concerns

Study No. \_\_\_\_\_

Date. \_\_\_\_\_



Please indicate if any of the following has been a cause of distress in the past week, including today.  
Be sure to check NO or YES for each.

NO	YES		NO	YES	
<input type="checkbox"/>	<input type="checkbox"/>	<b>Practical Problems</b>	<input type="checkbox"/>	<input type="checkbox"/>	<b>Physical Problems</b>
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Insurance	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
		<b>Family Problems</b>	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
		<b>Emotional Problems</b>	<input type="checkbox"/>	<input type="checkbox"/>	Eating
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
		<b>Spiritual/Religious Concerns</b>	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
<input type="checkbox"/>	<input type="checkbox"/>	Relating to God	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Loss of faith	<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet
			<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
			<input type="checkbox"/>	<input type="checkbox"/>	Sexual

Other Problems: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Emotion Thermometers (Thermometers shown in patients copy)

GUJARATI

પરિણીત વ્યક્તિ કોઈ સ્તર(કોલમ)માં, ગણા અકલ્પિતિયા દરમ્યાન, આજની સાથે, ભાવનાત્મક રીતે તમે કેટલી વાર અધ્યાનનો અનુભવ કર્યો છે તે જણાવવા માટે નંબર ૫૨ થી ૫૬ સુધી (સકેલ) કરો. ઈશી કોલમમાં આ સંબંધી તમને કેટલી મદદ જરૂરી છે તે દર્શાવો.

અભ્યાસ નં. ....

તારીખ

1. માનસિક પીડા (ડિપ્રેશન)    2. ચિંતા (એન્જાયટી)    3. ઉદાસી (ડિપ્રેશન)    4. ધુરસો (એંગર)    5. મદદ (રેલ્ફ)

નીચે જણાવેલ ભાવનામાંથી કોઈ ભાવના ગણા અકલ્પિતિયા દરમ્યાન, આજની સાથે, બે તમારી માનસિક પીડાનું કારણ બની શકે તે જણાવો. દરેક ભાવના માટે 'હા' (Yes) યા 'ના' (No) પર નિશાની કરો.

ના No	હા Yes		ના No	હા Yes	
		<b>અવધારિત મુશ્કેલીઓ</b>			<b>શારિરિક મુશ્કેલીઓ</b>
		<b>Practical Problems</b>			<b>Physical Problems</b>
<input type="checkbox"/>	<input type="checkbox"/>	લાઠેરચીલ	<input type="checkbox"/>	<input type="checkbox"/>	દુઃખ
<input type="checkbox"/>	<input type="checkbox"/>	ઇન્સુલિન	<input type="checkbox"/>	<input type="checkbox"/>	ઉભડા યા ચીનરી આવવી
<input type="checkbox"/>	<input type="checkbox"/>	કામ/સ્કુલ	<input type="checkbox"/>	<input type="checkbox"/>	વકાવડ
<input type="checkbox"/>	<input type="checkbox"/>	ટ્રાન્સપોર્ટ	<input type="checkbox"/>	<input type="checkbox"/>	ઉંઘ
<input type="checkbox"/>	<input type="checkbox"/>	ગાળકની સંભાળ	<input type="checkbox"/>	<input type="checkbox"/>	શરમાં આમનેમ દુરવામાં
			<input type="checkbox"/>	<input type="checkbox"/>	નબાચ/નિપાર વ્યામાં
			<input type="checkbox"/>	<input type="checkbox"/>	શ્વાસ લેવામાં
		<b>કીર્ત્ત્વિમક મુશ્કેલીઓ Family Problems</b>	<input type="checkbox"/>	<input type="checkbox"/>	આવામાં
<input type="checkbox"/>	<input type="checkbox"/>	આવીકાર સાથેનો વહેવાર	<input type="checkbox"/>	<input type="checkbox"/>	અપચો
<input type="checkbox"/>	<input type="checkbox"/>	ગાળકો સાથેનો વહેવાર	<input type="checkbox"/>	<input type="checkbox"/>	અંધકોષ(કોન્સીવેશન)
			<input type="checkbox"/>	<input type="checkbox"/>	અનિસાર(ડાયેરિયા)
		<b>ભાવનાત્મક મુશ્કેલીઓ</b>			
		<b>Emotional Problems</b>			
<input type="checkbox"/>	<input type="checkbox"/>	ચિંતા(માનસિક અસ્વસ્થતા)	<input type="checkbox"/>	<input type="checkbox"/>	મોડાનો દુઃખાવો
<input type="checkbox"/>	<input type="checkbox"/>	ડર/ભીક	<input type="checkbox"/>	<input type="checkbox"/>	પેશાબમાં ફેરફાર
<input type="checkbox"/>	<input type="checkbox"/>	ઉદાસી	<input type="checkbox"/>	<input type="checkbox"/>	નાચ
<input type="checkbox"/>	<input type="checkbox"/>	બિમા (ડિપ્રેશન)	<input type="checkbox"/>	<input type="checkbox"/>	સુષ્ટી ચામડી/ખાજવાળ
<input type="checkbox"/>	<input type="checkbox"/>	વખરાડ આવવો	<input type="checkbox"/>	<input type="checkbox"/>	શુષ્ક નાક/નાક વાલેવા માંડીને ગંધ થવું
			<input type="checkbox"/>	<input type="checkbox"/>	શ્વાસ/પરમમાં કળુંક ઓડાનું ધોલ નેવું આવવું
<input type="checkbox"/>	<input type="checkbox"/>	<b>આધ્યાત્મિક/ધાર્મિક ચિંતા</b>	<input type="checkbox"/>	<input type="checkbox"/>	સોજા વડવા/કુલેવું આવવું
		<b>Spiritual/Religious Concerns</b>			
<input type="checkbox"/>	<input type="checkbox"/>	અવધારને બચવું	<input type="checkbox"/>	<input type="checkbox"/>	અનિદ્ર સંબંધેને બચવું
<input type="checkbox"/>	<input type="checkbox"/>	શ્રધ્ધા/વિશ્વાસ ગુમાવવો			

બીજી મુશ્કેલીઓ:.....  
 .....  
 .....

**MINI - MENTAL ADJUSTMENT TO CANCER SCALE (MAC)**

Study No. \_\_\_\_\_

Date. \_\_\_\_\_

**Instructions**      These statements describe people's reactions to having cancer.  
Please circle the number indicating which best applies to you at present.

		Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me	Our use
1.	At the moment I take one day at a time	1	2	3	4	
2.	I see my illness as a challenge	1	2	3	4	
3.	I've put myself in the hands of God	1	2	3	4	
4.	I feel like giving up	1	2	3	4	
5.	I feel very angry about what has happened to me	1	2	3	4	
6.	I feel completely at a loss about what to do	1	2	3	4	
7	It is a devastating feeling	1	2	3	4	
8.	I count my blessings	1	2	3	4	
9.	I worry about the cancer returning or getting worse	1	2	3	4	
10.	I try to fight the illness	1	2	3	4	
11.	I distract myself when cancer thoughts come into my head	1	2	3	4	
12.	I can't handle it	1	2	3	4	
13.	I am apprehensive	1	2	3	4	
14.	I am not very hopeful about the future	1	2	3	4	
15.	I feel that nothing I can do to help myself	1	2	3	4	
16.	I think it is the end of the world	1	2	3	4	
17.	Not thinking about it help me cope	1	2	3	4	
18.	I am very optimistic	1	2	3	4	
19.	I've had a good life, what's left is a bonus	1	2	3	4	
20.	I feel that life is hopeless	1	2	3	4	
21.	I can't cope	1	2	3	4	
22.	I am upset about having cancer	1	2	3	4	
23.	I am determined to beat this disease	1	2	3	4	
24.	Since my cancer diagnosis I now realise how precious life is and I'm making the most of it	1	2	3	4	
25.	I have difficulty in believing that this happened to me	1	2	3	4	
26.	I make a positive effort not to think about my illness	1	2	3	4	
27.	I deliberately push all thoughts of cancer out of my mind	1	2	3	4	
28.	I suffer great anxiety about it	1	2	3	4	
29.	I am a little frightened	1	2	3	4	

Thank you for taking the trouble to complete this scale.

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Please Return to - Dr Alex Mitchell, Liaison Psychiatry, Brandon Unit, Leicester General Hospital, Leicester LE5 4PW

## કેન્સર સાથે લઘુ-માનસિક સમાયોજન પ્રમાણ (MAC)

અભ્યાસ વં. \_\_\_\_\_

તારીખ. \_\_\_\_\_

સૂચનાઓ

આ વિધાનો કેન્સર ઢોવા અંગે લોઢેની પ્રતિક્રિયાઓનું વર્ણન કરે છે.  
ઢવમાં તમને સીધી વધુ ઢાનુ પડતું ઢંચ તે દર્શાવતા નંબરની આસપાસ વર્તુળ ઢેસ્યા વિનંતી.

	થોક્સપણે મને લાગુ પડતું નથી	મને લાગુ પડતું નથી	મને લાગુ પડે છે	થોક્સપણે મને લાગુ પડે છે	અમારું ક્રેપયોગ
1.	શર્યામાં અંકી સમયે ઢું અંક ઢિવસ લાઉ ઢું.	1	2	3	4
2.	ઢું મારી માંઢરીને પડઢાર તરીકે જાઉ ઢું.	1	2	3	4
3.	મેં મારી જાતને જાનવાનઢા ઢાશમાં સાંપી છે.	1	2	3	4
4.	મેં સારા શવાની આશા ઢાંકી ઢીધી છે.	1	2	3	4
5.	મને જે શર્ઢ રઢું છે તે અંગે ઢું ખૂબ ઢુસ્સે ઢું.	1	2	3	4
6.	શુ કરવું જાઉંએ તે અંગે ઢું સંપૂર્ણ ઢુમાવ્યાનુ અનુભવું ઢું.	1	2	3	4
7.	આ ઢતાશ કરતી ઢાનણી છે.	1	2	3	4
8.	ઢું મારા આશીર્વાઢ ગઢ્ઢ ઢું.	1	2	3	4
9.	કેન્સર ઢરીથી જવાની કે વધુ ખત્રબ શવાની મને ઢિતા ઢાય છે.	1	2	3	4
10.	ઢું માંઢની સામે લડવાનાં પ્રવલ્ત કરું ઢું.	1	2	3	4
11.	કેન્સરના વિઢારો મારા મનજ્યામાં આવે ત્યારે ઢું મારી જાતને બીજા બાજુ ખેંચી લાઉ ઢું.	1	2	3	4
12.	ઢું તેને ઢાબુમાં ઢઈ શકીશ નહીં.	1	2	3	4
13.	મને પાસ્તી છે.	1	2	3	4
14.	ઢું ભવિષ્ય અંગે વધુ આઢાસઢા નથી.	1	2	3	4
15.	મને લાગે છે કે મારી જાતને મઢઢ કરવા ઢું કશું કરી શકીશ નહીં.	1	2	3	4
16.	મને લાગે છે કે મારી ઢૂનિયાનો અંત છે.	1	2	3	4
17.	તેના અંરે નહીં વિઢારવાથી મને ઢાબુ રાખવામાં મઢઢ મળે છે.	1	2	3	4
18.	ઢું ખૂબ આશાસઢા ઢું.	1	2	3	4
19.	મને સારી જિંઢી મળી ઢતી, જે ઢઈ બાકી રઢું તે બાંનસ છે.	1	2	3	4
20.	મને લાગે છે કે જિંઢી આશારઢિત છે.	1	2	3	4
21.	ઢું સામનો કરી શકીશ નહીં.	1	2	3	4
22.	કેન્સર શવાથી ઢું અસ્વસ્થ ઢું.	1	2	3	4
23.	આ રોગનાં સામનો કરવાનો મારો ઢંઢ નિર્ધાર છે.	1	2	3	4
24.	મને કેન્સર ઢોવાનુ નિઢાન શયું ત્યારથી ઢવે મને ઢારં છે કે જિંઢી કેટલી કીમતી છે અને ઢું તેનો મોઢાભાગનો લાભ લાઉ ઢું.	1	2	3	4
25.	આ મને શયું ઢોવાનું માનવામાં મને મુશ્કેલી પડે છે.	1	2	3	4
26.	ઢું મારી માંઢરી અંરે નહીં વિઢારવાનો વિપંચક પ્રવલ્ત કરું ઢું.	1	2	3	4
27.	ઢું ઢંરાઢાપૂર્વક કેન્સરના તમામ વિઢારોને મારા મનમાંથી બઢાર પાકેલું ઢું.	1	2	3	4
28.	ઢું તે અંગે ઢણી ઢિતા અનુભવું ઢું.	1	2	3	4
29.	ઢું થોઢોક કરેલો ઢું.	1	2	3	4

આ સ્કેવ પૂર્ણ કરવાની તસ્કી લેવા બઢલ તમારો આભાર માનું ઢું.

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પરત કરવા વિનંતી - Dr Alex Mitchell, Liaison Psychiatry, Brandon Unit, Leicester General Hospital, Leicester LE5 4PW

V1 13/06/06

# Hospital Anxiety and Depression Scale (HADS)

Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. Acta Psychiatr Scand 1983;67:361-370

Study No. \_\_\_\_\_

Date. \_\_\_\_\_

<p>(tick closest choice)</p> <p><b>A1 I feel tense or "wound up"</b></p> <table border="1"> <tr><td>Most of the time</td><td><input type="checkbox"/></td></tr> <tr><td>A lot of the time</td><td><input type="checkbox"/></td></tr> <tr><td>From time to time, occasionally</td><td><input type="checkbox"/></td></tr> <tr><td>Not at all</td><td><input type="checkbox"/></td></tr> </table> <p><b>A2 I get a sort of frightened feeling like "butterflies" in the stomach</b></p> <table border="1"> <tr><td>Not at all</td><td><input type="checkbox"/></td></tr> <tr><td>Occasionally</td><td><input type="checkbox"/></td></tr> <tr><td>Quite often</td><td><input type="checkbox"/></td></tr> <tr><td>Very often</td><td><input type="checkbox"/></td></tr> </table> <p><b>A3 I get a sort of frightened feeling as if something awful is about to happen</b></p> <table border="1"> <tr><td>Very definitely and quite badly</td><td><input type="checkbox"/></td></tr> <tr><td>Yes, but not too badly</td><td><input type="checkbox"/></td></tr> <tr><td>A little, but it doesn't worry me</td><td><input type="checkbox"/></td></tr> <tr><td>Not at all</td><td><input type="checkbox"/></td></tr> </table> <p><b>A4 I feel restless as if I have to be on the move</b></p> <table border="1"> <tr><td>Very much indeed</td><td><input type="checkbox"/></td></tr> <tr><td>Quite a lot</td><td><input type="checkbox"/></td></tr> <tr><td>Not very much</td><td><input type="checkbox"/></td></tr> <tr><td>Not at all</td><td><input type="checkbox"/></td></tr> </table> <p><b>A5 Worrying thoughts go through my mind</b></p> <table border="1"> <tr><td>A great deal of the time</td><td><input type="checkbox"/></td></tr> <tr><td>A lot of the time</td><td><input type="checkbox"/></td></tr> <tr><td>From time to time but not too often</td><td><input type="checkbox"/></td></tr> <tr><td>Only occasionally</td><td><input type="checkbox"/></td></tr> </table> <p><b>A6 I get sudden feelings of panic</b></p> <table border="1"> <tr><td>Very often indeed</td><td><input type="checkbox"/></td></tr> <tr><td>Quite often</td><td><input type="checkbox"/></td></tr> <tr><td>Not very often</td><td><input type="checkbox"/></td></tr> <tr><td>Not at all</td><td><input type="checkbox"/></td></tr> </table> <p><b>A7 I can sit at ease and feel relaxed</b></p> <table border="1"> <tr><td>Definitely</td><td><input type="checkbox"/></td></tr> <tr><td>Usually</td><td><input type="checkbox"/></td></tr> <tr><td>Not often</td><td><input type="checkbox"/></td></tr> <tr><td>Not at all</td><td><input type="checkbox"/></td></tr> </table>	Most of the time	<input type="checkbox"/>	A lot of the time	<input type="checkbox"/>	From time to time, occasionally	<input type="checkbox"/>	Not at all	<input type="checkbox"/>	Not at all	<input type="checkbox"/>	Occasionally	<input type="checkbox"/>	Quite often	<input type="checkbox"/>	Very often	<input type="checkbox"/>	Very definitely and quite badly	<input type="checkbox"/>	Yes, but not too badly	<input type="checkbox"/>	A little, but it doesn't worry me	<input type="checkbox"/>	Not at all	<input type="checkbox"/>	Very much indeed	<input type="checkbox"/>	Quite a lot	<input type="checkbox"/>	Not very much	<input type="checkbox"/>	Not at all	<input type="checkbox"/>	A great deal of the time	<input type="checkbox"/>	A lot of the time	<input type="checkbox"/>	From time to time but not too often	<input type="checkbox"/>	Only occasionally	<input type="checkbox"/>	Very often indeed	<input type="checkbox"/>	Quite often	<input type="checkbox"/>	Not very often	<input type="checkbox"/>	Not at all	<input type="checkbox"/>	Definitely	<input type="checkbox"/>	Usually	<input type="checkbox"/>	Not often	<input type="checkbox"/>	Not at all	<input type="checkbox"/>	<p>(tick closest choice)</p> <p><b>D1 I feel as if I am slowed down</b></p> <table border="1"> <tr><td>Nearly all the time</td><td><input type="checkbox"/></td></tr> <tr><td>Very often</td><td><input type="checkbox"/></td></tr> <tr><td>Sometimes</td><td><input type="checkbox"/></td></tr> <tr><td>Not at all</td><td><input type="checkbox"/></td></tr> </table> <p><b>D2 I still enjoy the things I used to enjoy</b></p> <table border="1"> <tr><td>Definitely as much</td><td><input type="checkbox"/></td></tr> <tr><td>Not quite as much?</td><td><input type="checkbox"/></td></tr> <tr><td>Only a little</td><td><input type="checkbox"/></td></tr> <tr><td>Hardly at all</td><td><input type="checkbox"/></td></tr> </table> <p><b>D3 I have lost interest in my appearance</b></p> <table border="1"> <tr><td>Definitely</td><td><input type="checkbox"/></td></tr> <tr><td>I don't take so much care as I should</td><td><input type="checkbox"/></td></tr> <tr><td>I may not take quite as much care</td><td><input type="checkbox"/></td></tr> <tr><td>I take just as much care as ever</td><td><input type="checkbox"/></td></tr> </table> <p><b>D4 I can laugh and see the funny side of things</b></p> <table border="1"> <tr><td>As much as I always could</td><td><input type="checkbox"/></td></tr> <tr><td>Not quite so much now</td><td><input type="checkbox"/></td></tr> <tr><td>Definitely not so much now</td><td><input type="checkbox"/></td></tr> <tr><td>Not at all</td><td><input type="checkbox"/></td></tr> </table> <p><b>D5 I look forward with enjoyment to things</b></p> <table border="1"> <tr><td>As much as I ever did</td><td><input type="checkbox"/></td></tr> <tr><td>Rather less than I used to</td><td><input type="checkbox"/></td></tr> <tr><td>Definitely less than I used to</td><td><input type="checkbox"/></td></tr> <tr><td>Hardly at all</td><td><input type="checkbox"/></td></tr> </table> <p><b>D6 I feel cheerful</b></p> <table border="1"> <tr><td>Not at all</td><td><input type="checkbox"/></td></tr> <tr><td>Not often</td><td><input type="checkbox"/></td></tr> <tr><td>Sometimes</td><td><input type="checkbox"/></td></tr> <tr><td>Most of the time</td><td><input type="checkbox"/></td></tr> </table> <p><b>D7 I can enjoy a good book or radio or TV program</b></p> <table border="1"> <tr><td>Often</td><td><input type="checkbox"/></td></tr> <tr><td>Sometimes</td><td><input type="checkbox"/></td></tr> <tr><td>Not often</td><td><input type="checkbox"/></td></tr> <tr><td>Very seldom</td><td><input type="checkbox"/></td></tr> </table>	Nearly all the time	<input type="checkbox"/>	Very often	<input type="checkbox"/>	Sometimes	<input type="checkbox"/>	Not at all	<input type="checkbox"/>	Definitely as much	<input type="checkbox"/>	Not quite as much?	<input type="checkbox"/>	Only a little	<input type="checkbox"/>	Hardly at all	<input type="checkbox"/>	Definitely	<input type="checkbox"/>	I don't take so much care as I should	<input type="checkbox"/>	I may not take quite as much care	<input type="checkbox"/>	I take just as much care as ever	<input type="checkbox"/>	As much as I always could	<input type="checkbox"/>	Not quite so much now	<input type="checkbox"/>	Definitely not so much now	<input type="checkbox"/>	Not at 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For our use

HADs -Anxiety subscale

HADs -Depression subscale

V1 13/06/06

# હોસ્પિટલ આતુરતા અને ડિપ્રેશનનું પ્રમાણ (HADS)

કિંગડમ હોસ્પિટલ, અને ધાર્મી, હાંશિપટ્ટા જાનુરતા અને ડિપ્રેશન પ્રમાણ, એડા હાઈલીએટ રાજ્ય 1983, 57 : 361-370

અભ્યાસ નં. \_\_\_\_\_  
તારીખ. \_\_\_\_\_

(સૌથી વજનની પસંદગી પર નિશાની કરો)

(સૌથી વજનની પસંદગી પર નિશાની કરો)

**A1** મને તણાવ કે વધુ ઉત્તેજના' ની લાગણી થાય છે

મોટાભાગનો સમય	<input type="checkbox"/>
પણો વધો સમય	<input type="checkbox"/>
વખતો-વખત, પ્રસંગોપાત	<input type="checkbox"/>
નિવડતુલ નહીં	<input type="checkbox"/>

**D1** મને એવું લાગે છે કે હું જાણું છું મંડ રહી ગયો છું.

લગભગ વધો સમય	<input type="checkbox"/>
પણીવખત	<input type="checkbox"/>
ક્યારેક	<input type="checkbox"/>
નિવડતુલ નહીં	<input type="checkbox"/>

**A2** મને પેટમાં 'એબેની' જેવી એક પ્રકારની ગભરાટની લાગણી થાય છે.

નિવડતુલ નહીં	<input type="checkbox"/>
પ્રસંગોપાત	<input type="checkbox"/>
પણી વખત	<input type="checkbox"/>
અનેક વખત	<input type="checkbox"/>

**D2** હું જેનાં આગલ લેવા ટેવાઈલાં છું તે વસ્તુઓમાં હજુ આનંદ લઉં છું.

ચોક્કસપણે વધો બધો	<input type="checkbox"/>
એટલાં બધો નહીં?	<input type="checkbox"/>
માત્ર થોડાંક	<input type="checkbox"/>
ભાગ્યે જ	<input type="checkbox"/>

**A3** મને, કશુંક બરાબ થવાનું છે તેવી એક પ્રકારના ભયની લાગણી થાય છે.

ખૂબ ચોક્કસપણે અને નિવડતુલ પરાગ રીતે	<input type="checkbox"/>
હા, પરંતુ ખૂબ બરાબ રીતે નહીં	<input type="checkbox"/>
સહેજ, પરંતુ તેની મને ખિતા નથી	<input type="checkbox"/>
નિવડતુલ નહીં	<input type="checkbox"/>

**D3** મેં મારા કંબાવના રસ ગુમાવ્યાં છે.

ચોક્કસપણે	<input type="checkbox"/>
મારે તેવી ખોઈએ તેટલાં સંભાળ હું લેતો નથી	<input type="checkbox"/>
હું વધુ સંભાળ નિવડતુલ લઈ શકીત નહીં	<input type="checkbox"/>
હું ઊંભરનો જેમ વધુમાં વધુ સંભાળ લઉં છું	<input type="checkbox"/>

**A4** હું જાણું છું કે તમે-ફરતાં હોઈ તેવી અંજાપાની લાગણી થાય છે.

ચોક્કસપણે ખૂબ	<input type="checkbox"/>
પણીબધી	<input type="checkbox"/>
ખૂબ વધુ નહીં	<input type="checkbox"/>
નિવડતુલ નહીં	<input type="checkbox"/>

**D4** હું વસ્તુઓની સ્મૃતિ બાજુ ઠરી શકું છું અને ખોઈ શકું છું.

હું ઊંભરતા કરી જુદું તેટલું વધુમાં વધુ	<input type="checkbox"/>
હવે એટલું બધું વધારે નહીં	<input type="checkbox"/>
ચોક્કસપણે હવે એટલું બધું નહીં	<input type="checkbox"/>
નિવડતુલ નહીં	<input type="checkbox"/>

**A5** મારા મનમાં ચિંતાપ્રક ધિચારો આવે છે.

સમયનો પણો વધો ભાગ	<input type="checkbox"/>
મોટાભાગનો સમય	<input type="checkbox"/>
સમય-સમયે પરંતુ વારંવાર નહીં	<input type="checkbox"/>
માત્ર પ્રસંગોપાત	<input type="checkbox"/>

**D5** હું વસ્તુઓ પ્રતિ આનંદથી આશાપૂર્વક ખોઈ છું.

મેં ક્યારેય જાનું હતું તે કરતાં વધુમાં વધુ	<input type="checkbox"/>
હું ટેવાયો હતો તે કરતાં કમ્ય બોધું	<input type="checkbox"/>
હું ટેવાયો હતો તે કરતાં ચોક્કસપણે બોધું	<input type="checkbox"/>
ભાગ્યે જ	<input type="checkbox"/>

**A6** મને આનંદ ગભરાટની લાગણી થાય છે.

ચોક્કસપણે વધો વખત	<input type="checkbox"/>
પણી વખત	<input type="checkbox"/>
બહુ વાર નહીં	<input type="checkbox"/>
નિવડતુલ નહીં	<input type="checkbox"/>

**D6** હું આનંદ અનુભવું છું.

નિવડતુલ નહીં	<input type="checkbox"/>
વાસ્તવ નહીં	<input type="checkbox"/>
કેટલાંક વખત	<input type="checkbox"/>
મોટાભાગનો સમય	<input type="checkbox"/>

**A7** હું આશમથી બેસી શકું છું અને ઠબવાશ અનુભવી શકું છું.

ચોક્કસપણે	<input type="checkbox"/>
સામાન્ય રીતે	<input type="checkbox"/>
પણીવાર નહીં	<input type="checkbox"/>
નિવડતુલ નહીં	<input type="checkbox"/>

**D7** હું સાથે પુસ્તક કે રેડિયો કે ટીવી કાર્ડન માણી શકું છું.

પણીવખત	<input type="checkbox"/>
ક્યારેક	<input type="checkbox"/>
બહુ વખત નહીં	<input type="checkbox"/>
ભાગ્યે જ	<input type="checkbox"/>

આમા ઉપબોગ માટે  
**HADS -આતુરતા પેટા-માપ**

**HADS -હતાશા પેટા-માપ**

V1 13/06/06

**Cancer Insight and Denial Questionnaire (CIDQ)** Study No. \_\_\_\_\_  
Date. \_\_\_\_\_

**Instructions** Below you will see a list of statements that are related to your illness.  
Please indicate (eg tick) the statement that you most agree with.

	Strongly disagree	Disagree	Some times	agree	Strongly agree	Our use
1. I keep health related issues to myself						D
2. No one has clearly told me that I have cancer						I
3. I think there has been a mistake in giving me a diagnosis of cancer						D
4. I don't really believe I have cancer						D
5. I have been told my cancer is curable						I
6. I have difficulty in believing that this happened to me						D
7. I avoid talking to strangers about my diagnosis						A
8. I try not to dwell on my illness						D
9. I avoid discussing painful issues with some health professionals						A
10. I pretend I do not have cancer						I
11. I cannot really see the point of having treatment						D
12. I may get better from this illness						D
13. I do not like to meet other people with cancer						A
14. I don't let myself get upset about my illness						D
15. I avoid reminders of cancer on TV, radio and newspapers						A
16. I have been given plenty of information about cancer						I

D = denial items 1,3,4,6,8,11,12,14

A = avoidance items 7,9,13, 15

I = Information items 2, 5,10, 16

## કેન્સર સૂઝ અને ઈન્કાર પ્રશ્નાવલિ (CIDQ)

અભ્યાસ નં. \_\_\_\_\_

તારીખ. \_\_\_\_\_

સૂચનાઓ તમારી માંદગી સાથે સંબંધિત વિધાનોની યાદી તમે નીચે જોશો.  
તમે જે વિધાન સાથે સૌથી વધુ સંમત હોવ તે દર્શાવવા (જેમ કે ખરાબી વિશાળી કરવી) વિનંતી.

	સંપૂર્ણ અસંમત	અસંમત	રેકમ્યારેક	સંમત	સંપૂર્ણ અસંમત	અપારો ઉપયોગ
1. આસંગ્યને લગતી બાબતો કું મારી પાસે રાખું છું.						D
2. કોઈએ મને કેન્સર હોવાનું સ્પષ્ટપણે જણાવ્યું નથી.						I
3. માસ કેન્સરનું નિદાન કરવામાં ભૂલ થઈ હોવાનું મારું માનવું છે.						D
4. મને કેન્સર થયું હોઈ શકે છે માનવામાં આસઈ નથી.						D
5. મારું કેન્સર મટી શકે તેમ હોવાનું મને જણાવાયું છે.						I
6. મને આ થયું હોવાનું માનવું માસ માટે મુશ્કેલ છે.						D
7. માસ નિદાન બંને અપણ્યા લોકો ની સાથે વાત કરવાનું કું ટાળું છું.						A
8. મારી માંદગી પર ધ્યાન ન આપવાની કું પ્રયત્ન કરું છું.						D
9. કોઈ આસંગ્ય વ્યવસાયિ સાથે દર્દભર્યા પ્રશ્નોની ચર્ચા કરવાનું કું ટાળું છું.						A
10. મને કેન્સર નથી છેવો કું ઢંગ કરું છું.						I
11. ખરેખર સાસ્વાર કસવવાનો મને ક્રંઈ ફાયદો કેજાતો નથી.						D
12. આ માંદગીમાંથી મને વધુ સારું થઈ શકશે.						D
13. કેન્સરવાળા બીજા લોકોને મળવું મને ગમતું નથી.						A
14. કું મારી માંદગી બંને મારી જાતને અસ્વસ્થ થવા કેતો નથી.						D
15. ટી.વી., રેડિયો અને સમાચારપત્રો પર કેન્સરની યાદ અપાવતી બાબતો જોવાનું ટાળું છું.						A
18. મને કેન્સર બંને વિપુલ માહિતી આપવામાં આવી છે.						I

D=ઈન્કારની બાબતો 1,3,4,6,8,11,12,14

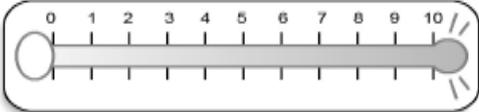
A=નિવારવાની બાબતો 7,9,13,15

I=માહિતીની બાબતો 2,5,10,16

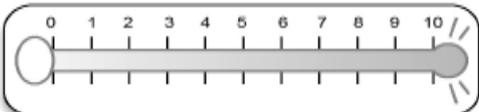
## The Brief Illness Perception Questionnaire (Thermometer Version2)

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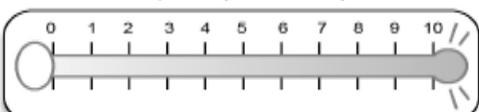
How much does your illness affect your life?

No effect  Severely

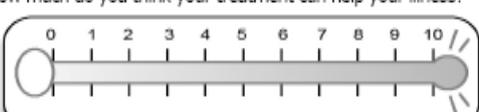
How much are you worried your illness will progress?

Not at all worried  Extremely worried

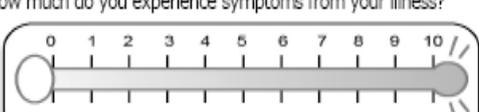
How much control do you feel you have over your illness?

Absolutely no control  Totally in control

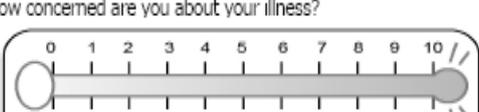
How much do you think your treatment can help your illness?

Not at all  Extremely helpful

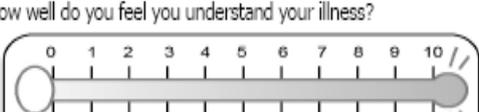
How much do you experience symptoms from your illness?

No symptoms at all  Many severe symptoms

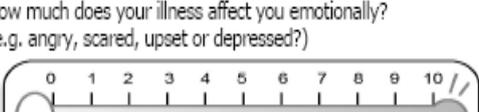
How concerned are you about your illness?

Not at all concerned  Extremely concerned

How well do you feel you understand your illness?

Don't understand at all  Understand very clearly

How much does your illness affect you emotionally?  
(e.g. angry, scared, upset or depressed?)

No emotional effects  Extremely affected emotionally

## The Brief Illness Perception Questionnaire

(Thermometers shown in patients' copy)

અભ્યાસ નં. \_\_\_\_\_ તારીખ \_\_\_\_\_

માંકીની ખણકારી અંગે સંક્ષિપ્ત પ્રશ્નાવલિ  
નીચેના પ્રશ્નો અંગે, જે તમારા અભિપ્રાય સાથે વધુ અનુકૂળ ક્રમ તો નંબર પર વર્તુળ દોરવા વિનંતી.

તમારી માંકીની તમારુ જીવનપર કેટલી અસર થઈ છે?	0 1 2 3 4 5 6 7 8 9 10	ખૂબ અસર નહીં	મારી જિંદગી પર તીવ્ર અસર
તમારી માંકી કેટલી લાંબી ચાલુ રહેશે તે અંગે તમે કેટલું માનો છો?	0 1 2 3 4 5 6 7 8 9 10	ઘણો ઓછા સમય	ક્રમગતી
તમારી માંકી પર તમારો કેટલો કાબુ હોવાનું તમને લાગે છે?	0 1 2 3 4 5 6 7 8 9 10	સંપૂર્ણપણે કોઈ કાબુ નહીં	અત્યંત પ્રમાણમાં કાબુ
તમારી સારવાર તમારી માંકીમાં કેટલી મદદ કરી શકતી હોવાનું તમે માનો છો ?	0 1 2 3 4 5 6 7 8 9 10	ખૂબ અસર નહીં	અત્યંત મદદરૂપ
તમારી માંકીનાં લક્ષણોનો તમે કેટલો અનુભવ કરો છો ?	0 1 2 3 4 5 6 7 8 9 10	અત્યંત ઓછા લક્ષણ નહીં	વહાવા તીવ્ર લક્ષણો
તમારી માંકીથી તમે કેટલા ચિંતાતુર છો ?	0 1 2 3 4 5 6 7 8 9 10	ખૂબ અસર નહીં	અત્યંત ચિંતા થાય
તમારી માંકી તમે કેટલી સારી રીતે સમજ્યા હોવાનું તમને લાગે છે?	0 1 2 3 4 5 6 7 8 9 10	ખૂબ અસર નહીં	ખૂબ સ્પષ્ટપણે સમજાયેલ છે
તમારી માંકી તમને ભાવનાત્મક રીતે કેટલી અસર કરે છે? (દા.ત. તેનાથી તમને ગુસ્સો, ડર, અસ્વસ્થતા કે કંટાળા થાય છે?)	0 1 2 3 4 5 6 7 8 9 10	ભાવનાત્મક રીતે ખૂબ અસર નહીં	ભાવનાત્મક રીતે અત્યંત અસર
તમારી માંકીના કારણે તમે માવતા હોવ તેવા વસ્તુઓની વધુ અગત્યનાં પરિબલોની ઇચ્છા કરવામાં યાદી કરવા વિનંતી. મારા માટે સૌથી અગત્યના કારણો છે :-	1. _____ 2. _____ 3. _____		

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V1 13/06/06

## PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

NAME: \_\_\_\_\_

DATE: \_\_\_\_\_

Over the *last 2 weeks*, how often have you been bothered by any of the following problems?  
(use "✓" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself in some way	0	1	2	3

add columns:

	+		+	
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(Healthcare professional: For interpretation of TOTAL, please refer to accompanying scoring card.)

TOTAL:

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10. If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

- Not difficult at all \_\_\_\_\_
- Somewhat difficult \_\_\_\_\_
- Very difficult \_\_\_\_\_
- Extremely difficult \_\_\_\_\_

PHQ-9 is adapted from PRIME MD TODAY, developed by Drs Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke, and colleagues, with an educational grant from Pfizer Inc. For research information, contact Dr Spitzer at [rls@columbia.edu](mailto:rls@columbia.edu). Use of the PHQ-9 may only be made in accordance with the Terms of Use available at <http://www.pfizer.com>. Copyright ©1999 Pfizer Inc. All rights reserved. PRIME MD TODAY is a trademark of Pfizer Inc.

## દરદીના સ્વાસ્થ્યને લગતી ટૂંકી પ્રશ્નાવલી

આ પ્રશ્નાવલી તમને રાકચ એટલી સાચામાં સાચી સારવાર આપવા માટેનો એક અપાયનો ભાગ છે. તમારા જવાબના આધારે તમારી સમસ્યાઓ સમજાવવામાં આવશે. મહેરબાની કરીને, દરેક સવાલનો રાકચ એટલો સચોટ જવાબ આપો. સિવાય કે તમને કોઈ સવાલ ઝોટી ટેવાની વિનંતી કરવામાં આવે.

દરદીનું ટૂંકું નામ \_\_\_\_\_ ઉંમર \_\_\_\_\_ લિંગ : સ્ત્રી  પુરુષ  આજની તારીખ \_\_\_\_\_

૧. છેલ્લાં ૨ અઠવાડિયામાં, તમને નીચેની કોઈપણ સમસ્યાનો કેટલી વાર અનુભવ થયો છે ?

	જરૂર નહીં	પણી વાર	અડધાથી વધારે દિવસોમાં	તરબતબ રોજ
ક. પ્રવૃત્તિ કરવામાં ઓછો સ્ત્રા અથવા ઓછો યાનંત	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ખ. ઠંડાચા, ઉઠાટી અથવા નિરાશા લાગવાં	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ગ. લેંધ મોટી આવવી, વચ્ચે લેંધ ઊઠી જવી, વધારે લેંધ આવવી	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ઘ. શાક અથવા અશક્તિ	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ચ. ભૂખ ઓછી લાગવી કે વધારે લાગવી	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
છ. તમને તમારા વિશે ખરાબ લાગે અથવા તમે વિષ્ણુન ગયા છો અથવા તમે તમારી અથવા તમારાં સ્વજનોની અપેક્ષા સંતોષી નથી એવી લાગણી થાય	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
જ. શાપાં વાંચવા કે ટીવી જોવા જેવી બાબતોમાં એકલા જ રહેવામાં તકલીફ	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ઝ. દલબંધાઈ અથવા બોલવાનું એટલું ઘીમું હોવ કે બીજા લોકોનું ધ્યાન જાત અથવા એનાથી ઊંચું, એટલો બધો સવાલ અથવા અસ્વસ્થતા કે તમે સમજતા કરતાં વધારે અડધાથી સમસ્યા ઠીક થતા હતા	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ટ. ગરબાને અથવા તમને પોતાને કોઈક રીતે ઈજા કરવાનો વિચાર આવે	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

૨. ચિંતા વિશેની પ્રશ્નાવલી

	ના	હા
ક. છેલ્લાં ૪ અઠવાડિયામાં, તમને ચિંતાના હુમલા, ગભરામણ થઈ છે ? એટલે કે અચાનક જ અથવા આતંકની લાગણી થઈ છે ?	<input type="checkbox"/>	<input type="checkbox"/>
<b>તમારો જવાબ "ના" હોય તો સવાલ ૩ વાંચો</b>		
ખ. આવું અગાઉ ક્યારેય બન્યું હતું ?	<input type="checkbox"/>	<input type="checkbox"/>
ગ. આમાંના અમુક હુમલા અચાનક એટલે કે એવી પરિસ્થિતિમાં આવ્યા હતા જેમાં તમે ચિંતિત અથવા અસ્વસ્થ બનવાની કલ્પના જ કરી ન હોય ?	<input type="checkbox"/>	<input type="checkbox"/>
ઘ. આવા હુમલાથી તમને ખૂબ ચિંતા થાય છે અથવા તમને આવી બીજી હુમલો આવી જશે એવી ચિંતા રહે છે ?	<input type="checkbox"/>	<input type="checkbox"/>
ચ. તમને ગભરામણનો છેલ્લો ગંભીર હુમલો આવ્યો ત્યારે તમને સ્વાસ લેવામાં તકલીફ, પરસેવો, ફેફસના ઘબઘારા વધી જવા, ચક્કર અથવા બેહોશી, અંતમાં ઝણઝણાટી થાય કે અથવા ખાલી ચહે, ઊંબઠા આવે અથવા પેટમાં ગડબડ થાય એવું થયું છે ?	<input type="checkbox"/>	<input type="checkbox"/>

૩. તમને આજ સુધીમાં આ પ્રશ્નાવલીમાંની કોઈપણ તકલીફ થઈ હોય તો તેને લીધે તમને તમારું કામ કરવામાં, વાસ્તુ ધ્યાન રાખવામાં અથવા બીજા લોકોના વહેવારમાં કેટલી તકલીફ પડી છે ?

જાણ તકલીફ નથી પડતી  થોડી તકલીફ  વધારે તકલીફ  ખૂબ તકલીફ

પાછળના પાના પર ચાલુ ➡

આધિકારકોષ્ટિક મોડ : મેન્ડર કોલેજ કોલેજીયમ - પો. કોડ ૩૮ ૧૬ અથવા પ. નો. ૩૮ ૧૬ - આ એલમાં એલ પાંચ અથવા વધારે સવાલના જવાબ "અડધાથી વધારે દિવસોમાં" હોય તો (કુલ ૧૫ની ગણતરી કરી પો. ૩૮ ૧૬ હોય તો). અધિકારકોષ્ટિક મોડ : મેન્ડર ૧૬ અથવા ૩૮ અને ૧૬-૩૮ વે, ૩૮, અથવા ૩૮ અને ૩૮ જવાબ "અડધાથી વધારે દિવસોમાં" હોય તો (કુલ ૧૫ની ગણતરી કરી પો. ૩૮ ૧૬ હોય તો). પ્લોટિંગ મોડ - પો. ૩૮-૩૮ અને ૩૮ જવાબ "ના" હોય તો.

English to Gujarati

Patient Study No.

## Patient's Understanding of their Illness

How would you describe your current illness/disease?

.....  
.....  
.....  
.....

What does having cancer mean to you?

.....  
.....  
.....  
.....

Were you given booklets about your treatment/illness?    Y     N

Was the written information given in your preferred language?    Y     N

Was the written information understandable?    Y     N

Please add below any additional comments you would like to make

.....  
.....  
.....  
.....

દર્દી અભ્યાસ નં. Patient Study No.

દર્દીઓની તેમની બિમારી વિશેની સમજ Patient's Understanding of their Illness

તમારી હાલની બિમારીનું તમે કઈરીતે વર્ણન કરશો? How would you describe your current illness/disease?

.....  
.....  
.....

કેન્સર હોવું તેનો મતલબ તમને શું લાગે છે? What does having cancer mean to you?

.....  
.....  
.....

તમારી સારવાર/બિમારી વિશે તમને માહિતીપત્રિકાઓ આપવામાં આવી હતી?

હા  ના

Were you given booklets about your treatment/illness?

શું લેખિત માહિતી તમારી પસંદગીની ભાષામાં આપવામાં આવી હતી?

હા  ના

Was the written information given in your preferred language?

શું લેખિત માહિતી સમજી શકાય તેવી હતી?

હા  ના

Was the written information understandable?

મહેરબાની કરીને જો તમે કોઈ સૂચનો કરવા માંગતા હો તો નીચે જણાવો

Please add below any additional comments you would like to make

.....  
.....  
.....

**PATIENT PROFILE**

**Patient Study No**

**Ethnic Origin**

I would describe myself as:

English	<input type="checkbox"/>	Indian	<input type="checkbox"/>	Black Caribbean	<input type="checkbox"/>
Scottish	<input type="checkbox"/>	Pakistani	<input type="checkbox"/>	Black African	<input type="checkbox"/>
Welsh	<input type="checkbox"/>	Bangladeshi	<input type="checkbox"/>	Black other	<input type="checkbox"/>
British	<input type="checkbox"/>	British/English/Asian	<input type="checkbox"/>		<input type="checkbox"/>
European	<input type="checkbox"/>	Sri Lankan	<input type="checkbox"/>		<input type="checkbox"/>
White other	<input type="checkbox"/>	Chinese	<input type="checkbox"/>		<input type="checkbox"/>
Other*	<input type="checkbox"/>				<input type="checkbox"/>

\* If other  
please state .....

**Country/Continent/Region of Birth**

**Languages Spoken**

England	<input type="checkbox"/>	India	<input type="checkbox"/>
Scotland	<input type="checkbox"/>	Pakistan	<input type="checkbox"/>
Wales	<input type="checkbox"/>	Bangladesh	<input type="checkbox"/>
Britain	<input type="checkbox"/>	Sri Lanka	<input type="checkbox"/>
Europe	<input type="checkbox"/>	African	<input type="checkbox"/>
Other*	<input type="checkbox"/>	Caribbean	<input type="checkbox"/>

Gujarati	<input type="checkbox"/>
Hindi	<input type="checkbox"/>
Punjabi	<input type="checkbox"/>
Urdu	<input type="checkbox"/>
Tamil	<input type="checkbox"/>
English	<input type="checkbox"/>

\* If other  
please state .....

**Religion**

**Educational Attainment**

Christian	<input type="checkbox"/>
Hindu	<input type="checkbox"/>
Muslim	<input type="checkbox"/>
Buddhist	<input type="checkbox"/>
None	<input type="checkbox"/>
Other*	<input type="checkbox"/>

\* If other  
please state .....

No formal education	<input type="checkbox"/>
Junior School (up to age 11)	<input type="checkbox"/>
Senior School (up to 15 – 16)	<input type="checkbox"/>
Sixth form (age 16 – 18)	<input type="checkbox"/>
College of University	<input type="checkbox"/>
Other*	<input type="checkbox"/>

\* If other  
please state.....

દર્દીનું ટૂંકું રેખાચિત્ર Patient Profile

દર્દી અભ્યાસ નં. Patient Study No   

## માનવ સમુદાયનું ઉગમ Ethnic Origin

હું મારી જાનને આ રીતે વર્ણવી શકું I would describe myself as:

અંગ્રેજી English	<input type="checkbox"/>	ભારતીય Indian	<input type="checkbox"/>	બ્લેક કારિબિયન Black Caribbean	<input type="checkbox"/>
સ્કોટીશ Scottish	<input type="checkbox"/>	પાકિસ્તાની Pakistani	<input type="checkbox"/>	બ્લેક આફ્રિકન Black African	<input type="checkbox"/>
વેલ્શ Welsh	<input type="checkbox"/>	બાંગ્લાદેશી Bangladeshi	<input type="checkbox"/>	બ્લેક બીજા Black other	<input type="checkbox"/>
બ્રિટિશ British	<input type="checkbox"/>	બ્રિટિશ/અંગ્રેજી/એશિયન British/English/Asian	<input type="checkbox"/>		<input type="checkbox"/>
યુરોપિયન European	<input type="checkbox"/>	શ્રીલંકન Sri Lankan	<input type="checkbox"/>		<input type="checkbox"/>
બોરા(બીજા) White other	<input type="checkbox"/>	આફ્રિકન African	<input type="checkbox"/>		<input type="checkbox"/>
બીજા* Other	<input type="checkbox"/>	ચાઇનીઝ Chinese	<input type="checkbox"/>		<input type="checkbox"/>

\* બીજા તો મહેરબાની કરીને જણાવો If other please state .....

દેશ/ખંડ/જન્મનો પ્રદેશ Country/Continent/Region of Birth	બોલી/ભાષા Language spoken
ઇંગ્લેન્ડ England	ગુજરાતી Gujarati
સ્કોટલેન્ડ Scotland	હિન્દી Hindi
વેલ્શ Wales	પંજાબી Punjabi
બ્રિટન Britain	ઉર્દૂ Urdu
યુરોપ Europe	તમિલ Tamil
બીજા* Other	અંગ્રેજી English

\*બીજા મહેરબાની કરીને જણાવો If other please state .....

ધર્મ Religion	શૈક્ષણિક સિદ્ધિ Educational Attainment
ક્રિસ્તિયન Christian	કોઈ શિક્ષણ નથી No formal education
હિન્દુ Hindu	જૂનિયર સ્કૂલ(11 વર્ષ સુધી) Junior School(upto age 11)
મુસ્લિમ Muslim	સિનિયર સ્કૂલ(15-18 સુધી) Senior School(upto 15-16)
બુદ્ધિસ્ટ Buddhist	6th ફોર્મ(16-18 વર્ષ) Sixth Form (age 16-18)
કોઈપણ નહીં None	કોલેજ/યુનિવર્સિટી College or University
બીજા* Other	બીજા* Other

\*બીજા મહેરબાની કરીને જણાવો  
If other please state .....\*બીજા મહેરબાની કરીને જણાવો  
If other please state .....

## References

- Abdullahi, A., Copping, J., Kessel, A., Luck, M. & Bonell, C., 2009. Cervical screening: Perceptions and barriers to uptake among Somali women in Camden, *Public Health*, 123 (10), pp. 680-685.
- Abramson, L.Y., Metalsky, G.I. & Alloy, L.B., 1989. Hopelessness depression: a theory based subtype of depression, *Psychological Review*, 96 (358), pp. 372.
- Admiraal, J.M., Reyners, A.K. & Hoekstra-Weebers, J.E., 2012. Do cancer and treatment type affect distress? *Psycho-oncology*, Oct 29
- Ahmad, F., Gupta, H., Rawlins, J. & Stewart, D.E., 2002. Preferences for gender of family physician among Canadian European-descent and South-Asian immigrant women, *Family Practice*, 19 (2), pp. 146-153.
- Ahmad, W.I., Kernohan, E.E. & Baker, M.R., 1989. Health of British Asians; a research review, *Community Medicine*, 11(1), pp. 49-56.
- Ahmad, W.I., Kernohan, E.E. & Baker, M.R., 1991. Patients' choice of general practitioner: importance of patients' and doctors' sex and ethnicity, *The British Journal of General Practice*, 41(349), pp. 330-331.
- Ahmed, S.M. & Lemkau, J.P., 2000. Cultural issues in the primary care of South Asians, *Journal of Immigrant Health*, 2 (2), pp. 89-96.

- Akechi, T., Okuyama, T., Imoto, S., Yamawaki, S. & Uchitomi, Y., 2001. Biomedical and psychosocial determinants of psychiatric morbidity among postoperative ambulatory breast cancer patients, *Breast Cancer Research and Treatment*, 65 (3), pp.195-202.
- 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, *Journal of Clinical Oncology* 22 (10), pp.1957-1965.
- Alexandraki, I. & Mooradian, A.D., 2010. Barriers related to mammography use for breast cancer screening among minority women, *Journal of the National Medical Association*, 102 (3), pp. 206-218.
- Ali, N., Atkins, K., Neal, R., 2006. The role of culture in the general practice consultation process *Ethnicity and Health*, 11(4), pp. 389-408.
- Allen, M., Allen, J., Hogarth, S with Marmot, M., 2013. *Working for Health Equity: the role of the health professional*, UCL Institute of Health Equity. Available from <http://www.instituteoftheequity.org/projects/working-for-health-equity-the-role-of-health-professionals> [Accessed 8 April 2013]
- American Psychiatric Association, 1994. *DSM-IV-TR: Diagnostic and statistical manual of mental disorders*, 4th edn, American Psychiatric Association, USA.
- Anand, A.S. & Cochrane, R., 2005. The mental health status of South Asian women in Britain: a review of the UK literature, *Psychology Developing Societies*, 17, pp. 195-214.

- Armstrong, K., McMurphy, S., Dean, L.T. , Micco, E., Putt, M., Halbert, C.H., Schwartz, J.S., Sankar, P., Pyeritz, R.E., Bernhardt, B. & Shea, J.A., 2008. Differences in the patterns of health care system distrust between blacks and whites, *Journal of General Internal Medicine*, 23 (6), pp. 827-833.
- Ashing, K.T., Padilla, G., Tejero, J. & Kagawa-Singer, M., 2003. Understanding the breast cancer experience of Asian American women, *Psycho-Oncology*, 12 (1), pp. 38-58.
- Ashing-Giwa, K.T., Tejero, J.S., Kim, J., Padilla, G.V. & Helleman, G., 2007. Examining predictive models of HRQOL in a population-based, multiethnic sample of women with breast carcinoma, *Quality of Life Research*, 16(3), pp. 413-428.
- Ashram Housing Association, 2008. *Breaking the Silence: a consultation on Mental Ill Health in South Asian Communities. Birmingham*. Available from <http://ashramha.org.uk> [accessed 5 April 2013]
- Aspinall, P.J., 1998. Describing the white ethnic group and its composition in medical research, *Social Science & Medicine* 47(11), pp. 1797-1808.
- Aspinall, P.J., 2002. Collective terminology to describe the minority ethnic population: the persistence of confusion and ambiguity in usage, *Sociology*, 36, pp. 803-816.
- Atesci, F.C., Baltarli, B., Oguzhanoglu, N.K., Karadag, F., Ozdel, O. & Karagoz, N., 2004. Psychiatric morbidity among cancer patients and awareness of illness, *Supportive Care in Cancer*, 12 (3), pp.161-167.

- Aujla, N., Skinner, T.C., Khunti, K. & Davies, M.J., 2009. The prevalence of depressive symptoms in a white European and South Asian population with impaired glucose regulation and screen-detected Type 2 diabetes mellitus: a comparison of two screening tools, *Diabetic Medicine*, 27, pp. 896-905.
- Bahl, V., 1996. Cancer and ethnic minorities: the Department of Health's perspective, *The British Journal of Cancer, supplement*, 29, pp. S2-10.
- Baile, W.F. & Aaron, J., 2005. Patient-physician communication in oncology: past, present, and future, *Current Opinion in Oncology*, 17(4), pp. 331-335.
- Bair, M.J., Robinson, R.L., Katon, W. & Kroenke, K., 2003. Depression and pain comorbidity: a literature review, *Archives of Internal Medicine*, 163(20), pp. 2433-2445.
- Bandura, A., 1997. *Self-efficacy: the exercise of control*. Freeman, New York.
- Banning, M., Hassan, M., Faisal, S. & Hafeez, H., 2010. Cultural interrelationships and the lived experience of Pakistani breast cancer patients, *European Journal of Oncology Nursing*, 14(4), pp. 304-309.
- Barroso, J., McMillan, S., Casey, L., Gibson, W., Kaminski, G. & Meyer, J., 2000. Comparison between African-American and white women in their beliefs about breast cancer and their health locus of control, *Cancer Nursing*, 23(4), pp. 268-276.
- Bates, B.R. & Harris, T.M., 2004. The Tuskegee study of untreated syphilis and public perception of biomedical research: a focus group study, *Journal of the National Medical Association*, 96, pp.1051-1064.

- Baxter, C., 1989. Cancer Support and Ethnic Minority and Migrant Worker Community: A Report Commissioned by Cancerlink cited in Thomas VN, (1997) Cancer and minority ethnic groups: factors likely to improve nurse-patient communication and facilitate the delivery of sensitive care, *Journal of Cancer Nursing*, 1(3) pp134-140, Cancerlink, London.
- BBC News, Leicester, 2011. 11th October 2011, *Mayor of Leicester claims £15 million government funding error*. Available from: <http://www.bbc.co.uk/news/uk-england-leicestershire-15237786> [accessed 18 April 2012].
- BBC News, Leicester, 2012. 12 December 2012, *Leicester: most ethnically diverse in region*, [Online]. Available from: <http://www.bbc.co.uk/news/uk-england-leicestershire-20678326> [accessed 14 December 2012].
- Beck, A.T., Steer, R.A. & Brown, G.K., 1996. *Manual for the Beck Depression Inventory-II*, Psychological Corporation, San Antonio, USA.
- Beck, A.T., Steer, R.A., Kovacs, M. & Garrison, B., 1985. Hopelessness and eventual suicide: a 10 year prospective study of patients hospitalized with suicidal ideation *American Journal of Psychiatry*, 142(5), pp. 559-563.
- Beck, A.T., Weissman, A., Lester, D. & Trexler, L., 1974. The measurement of pessimism: the hopelessness scale, *Journal of Consulting and Clinical Psychology*, 42(6), pp. 861-865.

- Beeken, R.J., Simon, A.E., von Wagner, C., Whitaker, K.L. & Wardle, J., 2011. Cancer fatalism: deterring early presentation and increasing social inequalities? *Cancer Epidemiology, Biomarkers & Prevention*, 20(10), pp. 2127-2131.
- Berkman, N.D., Sheridan, S.L., Donahue, K.E., Halpern, D.J. & Crotty, K., 2011. Low health literacy and health outcomes: an updated systematic review, *Annals of Internal Medicine*, 155(2), pp. 97-107.
- Berry, L.L., Parish, J.T., Janakiraman, R., Ogburn-Russell, L., Couchman, G.R., Rayburn, W.L. & Grisel, J., 2008. Patients' commitment to their primary physician and why it matters, *Annals of Family Medicine*, 6(1), pp. 6-13.
- Bhatnager, K. & Frank, J., 1997. Psychiatric disorders in elderly from the Indian subcontinent living in Bradford, *International Journal of Geriatric Psychiatry*, 12, pp. 907-912.
- 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.
- Bhopal, R., Kohli, H. & Rankin, J., 1997. Editors' practice and views on terminology in ethnicity and health research, *Ethnicity & Health*, 2(3), pp. 223-227.
- Bhopal, R.S., Phillimore, P. & Kohli, H.S., 1991. Inappropriate use of the term 'Asian': an obstacle to ethnicity and health research, *Journal of Public Health Medicine*, 13(4), pp. 244-246.

- Bhugra, D. & Ayonrinde, O., 2004. Depression in migrants and ethnic minorities, *Advances in Psychiatric Treatment*, 10, pp.13-17.
- Bhui, K., Bhugra, D., Goldberg, D., Sauer, J. & Tylee, A., 2004. Assessing the prevalence of depression in Punjabi and English primary care attenders: the role of culture, physical illness and somatic symptoms, *Transcultural Psychiatry*, 41(3), pp. 307-322.
- Bjelland, I., Dahl, A.A., Haug, T.T. & Neckelmann, D., 2002. The validity of the Hospital Anxiety and Depression Scale. An updated literature review, *Journal of Psychosomatic Research*, 52(2), pp. 69-77.
- Bjorck, J.P., Hopp, D.P. & Jones, L.W., 1999. Prostate cancer and emotional functioning, *Journal of Psychosocial Oncology*, 17(1), pp. 71-85.
- Bolam, B., Hodgetts, D., Chamberlain, K. Murphy, S. & Gleeson, K., 2003. Just do it- an analysis of accounts of control over health amongst lower socio-economic status groups, *Critical Public Health*, 13(1), pp. 15-31.
- Bonney, R., 2003. *Understanding and celebrating religious diversity. The growth of diversity in Leicester's places of worship since 1970*, University of Leicester, Leicester, UK.
- Bostock, S. & Steptoe, A., 2012. Association between low functional health literacy and mortality in older adults: longitudinal cohort study, *BMJ (Clinical Research ed.)*, 344, pp. e1602.

- Bottorff, J.L., Johnson, J.L., Bhagat, R., Grewal, S., Balneaves, L.G., Clarke, H. & Hilton, B.A., 1998. Beliefs related to breast health practices: the perceptions of South Asian women living in Canada, *Social Science & Medicine* 47(12), pp. 2075-2085.
- Box, V. & Anderson, Y., 1997. Cancer beliefs, attitudes and preventive behaviours of nurses working in the community, *European Journal of Cancer Care*, 6(3), pp. 192-208.
- Boyes, A.W., Girgis, A., D'Este, C. & Zucca, A.C., 2011. Flourishing or floundering? Prevalence and correlates of anxiety and depression among a population-based sample of adult cancer survivors 6 months after diagnosis, *Journal of Affective Disorders*, 135(1-3), pp. 184-192.
- Bradby, H., 2003. Describing ethnicity in health research, *Ethnicity & Health*, 8(1), pp 5-13.
- Brennan, J., 2001. Adjustment to cancer - coping or personal transition? *Psycho-Oncology*, 10(1), pp. 1-18.
- Brennan, P.L., Holland, J.M., Scutte, K.K. & Moos, R.H., 2012. Coping trajectories in later life: a 20 year predictive study *Aging and Mental Health*, 16(3), pp. 305-316.
- Brislin, R.W., 1970. Back-translation for crosscultural research, *Journal of Cross-Cultural Psychology*, 1, pp. 185-216.

- Broadbent, E., Petrie, K.J., Main, J. & Weinman, J., 2006. The brief illness perception questionnaire, *Journal of Psychosomatic Research*, 60(6), pp. 631-637.
- Brokalaki, E.I., Sotiropoulos, G.C., Tsaras, K. & Brokalaki, H., 2005. Awareness of diagnosis, and information-seeking behavior of hospitalized cancer patients in Greece, *Supportive Care in Cancer*, 13(11), pp. 938-942.
- Brothers, B.M. & Andersen, B.L., 2009. Hopelessness as a predictor of depressive symptoms for breast cancer patients coping with recurrence, *Psycho-Oncology*, 18(3), pp. 267-275.
- Brown, J.E., Butow, P.N., Culjak, G., Coates, A.S. & Dunn, S.M., 2000. Psychosocial predictors of outcome: time to relapse and survival in patients with early stage melanoma, *British Journal of Cancer*, 83(11), pp. 1448-1453.
- Buccheri, G., 1998. Depressive reactions to lung cancer are common and often followed by a poor outcome, *The European Respiratory Journal*, 11(1), pp. 173-178.
- Buckman, R., 1992. *Breaking Bad News: a guide for health care professionals*, 1st edn, John Hopkins University Press, Baltimore, USA.
- Burgess, C., Cornelius, V., Love, S., Graham, J., Richards, M. & Ramirez, A. 2005. Depression and anxiety in women with early breast cancer: five year observational cohort study, *British Medical Journal (Clinical research ed.)*, 330 (7493), pp. 702.

- Bussing, A., Ostermann, T. & Matthiessen, P.F., 2005. Search for meaningful support and the meaning of illness in German cancer patients, *Anticancer Research*, 25(2B), pp. 1449-1455.
- Butler, P., 2012. *India business etiquette and culture*, [Online]. Available from: <http://www.cyborlink.com/besite/india.htm>. [29 February 2012]
- Butow, P.N., Coates, A.S. & Dunn, S.M., 2000. Psychosocial predictors of survival: metastatic breast cancer, *Annals of Oncology*, 11(4), pp. 469-474.
- Calnan, M., Rowe, R. & Entwistle, V., 2006. Trust relations in health care: an agenda for future research, *Journal of Health Organization and Management*, 20( 5), pp. 477-484.
- Calnan, M.W. & Sanford, E., 2004. Public trust in health care: the system or the doctor? *Quality & Safety in Health Care*, 13(2), pp. 92-97.
- Cameron, I.M., Crawford, J.R., Lawton, K. & Reid, I.C., 2008. Psychometric comparison of PHQ-9 and HADS for measuring depression severity in primary care, *The British Journal of General Practice*, 58(546), pp. 32-36.
- Campbell, J.L., Ramsay, J. & Green, J., 2001. Age, gender, socio-economic, and ethnic differences in patients' assessments of primary health care, *Quality in Health Care*, 10(2), pp. 90-95.
- Cancer Research UK, 2006. *Cancer and its inequalities: an introduction to current evidence*, London. [Online]. Available from: <http://www.cancerresearchuk.org>

Cancer Research UK, 2009. 25/9/2009-last update, *Cancer stats-key facts*; [Online]. <http://info.cancerresearchuk.org/cancer.stats> [accessed 2 December 2012].

Cannon, B., Huffman, J.C. & Stern, T.A., 2004. The management of denial. in *Massachusetts General Hospital Guide to Primary Care Psychiatry*, ed. Stern, T.A., Herman, J.B., Slavin, P.L., 2nd edn, McGraw-Hill, New York, pp. 583-587.

Carlson, L.E., Angen, M., Cullum, J., Goodey, E., Koopmans, J., Lamont, L., MacRae, J.H., Martin, M., Pelletier, G., Robinson, J., Simpson, J.S., Speca, M., Tillotson, L. & Bultz, B.D., 2004. High levels of untreated distress and fatigue in cancer patients, *British Journal of Cancer*, 90(12), pp. 2297-2304.

Carpenter, W.R., Godley, P.A., Clark, J.A., Talcott, J.A., Finnegan, T., Mishel, M., Bensen, J., Rayford, W., Su, L.J., Fontham, E.T. & Mohler, J.L., 2009. Racial differences in trust and regular source of patient care and the implications for prostate cancer screening use, *Cancer*, 115(21), pp. 5048-5059.

Carroll, B.T., Kathol, R.G., Noyes, R., Jr, Wald, T.G. & Clamon, G.H., 1993. Screening for depression and anxiety in cancer patients using the Hospital Anxiety and Depression Scale, *General Hospital Psychiatry*, 15( 2), pp. 69-74.

Cartwright, A. & Martin, F.M., 1958. Some popular beliefs concerning the causes of cancer, *British Medical Journal*, 2(5096), pp. 592-594.

Carver, C.S., Scheier, M.F., Weintraub, J.K., 1989. Assessing coping strategies: a theoretical based approach. *Journal of Personality and Social Psychology*, 56, pp 267-283

Carver, C.S., Pozo, C., Harris, S.D., Noreiga, V., Scheier, M.F., Robinson, D.S., Keys, W., Moffat, F.L. & Clark, K.C., 1993. How coping mediates the effect of optimism on distress: a study of women with early stage breast cancer, *Journal of Personality and Social Psychology*, 65, pp. 375-390.

Carver, C.S., 1997. You want to measure coping but your protocol's too long: consider the brief COPE, *International Journal of Behavioural Medicine*, 4, pp 92-110

Cassileth, B.R., Lusk, E.J., Strouse, T.B., Miller, D.S., Brown, L.L. & Cross, P.A., 1985. A psychological analysis of cancer patients and their next-of-kin, *Cancer*, 55(1), pp. 72-76.

Chakravorty, S.G., Chakravorty, S.S., Patel, R.R., DeSouza, C.J. & Doongaji, D.R., 1993. Delay in specialist consultation in cancer patients, *Indian Journal of Cancer*, 30(2), pp. 61-66.

Chandra, P.S., Chaturvedi, S.K., Kumar, A., Subbakrishna, D.K., Channabasavanna, S.M. & Anantha, N., 1998. Awareness of diagnosis and psychiatric morbidity among cancer patients-a study from South India, *Journal of Psychosomatic Research*, 45(3), pp. 257-261.

Chattoo, S., Ahmad, W., Haworth, M. & Lennard, R., 2002. *South Asian and White Patients with advanced cancer: patients and families experiences of the illness and perceived needs of care: (Final Report to CRUK and The Department of Health), Leeds, Centre for Research in Primary Care, University of Leeds, Cancer Research UK, Department of Health, Leeds,UK.*

Chaturvedi, S.K., Chandra, P.S., Channabasavanna, S.M., Anantha, N., Reddy, B.K. M. & Sharma, S., 1996a. Levels of anxiety and depression in patients receiving radiotherapy in India, *Psycho-Oncology*, 5, pp. 343-346.

Chaturvedi, S.K., Shenoy, A., Prasad, K.M., Senthilnathan, S.M. & Premlatha, B.S., 1996b. Concerns, coping and quality of life in head and neck cancer patients, *Supportive Care in Cancer*, 4(3), pp. 186-190.

Chaturvedi, S.K., 2008. Ethical dilemmas in palliative care in traditional developing societies, with special reference to the Indian setting, *Journal of Medical Ethics*, 34(8), pp. 611-615.

Chaturvedi, S.K., Loiselle, C.G. & Chandra, P.S., 2009. Communication with relatives and collusion in palliative care: a cross cultural perspective, *Indian Journal of Palliative Care*, 15(1), pp. 2-9.

Choudhry, U.K., Srivastava, R. & Fitch, M.I., 1998. Breast cancer detection practices of South Asian women: knowledge, attitudes, and beliefs, *Oncology Nursing Forum*, 25(10), pp. 1693-1701.

- Ciaramella, A. & Poli, P., 2001. Assessment of depression among cancer patients: the role of pain, cancer type and treatment, *Psycho-Oncology*, 10(2), pp. 156-165.
- Clarke, J.A., Inui, T.S., Silliman, R.A., Bokhour, B.G., Krasnow, S.H., Robinson, R.A., Spaulding, M., & Talcott, J.A., 2003. Patients' perceptions of quality of life after treatment for early prostate cancer, *Journal of Clinical Oncology*, 21, pp. 3777-3784.
- Classen, C., Koopman, C., Angell, K. & Spiegel, D., 1996. Coping styles associated with psychological adjustment to advanced breast cancer, *Health Psychology*, 15(6), pp. 434-437.
- Clucas, M., 2009. The Irish health disadvantage in England: contribution of structure and identity components of Irish ethnicity, *Ethnicity & Health*, 14( 6), pp. 553-573.
- Cohen, J.W., 1988. *Statistical power analysis for the behavioural sciences*, 2nd edn, Lawrence Erlbaum Associates, Hillsdale, New Jersey.
- Colleoni, M., Mandala, M., Peruzzotti, G., Robertson, C., Bredart, A. & Goldhirsch, A., 2000. Depression and degree of acceptance of adjuvant cytotoxic drugs, *Lancet*, 356(9238), pp. 1326-1327.
- Conrad, M.M. & Pacquiao, D.F., 2005. Manifestation, attribution, and coping with depression among Asian Indians from the perspectives of health care practitioners, *Journal of Transcultural Nursing*, 16(1), pp. 32-40.

- Cordova, M.J., Giese-Davis, J., Golant, M., Kronnenwetter, C., Chang, V., McFarlin, S. & Spiegel, D., 2003. Mood disturbance in community cancer support groups: The role of emotional suppression and fighting spirit, *Journal of Psychosomatic Research*, 55(5), pp. 461-467.
- Craig, G., Atkin, K., Chattoo, S., & Flynn, R., (ed) 2012, Understanding 'race' and ethnicity, *The Policy Press, Bristol, UK*
- Cunningham, P.J., 2009. High medical cost burdens, patient trust and perceived quality of care, *Journal of General Internal Medicine*, 24(3), pp. 415-420.
- Dalal, A.K., 2000. Living with a chronic disease: healing and adjustment in Indian society, *Psychology and Developing Societies*, 12, pp. 67-68-81.
- Das, A.K., Olfson, M., McCurtis, H.L. & Weissman, M.M., 2006. Depression in African Americans: breaking barriers to detection and treatment, *The Journal of Family Practice*, 55(1), pp. 30-39.
- Deepak, N., 2004. *Beyond the barriers: providing cancer information and support for Black and minority ethnic communities*, Cancerbacup, London.
- Deimling, G.T., Wagner, L.J., Bowman, K.F., Sterns, S., Kercher, K. & Kahana, B., 2006. Coping among older-adult, long-term cancer survivors, *Psycho-Oncology*, 15(2), pp. 143-159.
- Dein, S., 2004. Explanatory models of and attitudes towards cancer in different cultures, *The Lancet Oncology*, 5(2), pp. 119-124.

Dein, S., 2005. Attitudes towards cancer among elderly Bangladeshis in London: a qualitative study, *European Journal of Cancer Care*,14(2), pp. 149-150.

Delgado-Rodriguez,M & Lorca,J., 2004. 'Bias', *Journal of Epidemiology& Community Health*, 58, pp. 635-641

Denzin, N.K., 1987. *The alcoholic self*, Sage, Newbury Park, California.

Department of Health,1998. *Independent inquiry into inequalities in health (The Acheson Report)* The Stationery Office, London. Available from: <http://www.archive.official-documents.co.uk/document/doh/ih/ih.htm>  
[Accessed January 2013]

Department of Health, 2000a. *The NHS Plan; A plan for investment, a plan for reform*. The Stationery Office, London. Available from: <http://www.dh.gov.uk/en/Publicationsandstatistics/Publications>, [Accessed January 2013]

Department of Health, 2000b. *National surveys of NHS patients, Cancer: national overview 1999/2000*, The Stationery Office London. Available from: <http://www.dh.gov.uk>, Department of Health, London. [Accessed January 2011]

Department of Health, 2001. *Research governance framework for health and social care*, The Stationery Office, London. Available from [www.dh.gov.uk](http://www.dh.gov.uk)  
[Accessed February 2011]

Department of Health, 2007. *Cancer Reform Strategy*, The Stationery Office, London. Available from

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_081007.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081007.pdf), [Accessed January 2013]

Department of Health / Healthcare Commission, 2008. *Report and analysis of the experience of patients in black and ethnic minority groups*, The Stationery Office, London. Available from

<http://www.dh.gov.uk/en/Publicationsandstatistics/> [Accessed January 2011]

Department of Health, 2009. *Report of the all party parliamentary group on cancer inquiry into inequalities in cancer*. Macmillan Cancer Support, UK.

Available from: <http://www.macmillan.org.uk>, [Accessed January 2013]

Department of Health, 2011. *Improving outcomes a strategy for cancer*. The Stationery office London. Available from

<https://www.gov.uk/government/publications/the-national-cancer-strategy-first-annual-report> [Accessed January 2012]

Department of Health, 2012. *Cancer patient experience survey 2011/12*. The Stationery office, London. Available from:

<https://www.gov.uk/government/publications/second-national-cancer-patient-experience-survey> [Accessed January 2013]

- Dilorio, C., Steenland, K., Goodman, Butler, S., Liff, J. & Roberts, P., 2011. Differences in treatment-based beliefs and coping between African American and white men with prostate cancer, *Journal of Community Health*, 36(4), pp. 505-512.
- Djulgovic, B., Kumar, A., Soares, H.P., Hozo, I., Belper, G., Clarke, M. & Bennett, C.L., 2009. Treatment success in cancer. New cancer treatment successes identified in Phase 3 randomised controlled trials conducted by the National Cancer Institute – Sponsored Co-operative Oncology Groups 1955 to 2006, *Archives of Internal Medicine*, 168, pp. 632-621.
- Do, K., Carpenter, W.R., Spain, P., Clark, J.A., Hamilton, R.J. & Galanko, J.A., 2010. Healthcare access and physician trust among prostate cancer patients, *Cancer Causes & Control*, 21, pp. 31-40.
- Dodd, M.J., Chen, S.G., Lindsey, A.M. & Piper, B.F., 1985. Attitudes of patients living in Taiwan about cancer and its treatment, *Cancer Nursing*, 8(4), pp. 214-220.
- Dogar, I.A., Azeem, I.A., Kiran, M., Hussain, I., Mehmood, K. & Hina, I., 2009. Depression and anxiety in cancer patients in out patient department of a tertiary care hospital in Pakistan, *Pakistan Journal of Medical Science*, 25(5), pp. 734-737.
- Donovan, S., Howell, E., Boyd, J., Graham, C. & Sheldon, H., 2007. *Increasing response rates amongst black and minority ethnic and seldom heard groups*. Picker Institute Europe, Oxford, UK. Available from: <http://www.nhssurveys.org/survey/524> [Accessed 10 March 2013]

- Dunkel-Schetter, C., Feinstein, L.G., Taylor, S.E. & Falke, R.L., 1992. Patterns of coping with cancer, *Health psychology*, 11(2), pp. 79-87.
- Dunn, L.B., Aouizerat, B.E., Cooper, B.A., Dodd, M., Lee, K., West, C., Paul, S.M., Wara, W., Swift, P. & Miaskowski, C., 2012. Trajectories of anxiety in oncology patients and family caregivers during and after radiation therapy, *European Journal of Oncology Nursing*, 16(1), pp. 1-9.
- Economic and Social Research Council (ESRC), 2006. *Final report of the devolution and constitutional change programme: devolution, public attitudes and national identity*, [http://www.devolution.ac.uk/final\\_report.htm](http://www.devolution.ac.uk/final_report.htm), ESRC, UK. [Accessed June, 2010]
- Edrington, J., Sun, A., Wong, C., Dodd, M., Padilla, G., Paul, S. & Miaskowski, C., 2010. A pilot study of relationships among pain characteristics, mood disturbances, and acculturation in a community sample of Chinese American patients with cancer, *Oncology Nursing Forum*, 37(2), pp. 172-181.
- Elam, G., McMunn, A., & Nazroo, J., 2001. *'Feasibility study for health surveys among black African people living in England. Final report – implications for the Health Survey for England 2003'*, Joint Health Surveys Unit of University College, London and the National Centre for Social Research, London.
- Elkin, E.B., Kim, S.H., Casper, E.S., Kissane, D.W. & Schrag, D., 2007. Desire for information and involvement in treatment decisions: elderly cancer patients' preferences and their physicians' perceptions, *Journal of Clinical Oncology*, 25(33), pp. 5275-5280.

Ell, K., Sanchez, K., Vourlekis, B., Lee, P.J., 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, *Journal of Clinical Oncology*, 23(13), pp. 3052-3060.

Ersek, M., 1992. Examining the process and dilemmas of reality negotiation, *Image – the Journal of Nursing Scholarship*, 24(1), pp. 19-25.

ETHNOS Research and Consultancy, 2005. "*Citizenship and belonging: What is Britishness?*" Commission for Racial Equality, London. Available from: [http://ethnos.co.uk/what\\_is\\_britishness\\_CRE.pdf](http://ethnos.co.uk/what_is_britishness_CRE.pdf) [Accessed 10 April 2010]

Facione, N.C., Miaskowski, C., Dodd, M.J. & Paul, S.M., 2002. "The self-reported likelihood of patient delay in breast cancer: new thoughts for early detection", *Preventive Medicine*, 34(4), pp. 397-407.

Fallowfield, L., Hall, A., Maguire, G.P. & Baum, M., 1990b. Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial, *British Medical Journal (Clinical research ed.)*, 301(6752), pp. 575-580.

Fallowfield, L., Ratcliffe, D., Jenkins, V. & Saul, J., 2001. Psychiatric morbidity and its recognition by doctors in patients with cancer, *British Journal of Cancer*, 84(8), pp. 1011-1015.

Finney, N. & Simpson, L., 2009. *Sleepwalking to segregation? Challenging myths about race and migration* First edn, The Policy Press, Bristol.

- Fogarty, L.A., Curbow, B.A., Wingard, J.R., McDonnell, K. & Somerfield, M.R., 1999. Can 40 seconds of compassion reduce patient anxiety? *Journal of Clinical Oncology*, 17(1), pp. 371-379.
- Folkman, S. & Lazarus, R.S., 1980. An analysis of coping in a middle-aged community sample, *Journal of Health and Social Behavior*, 21(3), pp. 219-239.
- Ford, J.G., Howerton, M.W., Lai, G.Y. Gary, T.L., Bolen, S., Gibbons, M.C., Tilburt, J., Baffi, C., Tanpitukpongse, T.P., Wilson, R.F., Powe, N.R. & Bass, E.B., 2008. Barriers to recruiting underrepresented populations to cancer clinical trials: a systematic review, *Cancer*, 112(2), pp. 228-242.
- Ford, S., Lewis, S. & Fallowfield, L., 1995. Psychological morbidity in newly referred patients with cancer, *Journal of Psychosomatic Research*, 39(2), pp. 193-202.
- Free, C. & McKee, M., 1998. The new NHS: from specialist services to special groups. Meeting the needs of black and minority ethnic groups, *British Medical Journal(Clinical research ed.)*, 316(7128), pp. 380.
- Freeman, H.P., 1989. Cancer in the socio-economically disadvantaged, *CA: a Cancer Journal for Clinicians*, 39(5), pp. 266-288.
- Freud, A., 1961. *The ego and the mechanisms of defense*, Hogarth, London.
- Fu, O.S., Crew, K.D., Jacobson, J.S., Greenlee, H., Yu, G., Campbell, J., Ortiz, Y., Hershman, D.L., 2009. Ethnicity and persistent symptom burst in breast cancer survivors *Journal of cancer survivorship*, 3, pp.241-250

- Furnham, A., Petrides, K.V. & Temple, J., 2006. Patient preferences for medical doctors, *British Journal of Health Psychology*, 11(pt 3), pp. 439-449.
- Gansler, T., Henley, S.J., Stein, K., Nehl, E.J., Smigal, C. & Slaughter, E., 2005. Socio-demographic determinants of cancer treatment health literacy, *Cancer*, 104(3), pp. 653-660.
- Gass, K.A. & Chang, A.S., 1989. Appraisals of bereavement, coping, resources, and psychosocial health dysfunction in widows and widowers, *Nursing Research*, 38(1), pp. 31-36.
- Gattellari, M., Butow, P.N. & Tattersall, M.H.N., 2001. Sharing decisions in Cancer Care, *Social Science and Medicine*, 52, pp. 1865-1878.
- George, M. & Margolis, M.L., 2010. Race and lung cancer surgery - a qualitative analysis of relevant beliefs and management preferences, *Oncology Nursing Forum*, 37(6), pp. 740-748.
- Gerrish, K., 2001. The nature and effect of communication difficulties arising from interactions between district nurses and South Asian patients and their carers, *Journal of Advanced Nursing*, 33(5), pp. 566-574.
- Ghods, B.K., Roter, D.L., Ford, D.E., Larson, S., Arbelaez, J.J. & Cooper, L.A., 2008. Patient-physician communication in the primary care visits of African Americans and whites with depression, *Journal of General Internal Medicine*, 23(5), pp. 600-606.

- Gilbert, P., Gilbert, J. & Sanghere, J., 2004. A focus group exploration of the impact of izzat, shame, subordination and entrapment on mental health and service use in South Asian women living in Derby, *Mental Health, Religion and Culture*, 7(2), pp. 109-130.
- Glanz, K. & Lerman, C., 1992. Psychosocial impact of breast cancer: A critical review, *Annals of Behavioural Medicine*, 14(3), pp. 204-12.
- Godden, S., Ambler, G. & Pollock, A.M., 2010. Recruitment of minority ethnic groups into clinical cancer research trials to assess adherence to the principles of the Department of Health Research Governance Framework: national sources of data and general issues arising from a study in one hospital trust in England, *Journal of Medical Ethics*, 36(6), pp. 358-362.
- Goldbeck, R., 1997. Denial in physical illness, *Journal of Psychosomatic Research*, 43(6), pp. 575-593.
- Gordon, H.S., Street, R.L., Jr, Sharf, B.F. & Soucek, J., 2006. Racial differences in doctors' information-giving and patients' participation, *Cancer*, 107(6), pp. 1313-1320.
- Goss, E., Lopez, A.M., Brown, C.L., Wollins, D.S., Brawley, O.W. & Raghavan, D., 2009. American society of clinical oncology policy statement: disparities in cancer care, *Journal of Clinical Oncology*, 27(17), pp. 2881-2885.
- Grassi, L., Giraldi, T., Messina, E.G., Magnani, K., Valle, E. & Cartei, G., 2000. Physicians' attitudes to and problems with truth-telling to cancer patients, *Supportive Care in Cancer*, 8(1), pp. 40-45.

Grassi, L., Travado, L., Gil, F., Sabato, S., Rossi, E., Tomamichel, M., Marmai, L., Biancosino, B., Nanni, M.G. & Group, T.S., 2010. Hopelessness and related variables among cancer patients in the Southern European Psycho-Oncology Study (SEPOS), *Psychosomatics*, 51(3), pp. 201-207.

Grassi, L., Travado, L., Moncayo, F.L., Sabato, S., Rossi, E. & SEPOS Group, 2004. Psychosocial morbidity and its correlates in cancer patients of the Mediterranean area: findings from the Southern European Psycho-Oncology Study, *Journal of Affective Disorders*, 83(2-3), pp. 243-248.

GREAT BRITAIN, *Education Act, 1944*, George V1, London. Available from:  
<http://www.legislation.gov.uk/ukpga/Geo6/7-8/31/contents/enacted>  
[Accessed 8 February 2013]

GREAT BRITAIN, *Fisher Education Act, 1918*, George V, London. Available from: <http://www.legislation.gov.uk/ukpga/Geo5/8-9/39/contents>  
[Accessed 8 February 2013]

GREAT BRITAIN, *Race Relations Amendment Act, 2000*, Elizabeth 11 The stationery office. Available from:  
<http://www.legislation.gov.uk/ukpga/2000/34/contents>.  
[Accessed 8 February 2013]

Greer, S. & Watson, M., 1987. Mental adjustment to cancer: its measurement and prognostic importance, *Cancer Surveys*, 6(3), pp. 439-453.

Greer, S., 2008. CBT for emotional distress of people with cancer: some personal observations, *Psycho-Oncology*, 17( 2), pp. 170-173.

- Gregg, J. & Curry, R.H., 1994. Explanatory models for cancer among African-American women at two Atlanta neighbourhood health centers: the implications for a cancer screening program, *Social Science & Medicine*, 39(4), pp. 519-526.
- Grewel, S., Botorff, J.L. & Hilton, B.A., 2005. The influence of family on immigrant South Asian women's health, *Journal of Family Nursing*, 11(3), pp. 242-263.
- Gurm, B.K., Stephen, J., Mackenzie, G., Doll, R., Barroetavena, M.C. & Cadell, S., 2008. Understanding Canadian Punjabi-speaking South Asian women's experience of breast cancer: A qualitative study, *International Journal of Nursing Studies*, 45(2), pp. 266-276.
- Haan, N., 1969. A tripartite model of ego functioning values and clinical and research applications, *The Journal of Nervous and Mental Disease*, 148(1), pp. 14-30.
- Hackett, T.P. & Cassem, N.H., 1974. Development of a quantitative rating scale to assess denial, *Journal of Psychosomatic Research*, 18(2), pp. 93-100.
- Halbert, C.H., Weathers, B., Delmoor, E., Mahler, B., Coyne, J., Thompson, H.S., Have, T.T., Vaughn, D., Malkowicz, S.B. & Lee, D., 2009. Racial differences in medical mistrust among men diagnosed with prostate cancer, *Cancer*, 115(11), pp. 2553-2561.

- Hall, M.A., Dugan, E., Zheng, B. & Mishra, A.K., 2001. Trust in physicians and medical institutions: what is it, can it be measured, and does it matter? *The Milbank Quarterly*, 79(4), pp. 613-39.
- Hall, M.A., Zheng, B., Dugan, E., Camacho, F., Kidd, K.E., Mishra, A. & Balkrishnan, R., 2002. Measuring patients' trust in their primary care providers, *Medical Care Research and Review*, 59(3), pp. 293-318.
- Hall, M.A., 2006. Researching medical trust in the United States, *Journal of Health Organization and Management*, 20(5), pp. 456-467.
- Hansson, M., Chotai, J., Nordstrom, A. & Bodlund, O., 2009. Comparison of two self-rating scales to detect depression: HADS and PHQ-9, *The British Journal of General Practice*, 59(566), pp. 283-8.
- Harrington, C.B., Hansen, J.A., Moskowitz, M., Todd, B.L. & Feuerstein, M., 2010. It's not over when it's over: long-term symptoms in cancer survivors - a systematic review, *International Journal of Psychiatry in Medicine*, 40(2), pp. 163-181.
- Hassanein, K.A.A.M., Musgrove, B.T. & Bradbury, E., 2001. Functional status of patients with oral cancer and its relation to style of coping, social support and psychological status, *British Journal of Oral and Maxillofacial Surgery*, 39, pp. 340-345.
- Heaton, C.J. & Marquez, J.T., 1990. Patient preferences for physician gender in the male genital/rectal exam, *The Family Practice Research Journal*, 10(2), pp. 105-115.

- Heim, E., Valach, L. & Schaffner, M.D., 1997. Coping and psychosocial adaptation: longitudinal effects over time and stages in breast cancer, *Psychosomatic Medicine*, 59, pp. 404-418.
- Helgeson, V.S., Snyder, P., Seltman, H., 2004. Psychological and physical adjustment to breast cancer over 4 years: identifying distinct trajectories of change *Health psychology*, 23(1), pp.3-15
- Henkel, V., Bussfeld, P., Moller, H.J. & Hegerl, U., 2002. Cognitive-behavioural theories of helplessness/hopelessness: valid models of depression? *European Archives of Psychiatry and Clinical Neuroscience*, 252(5), pp. 240-249.
- Herbert, J., 2008. *Negotiating boundaries in the city: migration, ethnicity and gender in Britain*, Ashgate, London.
- Hewitt, M., Greenfield, S. & Stovall, E., (eds) 2006. *From cancer patient to cancer survivor: lost in transition by the Committee on cancer survivorship :improving care and quality of life*, Institute of Medicine and National Research Council, 1st edn, The National Academies Press, USA.
- Heyland, D.K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., Shortt, S., Tranmer, J., Lazar, N., Kutsogiannis, J., Lam, M. et al. & Canadian Researchers End-of-Life Network(CARENET)., 2006. What matters most in end-of-life care: perceptions of seriously ill patients and their family members, *Canadian Medical Association Journal*, 174(5), pp. 627-633.

- Hillen, M.A., Onderwater, A.T., van Zwieten, M.C. de Haes, H.C. & Smets, E.M., 2011. Disentangling cancer patients' trust in their oncologist: a qualitative study, *Psycho-Oncology*. Apr; 21(4) pp.392-9.
- Hilton, B.A., Grewal, S., Popatia, N., Bottorff, J.L., Johnson, J.L., Clarke, H., Venables, L.J., Bilkhu, S. & Sumel, P., 2001. The desi way: traditional health practices of south Asian women living in Canada, *Health Care for Women International*, 22, pp. 553-554-567.
- Hinz, A., Krauss, O., Hauss, J.P., 2010. Anxiety and depression in cancer patients compared with the general population, *European Journal of Cancer Care*, 19(4), pp. 522-529.
- Hipkins, J., Whitworth, M., Tarrier, N. & Jayson, G., 2004. Social support, anxiety and depression after chemotherapy for ovarian cancer: a prospective study, *British Journal of Health Psychology*, 9(4), pp. 569-581.
- Holland, J.C., Breitbart, W.S., Jacobsen, P.B., Lederberg, M.S., Loscalzo, M.J. & McCorkle, R. (eds) 2010. *Psycho-Oncology*, 2nd edn, Oxford University Press, USA.
- Hopko, D.R., Bell, J.L., Armento, M.E.A., Robertson, S.M.C., Hunt, M.K., Wolf, N.J. & Mullane, C., 2008. The phenomenology and screening of clinical depression in cancer patients, *Journal of Psychosocial Oncology*, 26(1,) pp. 31-51.
- Hopwood, P. & Stephens, R.J., 2000. Depression in patients with lung cancer: prevalence and risk factors derived from quality-of-life data, *Journal of Clinical Oncology*, 18(4), pp. 893-903.

- Horowitz, M.J., 1988, *Introduction to Psychodynamics*, Basic Books Inc, New York.
- Hotopf, M., Chidgey, J., Addington-Hall, J. & Ly, K.L., 2002. Depression in advanced disease: a systematic review Part 1. Prevalence and case finding, *Palliative Medicine*, 16(2), pp. 81-97.
- Hoyer, M., Johansson, B., Nordin, K., Bergkvist, L., Ahlgren, J., Lidin-Linqvist, A., Lambe, M. & Lampic, C., 2011. Health-related quality of life among women with breast cancer-a population-based study, *Acta Oncologica*, 50(7), pp. 1015-1026.
- Hudson, P.L., Thomas, K., Trauer, T., Remedios, C. & Clarke, D., 2011. Psychological and social profile of family caregivers on commencement of palliative care, *Journal of Pain and Symptom Management*, 41(3), pp. 522-534.
- Husain, M.I., Waheed, W. & Husain, N., 2006. Self-harm in British South Asian women: psychosocial correlates and strategies for prevention, *Annals of General Psychiatry*, 5, pp. 7.
- Hussain-Gambles, M., Atkin, K. & Leese, B., 2006. South Asian participation in clinical trials: the views of lay people and health professionals, *Health Policy* 77(2), pp. 149-165.
- Hussain-Gambles, M., Leese, B., Atkin, K., Brown, J., Mason, S. & Tovey, P., 2004. Involving South Asian patients in clinical trials, *Health Technology Assessment (Winchester, England)*, 8(42), pp. iii, 1-109.

INDIAN CONSTITUTION, *The right of children to free and compulsory education Act*, 2009, Available from:

<http://164.100.24.219/BillsTexts/RBillTexts/PassedRajyaSabha/right%20of%20children%20AS%20PASSED.pdf> [2013, March/31]

Information Commissioner's Office, 2010. June 15 2010-last update, *Poor data security in the NHS*: [www.ico.gov.uk](http://www.ico.gov.uk) [Accessed 21 March 2012].

Ipsos MORI / BMA, 2011. 27 July 2011-last update, *Doctors are most trusted profession-politicians least trusted* [Homepage of Ipsos MORI], [Online].: <http://www.ipsos-mori.com/researchpublications/researcharchive/2818/Doctors-are-most-trusted-profession-politicians-least-trusted.aspx> [ Accessed 23 September 2011].

Ipsos MORI / Healthcare Commission, 2006. 30 October 2006-last update, *Understanding public and patient attitudes to the NHS* [Homepage of Ipsos MORI], [Online]. <http://www.ipsos-mori.com/researchpublications/researcharchive/306/Understanding-Public-And-Patient-Attitudes-To-The-NHS.aspx> [ Accessed 23 September 2011].

Islam, M., 1995. Bangladeshi migration: an impact study in *The Cambridge Survey of World Migration*, ed. R. Cohen, 1st edn, Cambridge University Press, Cambridge, pp. 360-366.

- Jacob, K.S., Bhugra, D., Lloyd, K.R. & Mann, A.H., 1998. Common mental disorders, explanatory models and consultation behaviour among Indian women living in the UK, *Journal of the Royal Society of Medicine*, 91(2), pp. 66-71.
- Jadoon, N.A., Munir, W., Shahzad, M.A. & Choudhry, Z.S., 2010. Assessment of depression and anxiety in adult cancer outpatients: a cross-sectional study, *BMC Cancer*, 10, pp. 594.
- Jamal, D. & Dugdale, G., 2010., [last update 30/3/2010], *Literacy: State of the Nation: A picture of literacy in the*, [Online]. Available from: [http://www.literacytrust.org.uk/assets/0000/3816/FINAL\\_Literacy\\_State\\_of\\_the\\_Nation\\_-\\_30\\_March\\_2010.pdf](http://www.literacytrust.org.uk/assets/0000/3816/FINAL_Literacy_State_of_the_Nation_-_30_March_2010.pdf) [accessed 8 December 2012].
- James, A., Daley, C.M. & Greiner, K.A., 2011. Cutting on cancer: attitudes about cancer spread and surgery among primary care patients in the U.S.A, *Social Science & Medicine*, 73(11), pp. 1669-1673.
- Janis, I.L., 1958. *Psychological stress. Psychoanalytic and Behavioural Studies of Surgical Patients*, 1st edn, Wiley, New York.
- Jarvis, M., 2004. *Psychodynamic psychology: classical theory and contemporary research* 1st edn, Thomson Learning, London.
- Jenkins, R., Bebbington, P., Brugha, T.S., Farrell, M., Lewis, G. & Meltzer, H., 1998. British psychiatric morbidity survey, *The British Journal of Psychiatry*, 173, pp. 4-7.

Jivraj, S., 2013. How can we count immigration and integration? The Dynamics of Diversity: evidence from the 2011 census, Centre on Dynamics of ethnicity, University of Manchester. Accessible from [http://www.ethnicity.ac.uk/census/869\\_CCSR\\_Bulletin\\_Counting\\_the\\_immigrant\\_population\\_v5.pdf](http://www.ethnicity.ac.uk/census/869_CCSR_Bulletin_Counting_the_immigrant_population_v5.pdf) [Accessed 8 April 2013]

Jobanputra, R. & Furnham, A., 2005. British Gujarati Indian immigrants' and British Caucasians' beliefs about health and illness, *The International Journal of Social Psychiatry*, 51(4), pp. 350-364.

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, pp. 283.

Johnson, J.L., Bottorff, J.L., Balneaves, L.G., Grewal, S., Bhagat, R., Hilton, B.A. & Clarke, H., 1999. South Asian womens' views on the causes of breast cancer: images and explanations, *Patient Education and Counseling*, 37(3), pp. 243-254.

Johnson, M.R.D., Owen, D., Blackburn, C., Rehman, H. & Nazroo, J., 2000. *Black and Minority Ethnic Groups in England: The Second Health and lifestyles Survey*, London Health Education Authority, London.

Johnston, P., 2001. *Tory MP leads English protest over census*, 23rd April edn, The Daily Telegraph, London.

- Kaiser, K., Rauscher, G.H., Jacobs, E.A., Strenski, T.A., Ferrans, C.E. & Warnecke, R.B. 2011. The import of trust in regular providers to trust in cancer physicians among white, African American, and Hispanic breast cancer patients, *Journal of General Internal Medicine*, 26(1), pp. 51-57.
- Kangas, M., Henry, J.L. & Bryant, R.A. 2007. Correlates of acute stress disorder in cancer patients, *Journal of Traumatic Stress*, 20(3), pp. 325-334.
- Kaptein, A.A., Yamaoka, K., Snoei, L. Kobayashi, K., Uchida, Y., van der Kloot, W.A., Tabei, T., Kleijn, W.C., Koster, M., Wijnands, G., Kaajan, H., Tran, T., Inoue, K., van Klink, R., van Dooren-Coppens, E., Dik, H., Hayashi, F., Willems, L., Annema-Schmidt, D., Annema, J., van der Maat, B., van Kralingen, K., Meirink, C., Ogoshi, K., Aaronson, N., Nortier, H. & Rabe, K. 2011. Illness perceptions and quality of life in Japanese and Dutch patients with non-small-cell lung cancer, *Lung Cancer*, 72(3), pp. 384-390.
- Karasz, A. 2005. Cultural differences in conceptual models of depression, *Social Science & Medicine*, 60(7), pp.1625-1635.
- Karbani, G., Lim, J.N., Hewison, J., Atkins, K., Horgan, K., Lansdowne, M., Chu, C.E, I, 2011. Culture, attitude and knowledge about breast cancer and preventative measures: a qualitative study of South Asian breast cancer patients in the UK, *Asian Pacific Journal of Cancer Prevention*, 12(5), pp. 1619-1629.
- Karim, K., Bailey, M. & Tunna, K. 2000. Non white ethnicity and the provision of specialist palliative care services: factors affecting doctors' referral patterns, *Palliative Medicine*, 14(6), pp. 471-478.

Keefe, D.M., Schubert, M.M., Elting, L.S. ., Sonis, S.T., Epstein, J.B., Raber-Durlacher, J.E., Migliorati, C.A., McGuire, D.B., Hutchins, R.D., Peterson, D.E & Mucositis Study Section of the Multinational Association of Supportive Care in Cancer and the International Society for Oral Oncology, 2007. Updated clinical practice guidelines for the prevention and treatment of mucositis, *Cancer*, 109(5), pp. 820-831.

Kelly, M.M., Tyrka, A.R., Price, L.H. & Carpenter, L.L., 2008. Sex differences in the use of coping strategies: predictors of anxiety and depressive symptoms, *Depression and Anxiety*, 25(10), pp. 839-846.

Kendrick, T., Dowrick, C., McBride,, A. Howe, A., Clarke, P., Maisey, S., Moore, M. & Smith, P.W., 2009. Management of depression in UK general practice in relation to scores on depression severity questionnaires: analysis of medical record data, *British Medical Journal (Clinical research ed.)*, 338, pp. 750.

Kerssens, J.J., Bensing, J.M. & Andela, M.G., 1997. Patient preference for genders of health professionals, *Social science & Medicine*, 44(10), pp. 1531-1540.

Kessels, R.P. 2003. Patients' memory for medical information, *Journal of the Royal Society of Medicine*, 96(5), pp. 219-222.

King, M., Nazareth, I., Levy, G. 2008. Prevalence of common mental disorders in general practice attendees across Europe, *The British Journal of Psychiatry*, 192(5), pp. 362-367.

- Kishore, J., Ahmad, I., Kaur, R. & Mohanta P, K., 2008. Beliefs and perceptions about cancers among patients attending radiotherapy OPD in Delhi, India, *Asian Pacific Journal of Cancer Prevention*, 9(1), pp. 155-158.
- Kissane, D.W., Maj, M. & Sartorius, N., (eds) 2011. *Depression and Cancer*, 1st edn, Wiley-Blackwell, West Sussex, UK.
- Kochhar, P.H., Rajadhyaksha, S.S. & Suvarna, V.R., 2007. Translation and validation of brief patient health questionnaire against DSM IV as a tool to diagnose major depressive disorder in Indian patients, *Journal of Postgraduate Medicine*, 53(2), pp. 102-107.
- Kohli, N. & Dala, A.K., 1998. Culture as a factor in causal understanding of illness: A study of cancer patients, *Psychology Developing Societies*, 10(2), pp. 115-129.
- Kornblith, A.B., Herr, H.W., Ofman, U.S., Scher, H.I. & Holland, J.C., 1994. Quality of life of patients with prostate cancer and their spouses. The value of a database in clinical care, *Cancer*, 73(11), pp. 2791-2802.
- 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*, 16, pp. 605-613.
- Kroenke, K, Johns, S.A.,Theobod.D., Wu.J.,Tu.W., 2013. Somatic symptoms in cancer patients trajectory over 12 months and impact on functional status and disability Support Care Cancer, 21, pp.765-773.

- Kumar, S., Shaikh, A.J., Khalid, S. & Masood, N., 2010. Influence of patient's perceptions, beliefs and knowledge about cancer on treatment decision making in Pakistan, *Asian Pacific Journal of Cancer Prevention*, 11(1), pp. 251-255.
- Lam, W.W.T., Bonanno, G.A., Mancini, A.D., Ho, S., Chan, M., Hung, W.K., Or, A. Fielding, R., 2010. Trajectories of psychological distress among Chinese women diagnosed with breast cancer, *Psycho Oncology* 19, pp.1044-1051
- Lampic, C., Wennberg, A., Schill, J.E., Glimelius, B., Brodin, O. & Sjoden, P.O., 1994. Coping, psychosocial well-being and anxiety in cancer patients at follow-up visits, *Acta Oncologica* 33(8), pp. 887-894.
- Lane, D.A., Jajoo, J., Taylor, R.S., Lip, G.Y., Jolly, K. & Birmingham Rehabilitation Uptake Maximisation (BRUM) Steering Committee, 2007. Cross-cultural adaptation into Punjabi of the English version of the Hospital Anxiety and Depression Scale, *BMC Psychiatry*, 7, pp. 5.
- Lannin, D.R., Mathews, H.F., Mitchell, J., Swanson, M.S., Swanson, F.H. & Edwards, M.S., 1998. Influence of socio-economic and cultural factors on racial differences in late-stage presentation of breast cancer, *JAMA : the Journal of the American Medical Association*, 279(22), pp. 1801-1807.
- Lazarus, R.S., 1981. Denial its costs and benefits in *Living and dying with cancer*, ed. P. Ahmad, first edn, Elsevier, New York, pp. 179-203.
- Lazarus, R.S., 1983. The costs and benefits of denial in *The Denial of Stress*, ed. S. Breznitz, International Universities Press, New York, pp. 1-30.

- Lazarus, R.S., 1993. Coping theory and research: past, present, and future, *Psychosomatic Medicine*, 55(3), pp. 234-247.
- Lazarus, R.S., Folkman, S. & Adams, S. 1984. *Stress, appraisal and coping*, Springer, New York.
- Lee, Y.Y. & Lin, J.L., 2009. Trust but verify: the interactive effects of trust and autonomy preferences on health outcomes, *Health Care Analysis : Journal of Health Philosophy and Policy*,17(3), pp. 244-260.
- Leicester City Council, 2008. *Annual Local Area Labour Force Survey 2002-3*, cited in *The Diversity of Leicester; A Demographic Profile*, 2008, Available from: <http://www.leicester.gov.uk/your-council-services/council-and-democracy/city-statistics/languagestatistics/> [Accessed 31 March 2013]
- Leicester City Council, 2011. Available from: <http://www.leicester.gov.uk/your-council-services/council-and-democracy/city-statistics/languagestatistics/> [Accessed 31<sup>st</sup> March 2013]
- Levene, I. & Parker, M., 2011. Prevalence of depression in granted and refused requests for euthanasia and assisted suicide: a systematic review, *Journal of Medical Ethics*, 37(4), pp. 205-211.
- Leventhal, H., Nerenz,D.R., Steele,D.J., 1984. Illness representations and coping with health threats in *Handbook of Psychology and Health, Volume IV: social psychological aspects of health*, eds. A. Baum, S.E. Taylor & J.E. Singer, Erlbaum, Hillside, New Jersey, pp. 219-252.

- Levin, T.T. & Alici, Y., 2010. Anxiety Disorders in *Psycho-Oncology*, ed. J. Holland C., 2nd edn, pp. 324.
- Lewis, P.A., Charny, M., Lambert, D. & Coombes, J., 1989. A fatalistic attitude to health amongst smokers in Cardiff, *Health Education Research; Theory and Practice*, 4(3), pp. 361-365.
- Livneh, H., 2000. Psychosocial adaptation to cancer: the role of coping strategies, *Journal of Rehabilitation*, 66(2), pp. 40-49.
- Livneh, H., 2009. Denial of chronic illness and disability: part II, research findings, measurement considerations, and clinical aspects, *Rehabilitation Counselling Bulletin*, 53, pp. 44-55.
- Lo, C., Zimmermann, C., Rydall, A., Walsh, A., Jones, J.M., Moore, M.J., Shepherd, F.A., Gagliese, L. & Rodin, G., 2010. Longitudinal study of depressive symptoms in patients with metastatic gastrointestinal and lung cancer, *Journal of Clinical Oncology*, 28(18), pp. 3084.
- LoConte, N.K., Eckhoff, J., Hyde, J. & Schiller, J.H., 2008. Assessment of guilt and shame in patients with non small cell lung cancer compared with patients with breast and prostate cancer, *Clinical Lung Cancer*, 9(3), pp. 171-178.
- Lorant, V., Deliege, D., Eaton, W., Robert, A., Philippot, P. & Anseau, M., 2003. Socio-economic inequalities in depression: a meta-analysis, *American Journal of Epidemiology*, 157(2), pp. 98-112.

- Lord, K., Mitchell, A.J., Ibrahim, K., Kumar, S., Rudd, N. & Symonds, P. 2011.  
The beliefs and knowledge of patients newly diagnosed with cancer in a UK ethnically diverse population, *Clinical Oncology*. 24, pp. 4-12.
- Lord, K, Ibrahim, K., Kumar, S., Rudd, N., Mitchell, A.J & Symonds, P. 2012  
Measuring trust in healthcare professionals- A study of ethnically diverse UK cancer patients, *Clinical Oncology*. 24, pp 13-21
- Lord, K.W.E., Ibrahim, K., Kumar, S., Mitchell, A.J., Rudd, N. & Symonds, R.P.  
Are depressive symptoms more common among British South Asian compared to British White cancer patients; a cross sectional study, *British Medical Journal 'Open'* 2013;3:e002650.
- Luckett, T., Goldstein, D., Butow, P.N., Gebiski, V., Aldridge, L.J., McGrane, J., Ng, W. & King, M.T., 2011. Psychological morbidity and quality of life of ethnic minority patients with cancer: a systematic review and meta-analysis, *The Lancet Oncology*, 12(13), pp. 1240-1248.
- Mainous, A.G., Kern, D., Hainer, B., Kneuper-Hall, R., Stephens, J. & Geesey, M.E., 2004. The relationship between continuity of care and trust with stage of cancer at diagnosis, *Family Medicine*, 36(1), pp. 35-39.
- Major, B. & Schmader, T., 1998. Coping and stigma through psychological disengagement in *Prejudice: The Target's Perspective*, eds. J.K. Swim & C. Stangor, Academic Press, San Diego, California, pp. 219-241.
- Makrilia, N., Indeck, B., Syrigos, K. & Saif, M.W., 2009. Depression and pancreatic cancer: a poorly understood link, *Journal of the Pancreas*, 10(1), pp. 69-76.

- Margolis, M.L., Christie, J.D., Silvestri, G.A., Kaiser, L., Santiago, S. & Hansen-Flaschen, J., 2003. Racial differences pertaining to a belief about lung cancer surgery: results of a multicenter survey, *Annals of Internal Medicine*, 139(7), pp. 558-563.
- Marmot, M., 2010, *Fair Society, Healthy Lives; A strategic review of health inequalities in England post-2010*, Institute of Health Equity. Available from <http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review> [Accessed February 2011/March 2013]
- Massie, M.J., 2004. Prevalence of depression in patients with cancer, *Journal of the National Cancer Institute Monographs*, 32(32), pp. 57-71.
- McCaul, K.D., Sandgren, A.K., King, B., O'Donnell, S., Branstetter, A. & Foreman, G., 1999. Coping and adjustment to breast cancer, *Psycho-Oncology*, 8(3), pp. 230-236.
- McFall, S.L., 2012, *Understanding society: findings 2012*. Institute for social and economic research, University of Essex, Colchester.
- McKinstry, B., Ashcroft, R.E., Car, J., Freeman, G.K. & Sheikh, A., 2006. Interventions for improving patients' trust in doctors and groups of doctors, *Cochrane database of systematic reviews (Online)*, 3, pp. CD004134.
- McPherson, C.J., Wilson, K.G., Lobchuk, M.M. & Brajtman, S., 2007. Self-perceived burden to others: patient and family caregiver correlates, *Journal of Palliative Care*, 23(3), pp. 135-142.

- Mechanic, D. & Meyer, S., 2000. Concepts of trust among patients with serious illness, *Social Science & Medicine*, 51(5), pp. 657-668.
- Mesquita, B., 2001. Emotions in collectivist and individualist contexts, *Journal of Personality and Social Psychology*, 80(1), pp. 68-74.
- Miles, A., Rainbow, S. & von Wagner, C. 2011. Cancer fatalism and poor self-rated health mediate the association between socio-economic status and uptake of colorectal cancer screening in England, *Cancer Epidemiology, Biomarkers & Prevention*, 20(10), pp. 2132-2140.
- Miller, D.L., Manne, S.L., Taylor, K., Keates, J. & Dougherty, J., 1996. Psychological distress and well-being in advanced cancer: The effects of optimism and coping, *Journal of Clinical Psychology in Medical Settings*, 3, pp. 115-130.
- Miller, S.M., 1996. Monitoring and blunting of threatening information in *Cognitive Interference: theory and findings*, eds. I. Sarason G., G. Pierce R. & B. Sarason, Lawrence Erlbaum Associates Inc, New Jersey, pp. 175-187.
- Miller, S.M., Rodoletz, M., Mangan, C.E., Schroeder, C.M. & Sedlacek, T.V., 1996. Applications of the monitoring process model to coping with severe long-term medical threats, *Health Psychology*, 15(3), pp. 216-225.
- Missinne, S. & Bracke, P., 2012. Depressive symptoms among immigrants and ethnic minorities: a population based study in 23 European countries, *Social Psychiatry and Psychiatric Epidemiology*, 47(1) pp. 97-109.
- Mitchell, A.J., 2007, *Personal communication*.

- Mitchell, A.J., Vaze, A. & Rao, S., 2009. Clinical diagnosis of depression in primary care: a meta-analysis, *Lancet*, 374(9690), pp. 609-619.
- Mitchell, A.J., Baker-Glenn, E.A., Granger, L. & Symonds, P., 2010a. Can the Distress Thermometer be improved by additional mood domains? Part I. Initial validation of the Emotion Thermometers tool, *Psycho-Oncology*, 19(2), pp. 125-133.
- Mitchell, A.J., Baker-Glenn, E.A., Park, B., Granger, L. & Symonds, P., 2010b. Can the Distress Thermometer be improved by additional mood domains? Part II. What is the optimal combination of Emotion Thermometers? *Psycho-Oncology*, 19(2), pp. 134-140.
- Mitchell, A.J., Chan, M., Bhatti, H., Halton, M., Grassi, L., Johansen, C. & Meader, N., 2011a. Prevalence of depression, anxiety, and adjustment disorder in oncological, haematological, and palliative-care settings: a meta-analysis of 94 interview-based studies, *The Lancet Oncology*, 12(2), pp. 160-174.
- Mitchell, A.J., Lord, K. & Symonds, R.P., 2011b. *How many people with distress want professional help for their condition*, Poster edn, APOS.
- Mitchell, A.J., Lord, K. & Symonds, P., 2012. Which symptoms are indicative of DSMIV depression in cancer settings? An analysis of the diagnostic significance of somatic and non-somatic symptoms, *Journal of Affective Disorders*, 138(1-2), pp. 137-148.

- Modood, T.R., Berthoud, J., Lakey, J., Nazroo, J., Smith, P., Virdee, S. & Beishon, S., (eds) 1998. *Ethnic Minorities in Britain: diversity and disadvantage*, Policy Studies Institute, London.
- Molassiotis, A., Fernandez-Ortega, P., Pud, D., Ozden, G., Platin, N., Hummerston, S., Scott, J.A., Panteli, V., Gudmundsdottir, G., Selvekerova, S., Patiraki, E. & Kearney, N., 2005. Complementary and alternative medicine use in colorectal cancer patients in seven European countries, *Complementary Therapies in Medicine*, 13(4), pp. 251-257.
- Montazeri, A., Milroy, R., Hole, D., McEwen, J. & Gillis, C.R., 1998b. Anxiety and depression in patients with lung cancer before and after diagnosis: findings from a population in Glasgow, Scotland, *Journal of Epidemiology and Community Health*, 52(3), pp. 203-204.
- Moos, R.H. & Holahan, C.J., 2003. Dispositional and contextual perspectives on coping: toward an integrative framework, *Journal of Clinical Psychology*, 59(12), pp. 1387-1403.
- Moos, R.H. & Schaefer, A., 1984. The Crisis of Physical Illness: an Overview and Conceptual Approach in *Coping with Physical Illness: New Perspectives*, Vol. 2, ed. R.H. Moos, Plenum Press, New York.
- Morgan, C., Park, E. & Cortes, D.E., 1995. Beliefs, knowledge, and behavior about cancer among urban Hispanic women, *Journal of the National Cancer Institute Monographs*, 18(18), pp. 57-63.
- Morgan, P.D., Tyler, I.D. & Fogel, J., 2008. Fatalism revisited, *Seminars in Oncology Nursing*, 24(4), pp. 237-245.

- Morse, R., Kendell, K. & Barton, S., 2005. Screening for depression in people with cancer: the accuracy of the hospital anxiety and depression scale. 9: 188– 196, *Clinical Effectiveness in Nursing*, 9, pp. 188-196.
- Moss-Morris, R., Weinman, J., Petrie, K.J., Horne, R., Cameron, L.D. & Buick, D., 2002. The Revised Illness Perception Questionnaire (IPQ-R), *Psychological Health*, 17, pp. 1-16.
- Moyer, A., Levine, E.G. & Levy, A.G., 1998. Clarification of the conceptualization and measurement of denial in psychosocial oncology research, *Annals of Epidemiology*, 20(3), pp. 149-160.
- Muckaden, M.A., Tulshan, R., Carvalho, M. & Pinto, M., 2005. Psychosocial issues faced by women with incurable cervical cancer in India: How can we help? *Indian Journal of Palliative Care*, 11, pp. 94-97.
- Murray-Garcia, J.L., Selby, J.V., Schmittdiel, J., Grumbach, K. & Quesenberry, C.P. Jr., 2000. Racial and ethnic differences in a patient survey: patients' values, ratings, and reports regarding physician primary care performance in a large health maintenance organization, *Medical Care*, 38(3), pp. 300-310.
- Muslim Women's Network, 2006. *She Who Disputes*. Available from <http://www.mwnuk.co.uk> [accessed 8 April 2013]
- Muthu Kumar, D., Symonds, R.P., Sundar, S., Ibrahim, K., Savelyich, B.S. & Miller, E et al. 2004. Information needs of Asian and White British cancer patients and their families in Leicestershire: a cross-sectional survey, *British Journal of Cancer*, 90(8), pp. 1474-1478.

National Audit Office, 2005. *Tackling cancer: improving the patient journey*  
[http://www.nao.org.uk/publications/0405/tackling\\_cancer.aspx](http://www.nao.org.uk/publications/0405/tackling_cancer.aspx), NAO,  
London. [Accessed November 2012]

National Cancer Institute, 2012. 1/26/2012-last update, *Depression: Overview (Health Professional Version)* [Online]. Available from:  
<http://cancer.gov/cancertopics/pdq/supportivecare/depression/HealthProfessional> [Accessed 2 July 2012].

National Comprehensive Cancer Network (NCCN), 2011. December 10th 2010-last update, *NCCN guidelines: distress management* [Online]. Available from: [http://www.nccn.org/professionals/physician\\_gls/f\\_guidelines.asp](http://www.nccn.org/professionals/physician_gls/f_guidelines.asp) [Accessed 25 September 2011].

National Institute for Health and Clinical Excellence (NICE), 2011. [last update February 2010], *Clinical knowledge summaries (CKS) clinical topics. depression; prevalence* [Online] Available from:  
[http://www.cks.nhs.uk/depression/management/scenario\\_bereavement/view\\_full\\_scenario#-402794](http://www.cks.nhs.uk/depression/management/scenario_bereavement/view_full_scenario#-402794) [Accessed 26 June 2012].

National Institute of Mental Health, 2008. *The numbers count: mental illness in America' 'Science on Our Minds' Fact Sheet series*, [Online]. Available from:  
<http://www.nimh.nih.gov/statistics/index.shtml> [Accessed June, 2012 ].

Nazroo, J.Y., 1997. *Ethnicity and mental health (Report No. 842)*, Policy Studies Institute, London.

Nazroo, J.Y., 2003. The structuring of ethnic inequalities in health: economic position, racial discrimination, and racism cited in 'postnote' ethnicity and health, parliamentary office for science and technology January 2007, no 276, [www.parliament.uk/postnote](http://www.parliament.uk/postnote), *American Journal of Public Health*, 93(2), pp. 277-284.

NCCN (National Comprehensive Cancer Network), 2011. January 2011-last update, *NCCN Clinical Practice Guidelines in Oncology Distress Management* [www.nccn.org](http://www.nccn.org) [Accessed 18 October 2011].

Nelson, K., Geiger, A.M. & Mangione, C.M., 2002. Effect of health beliefs on delay in care for abnormal cervical cytology in a multi ethnic population, *Journal of General Internal Medicine*, 17(9), pp. 705-716.

Newsom-Davis, T., Kenny, L., Al-Shakarchi, I., George, J., Wong, E. & Waxman, J., 2009. Voodoo dolls and the cancer patient: patients do trust their doctors, *QJM : monthly journal of the Association of Physicians*, 102(5), pp. 311-319.

Newton, T.L. & Contrada, R.J., 1994. Alexithymia and repression: contrasting emotion-focused coping styles, *Psychosomatic Medicine*, 56(5), pp. 457-462.

Ngo-Metzger, Q., Kaplan, S.H., Sorkin, D.H., Clarridge, B.R. & Phillips, R.S., 2004. Surveying minorities with limited-English proficiency: does data collection method affect data quality among Asian Americans?, *Medical Care*, 42(9), pp. 893-900.

- Niederdeppe, J. & Levy, A.G., 2007. Fatalistic beliefs about cancer prevention and three prevention behaviors, *Cancer Epidemiology, Biomarkers & Prevention*, 16(5), pp. 998-1003.
- Njoku, M.G., Jason, L.A. & Torres-Harding, S.R., 2005. The relationships among coping styles and fatigue in an ethnically diverse sample, *Ethnicity & Health*, 10(4), pp. 263-278.
- Nordin, K. & Glimelius, B., 1998. Reactions to gastrointestinal cancer--variation in mental adjustment and emotional well-being over time in patients with different prognoses, *Psycho-Oncology*, 7(5), pp. 413-423.
- O'Brien, C.W. & Moorey, S., 2010. Outlook and adaptation in advanced cancer: a systematic review, *Psycho-Oncology*, 19(12), pp. 1239-1249.
- Office for National Statistics, 1992. *1991 Census*, [Online]. Available from: <http://www.ons.gov.uk/ons/guide-method/census/1991-and-earlier-censuses/index.html> [Accessed 2008].
- Office for National Statistics, 2002. *2001 Census* [Online]. Available from: <http://www.ons.gov.uk/index.html> [Accessed 2007-2011].
- Office for National Statistics, 2009a. *2007-08 Citizenship survey report identity and values topic*, chapter 4 'national identity' p20-32 [Online]. Available from: [www.communities.gov.uk](http://www.communities.gov.uk) [Accessed 29 July 2012].

Office for National Statistics, 2009b. *Final recommended questions for the 2011 census in England and Wales-Language* The Stationery Office, London. Available from: <http://www.ons.gov.uk/ons/>. [Accessed January 2010]

Office for National Statistics, 2011b. *Neighbourhood Statistics 'Summary Statistics', citing indices of deprivation, 2007, UK Department for Communities and Local Government*, [Online]. Available from: <http://www.neighbourhood.statistics.gov.uk/> [Accessed 2007-2012].

Office for National Statistics, 2012a. 11 December 2012-last update, 2011 Census, *Table KS201EW; Ethnic groups: local authorities in England and Wales*, [Online] The Stationery Office, London. Available from: <http://www.ons.gov.uk/ons/search/index.html?newquery=KS201EW> [Accessed 5 January 2013]

Office for National Statistics, 2012b. 16 July 2012-last update, 2011 Census; *Table P07; Number of usual residents living in households and communal establishments, local authorities in England and*, [Online]. The Stationery office, London. Available from: <http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-257414> [Accessed 29 July 2012].

Office for National Statistics, 2012c. 11 December 2012-last update, 2011 Census; *Table QS803EW; Length of residence in the UK, local authorities in England and Wales* The Stationery Office, London. [Online]. Available from: <http://www.ons.gov.uk/ons/search/index.html?newquery=QS803EW> [Accessed 16 December 2012].

Office for National Statistics, 2012d. December 11th 2012-last update, 2011

*Census; Table K2209EW; Religion, local authorities in England and Wales*

The Stationery Office, London [Online]. Available from:

<http://www.ons.gov.uk/ons/search/index.html?newquery=religion> [Accessed 13 December 2012].

Office for National Statistics, 2012e. 11 December 2012-last update, 2011

*Census; Table KS206EW; Household languages; local authorities in*

*England and Wales*, The Stationery Office, London. [Online]. Available

from:

<http://www.ons.gov.uk/ons/search/index.html?pageSize=50&sortBy=none&sortDirection=none&newquery=2011+census+language> [Accessed 13 December 2012].

Office for National Statistics, 2013. 26 March 2013-last update, 2011 Census,

Table QS214EW; National Identity (detailed) local authorities in England and

Wales, The Stationery Office, London [Online] Available from:

<http://www.ons.gov.uk/ons/search/index.html?newquery=ethnic+identity>  
[Accessed 29 March 2013]

Ong, K.J., Back, M.F., Lu, J.J., Shakespeare, T.S. & Wynne, C.J., 2002.

Cultural attitudes to cancer management in traditional South-East Asian patients, *Australasian Radiology*, 46(4), pp. 370-374.

Osborne, R.H., Elsworth, G.R. & Hopper, J.L., 2003. Age-specific norms and

determinants of anxiety and depression in 731 women with breast cancer

recruited through a population-based cancer registry, *European Journal of Cancer*, 39(6), pp. 755-762.

- Osborne, R.H., Elsworth, G.R., Kissane, D.W., Burke, S.A. & Hopper, J.L., 1999. The Mental Adjustment to Cancer (MAC) scale: replication and refinement in 632 breast cancer patients, *Psychological Medicine*, 29(6), pp. 1335-1345.
- Ostler, K., Thompson, C., Kinmonth, A.L., Peveler, R.C., Stevens, L. & Stevens, A., 2001. Influence of socio-economic deprivation on the prevalence and outcome of depression in primary care: the Hampshire Depression Project, *The British Journal of Psychiatry*, 178(1), pp. 12-17.
- Pagan, J.A., Balasubramanian, L. & Pauly, M.V. 2007. Physicians' career satisfaction, quality of care and patients' trust: the role of community uninsurance, *Health Economics, Policy, and Law*, 2(4), pp. 347-362.
- Pandey, M., 2004. Quality of life of patients with cancer in India: challenges and hurdles in putting theory into practice, *Psycho-Oncology*, 13(6), pp. 429-433.
- Pandey, M., Thomas, B.C., Ramdas, K. & Nandamohan, V. 2006. Factors influencing distress in Indian cancer patients, *Psycho-Oncology*, 15(6), pp. 547-550.
- Parekh, B., 2000. *Report of the commission on the future of multi-ethnic Britain*, Runnymede Trust, London. Available from:  
<http://www.runnymedetrust.org/projects/meb/report.html>  
[Accessed January 2011]

- Parades, T., Pereira, M., Simoes, M.R., Canavarro, M.C., 2012. A longitudinal study on emotional adjustment of sarcoma patients; the determinant role of demographic, clinical and coping variables, *European Journal of Cancer Care*, 21, pp. 41-51.
- Pargament, K.I., Koenig, H.G., Tarakeshwar, N. & Hahn, J., 2004. Religious coping methods as predictors of psychological, physical and spiritual outcomes among medically ill elderly patients: a two-year longitudinal study, *Journal of Health Psychology*, 9(6), pp. 713-730.
- Parsa,P., Kandiah,M., Rahman,H.A., Mohd Zulkefli,N.A. 2006. Barriers for breast cancer screening among Asian women: a mini literature review, *Asian pacific journal of cancer prevention*, 7, pp.509-514
- Patel, V. & Kleinman, A., 2003. Poverty and common mental disorders in developing countries, *Bulletin of the World Health Organization*, 81, pp. 601-615.
- Peach, C., 2006. Demographics of BrAsian Settlement,1951-2001 in *A Postcolonial People, South Asians in Britain*, eds. A. Ali, V.S. Kalra & S. Sayyid, First edn, Hurst and Company, London, pp. 168-181.
- Petticrew, M., Bell, R. & Hunter, D., 2002. Influence of psychological coping on survival and recurrence in people with cancer: systematic review, *British Medical Journal(Clinical research ed.)*, 325(7372), pp. 1066.
- Pfeffer, N., 2004. Screening for breast cancer: candidacy and compliance, *Social science & Medicine*, 58(1), pp. 151-160.

- Poureslami, I., Rootman, I., Doyle-Waters, M.M., Nimmon, L. & Fitzgerald, J.M., 2011. Health literacy, language, and ethnicity-related factors in newcomer asthma patients to Canada: a qualitative study, *Journal of Immigrant and Minority Health / Center for Minority Public Health*, 13( 2), pp. 315-322.
- Powe, B.D. & Finnie, R., 2003. Cancer fatalism: the state of the science, *Cancer Nursing*, 26(6), pp. 454-65.
- Powe, B.D. & Johnson, A., 1995. Fatalism amongst African Americans: philosophical perspectives, *Journal of Religious Health*, 34(2), pp. 119-125.
- Powe, B.D., 1997. Cancer fatalism-spiritual perspectives, *Journal of Religion and Health*, 36(2), pp. 135-144.
- Powe, B.D., Hamilton, J. & Brooks, P., 2006. Perceptions of cancer fatalism and cancer knowledge: a comparison of older and younger African American women, *Journal of Psychosocial Oncology*, 24(4), pp. 1-13.
- Prieto, J.M., Blanch, J., Atala, J., Carreras, E., Rovira, M., Cirera, E. & Gasto, C., 2002. Psychiatric morbidity and impact on hospital length of stay among hematologic cancer patients receiving stem-cell transplantation, *Journal of Clinical Oncology*, 20(7), pp. 1907-1917.
- Pringle, M. & Rothera, I., 1995. *Ethnic group data collection in primary care: problems and solutions*, University of Nottingham Medical School, Nottingham.

- Rabinowitz, T. & Peirson, R., 2006. Nothing is wrong, doctor: understanding and managing denial in patients with cancer, *Cancer Investigation*, 24(1), pp. 68-76.
- Radloff, L., 1977. The CES-D scale: a self-report depression scale for research in the general, *Applied Psychological Measurement*, 1, pp. 385-401.
- Randhawa, G. & Owens, A., 2004. The meanings of cancer and perceptions of cancer services among South Asians in Luton, UK, *British Journal of Cancer*, 91(1), pp. 62-68.
- Rankin, J. & Bhopal, R., 1999. 'Current census categories are not a good match for identity', *British Medical Journal*, 318, pp. 1696.
- Ray, K. & Mandal, S., 2004. Knowledge about cancer in West Bengal - a pilot survey, *Asian Pacific Journal of Cancer Prevention*, 5(2), pp. 205-212.
- Redeker, C., Wardle, J., Wilder, D., Hiom, S. & Miles, A., 2009. The launch of Cancer Research UK's 'Reduce the Risk' campaign: baseline measurements of public awareness of cancer risk factors in 2004, *European Journal of Cancer*, 45(5), pp. 827-836.
- Richardson, M.A., Sanders, T., Palmer, J.L., Greisinger, A. & Singletary, S.E., 2000. Complementary/alternative medicine use in a comprehensive cancer center and the implications for oncology, *Journal of Clinical Oncology*, 18, (13), pp. 2505-2514.

Rimer, B., Jones, W.L., Keintz, M.K., Catalano, R.B. & Engstrom, P.F., 1984.

Informed consent: a crucial step in cancer patient education, *Health Education Quarterly*, 10(1)Suppl, pp. 30-42.

Robb,K., Stubbings,S., Ramirez,A., Macleod,U., Austoker,J., Waller,J.,

Hiom,S., Wardle,J., 2010. Public awareness of cancer in Britain: a population-based survey of adults, *British Journal of Cancer*, 101 pp. s18-s23

Roberts, C.S., Cox, C.E., Reintgen, D.S., Baile, W.F. & Gibertini, M., 1994.

Influence of physician communication on newly diagnosed breast patients' psychologic adjustment and decision-making, *Cancer*, 74(1)Suppl, pp. 336-341.

Roesch, S.C., Adams, L., Hines, A., Palmores, A., Vyas, P., Tran, C., Pekin, S.

& Vaughn, A.A., 2005. Coping with prostate cancer: a meta-analytic review, *Journal of Behavioral Medicine*, 28(3), pp. 281-293.

Roff, L.L., Simon, C.E., Nelson-Gardell, D. & Pleasants, H.M., 2009. Spiritual

support and African American breast cancer survivors, *Affilia*, 24, pp. 285-299.

Rooney, L.K., Bhopal, R., Halani, L., Levy, M.L., Partridge, M.R., Netuveli, G.,

Car, J., Griffiths, C., Atkinson, J., Lindsay, G. & Sheikh, A., 2011.

Promoting recruitment of minority ethnic groups into research: qualitative study exploring the views of South Asian people with asthma, *Journal of Public Health*, 33(4), pp. 604-615.

- Ross, S., Grant, A., Counsell, C., Gillespie, W., Russell, I. & Prescott, R., 1999. Barriers to participation in randomised controlled trials: a systematic review, *Journal of Clinical Epidemiology*, 52(12), pp. 1143-1156.
- Roth, A.J., Kornblith, A.B., Batel-Copel, L., Peabody, E., Scher, H.I. & Holland, J.C., 1998. Rapid screening for psychologic distress in men with prostate carcinoma: a pilot study, *Cancer*, 82(10), pp. 1904-1908.
- Roth, S. & Cohen, L.J., 1986. Approach, avoidance, and coping with stress, *The American Psychologist*, 41(7), pp. 813-819.
- Rottmann, N., Dalton, S.O., Christensen, J., Frederiksen, K. & Johansen, C., 2010. Self-efficacy, adjustment style and well-being in breast cancer patients: a longitudinal study, *Quality of Life Research*, 19(6), pp. 827-836.
- Roy, R., 2004. *Evaluation of coping strategies among British Asian and British Caucasian patients with their diagnosis of cancer*, dissertation MSc, University of Nottingham, UK.
- Roy, R., Symonds, R.P., Kumar, D.M., Ibrahim, K., Mitchell, A. & Fallowfield, L., 2005. The use of denial in an ethnically diverse British cancer population: a cross-sectional study, *British Journal of Cancer*, 92(8), pp. 1393-1397.
- Salander, P. & Windahl, G., 1999. Does 'denial' really cover our everyday experiences in clinical oncology? A critical view from a psychoanalytic perspective on the use of 'denial', *The British Journal of Medical Psychology*, 72(2), pt 2, pp. 267-279.

Salvo, N., Zeng, L., Zhang, L., Leung, M., Khan, L., Presutti, R., Nguyen, J., Holden, L., Culleton, S. & Chow, E., 2012. Frequency of reporting and predictive factors for anxiety and depression in patients with advanced cancer, *Clinical Oncology*, 24(2), pp. 139-148.

Sanderson, S.C., Waller, J., Jarvis, M.J., Humphries, S.E. & Wardle, J., 2009. Awareness of lifestyle risk factors for cancer and heart disease among adults in the UK, *Patient Education and Counseling*, 74(2), pp. 221-227.

Saunders, C.S., 1967. *The management of terminal illness*, Hospital medicine publications, London.

Schillinger, D., Grumbach, K., Piette, J., Wang, F., Osmond, D., Daher, C., Palacios, J., Sullivan, G.D. & Bindman, A.B., 2002. Association of health literacy with diabetes outcomes, *JAMA*, 288(4), pp. 475-482.

Schou, I., Ekeberg, O., Ruland, C.M., Sandvik, L. & Karesen, R., 2004. Pessimism as a predictor of emotional morbidity one year following breast cancer surgery, *Psycho-Oncology*, 13(5), pp. 309-320.

Schouten, B.C. & Meeuwesen, L., 2006. Cultural differences in medical communication: a review of the literature, *Patient Education and Counseling*, 64(1-3), pp. 21-34.

Schwartz, C.E., Daltroy, L.H., Brandt, U., Friedman, R. & Stolbach, L., 1992. A psychometric analysis of the Mental Adjustment to Cancer scale, *Psychological Medicine*, 22(1), pp. 203-210.

- Sellick, S.M. & Edwardson, A.D., 2007. Screening new cancer patients for psychological distress using the hospital anxiety and depression scale, *Psycho-Oncology*, 16(6), pp. 534-542.
- Seth, T., Kotwal, A., Thakur, R., Singh, P. & Kochupillai, V., 2005. Common cancers in India: knowledge, attitudes and behaviours of urban slum dwellers in New Delhi, *Public Health*, 119(2), pp. 87-96.
- Shah, J.Y., Phadtare, A., Rajgor, D., Vaghasia, M., Pradhan, S., Zelko, H. & Pietrobon, R., 2010. What leads Indians to participate in clinical trials? A meta-analysis of qualitative studies, *PloS one*, 5(5), pp. e10730.
- Sharf, B.F., Stelljes, L.A. & Gordon, H.S., 2005. 'A little bitty spot and I'm a big man': patients' perspectives on refusing diagnosis or treatment for lung cancer, *Psycho-Oncology*, 14(8), pp. 636-646.
- Shavers, C., Bakos, A., Sheppard, V., 2010. Race ethnicity and pain among the US adult population *Journal of Health Care for the Poor and Underserved*, 21(1) pp.1-20.
- Sheikh, A., 2006. Why are ethnic minorities under-represented in US research studies?, *PLoS medicine*, 3(2), pp. e49.
- Shi, Q., Smith, T.G., Michonski, J. D., Stein, K.D., Kaw, C., Cleeland, C.S., 2011. Symptom burden in cancer survivors 1 Year After diagnosis, *Cancer*; 117, pp.2779–2790.

- Shumay, D.M., Maskarinec, G., Kakai, H., Gotay, C.C. & Cancer Research Center of Hawaii, 2001. Why some cancer patients choose complementary and alternative medicine instead of conventional treatment, *The Journal of Family Practice*, 50(12), pp. 1067.
- Singer, S., Kuhnt, S., Gotze, H., Hauss, J., Hinz, A., Liebmann, A., Kraub, O., Lehmann, A. & Schwarz, R., 2009. Hospital anxiety and depression scale cutoff scores for cancer patients in acute care, *British Journal of Cancer*, 100, pp. 908-912.
- Singleton, N., Bumpstead, R., O'Brien, M., Lee, A. & Meltzer, H., 2001. *Psychiatric morbidity among adults living in private households* <http://www.esds.ac.uk/doc/4653%5Cmrdoc%5Cpdf%5C4653userguide2.pdf>, The Stationery Office, London [Accessed February 2008]
- Sirwardene, A.N., 2004. Specific Health Issues in Ethnic Minority Groups, *Diversity in Medicine*, 6(1), pp. 34-42.
- Smith, K., 2002. Some critical observations on the use of the concept of 'ethnicity' in M0dood et al Ethnic Minorities in Britain , *Sociology*, 36(2), pp. 399-417.
- Smith, L.K., Botha, J.L., Benghiat, A. & Steward, W.P., 2003a. Latest trends in cancer incidence among UK South Asians in Leicester, *British Journal of Cancer*, 89(1), pp. 70-73.
- Smith, E.M., Gomm, S.A. & Dickens, C.M., 2003b. Assessing the independent contribution to quality of life from anxiety and depression in patients with advanced cancer, *Palliative Medicine*, 17(6), pp. 509-513.

- Smith, L.K., Pope, C. & Botha, J.L., 2005. Patients' help-seeking experiences and delay in cancer presentation: a qualitative synthesis, *Lancet*, 366( 9488), pp. 825-831.
- Smith, T.B., McCullough, M.E. & Poll, J., 2003b. Religiousness and depression: evidence for a main effect and the moderating influence of stressful life events, *Psychological Bulletin*, 129(4), pp. 614-636.
- Snaith, R.P., 2003. The Hospital Anxiety and Depression Scale, *Health and Quality of Life Outcomes*, 1, pp. 29.
- Soler-Vila, H., Kasl, S.V. & Jones, B.A., 2005. Cancer-specific beliefs and survival: a population-based study of African-American and White breast cancer patients, *Cancer Causes & Control*, 16(2), pp. 105-114.
- Somers, J.M., Goldner, E.M., Waraich, P. & Hsu, L., 2006. Prevalence and incidence studies of anxiety disorders: a systematic review of the literature, *Canadian Journal of Psychiatry*, 51(2), pp. 100-113.
- Sood, A., Prasad, K., Chhatwani, L., Shinozaki, E., Cha, S.S., Loehrer, L.L. & Wahner-Roedler, D.L., 2009. Patients' attitudes and preferences about participation and recruitment strategies in clinical trials, *Mayo Clinic proceedings*,. 84(3), pp. 243-247.
- Spencer, R., Nilsson, M., Wright, A., Pirl, W. & Prigerson, H., 2010. Anxiety disorders in advanced cancer patients: correlates and predictors of end-of-life outcomes, *Cancer*, 116(7), pp. 1810-1819.

- Spitzer, R.L., Kroenke, K. & Williams, J.B., 1999. Validation and utility of a self report version of PRIME-MD: the PHQ primary care study. *Primary Care Evaluation of Mental Disorders, Patient Health Questionnaire, Journal of the American Medical Association*, 282(18), pp. 1737-1744.
- Sproston, K. & Mindell, J., 2004. [last update,2006] *Health Survey for England: The health of minority ethnic groups [Online] Available from: <http://www.ic.nhs.uk/pubs/hse04ethnic>, [Accessed 29 July 2012].*
- Sproston, K. & Nazroo, J.Y., 2002. *Ethnic minority psychiatric illness rates in the community (EMPIRIC): Quantitative Report. Available from:[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH\\_4005698](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsStatistics/DH_4005698), Department of Health, London.*
- Stanton, A.L. & Snider, P.R., 1993. Coping with a breast cancer diagnosis: a prospective study, *Health Psychology*, 12(1), pp. 16-23.
- Stark, D., Kiely, M., Smith, A., Velikova, G., House, A. & Selby, P., 2002. Anxiety Disorders in Cancer Patients: Their Nature, Associations, and Relation to Quality of Life, *Journal of Clinical Oncology*, 20(14), pp. 3137-3148.
- Stark, D.P. & House, A., 2000. Anxiety in cancer patients, *British Journal of Cancer*, 83(10), pp. 1261-1267.

- Stead, M., Cameron, D., Lester, N., Parmar, M., Haward, R., Kaplan, R., Maughan, T., Wilson, R., Campbell, H., Hamilton, R., Stewart, D., O'Toole, L., Kerr, D., Potts, V., Moser, R., Darbyshire, J., Selby, P. & National Cancer Research Networks across the UK, 2011. Strengthening clinical cancer research in the United Kingdom, *British Journal of Cancer*, 104(10), pp. 1529-1534.
- Stefanek, M., McDonald, P.G. & Hess, S.A., 2005. Religion, spirituality and cancer: current status and methodological challenges, *Psycho-Oncology*, 14(6), pp. 450-463.
- Straughan, P.T. & Seow, A., 1998. Fatalism reconceptualized: a concept to predict health screening behavior, *Journal of Gender, Culture and Health*, 3(2), pp. 85-100.
- Suls, J. & Fletcher, B. 1985. The relative efficacy of avoidant and non avoidant coping strategies: a meta-analysis, *Health Psychology*, 4(3), pp. 249-288.
- Sykes, J.B., (ed) 1982. *The Concise Oxford Dictionary of Current English*, 7th edition edn, Clarendon Press, Oxford.
- Symonds, R.P., Lord, K., Mitchell, A.J. & Raghavan, D., 2012. Recruitment of ethnic minorities into clinical trials: experience from the front lines, *British Journal of Cancer*, 107, pp. 1017-1021.
- Syrjala, K.L. & Chapko, M.E., 1995. Evidence for a biopsychosocial model of cancer treatment-related pain, *Pain*, 61(1), pp. 69-79.

- 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, *British Medical Council Public Health*, 8.
- Taylor, S.E. & Armor, D.A., 1996. Positive illusions and coping with adversity, *Journal of Personality*, 64(4), pp. 873-898.
- Taylor, S.E. & Brown, J.D., 1988. Illusion and well-being: a social psychological perspective on mental health, *Psychological Bulletin*, 103(2), pp. 193-210.
- The National Centre for Languages (CILT), *Languages in the population*  
[Homepage of CILT], [Online]. Available from:  
[http://www.cilt.org.uk/home/research\\_and\\_statistics/statistics/languages\\_in\\_the\\_population.aspx](http://www.cilt.org.uk/home/research_and_statistics/statistics/languages_in_the_population.aspx) [Accessed 25 June 2012].
- Thomas, B.C., Devi, N., Sarita, G.P. et al., 2005. Reliability & validity of the Malayalam hospital anxiety & depression scale (HADS) in cancer patients, *The Indian Journal of Medical Research*, 122(5), pp. 395-399.
- Tweed, R.G., White, K. & Lehman, D.R., 2004. Culture, stress and coping: internally-and externally targeted control strategies of European Canadians, East Asian Canadians and Japanese, *Journal of Cross-Cultural Psychology*, 35, pp. 668-652.

U.S. Department of Health and Human Services, 1999. *'Culture Race and Ethnicity: A supplement to 'Mental health: A report of the Surgeon General'*  
Available from: <http://www.ncbi.nlm.nih.gov/books/NBK44243/>, U.S.  
Department of Health and Human Services, Rockville MD. [Accessed  
September 2012]

Umezawa, Y., Lu, Q., You, J., 2012. Belief in divine control, coping, and  
race/ethnicity among older women with breast cancer, *Annals of Behavioral  
Medicine*, 44(1), pp. 21-32.

University Hospitals of Leicester NHS Trust , 2011. *Trusttalk*, April edn,  
University Hospitals of Leicester NHS Trust, Leicester.

Vaillant, G.E., 1979. Health consequences of adaptation to life, *The American  
Journal of Medicine*, 67(5), pp. 732-734.

van der Schee, E., Braun, B., Calnan, M. et al., 2007. Public trust in health care:  
a comparison of Germany, The Netherlands, and England and Wales,  
*Health Policy (Amsterdam, Netherlands)*, 81(1), pp. 56-67.

van't Spijker, A., Trijsburg, R.W. & Duivenvoorden, H.J., 1997. Psychological  
sequelae of cancer diagnosis: a meta-analytical review of 58 studies after  
1980, *Psychosomatic Medicine*, 59(3), pp. 280-293.

Velikova, G., Booth, L., Johnston, C., Forman, D. & Selby, P., 2004. Breast  
cancer outcomes in South Asian population of West Yorkshire, *British  
Journal of Cancer*, 90(10), pp. 1926-1932.

- Verhoef, M.J., Rose, M.S., White, M. & Balneaves, L.G., 2008. Declining conventional cancer treatment and using complementary and alternative medicine: a problem or a challenge? *Current Oncology (Toronto,)*, 15 Suppl 2, pp. s101-6.
- Vogel, B.A., Leonhart, R. & Helmes, A.W., 2009. Communication matters: the impact of communication and participation in decision making on breast cancer patients' depression and quality of life, *Patient Education and Counseling*, 77(3), pp. 391-397.
- Von Elm, E, Altman, DG, Egger M., Altman,D.G., Pocock,S.J., Gotsche,P and Vandebroache, J.P., 2007. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Statement *Epidemiology* 18 (6) p. 800-804.
- Vos, M.S. & de Haes, J.C., 2007. Denial in cancer patients, an explorative review, *Psycho-Oncology*, 16(1), pp. 12-25.
- Walker, J., Hansen, C.H., Butcher, I., Sharma, N., Wall, L., Murray, G. & Sharpe, M., 2011. Thoughts of death and suicide reported by cancer patients who endorsed the Suicidal Thoughts item of the PHQ-9 during routine screening for depression, *Psychosomatics*, 52(5), pp. 424-427.
- Walker, J., Postma, K., McHugh., G.S. Rush, R., Coyle, B., Strong, V. & Sharpe, M., 2007. Performance of the Hospital Anxiety and Depression Scale as a screening tool for major depressive disorder in cancer patients, *Journal of Psychosomatic Research*, 63(1), pp. 83-91.

- Walker, M.S., Zona, D.M. & Fisher, E.B., 2006. Depressive symptoms after lung cancer surgery: Their relation to coping style and social support, *Psycho-Oncology*, 15(8), pp. 684-693.
- Waller, J., Robb, K., Stubbings, S., Ramirez, A., Macleod, U., Austoker, J., Hiom, S. & Wardle, J., 2009. Awareness of cancer symptoms and anticipated help seeking among ethnic minority groups in England, *British Journal of Cancer*, 101, pp. 24-30.
- Wan Chan-Kuk, S., 2000. *Coping and psychological outcomes of newly diagnosed cancer patients and the people without cancer*, thesis, PhD, University of Hong Kong. Available from: <http://sunzi.lib.hku.hk/hkuto/record/B29727595> edn, University of Hong Kong, [Accessed June, 2008]
- Waraich, P., Goldner, E.M., Somers, J.M. & Hsu, L., 2004. Prevalence and incidence studies of mood disorders: a systematic review of the literature, *Canadian Journal of Psychiatry*, 49(2), pp. 124-138.
- Wasteson, E., Brenne, E., Higginson, I.J., Hotopf, M., Lloyd-Williams, M., Kaasa, S., Loge, J.H. & European Palliative Care Research Collaborative (EPCRC), 2009. Depression assessment and classification in palliative cancer patients: a systematic literature review, *Palliative Medicine*, 23(8), pp. 739-753.
- Watson, M., Greer, S., Blake, S. & Shrapnell, K., 1984. Reaction to a diagnosis of breast cancer. Relationship between denial, delay and rates of psychological morbidity, *Cancer*, 53(9), pp. 2008-2012.

- Watson, M., Greer, S., Rowden, L., Gorman, C., Robertson, B., Bliss, J.M. & Tunmore, R., 1991. Relationships between emotional control, adjustment to cancer and depression and anxiety in breast cancer patients, *Psychological Medicine*, 21(1), pp. 51-57.
- Watson, M., Law, M., Dossantos, M., Greer, S., Baruch, J. & Bliss, J.M., 1994. The Mini-Mac; Further development of the mental adjustment to cancer scale, *Journal of Psychosocial Oncology*, 12(3), pp. 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, *Psychological Medicine*, 34(8), pp. 1543-1551.
- Weinman, J., Petrie, K.J., Moss-Morris, R. & Horne, R., 1996. The Illness Perception Questionnaire: a new method for assessing the cognitive representation of illness, *Psychological Health*, 11, pp. 431-445.
- Weisman, A.D. & Hacker, T.P., 1961. Predilection to death: death and dying as a psychiatric problem, *Psychosomatic Medicine*, 23, pp. 323.
- Wells, A.A. & Zebrack, B., 2008. Psychosocial barriers contributing to the under-representation of racial/ethnic minorities in cancer clinical trials, *Social Work in Health Care*, 46(2), pp. 1-14.
- Wheeler, S. & Lord, L., 1999. Denial: a conceptual analysis, *Archives of Psychiatric Nursing*, 8(6), pp. 311-320.

- Wilkinson, C., Khanji, M., Cotter, P.E., Dunne, O. & O'Keeffe, S.T., 2008. Preferences of acutely ill patients for participation in medical decision-making, *Quality & Safety in health Care*, 17(2), pp. 97-100.
- Willgerodt, M., Kataoka-Yahiro, M. & Cerl A, C., 2005. Issues of instrument translation in research in Asian immigrant populations, *Journal of Professional Nursing*, 21(4), pp. 231-239.
- Williams, D.R., Gonzalez, H.M., Neighbors, H., Nesse, R., Abelson, J.M., Sweetman, J. & Jackson, J.S., 2007. Prevalence and distribution of major depressive disorder in African Americans, Caribbean Blacks, and Non-Hispanic Whites: results from the National Survey of American Life, *Archives of General Psychiatry*, 64(3), pp. 305-315.
- Wilson, K.C., Chen, R., Taylor, S., McCracken, C.F. & Copeland, J.R., 1999. Socio-economic deprivation and the prevalence and prediction of depression in older community residents. The MRC-ALPHA Study, *The British Journal of Psychiatry*, 175, pp. 549-553.
- Wold, K.S., Byers, T., Crane, L.A. & Ahnen, D., 2005. What do cancer survivors believe causes cancer? (United States), *Cancer Causes & Control*, 16(2)2, pp. 115-123.
- Wong-Kim, E., Sun, A. & DeMattos, M.C., 2003. Assessing cancer beliefs in a Chinese immigrant community, *Cancer Control: journal of the Moffitt Cancer Center*, 10(5) Suppl, pp. 22-28.

World Business Culture, 2012. *Indian communication*, [Online]. Available from:  
<http://worldbusinessculture.com/Indian-Business-Communication-Style.html>  
[Accessed 28 June 2012].

Wright, E.B., Holcombe, C. & Salmon, P., 2004. Doctors' communication of trust, care, and respect in breast cancer: qualitative study, *British medical Journal (Clinical research ed.)*, 328(7444), pp. 864.

Yi, J.K., Swartz, M.D. & Reyes-Gibby, C.C., 2011. English proficiency, symptoms, and quality of life in Vietnamese- and Chinese-American breast cancer survivors, *Journal of Pain and Symptom Management*, 42(1), pp. 83-92.

Yoon, J., Malin, J.L., Tisnado, M., Adams, J.L., Timmer, M.J., Ganz, P.A., Kahn, K.L., 2008. Symptom management after breast cancer treatment: is it influenced by patient characteristics? *Breast Cancer Research and Treatment*, 108(1), pp. 69-77

Zabora, J.R., Brintzenhofesoc, K., Curbow, B., Hooker, C. & Piantadosi, S., 2001. The prevalence of psychological distress by cancer site, *Psycho-Oncology*, 10(1), pp. 19-28.

Zigmond, A.S. & Snaith, R.P., 1983. The hospital anxiety and depression scale, *Acta Psychiatrica Scandinavica*, 67(6), pp. 361-370.

Zigmond, A.S. & Snaith, R.P., 1992, unpublished data cited in thesis by Roy, R., 2004. Evaluation of coping strategies among British Asian and British Causasian patients with their diagnosis of cancer, University of Nottingham.

