

Barts Explanatory Model Inventory: The exploration of cross-cultural variations in perceptions of mental distress

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Barts Explanatory Model Inventory –
~~The development of an instrument and the exploration of variations in~~
~~perceptions of mental distress in three ethnic groups –~~

THE EXPLORATION OF CROSS-CULTURAL VARIATION/
IN PERCEPTIONS OF MENTAL DISTRESS.

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Submitted in accordance with the guidelines of Doctor of Philosophy



Abstract

Cultural variations in individuals' perceptions of mental distress are an important issue for health care. They can affect communication between health professionals and mentally distressed individuals and might be one explanation for problematic diagnosis, poor service uptake and negative outcome for individuals from ethnic minorities. This PhD a) explores how cultural variations in perceptions of mental distress have been assessed in the past b) reports the construction and development of a new instrument, the Barts Explanatory Model Inventory (BEMI) and c) uses the instrument to explore associations between illness perceptions and ethnic background, acculturation processes and psychiatric 'caseness' in three different ethnic groups. It was found that significant ethnic variations existed in perceptions about physical complaints, spiritual, physical and psychosocial causes, expected timeline, psychological consequences and helpful treatment. For example individuals from White British background found 'alternative or complementary' treatments helpful ($\chi^2=12.035$, $p<.01$); individuals from Bangladeshi and Caribbean background on the other hand preferred 'medical' ($\chi^2=6.597$, $p<.05$) or 'spiritual' interventions ($\chi^2=17.916$, $p<.001$). The survey also found that perceptions contribute significantly to predicting psychiatric caseness ($R^2=.577$, $p<.0001$) and are in turn also helping to predict how long migrants have been in the UK ($R^2=.581$ $p<.0001$). The findings support the notion of assessing cultural variations in perceptions in health care as a feasible as well as necessary endeavour.

Table of Contents

Abstract	1
Chapter 1 Introduction and Definition of Terminology.....	8
Chapter 2 Review of illness perception theories and existing assessment tools	
2.1. General theoretical background.....	14
2.1.2. Theories about illness perceptions	
2.1.2.1. Kleinman’s Explanatory Model Approach.....	18
2.1.2..2. Leventhal’s Common Sense Illness Representation Approach.....	23
2.2. Review of existing assessment tools	
2.2.1. Kleinman’s open-ended questions	33
2.2.2. Explanatory Model Interview Catalogue.....	35
2.2.3. Short Explanatory Model Interview.....	37
2.2.4. Mental Distress Explanatory Model Questionnaire	39
2.2.5. Illness Perception Questionnaire – Revised.....	40
Chapter 3 A qualitative analysis of published literature accounts of distress and the Development of the Barts Explanatory Model Inventory	
3.1. Review of published accounts of distress	
3.1.1. Background	46
3.1.2. Methods and Sample	48
3.1.3. Qualitative Analyses.....	56
3.1.4. Results of Qualitative Analyses.....	66
3.1.5. Triangulation of the Findings.....	73
3.1.6. Discussion	74
3.2. Development of the Barts Explanatory Model Inventory	
3.2.1. General consideration	75
3.2.2. Development of the Interview	76
3.2.3. Development of the Checklist.....	84
Chapter 4 The Pilot Study	
4.1. Background.....	88
4.2. Methods	88
4.2.1. Design	88
4.2.2. Sampling	89
4.2.3. Materials.....	90
4.2.3. Procedure.....	90

4.3. Results	
4.3.1. Recruitment.....	93
4.3.2. Descriptive information.....	94
4.4. General Discussion of the Pilot Study and Research Protocol	
4.4.1. Sampling and comparison of planned to actual recruitment ..	98
4.4.2. Problematic issues in the administration of the BEMI, IPQ-R and Acculturation scales	99
4.5. Reliability of the BEMI.....	103
4.6. Validity of the BEMI.....	104
4.7. Conclusions of the pilot study and implications for main survey	112

Chapter 5 The Main Survey

5.1. Methodology	
5.1.1. Study Design	114
5.1.2. Hypotheses	114
5.1.3. Research Team.....	115
5.1.4. Sample	116
5.1.5. Procedure.....	117
5.2. Materials	
5.2.1. Screening instrument	118
5.2.2. BEMI.....	119
5.2.3. CIS-R.....	127
5.2.4. Acculturation.....	127
5.3. Results	
5.3.1. Sample	128
5.3.2. Descriptive statistics	129
5.3.3. Inferential statistics	
5.3.3.1. Hypothesis 1	134
5.3.3.2. Hypothesis 2.....	171
5.3.3.3. Hypothesis 3.....	175

Chapter 6 Discussion

6.1. Barts Explanatory Model Framework Development – the conceptualisation and assessment of cultural variations in perceptions of distress.....	181
6.2. Researching cultural variations in perceptions of mental distress	188
6.3. Perceptions of Distress are associated with absence or presence of mental distress (psychiatric caseness).	200

References	206
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Appendices

A1) Barts Explanatory Model Inventory – first draft	231
A2) Screening instrument	240
A3) Illness Perceptions Questionnaire – Revised	244
A4) Acculturation Scale	248
A5) Clinical Interview Schedule Revised	249
A6) Barts Explanatory Model Inventory	274
A7) Selected items of Mena et al’s Subject’s Loyalty Scale and Ethnic Minority Stress Scale – Relabelled Cultural Identity Scale	282
A8) BEMI – Data management tool	283
A9) List of community organisations and their remit	287
A10) Partial Correlation Matrix of Age, Length of Stay in UK and Perception variables	288
A11) Correlation Matrix of Psychiatric Caseness, Ethnicity and Perception variables	289

Figures and Tables

Figure 1 Popular EM's, Semantic Networks, and Health Care Seeking (Kleinman, 1980b)	21
Figure 2 Self-regulation model adapted (Leventhal et al, 1992)	25
Figure 3 Transdisciplinary Approach to Health Care (Albrecht et al, 1998)	30
Figure 4 Philosophical strands and social science techniques	56
Figure 5 Schematisation of Gopal's Account	61
Figure 6 Schematisation of S's Account	63
Figure 7 Perceptions about the identity of distress (BEMI-I).....	122
Figure 8 Perceptions about the identity of distress (BEMI-C)	124
Figure 9 Perceptions about the cause of distress (BEMI-I)	130
Figure 10 Perceptions about the cause of distress (BEMI-C).....	132
Figure 11 Perceptions about the consequence of distress (BEMI-I).....	140
Figure 12 Perceptions about the consequence of distress (BEMI-C).....	142
Figure 13 Perceptions about the treatment of distress (BEMI-I).....	148
Figure 14 Perceptions about the treatment of distress (BEMI-C)	150
Table 1 Kleinman, Leventhal and Trans-disciplinary Approach.....	32
Table 2 Exclusion and Inclusion Criteria for Literature Accounts.....	50
Table 3 Literature Accounts	51
Table 4 Group comparison of Lay perceptions	65
Table 5 Cultural variations in perceptions about the Identity of distress described in conceptual themes	68
Table 6 Cultural variations in perceptions about the cause of distress described in conceptual themes	70
Table 7 Cultural variations in perceptions about the consequences of distress described in conceptual themes	72
Table 8 Cultural variations in perceptions about the treatment of distress described in conceptual themes	73
Table 9 Planned recruitment for the pilot study	92
Table 10 Actual recruitment for the pilot study.....	94
Table 11 Sociodemographic and cultural information for participants of the pilot study	95
Table 12 Mental health results for participants of the pilot study.....	96
Table 13 Preliminary perception results.....	97
Table 14 Changes to the BEMI Draft to Main Survey BEMI	101
Table 15 Sampling locations.....	129
Table 15 Social demographic findings	131
Table 16 Acculturation findings.....	133
Table 17 Mental Distress	134
Table 18 Perceptions of the Identity of Distress by ethnic groups – Interview.....	139
Table 19 Perceptions of the Identity of Distress by ethnic groups – Checklist	141
Table 20 Perceptions of the Cause of Distress by ethnic groups – Interview.....	147

Table 21 Perceptions of the Cause of Distress by ethnic groups – Checklist.....	149
Table 22 Perceptions of the Course of Distress - Interview	152
Table 23 Perceptions of the Consequences of Distress by ethnic group – Interview	157
Table 24 Perceptions of the Consequences of Distress by ethnic groups – Checklist	159
Table 25 Perceptions of the Consequences of Distress by ethnic groups – Structured interview Questions	161
Table 26 Perceptions of the Treatment of Distress by ethnic groups – Interview....	165
Table 27 Perceptions of the Treatment of Distress by ethnic groups – Checklist....	167
Table 28 Internal Reliability of the Clusters	170
Table 29 Perceptions stratified by exposure to host culture in years split by median	172
Table 30 Experienced Stress by CISR caseness and ethnic background.....	175
Table 31 Content of Perception themes stratified by psychiatric caseness and ethnic background and Chi Square tests	177
Table 29 Number of Perception themes stratified by psychiatric caseness and Ethnic background and ANOVAs.....	178

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Chapter 1 Introduction and Definition of Terminology

“The concept of what constitutes mental illness varies among cultures based on local beliefs and practices. A programme aimed at preventing certain mental health related problems might not be appropriately suited in such conditions if the programmes have not been tested across cultures. It is crucial to identify the needs in a population” (Saraceno & Saxena, 2002)

The World Health Organisation has identified that mental health problems are going to be the most common cause for disability worldwide by 2030 (World Health Organisation 2001) and naturally interventions to prevent mental illness and promote mental health are an important national and international issue. What makes these interventions difficult and complicated are the variations in the needs of culturally different populations as noted by the WHO task group above. How individuals might perceive mental distress and what they believe to be helpful and beneficial treatment depends on local, societal and cultural norms and influences pathways to mental health services (Bhui, Stansfeld, Hull, Priebe, Mole, & Feder, 2003). Hence individuals' perception of their symptoms, their appraisal of these indicators and what they perceive to be adequate treatment need to be identified to be able to help them more efficiently. The influence of 'culture' is extremely important as illness experiences are informed by the way we live and are dependent on the cultural environment that we live in (Raguram, Weiss, Keval, & Channabasavanna, 2001). This thesis examines the question how variations in perceptions of mental distress might be best assessed on an individual and population level.

Before I begin with a detailed theoretical exploration of cultural variations in perceptions, I will define terminology that has been used in the remaining sections of this PhD, and its background, in order to acknowledge the context (cultural psychiatry/ cross-cultural health psychology) in which this piece of research fits.

Mental health problems, characterised by changes in cognitive processes and mood, constitute the world's most disabling and most prevalent disorders. In particular, depression was singled out to become the most common cause of disability in the industrialised world by 2030 and only second heart disease on a global scale (World Health Organization, 2001). The development of effective global interventions to treat and prevent mental health problems is undermined, however, by noticeable variability in the cross-cultural variations in the 'prevalence' of mental disorders. In China for example, depression is noticeably less diagnosed, and conditions like neurasthenia or Chronic Fatigue Syndrome (CFS) are as prevalent as depression in the industrialised world (Kleinman, 1988b). Initially, it was assumed that cultural differences are due to diversity in the diagnostic process and efforts were made to standardise the diagnostic procedures across the globe. Diagnostic manuals (e.g. DSM IV and ICD 10) were developed to increase reliability in the diagnostic process. According to DSM IV (1994), depression is centred on a core emotional state of dysphoria accompanied by additional psychological, behavioural and somatic symptoms. After introducing the manuals, it became apparent that the diagnoses have been mainly accurate, but that cultural norms seemed to exert a greater influence on presentation with mental health problems. Anthropological research found, for example, that voicing 'dysphoric feelings' was not sanctioned in interdependent or so-called 'collectivistic' cultures (Krause, 1989), and that individuals were therefore less likely to present with dysphoric feelings in clinical settings.

To understand the cultural variations in mental health problems, it was argued that one should firstly develop a deeper understanding of the problem by exploring the patients' perspective. Following Eisenberg's distinction between 'disease' (i.e. a professional conception characterised by pathophysiological changes, prognosticated course and outcome) and 'illness' (i.e. the subjective personal experience of disease by the afflicted person) (Eisenberg, 1977), this PhD focussed on individuals' perception of 'illness'.

Understanding how distressed individuals perceive their distress, how they deal with it, and what help-seeking patterns they display might offer a deeper insight into cultural variations in 'illness' behaviour and might also help us to understand more of the global diversity in the prevalence of mental health problems.

To further shift away from mental 'disorders' and 'disease' and circumvent problems with the cross-cultural validity of psychiatric diagnoses, I have tried throughout this PhD to employ terminology that is independent of professional terms. This also justified a lack of focus on a particular condition e.g. depression, but rather on individuals who could be described as suffering from 'mental distress' (an independent overarching term for mental dysfunction and discomfort). There are a number of difficulties associated with moving from psychiatric disorders towards an overarching condition of mental distress. What is mentally distressing and what is considered mental distress varies widely both between individuals and also between cultural groups (Baer, Weller, de Alba Garcia, Glazer, Trotter, Pachter, & Klein, 2003). In particular, the language used to describe or express distress appears to vary greatly, which does not unequivocally determine that the *experience* of distress is also individually and culturally different.

How one elicits and reliably measures evaluations and experience independent from communication and expression has so far remained an unresolved issue. Therefore clinicians and researchers commonly use several proxy indicators and assessments. One outcome measure of such a mental state assessment is the use of psychiatric diagnostic labels - having been developed by a group of experts and having clear guidelines as to which experiences and symptoms link in with which diagnostic label. However, cross-cultural psychiatrists also identified problems with the validity of diagnostic criteria and psychiatric labels across cultures (Giosan, Glovsky, & Haslam, 2001; Rodrigues, Patel, Jaswal, & de Souza, 2003). They requested therefore that as much consideration should

be given to the issue of cross-cultural validity as has been given to reliability of diagnosis and terminology used in cross-cultural psychiatry (Kleinman, 1987a).

Research from the field of emotion and non-verbal expressions (Ekman, 1993) and Western Psychiatry (Kirmayer, 1989; Patel, 2001) nevertheless suggests that there are some universal or core patterns of “suffering” and “distress”. It is felt therefore that individuals across the globe share the capability to experience and communicate distress albeit maybe not being familiar with the concept of mental health or psychiatric labels. It appears indeed few lay people use psychiatric terminology to relay their experience of distress (Rodrigues et al, 2003). This PhD uses therefore terminology that is closest to a lay person’s terminology and independent of professional biomedical psychiatric constructs. Therefore the term ‘mental distress’ was adopted.

When one wants to research the effects of culture on perceptions, one is inevitably faced with the problem how to assess culture as it is an ever changing dynamic process (Andrews & Boyle, 1995). Race, ethnicity and culture are often used interchangeably in everyday language, but transcultural experts prefer to distinguish and ascribe different meaning to these constructs (Watt & Norton, 2004). For example Fernando (1991) states that ‘race’ is mainly describing physical differences between individuals, ‘culture’ refers to sociological differences and ‘ethnicity’ involves psychological issues (Fernando, 1991). However since biological sciences identified little to no differences in the genetic make up to support assumed biological differences in phenotypic features such as skin colour and bone structure, it has become highly contentious to use the term ‘race’ and/ or talk of racial differences. Ethnicity or individuals’ ethnic background is commonly used to describe classes of person, however this also is contentious as it is can change over time and emphasises difference between people rather than similarities (Hillier, 1997). Members of same ethnic background share commonly a cultural heritage in terms of

language, values, religion, customs and attitudes and common past. However as global migration is increasing, ethnic groups and group membership appear to be continuously changing, ethnic and cross-cultural research has recently veered towards examining the influences of 'culture' – generally referring to thoughts and beliefs, diet, dress, music and art. The concept of culture seems more sensitive to changes in relation to migration as individuals can embrace different aspects of old and new culture, and hence develop new cultural identities. The concept of culture has evolved over time and many different definitions exist. The most commonly popular definition for the term 'culture' is 'the distinctive way of life that characterises a given community' (Logan & Semmes, 1986). However, this seems no longer applicable in a world order, where cultural groups can often no longer be defined by their geographical location as migration and cultural exchange are uninhibited. The one that has been adopted in this PhD defines culture as 'systems of shared ideas, systems of concepts and rules and meanings that are expressed in the ways human beings live' ((Keesing, 1981), p.8). The definition seems to be most the most suitable to examine commonalities in thinking and perceptions. The main subject of this PhD examined ethnic variations in perceptions, but also explored cultural influences such as length of length of stay.

A definition for the term 'Western' is necessary as it has occasionally been used in this PhD to describe norms that are indicative of industrialised individualistic cultures such as the European and North American cultures, generally to compare them with norms of less industrialised or collectivistic cultures.

Finally I will use the term 'perceptions' throughout the PhD rather than 'beliefs' or 'ideas' about illness as perception is used in cognitive psychology to incorporate two components: observation and interpretation of situations and life events. The term 'perceptions' includes some acknowledgement of how daily activities and situations are

reflected upon whereas terms such as 'beliefs' are less flexible. Another reason to choose it was to be independent of specific perceptions of illness related theory-base (explanatory model, illness representation).

The structure of this thesis will follow the intellectual journey taken during my work on the PhD. After the terminology and definitions are introduced in this chapter, the second chapter proceeds with the exploration of theories of perceptions of distress, formulates the hypotheses that were examined in the empirical work and concludes with the premises for a new transdisciplinary framework. Then currently available assessment instruments will be described and subsequently reviewed on the basis of the previously identified premises and published information. That review will show that current instruments are poorly adapted to cultural variability in perceptions, and that a new appropriately sensitive, instrument is needed. In the third chapter, the development of such an instrument is presented, the BEMI. The BEMI is designed to be a comprehensive cross-culturally valid instrument for assessing perceptions of mental distress (Barts Explanatory Model Inventory - BEMI). The fourth chapter describes the first research component of the thesis, the pilot study, which tested the research protocol and the BEMI's validity in the field. The results led to a consolidation of a research strategy and to small alterations of the research protocol and the BEMI. The fifth chapter reports the main research component of the thesis an epidemiological survey of perceptions of distress in three ethnic groups. The final chapter discusses and appraises the main findings of the PhD and identifies areas for further development.

“There is nothing so practical as a good theory” (Lewin, 1951)

2.1. Review of theories of perceptions

To understand cultural variations in perceptions it seems sensible to explore constructivist theories of cognition, in particular the theoretical and experimental work of psychologist Frederic Charles Bartlett (1886-1969), as his work influenced significantly by anthropological questions (Brewer, 2000). Bartlett's experimental studies explored effects on memory and recall, and firstly demonstrated how cognition can be flexibly responding to the demands of the environment. He presented individuals with information, which he asked them to remember and tested their recall a week later. In a second condition he asked individuals to remember the same information, but he presented additional information *after* the initial information was presented. He found that individuals unconsciously integrated additional information into their memory and interpreted it with a particular autobiographical angle (Bartlett, 1932).

Hence, the action to recall information was independent of *when* individuals received information, leading Bartlett to believe that there must be an unconscious mental 'storage' location that holds previously acquired information, but that is also amenable to change and is thus fairly fluid. He used the term 'schema' to describe the 'hypothetical entity that refers to the storage of knowledge in human minds'. However, Bartlett being truly influenced by anthropology stretched boundaries of traditional cognitive theory further and noted that individual cognitions are linked to interpersonal settings and functions to adapt to the environment. According to schema theory, learning occurs by acquiring and using information that is congruent with an existing schema and disregarding information that does not fit to the existing information. By filling and linking these 'half-painted' pictures with others, more complex knowledge structures evolve. Schemas were to combine generic information and episodic memories and are hence both culturally valid as well as

intra-individually constituted and activated unconsciously and automatically. Despite his theory being only one among several cognitive psychological theories of learning (e.g. Information Processing Approach (David, Miclea, & Opre, 2004), Piaget's Theory of Cognitive Development (Piaget, 1967)), his constructivist theory is unprecedented in its acknowledgement of social influences on cognition and has also recently received ample support from neuropsychological evidence on physiological processes in learning (Macrae & Bodenhausen, 2000).

In social cognition and constructivism, the function of cognition (including perceptions) is characterised by containing and processing knowledge acquired via experience and exposure. Therefore the more exposure individuals have to different perceptions of distress, the more diverse their cognitions of distress will be. This would also suggest that cultural factors that influence our understanding of distress would lead us to perceive distress in culturally sanctioned ways and that differences between cultures would also lead to differences in perceptions.

The first hypothesis derived of the literature is therefore that 1) perceptions of distress are associated with individuals' cultural (ethnic) background.

In addition, perceptions and cognitions facilitate communication and remembering since they adjust to interaction and active thought processes. Therefore, they are likely to change when acquiring new information if the new information contradicts old information, requiring individuals to adapt their old perceptions. If one was trying to understand cultural variations in outcome and access to services by looking at perceptions one should include a) an assessment of perceptions of diverse ethnic groups as they are likely to be exposed to different cultural influences and b) examine exposure to other cultures to see whether perceptions tend to shift over time. The process of culture exchange has been called

'acculturation' and was initially thought of as a linear unidirectional construct so that as one leaves the original cultural influences behind one begins to embrace the new.

The second hypothesis of this PhD is therefore 2) 'Perceptions of distress are associated with acculturative processes.' Following Bartlett's studies, perception change/ adaptation is subconscious and subject to exposure, hence one might therefore hypothesise 2a) that 'With greater exposure to host culture, perceptions will adjust towards those of the host culture'.

Cross-cultural psychologist Berry has firstly provided a bi-directional model of acculturation by differentiating between two dimensions: the intercultural 'contact/ exposure' and the 'desire to maintain' minority status and past cultural traditions (Berry, 1990). His model therefore differentiates between four different reactions when individuals from one culture get in contact with those of another culture. The first reaction is assimilation, which entails to entirely embrace all cultural values of the host culture and devalue those of the original culture. The second reaction is integration i.e. favouring different aspects of one's cultural roots and the host culture. A diverse reaction is to favour only minorities' cultural roots (traditionalism) and finally the fourth reaction is to reject both cultures (marginalisation). Integration is the most favoured acculturative strategy in multi-cultural societies and most likely to lead to positive adaptation (Berry, Poortinga, Segall, & Dasen, 2002).

Berry further argued that there are 5 phases in which the individual moves from 1) pre-contact, to 2) contact phase with cultural exchange from one cultural group to the other but predominantly flowing from the dominant to the non-dominant culture, to a possible 3) conflict phase in which tension and pressure are becoming apparent, culminating in a 4) crisis phase in which a solution is required and a possible 5) adaptation is the result (Berry

& Kim, 1988). He argued that acculturative stress and adaptation need to be considered always with pre-contact social conditions (Berry, 1997), which can be distinguished in 'push and pull' factors that instigate the move to another country. Push factors i.e. trauma, war, famine, forced migration are generally associated with greater acculturative stress than pull factors i.e. economic advantage, voluntary migration. Individual influences such as the level of education, employment value, self-esteem, achievement motivation and cognitive style are also important determinants for adaptation (Berry & Kim, 1989). In the contact phase, cultural distance between the two groups as well as experiences prior contact set the stage for future evaluations. Finally if expectations are higher than actual achievement, this may also lead conflict and acculturative stress and eventually to mental health problems. In consequence to Berry's findings and theories, one might expect greater acculturative stress in individuals that experienced recent trauma, in individuals whose cultural background is distant from the host culture and where level of education is low and expectations are higher than actual achievement. Further epidemiological (national and international) studies on acculturative stress might therefore examine acculturative strategies – 'exposure and desire to maintain cultural heritage' in conjunction with these additional variables in determining mental health problems in migrants and ethnic minorities.

An important addition to the operation of mental processes (i.e. cognition) has come from the findings of psychiatry and psychotherapy, which revealed how perceptions are largely determined by individuals' affective states. This was perhaps best explained by (Ciompi, 1991) who described the psyche as containing 'programmes for feeling, thinking and behaviour' p.97. Feelings act as gateways for the storage and retrieval of thoughts, perceptions and memories. Therefore in a stable emotional state, different kinds of cognitions will be accessed than in elevated emotional states. The initial suggestion was therefore that individuals who are more distressed should have different perceptions

regarding their distress than individuals who are not so distressed. In consequence, it seems that cognitions of distress should be linked to the experience of distress itself.

The third hypothesis of this PhD is therefore that 3) Perceptions of distress are associated with absence or presence of mental distress (psychiatric caseness).

Following this general introduction to theories of cognition, their determinants and function, particular theories concerned with illness and distress cognition will be examined. Although there are a large number of theories on illness, distress and health behaviour (e.g. the Health Belief Model (Rosenstock, Strecher, & Becker, 1988); Self-Efficacy (Bandura, Adams, & Beyer, 1977; Bandura, Pastorelli, Barbaranelli, & Caprara, 1999); Theory of Reasoned Action and Planned Behaviour (Ajzen, 1972; Madden, 1992)), two theories have dominated social science research on lay perceptions of illness: Arthur Kleinman's 'explanatory model' of approach and Howard Leventhal's theory of self-regulation and its associated 'common-sense approach' of illness representations. As these have been most extensively researched a detailed elaboration of each is provided below.

2.1.1) Explanatory Model Approach

Firstly, Arthur Kleinman's theoretical developments and research will be described since his work has been a major inspiration in this field. Psychiatrist Kleinman was trained in medical anthropology and investigated lay perceptions of illness and their contrast to health professionals' beliefs about illness since the 1970s e.g. (Kleinman, 1980b; e.g. Kleinman, Kunstadter, Alexander, & Gate, 1978; Kleinman, 1977c). In one of his first influential articles, Kleinman, Eisenberg and Good (1978) critically commented on the biomedical focus on 'curing' disease in a mechanistic sense rather than focussing on 'healing'. They skilfully unfolded the need to explore a patient's model or version of their

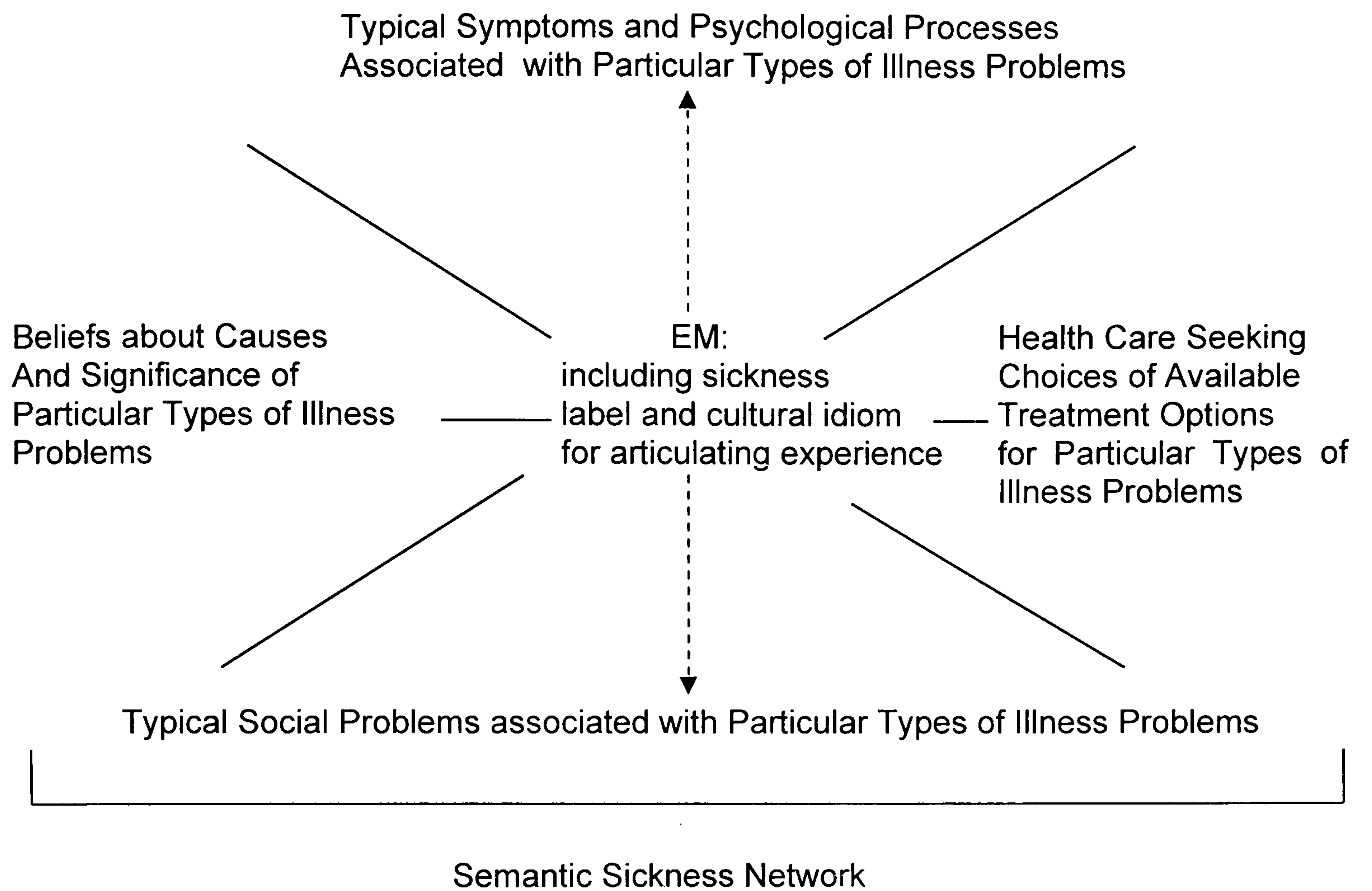
illness by illustrating its effect on care in a number of somatic and psychiatric cases (Kleinman, Eisenberg, & Good, 1978). Their second case presentation describes a 60 year old Protestant grandmother, who induced urinating and vomiting consistently into her bed after an operation for pulmonary oedema. She had been told that she had 'water in the lungs' and her behaviour was informed by her conception of the chest being hooked up to two pipes to mouth and urethra. She thought that she would try to remove as much fluid as possible by clearing those pipes and her efforts would therefore help her to cure her disease faster than with medical care alone. Only careful communication and illustrations of the structure and organs of the body lead to a change in perception and hence behaviour.

Kleinman, Eisenberg and Good (1978) described the need for a clinical social science that differentiates between disease (the professional conception) and illness (the patient conception). They firstly hypothesised that where only disease is treated; care will be less satisfactory to the patient and less clinically effective than where both disease and illness are treated together (p256). In the same year, he also described the tension between the patient and doctor in their ambitions to the professional Western medical doctor the disease problems are most 'real' in contrary to the illness problems which are more 'real' to the patient (Kleinman, 1978). He idealistically suggested that clinicians could elicit the patients' understanding, secondly present their own model in simple language and compare the two in order to identify areas of tension and conflict to then develop treatment recommendations in conjunction with the patient. Kleinman then coined a label for patient or lay perspectives as the 'explanatory model' (EM) of illness (1980b). 'Explanatory models' have since become a landmark for cultural variations in lay perceptions of illness, since Kleinman developed his theory on the basis of fieldwork in psychiatric settings in Taiwan and the Republic of China (Kleinman, 1982a; Kleinman, 1980a; Kleinman, Ravitz, & Koran, 1972; Kleinman, 1988b; Kleinman, 1982b; Lee &

Kleinman, 1997). His research for example showed that Chinese patients often exhibited ethnocentrism when appraising Western medication and viewed Chinese medicines as more effective. He was one of the first researchers to recognise the importance of cultural norms and stigma on patients' behaviour and has produced a considerable bulk of literature on cross-cultural psychiatry (e.g. (Kleinman, 1982a; Kleinman, 1983; Kleinman, 1980a; Kleinman, 1981; Kleinman, 1977a; Kleinman, 1980b; Kleinman & Gale, 1982; Kleinman, 1988a; Kleinman, 1992)

Kleinman tentatively postulated that individuals' EMs can help clinicians with the development of their construction of disease by informing them about 1) Pathophysiology, 2) Onset of symptoms, 3) Aetiology, 4) Course of the illness, 5) Treatment (Kleinman, 1977b). He argued, however, that the information of these five categories was not straight forward since EMs rarely possessed formal organisation and specificity as they are only partially conscious and partly outside consciousness (Kleinman, 1980b). He said that they are generally not coherent and unambiguous structures within larger cognitive systems and that they are only assembled in response to particular illness episodes. He views the function of EMs as interrelating illness beliefs, norms and experiences to support decision making for the patient. Figure illustrates how he views EMs fit into health care and help-seeking (Kleinman, 1980b) p. 108).

Figure 1 Popular EMs, Semantic Networks, and Health Care Seeking – Kleinman, 1980b



His early work is associated with the differences between patients and doctors as well as the differences between different cultures and he highlights the processes of communication in the clinical setting and the creation of conflict. He argues that when there is a large 'cognitive distance' between the patient and the doctor's EM and communication during the consultation does not reduce this distance, outcome is unclear as conflict evolves. He therefore argued that the clinician should try to reduce the conflict by eliciting the patient model and communicating his own model in ways that are understandable and acceptable to the patient.

In later work, he continued to criticise professional Western (in particular North American) psychiatry by arguing that the mainstream is ignoring the majority of the world and minority ethnic perceptions and treat the concept of culture as an arbitrary superimposed obstacle hindering progress to advance of 'real' biological processes in the development of disease (Lewis-Fernandez & Kleinman, 1994). His research and stance to psychiatric

services has then attracted a large group of medical anthropologists and well as cultural psychiatrists to explore the importance of explanatory models in various cultural groups as well as transgressing the borders of mental to physical illness (e.g. (Bhui & Bhugra, 2003; Bhui, 2000; Cohen, Tripp-Reimer, Smith, & Sorofman, 1994; Jaber, Steinhardt, & Trilling, 1991; Joel, Sathyaseelan, Jayakaran, Vijayakumar, Muthurathnam, & Jacob, 2003; Kleinman, 1987b; Lloyd, Jacob, Patel, St Louis, Bhugra, & Mann, 1998; Massoth, 1993; Mauksch & Roesler, 1990; McCabe & Priebe, 2004; Parsons, 1984; Patel, 1995; Weiss, Sharma, Gaur, Sharma, Desai, & Doongaji, 1986; Weiss, 1997; Williams & Healy, 2001)

The main limitation of Kleinman's theory seems to be that it failed to specify what the 'model' actually is and how it might work in influencing individuals' behaviour outside the clinical setting. From a psychological viewpoint, one would say that his theory has high validity by demonstrating cultural variations in the content of perceptions, but its predictive value has so far not been demonstrated. The theory's main strength on the other hand is that it raised attention to cultural variations and was an inspiration for researchers, which produced empirical data that attests to the importance of the function of perceptions in guiding people's behaviour and the role of illness in different societies.

Kleinman's acknowledgement of the irrationality of human thinking and the resulting characteristics of the EM approach made it difficult to test the approach empirically. This might be considered acceptable when one considers the remit of the theory. The explanatory model was intended to be a heuristic qualitative research approach, which aimed for the inclusion of an illness narrative and a mini-ethnography of the illness experience (personal communication with Arthur Kleinman, August 2001). Although this makes it difficult to adapt and test the theory in quantitative research, one should not see this as a flaw of the theory, but rather as an approach consistent with the assumptions of the discipline of anthropology.

Explanatory model research has focused mainly on the way lay people perceive the *aetiology* of their illness, but not so much on how it might alter or influence future behaviour, what consequences the illness might have for the person or how long it might last. A predominant focus on individuals' perceptions about the cause of illness evokes what could be considered an 'illusion', that there should be a direct linear relationship between causal attributions and individuals' coping response. However, health psychological research suggests that this is not necessarily so and although associations between attributions and behaviour are important, most research supports an indirect association between causal attributions and outcome (Roesch & Weiner, 2001). A focus on aetiology, leads one to learn a lot about cultural values and how they might affect attribution, but it might not be as fruitful for predicting health behaviours and service use as one is likely to overlook other important components of individuals' illness cognitions.

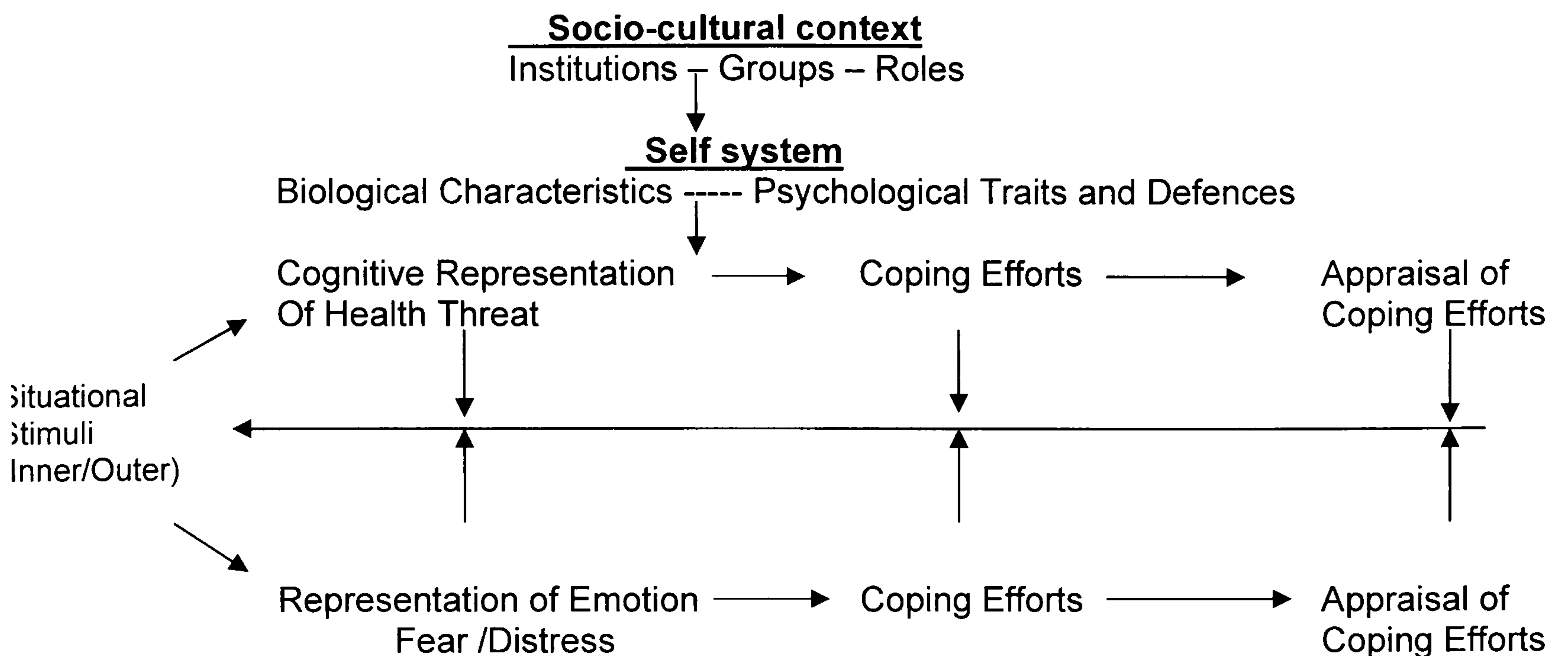
2.1.2) Illness representation approach

Howard Leventhal's theoretical approach was followed a programme of experimental research on health behaviour with a focus on smoking and smoking cessation. His research initially focussed on exploring the '*Revised Drive Reduction Theory*' (Dollard & Miller, 1950). This theory proposes that individuals engage in protective behaviour to minimise their drive for fear when faced with threatening stimuli (Dollard & Miller, 1950). To test the theory's predictive value on health behaviour, Leventhal and colleagues exposed individuals to a number of potentially threatening pieces of information about their health. They then measured affect, i.e. mood, attitudes and intentions about health protective behaviours, and recorded whether the participating individuals had executed their plans (e.g. (Leventhal, 1970; Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller, & Robitaille, 1997; Leventhal & Singer, 1966; Leventhal & Watts, 1966; Leventhal, Watts, & Pagano, 1967)). Many experiments were conducted, refined and adjusted, but the Revised Drive Reduction Theory was not fully supported by the

evidence since individuals initially *avoided* any health protective actions (e.g. performing dental hygiene (Leventhal & Singer, 1966) or giving up smoking (Leventhal & Watts, 1966; Leventhal et al, 1967)). This 'panic phase' was accompanied by great affective arousal, which subsided over time. Subsequently, individuals responded in the intended way, *if* they were provided with structured advice or action plans. Leventhal deduced that the motivation for this action was hence not to be found in the drive reduction or affective response, but in the cognitive appraisal of the health threat (Leventhal, 1971). His experimental studies showed that induced fear created attention to what was happening inside the body in terms of concrete perceptual codes but that individuals also wondered what to do about it in more abstract terms (Leventhal et al, 1997).

The *common sense model* or *parallel response framework* (depicted in figure 2 below) was first published in 1970 as an attempt to bring together emotional and cognitive responses to health threats (Lau & Hartman, 1983; Leventhal, 1970). In this model two largely independent processing systems deal with the 'objective cognitive' representation of the threat, its coping procedures and appraisal, and also the 'subjective emotional' processes, associated coping behaviour and evaluative processes (Hagger & Orbell, 2003).

Figure 2 Self-regulation model adapted from Leventhal et al, 1992



In order to substantiate the common-sense model's validity and applicability, Lau and Hartman then explored how illness representations are constructed in the mind, and tried to determine the content of the representation by open ended interviews (1983). They identified five domains of illness representations: 1) identity (disease label and symptoms); 2) time-line of the course of the illness (Acute, cyclic, chronic); 3) physical, social and economic consequences; 4) antecedent causes; and 5) potential for cure and/or control (Lau & Hartman, 1983), which have since formed the core content of Leventhal's cognitive illness representation.

After the experimental studies he examined the theoretical value of his model on illness management, symptom reporting and adherence to treatment (Baumann, Zimmerman, & Leventhal, 1989; Diefenbach & Leventhal, 1996; Leventhal, Hansell, Diefenbach, Leventhal, & Glass, 1996; Leventhal, Diefenbach, & Leventhal, 1992). He found that individuals were not able to identify indicators for disease constructs such as hypertension correctly and indeed that there was no correlation between perceptions of elevated blood pressure and the 'real' blood pressure as measured by an assessment tool (Baumann & Leventhal, 1985). He further identified the need for individuals to give their experience a

name and identified the patient as an active problem solver who will seek information of the label of his symptom, but also in consequence seek the symptoms that confirm the disease label (Baumann, Cameron, Zimmerman, & Leventhal, 1989; Diefenbach & Leventhal, 1996). In terms of assessing or eliciting the illness representation, Diefenbach and Leventhal report that it might be advisable to assess the flare up or onset of the disease within a specified timeframe. They also advise of both interview and questionnaire as the best possible way to assess illness representations, but also declare the limitations in terms of time constrain the usefulness of mixed methods (Diefenbach & Leventhal, 1996). His ideas and theory have equally transcended its original remit and have been examined in a variety of physical and psychological conditions and health behaviours (Barrowclough, Lobban, Hatton, & Quinn, 2001; French, Marteau, Senior, & Weinman, 2002; Hagger & Orbell, 2003; Horne, James, Petrie, Weinman, & Vincent, 2000; Lawson, Bundy, Lyne, & Harvey, 2004; Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2001; Moss-Morris, Petrie, & Weinman, 1996; Petrie, Weinman, Sharpe, & Buckley, 1996; Pimm & Weinman, 1998; Preville, Potvin, Boyer, & Boulerice, 2000; Rutter & Rutter, 2002; Scharloo, Kaptein, Weinman, Hazes, Willems, Bergman, & Rooijmans, 1998; Weinman, Petrie, Moss-Morris, & Horne, 1996; Williams, Weinman, Dale, & Newman, 1995).

Leventhal's theory has also had its share of critics, as cross-cultural researchers asserted that there is no role in it for culture and the person's perception of 'self', other than their impact on the representation (Klonoff & Landrine, 1994). Researchers found it problematic to support this model in its entirety due to difficulties in its operationalisation as a whole. Although the crux of Leventhal's theory states that 'representations' change in a dynamic process, Kleinman rightly pointed out that human beings seem to hold at times a number of irreconcilable attributions. Therefore one might also criticise the terminology of illness 'representation' as a 'representation' seems to refer to a momentarily static concept,

whereas it might be preferable to think of perceptions as many influences competing for attention and consideration.

However this theory's unequivocal strengths are in the demonstrated link between perceptions and behaviour. A meta-analytic review of the research on the 'common sense model' found strong support for the predictive value of the model (Hagger & Orbell, 2003). Hagger and Orbell asserted that across 45 studies avoidance and emotion expression were strongly and significantly linked to individuals perceiving themselves to be highly symptomatic i.e. perceiving themselves to be afflicted by many symptoms. Perceived controllability of illness was positively associated with: expressing emotions, problem focussed coping strategies, psychological well-being, social functioning and vitality. High levels of perceived negative consequences and chronic timelines were on the other hand negatively related to well-being and social roles (Hagger & Orbell, 2003).

On the whole the Explanatory Model and the Illness Representation theory have provided more detail than the general theory of cognition by identifying a) the importance of cultural variations in understanding of mental distress and b) the link between illness cognitions and behaviour. Both were bounded by rules of their own disciplines anthropology and psychology whose researchers often have been described as adopting an *emic* or *etic* approach (Pike, 1967). These terms have been adopted from linguistic *phonemic* sounds, which characterises sounds that are language and culture bound; and *phonetic* sounds which appear to be universally applicable to all human beings. Although operationalising both concepts unequivocally in relation to cross-cultural research is impossible (Jahoda, 1977), there some distinctions and criticisms keep recurring in the literature (Berry, 1969; Helfrich, 1999). The main issues have been summarised in the following paragraphs.

Emic research is mainly stemming from anthropological and social science research and emphasises the concept of *culture as a process* which influences all aspects of life. The logical approach to research from an emic standpoint is therefore cultural relativism (Helfrich, 1999; Murphy, 1982) i.e. comparison between cultural groups is not allowed as one cannot grasp the complexity of the cultural processes involved in two cultures. Methodologically information is obtained mainly via ethnography, observation and qualitative interviews. The main criticism of the emic approach is that relying on interviews and observation alone invites systematic bias (such as social desirability (Holtgraves, 2004; Leak, 2004) and hindsight (Fischhoff, 1975; Snyder, 1984) bias). Interviewees and interviewers are influenced by wanting to be socially 'desirable' and may therefore report deliberately false answers in order to create a 'good' impression, and/or individuals are subject to self-deception and report events and processes that they believe to be true, but that are not true (as in the examples of Bartlett's experiments, see p.14). Findings derived with an emic approach cannot differentiate the insights about the culture from the equally culture-bound conceptions of the researcher, which results in arbitrariness (Helfrich, 1999) and makes it difficult to determine the reliability of the research. A related criticism of the emic approach to cultural research is that findings are not following the principles of scientific knowledge such as falsification (Popper, 1963), by producing insights which some would describe as 'self-contained' and hence 'complete' contrary to etic research that evolved from prior research and appear more penetrable by scientific scrutiny.

Etic research on the other hand treats culture as a static influence and is the basis of most cross-cultural research that tries to unravel cultural differences. The main criticism is that it overlooks the fact that culture is not simply an independent variable in the usual sense (Hesse, 1988). Comparative studies between cultural groups need to present differences in conjunction with other influences (e.g. education, verbal ability, deprivation) to give a full picture (Hesse, 1988). If comparative data is not set in context, simplistic interpretations

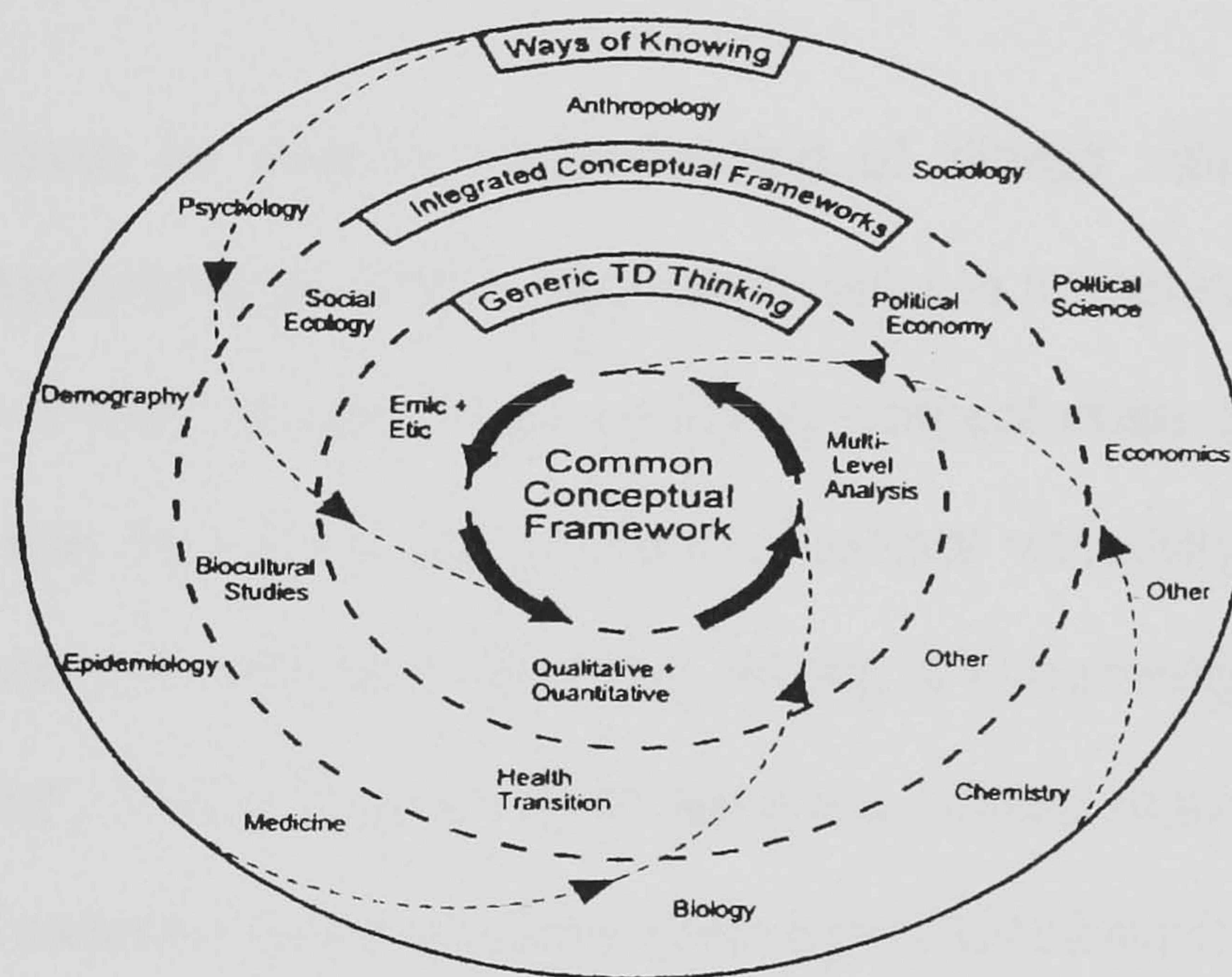
as presented in early work on intelligence between Black and White Americans – are enforcing prejudicial views and opinions (Colman, 1972). Furthermore, contemporary society is characterised by migration and exchange between cultures and is dominated by change rather than tradition (Helfrich, 1999), which means culture is dynamic variable.

Cultural or indigenous psychologists argue that there is a third way to examine cultural differences. Berry suggested that one could develop a 'derived' rather than the 'imposed' etic research structure which explores the views of one culture first, develops a theory and then validates the theory by applying it to a second culture (Berry, 1989). Helfrich suggested that the process between the cultural influence, the individual and ecological task demands might be best described as triarchic resonance (Helfrich, 1999). Resonance is understood here as the product of each "individual's basic biological 'endowment' whose characteristics can be amplified or suppressed by external forces. The external forces can be described as the totality of experiences to which the individual has been exposed" (Helfrich, 1999, p.139). All cultural psychologist approaches are allowing for comparisons between cultural groups (hence etic in their outlook), but they argue that one needs to include the emic perspective to ensure comparability and explain behaviour comprehensively; this approach was adopted in this thesis.

In order to help the clinical setting and to advance our current understanding of illness cognition, suffering and distress, it seemed important to expand the currently available information and integrate the knowledge in an open transdisciplinary approach. Higginbotham et al produced a compelling account for such transdisciplinary work in their book *Health Social Science* (Higginbotham, Albrecht, & Connor, 2001). They argue that 'intradisciplinary' thinking is often ill-equipped to appreciate the complexity of the complete range of factors that contribute to health and illness and that 'interdisciplinary' thinking allows us to synthesise knowledge so that boundaries disappear. 'Transdisciplinary'

thinking, however, despite being cognisant of the disciplinary boundaries, transcends and promotes new conceptual frameworks, which are appreciated and understood by a variety of disciplines. Higginbotham et al previously produced a model of this transdisciplinary approach and (see Figure 2 (Albrecht, Freeman, & Higginbotham, 1998). By this approach many sources might be accessed to develop a comprehensive theory about the expression, perception and understanding of health and illness.

Figure 3 Transdisciplinary Approach to Health Care (Albrecht et al, 1998)



The dynamic process of transdisciplinary thinking.

To summarise so far, it seems that our cognitions and perceptions of the world and ourselves are dependent on our experiences (and thereby cultural influences). Independently, psychotherapeutic theories suggest that mood acts as the universal gateway to perceptions, and therefore access to perceptions about distress is dependent on our mood. A short review of the existing theories of illness perceptions showed that they are bounded within their disciplines anthropology/ psychiatry and psychology, but that both argue that perceptions are mostly focussed on five similar domains (Bhui &

Bhugra, 2001). The EM approach states that individuals' models shed light on five domains, which are closely linked to professional conceptualisation of 'disease' (1 pathophysiology, 2 aetiology, 3 time and mode of onset of symptoms, 4 course and 5 treatment). Illness representation approach appears closer to the lay person in terms of the terminology used as it refers to the five domains as (1 identity, 2 cause, 3 timeline, 4 consequence and 5 control/cure of illness. However, one notices that there seems to be a trade off in terms of the identity component, in that what Leventhal understands to be identity still refers to the professional conception of disease by talking of 'symptoms' and 'labels'.

Since this work focuses on diverse understanding of 'illness' rather than 'disease' I avoided the use of 'symptoms' or 'labels' and simply refer to terminology and language of lay individuals. Also it was thought to be useful to conceptualise the remit of the five domains in broader way to suit the assessment of cultural variability in perceptions and the problems they posed in research (Boynton, Wood, & Greenhalgh, 2004) and health care (Henley & Schott, 1999). Boynton et al asserted among many other transcultural researchers that it is essential to be concrete when trying to convey information in diverse languages in contrast to abstract assessments (Boynton et al., 2004). That is, one needs to pay attention to the language used to express distress, the language used to complain and the non-verbal ways in which individuals communicate distress to be able to identify it and understand cultural variation. Furthermore, it is important to be concrete about the timeline and hence differentiate between perceived differences in the actual duration and the expected timeline as there is some evidence that there are cultural differences in the expectation of continuous or chronic timelines (Morgan, 1988).

Psychological and spiritual consequences of distress should also be included as the previous identified ones (ecological, physical etc) seem to refer rather to the professional

medical model of distress as a disease. In the fifth domain of control cure and treatment, it is known that there is a high level of complementary and traditional healing approaches among ethnic minorities for distress (Sembhi & Dein, 1998), so one might want to measure cultural variations in perceptions about treatment by assessing them concretely. One might also want to research how people evaluate their help-seeking attempts and what sort of expectations they hold how the distress should be best dealt with. The two theories' assumptions about the structure of illness perceptions and the evolved transdisciplinary approach have been outlined in table 1 below.

Table 1 Explanatory Model, Illness Representation and Perceptions of Distress Approach

	Explanatory Model – Psychiatry/ Anthropology	Illness Representation – Psychological	Distress Perceptions – Transdisciplinary Approach
1	Pathophysiology	Identity (Symptom, Labels)	Expression (Complaints, Non-verbal Communication, Perceived Symptoms and Labels)
2	Aetiology	Cause	Explanation (s) / Perceived Causes
3	Time and Mode of Onset of Symptoms	Timeline (Acute, Chronic, Cyclic)	Past Duration and Expected Temporal Course
4	Course Of Sickness (Severity and sickness role – acute, chronic impaired)	Consequences (Physical, Social and Economic)	Psychological (Cognitive & Emotional) & Spiritual AND Physical, Social, Economic Consequences
5	Treatment	Control/ Cure	Healing expectations & Previous Attempts to Control/ Cure Distress

The information presented so far reviewed theoretical background to illness perception research, identified similarities and differences between the approaches and described a trans-disciplinary approach. The material advances current knowledge by showing the strengths and weaknesses of each approach with regard to cross-cultural research and identifies that a complementary approach is needed. The next section of the chapter will explore how far have been incorporated in the current available assessment tools and their general suitability towards assessing cultural variations in perceptions.

2.2. A review of the current methodologies to assess perceptions of distress

The next section of review focuses on conventional assessment methods (interviews, questionnaires), despite the possibility that alternative methods (drawing pictures, sorting pebbles etc) may be easier to implement in clinical care. However, findings from these unstandardised techniques seem to be more difficult to interpret and also there is limited evidence as to how such techniques perform cross-culturally. Among these standardised conventional methods, five have been identified as the most commonly used published instruments to assess Explanatory Models and Illness Perceptions: a) Kleinman's nine open-ended questions (K8) (Kleinman, 1980b), b) the Explanatory Model Interview Catalogue (EMIC) (Weiss, Doongaji, Siddhartha, Wypij, Pathare, Bhatawdekar, Bhave, Sheth, & Fernandes, 1992; Weiss, 1997), c) Short Explanatory Model Interview (SEMI) (Lloyd et al, 1998), d) the Mental Distress Explanatory Model Questionnaire (MDEMQ) (Eisenbruch, 1990; Kleinman, 1980b), and e) the Illness Perception Questionnaire/ Illness Perception Questionnaire-Revised (IPQ-R/ IPQ) (Moss-Morris et al, 2001; Weinman et al, 1996). Each instrument's characteristics will be described and then evaluated.

2.2.1) Kleinman's 8 Open-ended questions (K8) (Kleinman, 1980b)

Arthur Kleinman introduced the first assessment of explanatory models tentatively stating that he generally would ask open-ended questions about a person's explanatory model in his book *Patients and Healers in the Context of Culture* (Weiss et al, 1986). Only if these are not fruitful, in a footnote on p. 106 he described the following 8 questions that might be helpful in assessing explanatory models.

1) *What do you call your problem? What name does it have?*

2) *What do you think has caused your problem?*

3) *Why do you think it started when it did?*

4) *What does your sickness do to you? How does it work?*

5) *How severe is it? Will it have a short or a long course?*

6) *What do you fear most about your sickness?*

7) *What are the chief problems that your illness has caused to you?*

8) *What kind of treatment do you think you should receive? What are the most important results you hope to receive from your treatment?*

In the same footnote, Kleinman also considered the circumstances under which an assessment should be conducted. He argued that assessments at home would produce more accurate results than assessments in clinical settings and emphasised the importance of demonstrating a genuine, non-judgmental interest in patients' beliefs. This footnote is the only reference to guide users as to *how* EMs should be elicited. Kleinman appeared cautious of laying out specific assessment methods, and others speculated that this was intentional, because over-specifying the operational aspect of EM assessment would undermine the development of cultural sensitivity (Weiss, 1997). This lack of specificity as to how EMs should be assessed posed considerable problems for clinicians and epidemiological research that tried to evaluate the EM concept in terms of predicting health service utilisation and outcome.

Kleinman's statement that he would normally ask 'general, open-ended questions about patients' explanatory models' is problematic as his texts offer so little formalisation as to what an explanatory model actually contains, i.e. what it is and what it is not. Many possible questions come to mind that are related to the patient's model; but his 8 questions further suggest that his main focus is on individuals' perceptions of complaints/ their severity, causes, course, consequences and control. His lack of detail in operationalising the content and structure of the model and its assessment also questions the reliability of elicited data. Indeed, Weiss et al attempted to utilise these 8 questions in their research on tropical disease and mental health and found it difficult to a) document

the interaction between researcher and participants and b) classify notions of an individual's EM (Weiss, 1997). In response to these findings, Weiss and colleagues developed a more structured technique that would allow for an accurate assessment of individuals' EM, and would be more specific as to what would happen in the elicitation process.

2.2.2) Explanatory Model Interview Catalogue (EMIC) (Weiss et al, 1992; Weiss, 1997)

The EMIC was developed by Weiss and colleagues (1992) and was devised as a 'catalogue' of explanatory model interviews that explored patients' explanatory models of different physical and mental conditions. The EMIC lists information needed for coding and comparing explanations from large numbers of individuals and provides a framework in which the meaning of explanations could be explored. Although it provides an assessment structure, the EMIC is very flexible to allow the researcher to adapt question wording and elaborate on questions and issues that are of particular interest to them. There are two components: the first (A) features guidelines, how an explanatory model interview should be conducted and the second (B) contains the 'operational formulation of illness explanatory models for EMIC interviews' (Weiss, 1997).

A) Guidelines for the EMIC

The EMIC guidelines say that the interview should begin with an empowering introduction about how the research is interested in the individual's personal beliefs and will not be used to make clinical judgements i.e. clinical decisions. Then the interview proceeds to ask questions of both open-ended and structured nature. In his previous research Weiss found how individuals mention an unbalanced diet in terms of bodily humours as a cause for illness, but only in the context of probed, structured questions. Weiss et al therefore included structured questions to avoid that influential perceptions are omitted in the open-ended assessment, but does not necessarily specify how they should be formulated.

Summaries are made at the end of each section to evaluate the importance of different perceptions and their change over time. Finally, the EMIC also features prose elaboration or narrative exploration of an individual's illness experience to guide coding and to explore the data qualitatively.

B) The operational formulation of an explanatory model

The explanatory model is formalised in the EMIC in five sections: patterns of distress, perceived causes, help-seeking and treatment, general illness beliefs and disease specific queries. The first section, 'patterns of distress', features perceptions of the identity and consequences of an illness: illness-related problems, names of the illness, social, psychological and economic consequences of illness, stigma and impact on family/ marital prospects. 'Perceived causes' describes 8 different themes of causes such as foods, infections etc. In the help seeking section, first home remedies and family support, then healers of different types are mentioned and finally individuals are asked to evaluate their past experiences and their current preferences. As the explanatory model theory is ethnographic, individuals' perceptions and beliefs of other illnesses may also be explored along with the relationship between mind and body. Disease specific queries are also included to assess how differentiated an individual's explanatory model is for particular conditions to contrast it with general ones.

The EMIC helps researchers to manage and organise their data and describes the form of data sets that can be developed. It suggests that items should be differentially weighted depending on whether they were probed or spontaneously elicited, emphasised or mentioned, seen as important, or identified as the first perceived cause. The authors also suggest that in some studies perceptions of causes might become so large that they can be collapsed into summary group categories as long as there is flexibility in how the categories are assessed.

The most predominant weakness of the EMIC is that it is an extremely lengthy and time-consuming form of assessment. Jadhav et al reported that the interviews can take up to 2 hours to administer (Jadhav, Weiss, & Littlewood, 2001), which makes it impossible for use in standard clinical care and also most population research. It further shies away from listing detailed perceptions, so that researchers cannot be sure whether their open-ended queries or even their structured assessment possibly omit important beliefs. As all the data collection is conducted by face to face contact, it can also be biased by the general interaction with the researcher (Boynton et al, 2004). It seems therefore, although the EMIC formalises more what EMs are and how they could be assessed, not all problems could be overcome.

2.2.3) Short Explanatory Model Interview (SEMI) (Lloyd et al, 1998)

The SEMI was developed in order to address some of the 'impracticalities' of the EMIC and to shorten the enquiry. The guidelines for use are similar to the EMIC's as they encourage individuals to talk openly about their 'attitudes and experiences', but also enable researchers to use probes (i.e. more structured questions) in areas of their own interests. The content of the SEMI extends the EMIC by incorporating the assessment of socio-demographic information, but also reduces it with an exclusive focus on mental illness and exclusion of other illness beliefs. The interview is divided into 5 sections: personal and cultural background, nature of the problem, help-seeking, interaction with healer, and beliefs about mental illness. The first section ascertains demographic information and information about social situation. Individuals are asked to report how they named their problems and their reason for consulting, perceived causes, consequences and severity and the effects they experienced in the second section. They are asked to list help seeking in the third section and to evaluate the interaction with their healer in the fourth. The fifth section assesses perceptions by describing vignettes of common mental

disorders, 'depression', 'somatisation' and 'phobia', and asking individuals to evaluate them. The evaluation contains an assessment as to whether the case is a problem, what it is or whether it is an illness, what they perceive the causes to be and what the patient and the doctor should do about it.

The authors estimated that the interview should be completed in 30-45 minutes, much less than the time needed for an EMIC interview. It uses non-technical language that can be easily translated, and it can be employed to conduct quantitative and qualitative analyses (Lloyd et al, 1998). Also an immediate advantage is the incorporation of individuals' socio-demographic background as one can control for mediating or moderating variables of EMs with other measures. Two imperfections, however, are apparent. The first is the exclusive focus on mental illness. Despite the clear theoretical and professional distinction between mental and physical *disease*, cross-cultural research suggests that mental and physical *illness* might not necessarily be distinct. This is the result of the mind-body split not being universally endorsed by the lay population across the globe (Kleinman & Kleinman, 1991; Sobo, 1996; Torsch & Xueqin-Ma, 2000; Tung, 1994; Van Moffaert, 1998). Labelling illness as mental or physical in nature seems to be largely dependent on historical, political and demographic influences.

The second imperfection is the inclusion of supposedly 'universal' vignettes as a measurement of beliefs about mental health in general. How can researchers ensure that these are meaningful and applicable to individuals from different cultures? Furthermore, the SEMI focuses its attention on health settings as it requires individuals to talk about the nature of their 'presenting problem'. Nevertheless, the SEMI appears useful to assess and formalise EMs in a time-limited situation, and is not intended to replace detailed ethnographic enquiries. Findings from the first study to use the SEMI suggest that it can answer crucial cross-cultural questions (Lloyd et al, 1998). Lloyd et al found that African

and British people have significantly different perceptions about causes of their presenting problem, and also that different British ethnic groups have different opinions as to whether common mental disorders are a problem or an illness (Lloyd et al, 1998). Therefore the SEMI appears to have great potential, although some of the methodological and conceptual problems of the EMIC have not been completely addressed.

2.2.4) Mental Distress Explanatory Model Questionnaire (MDEMQ) (Eisenbruch & Handelman, 1990)

The MDEMQ is a questionnaire, that was developed on a basis of a review of social science taxonomies of illness and illness causation (Foster, 1976; Landy, 1983; Murdock, Wilson, & Frederick, 1978a; Murdock, Wilson, & Frederick, 1978b; Young, 1976b; Young, 1976a). Murdock's combined emic/etic approach was used as a starting point for generating items for a culture specific Cambodian Explanatory Model Schedule (CEMS) questionnaire (Eisenbruch & Handelman, 1990). The CEMS was later extended with the aim of producing a universally applicable questionnaire, the MDEMQ (Eisenbruch, 1990). The MDEMQ is a questionnaire that consists of three parts, a demographic section, an introductory statement about the variety of forms that mental distress can take and a list of 45 causes. The individual has to evaluate on a five point Likert Scale, how likely or unlikely it is that this cause contributes to any form of mental distress.

The MDEMQ focuses entirely on the causal domain, and administration should take between ten and twenty minutes. It requires a high level of literacy and presumes a certain level of familiarity with questionnaire use, which some might view as acceptable as it is mainly intended to be used in Western settings. The main weakness of the MDEMQ is the method that requires individuals to relate specific causes to *any* form of mental distress, not necessarily their own and this seems indeed highly variable (Prohaska, Leventhal, Leventhal, & Keller, 1985). One person might think of 'distress' and envisage a

schizophrenic person they've seen on the TV, another might be thinking of their own experience of depression, a third might be thinking of a family member with a phobia. When it is not clear what form of mental distress the thoughts relate to, it is impossible to know what the findings mean. It seems obvious that individuals should evaluate a personal experience differently from experiences of family members or those of anonymous individuals from the public. They generally have a more optimistic and favourable perception of illness and other risks for themselves than for the public at large and other individuals they know (Watson, 1982). The tool assesses 45 causes that were developed out of previous taxonomies; the risk of omitting important ones is thereby reduced, which might be seen as a strength of the instrument. However, the tool is not well suited to clinical care as there seems to be no distinction between what a person might personally perceive to be cause of *their* distress and the cause of mental distress in general. One might want to adapt the MDEMQ further to explore its usefulness in clinical settings. The more important limitation of the MDEMQ is that it focuses only on causal attributions alone. Despite this being an interesting area of investigation of cultural diversity, a meta-analytic review of the evidence on coping with illness found that causal attributions have in most situations only an indirect relationship with outcome and coping (Roesch & Weiner, 2001). The meta-analysis of the illness perception research additionally found that causal perceptions are not as central in predicting health behaviours (Hagger & Orbell, 2003). Therefore the MDEMQ might not be seen as a comprehensive measure.

2.2.5) Illness Perception Questionnaire – Revised (IPQ-R), Illness Perception Questionnaire (IPQ) (Moss-Morris et al, 2001; Weinman et al, 1996)

The Illness Perception Questionnaire was developed to unite different assessment methods that tried to evaluate the self-regulatory model of health behaviour. Leventhal and colleagues used initially in-depth, semi-structured interviews to elicit perceptions and

then proceeded to use questionnaires for specific patient groups. These did provide important in-depth findings, but were seen as problematic as qualitative research analyses and interpretation are so time consuming that samples have to be kept small. Weinman et al developed the IPQ to have a theoretically based brief assessment tool, which enabled them to compare perceptions of different patient groups (Weinman, Petrie, Moss-Morris & Horne, 1996). The initial version contained perception items about identity, cause, consequence, timeline and control. Identity was assessed by listing 12 'common symptoms' from other physical health checklists, which each individual had to rate on a 4 point scale, from 'never' to 'all of the time'. Perceptions of all the other domains was presented in statement format (e.g. for cause: 'my illness is hereditary – it runs in my family'. time-line: 'My illness will last a short time.' consequence: 'My illness has strongly affected the way others see me.', and control/cure: 'Recovery from my illness is largely dependent on chance or fate.'). These items were evaluated by patients using a five point scale from 'strongly agree' to 'strongly disagree'. The IPQ items are presented in a mixed order and apart from the causal domain all items can be summed to derive an overall score for each domain. Causal items are treated independently as they are conceptually different, although the authors suggest that a possible aggregation of external and internal perceptions about causes might be useful for certain research questions. One can also exchange the term 'illness' with specific names for each condition, and a carer version is also available to assess the perceptions of others about the illness.

Weinman et al have presented findings from seven different illness groups to evaluate the reliability and validity of their measure. They twice assessed reliability by testing a sample with renal problems and myocardial infarction and found it to be reliable (Cronbach's Alpha .73 - .83). They compared it with seven health cognition and health behaviour measurements to examine concurrent validity, which was seen as encouraging. Discriminant validity was determined by assessing scores in four different patient groups.

They also determined the predictive validity by subsequent assessment of 3 and 6 months follow up of their myocardial infarction group, and found that consequences and control perceptions were related to greater perceived control over heart problems and a perceived greater likelihood of a future MI. Weinman et al also reported in their discussion that individuals' completion of the IPQ was better when they had been briefly interviewed previously (Weinman, Petrie, Moss-Morris & Horne, 1996).

Before an evaluation of the IPQ is presented, I shall firstly describe the changes that have been made to the IPQ in the revised version published in 2001. The IPQ-R was extended to improve the psychometric properties of the time-line and the control/cure scales by including more items, and this opportunity was used to include additional sub-scales (Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2001). The additional scales included perceptions of a meta-cognition domain called 'illness coherence' (is my illness coherent with my other beliefs, does it make sense to me), 'cyclical' time-line dimension (my illness comes and goes) and emotional representation (a sub-set of 6 affective responses). This time they showed reliability of the scale in a sample of 711 patients from eight different illness groups. They also slightly changed the instructions and set up of the questionnaire. In the identity section, individuals were asked whether they had experienced the symptom since they developed their illness, and whether the symptom in their mind was related to the illness. Only the second scale was understood to be the identity domain, therefore one could distinguish between a general somatisation effect and perceptions regarding the illness identity. Then perceptions about consequences, timeline, control/cure, coherence and emotions were presented in the original Likert scale format. The causal section was presented separately, but the number of items was also increased from ten to eighteen, and an open-ended question was asked to name the three most important causes of their illness.

To evaluate the internal reliability of the scale, Moss-Morris et al conducted a principal components analysis, which accounted for a significant proportion of the variance, and determined Cronbach's Alpha (.79 -.89). Test-retest reliability was determined by questioning renal dialysis and rheumatoid arthritis patients over three weeks and six months. Correlations between the two dates were acceptable (over .5) in most samples. Divergent validity was assessed by comparing results with trait affect, and the most significant relation was with the emotional representation ($r=.54$). There were also associations with strong illness identity, chronic and cyclical timeline, beliefs in serious consequences and internal cause attributions, and trait affect as measured by the Positive And Negative Affect Scale (Watson, Clark, & Tellegen, 1988). Discriminant validity was assessed by comparing perceptions of acute and chronic patients. It was found that chronic patients' perceptions differed from acute patients' perceptions in a number of ways. Chronic patients had a stronger identity with their illness (i.e. more related symptoms), a more chronic and cyclical timeline. They perceived their illness to have more serious consequences and less controllable. Criterion validity or predictive validity was determined by assessing adjustment to illness by including a measure of sickness-related dysfunction and fatigue in MS patients. Illness perceptions predicted fatigue and dysfunction, and the 'cognitive' aspects of the IPQ predicted 36% of the variance of the scores on the 'emotional' subscale (Moss-Morris et al, 2001).

The IPQ and IPQ-R are relatively short questionnaires intended mostly to document perceptions of physical illnesses, and reliability and validity have been extensively evaluated. By asking individuals to evaluate 'general' statements about illness it seems that the main setting that the IPQ was intended to be used in was the research setting (population groups) and not necessarily clinical care (individual). A meta-analytic review of research utilising the IPQ showed that the scores predicted both positive and negative outcomes across illness groups (Hagger and Orbell, 2003). As the questionnaire seems to

require a certain level of literacy, and also familiarity with psychological questionnaires, this suggests that it might well be problematic for research involving individuals with reading difficulties and non-familiarity with questionnaire research, such as children or illiterate adults. Another conceptual problem is that the items (e.g. control/cure *Nothing I do will affect my illness, I have the power to influence my illness*) assess narrow, abstract concepts. Some items try to assess an endorsement of certain illness 'beliefs' (i.e. whether individuals believe that they can influence their illness or not, or whether they conceive their illness to be serious or not); but they do not assess concretely what individuals fear, or what they think they can do to control their illness. It seems likely therefore that this measure might not be useful to understand cultural variations in perceptions since such abstract views as one's personal control of illness seem influenced by a multitude of cultural, religious and political factors or values. The IPQ assesses perceptions from an etic view, assuming that they hold true for individuals from all cultural backgrounds, but (to the author's knowledge) little research evaluated its validity in Non-Western cultures. Therefore if one intends to do comparative research with Non-Western groups one should be cautious at interpreting the findings, as the findings might be too far removed from the person's cultural frame of reference and might not be meaningful. Also, as outlined in the previous chapter, one might want to expand the assessment to determine specific concrete consequences that individuals fear for their illness (e.g. death, losing their job), specific timelines they endured and expect their distress to last (2 weeks or 2 months), and specific treatments that individuals have sought and found helpful. As this format was not judged to be appropriate to document cultural diversity of experiences and perceptual processes of distress, it was necessary to devise a new instrument for the assessment of cultural variations in perceptions.

The present section has reviewed the most commonly used instruments of the explanatory model and illness representation approach. It identified that most assessments are not

suitable for comparative research between Western and Non-Western cultures. A new tool is warranted and in the next section a literature review was therefore conducted to explore how one might best assess cultural diversity in perceptions.

Chapter 3 – Literature review - Qualitative analyses of subjective literature accounts and the development of a new assessment instrument for the investigation of cultural variations in perceptions of mental distress

3.1. Literature Review

3.1.1. Background and Aim

Cultural diversity in perceptions of distress has been observed across the globe: 1) An Ethiopian woman expresses her distress by complaining of 'having a snake in her leg', an idiomatic expression for having problems with her mother in law (Schreiber, 2001). 2) In Israel, an ultra-orthodox Jewish man witnesses a serious traumatic accident. He complains of an intrusive image following him around afterwards, weakening his ability to concentrate at work and evoking feelings of guilt and anxiety (Witztum & Goodman, 1999). 3) A Puerto Rican matriarch's screaming and physical violence were observed to be an 'appropriate' distress response when a family member was diagnosed with severe illness (Guarnaccia, Rivera, Franco, & Neighbors, 1996). By just exploring these three accounts one can imagine the diversity in cultural variations in experienced distress and different culturally sanctioned ways to deal with it. Both seem to be idiosyncratic to the individual, but also follow culturally bound symbolic rules. Treatment approaches range from behavioural changes as in the case of the Puerto Rican to traditional faith healing with exorcism as described in relation to the ultra-orthodox Israeli. To enable a comprehensive and reliable assessment of cultural variations in perceptions; I firstly considered whether a common framework was possible in which cultural variations could be conceptualised from a lay perspective.

In the aim to define cultural differences, anthropological research differentiates between adopting an *experience near* (*emic*- from phonemic i.e. phonologically unique) or *experience far* (*etic*- from phonetic i.e. phonologically universal) approach. Etic

approaches to mental health tend to see cultural variations in symptomatology/ manifestations of mental distress as context driven and idiosyncratic, but allege that there is an underlying syndrome, which is universal in nature. In psychological terms one would describe these as top-down approaches to mental health. Emic advocates, on the contrary, view the nature of the complaints as the crux of the problem and appear to construct mental illness from culturally formed expressions and their uniqueness. These would be referred to in psychological terminology as bottom-up approaches to mental health.

It seemed common-sensical to develop a framework of cultural variations on the basis of client needs i.e. an emic or bottom-up-approach. Assembling raw qualitative data from around the globe would have been an unfeasible task as one would need access to a multitude of locations and knowledge of different languages. Analysing and interpreting raw qualitative data would need even more resources such as familiarity with different languages, and considerable time and money to undertake this endeavour, which would surpass the capability of one's lifetime. The only viable alternative to complete this task in the allocated time of the PhD was to explore cultural variations in subjective accounts described in the literature. Premises of the literature review were established to ensure that it comprehensively represented culturally diverse accounts and focussed on the individual's perspective:

1. To identify and obtain subjective 'emic' accounts of diverse perceptions of mental distress;
2. To explore whether a cross-cultural framework can be realised on the basis of a literature review of subjective accounts;
3. If such a conceptual framework was possible to devise an assessment tool that was able to identify cultural variations in perceptions, but still remained focussed on the lay perspective.

3.1.2. Methods 1

A literature search was conducted to identify anthropological, psychiatric, psychological and sociological accounts of distress. The literature search strategies were developed with the help and support of the medical librarian from Barts & the Royal London Medical School and other librarians from the University of London library (Senate House). Firstly, bibliographic literature searches were conducted using the following databases: Anthropology Index Online, Anthropological Literature, BIDS (ingenta), Embase, International Bibliography of the Social Sciences, Medline/PubMed available on Ovid, PsychINFO available on Ovid, and Web of Science. Further formal searches were conducted on other internet based search engines e.g. BioMednet, BMJ, JPET, Social Science and Medicine abstracts, American Journal of Psychiatry, American Psychological Association and other publishing engines. No limit (e.g. publication year, number of accounts per cultural group) was set on these searches and terms included EXPLANATORY MODEL (S), ILLNESS REPRESENTATION (S), DISTRESS, DEPRESSION, MENTAL HEALTH, BELIEF(S), UNDERSTANDING, PERCEPTION (S), TREATMENT, HEALING, IDENTITY, CAUSE, CULTURE, RACE, ETHNICITY. The search terms were originally chosen from reading around the literature Kleinman's original work. It was identified later that key words such as ANXIETY, COMORBIDITY, PSYCHIATR*, MOOD, PSYCHOL* were missing and literature searches were reran using those terms.

The abstracts of these references were read to establish relevance and were assessed against inclusion and exclusion criteria that have been summarised in table 2. The two inclusion criteria were: a) they must contain a detailed *emic* description of at least one individual's perceptions of mental distress; b) they must contain enough detail to be analogue to an actual account. In the main qualitative anthropologists' accounts, psychiatrists' case studies and ethnographies were considered. For example in Dein &

Sembhi's description of five individual cases (Dein & Sembhi, 2001) and their help-seeking behaviour two of five cases met the inclusion criteria as they were focussing on individual accounts of distress. The criteria to exclude articles were: c) Group analyses in which the experiences of individual cases could not be discerned (for example, British Caribbeans (Littlewood & Lipsedge, 1988); d) quantitative cross-cultural comparisons; and e) articles featuring so called psychotic illnesses. Although the distinction between psychotic and neurotic disorders is somewhat blurred – it was decided to exclude psychotic articles as perceptions might be the result of delusions and hallucinations. f) Articles that focussed on selective aspects of distress, such as stigma or somatisation, were inspected only to get background knowledge of the field, but were excluded as material for the analysis. Articles were obtained from the University of London libraries and the British Library.

Hand searches of the following journals were also conducted: Social Science and Medicine; Transcultural Psychiatry; Journal of Cross-Cultural Psychology; Culture, Medicine and Psychiatry; Medical Anthropology; Medical Anthropology Quarterly; Anthropology & Medicine, and the Journal of Mental Health. Scanning reference lists of already obtained articles has also helped us to identify additional articles. We developed a reference database of 1128 articles on descriptions of distress, from which 40 article (containing 86 accounts) met the inclusion criteria. Articles needed sufficient detail and had to include also perceptions of different domains.

In order to avoid a dominance of particular cultures (e.g. Asian), which were more often reported in the literature than others, it was decided that no more than 5 accounts would be considered from one cultural group. The 5 different accounts were chosen by considering the quality and content of the description. E.g. if there were accounts that only included a very limited amount of information and the information was intermingled with



professional conceptions - it was not included if there were more detailed accounts available that were more suitable. When there were accounts describing similar explanatory models of distress (such as possession or Ayurvedic qualities of food) and another added a completely new and not reported perception e.g. the conflict of living in a new culture and traditional family values, it was decided to include the new account. This was done under the assumption that the information of a similar perception would be replicate information that was already contained and further that more diverse perceptions would also show the diversity within cultural groups.

Table 2 Exclusion and Inclusion Criteria for Literature Accounts

Included were articles that:	Excluded were articles that:
Were qualitative papers (i.e. anthropologist's accounts, psychiatric/psychological case studies and ethnographies	Were quantitative papers
Contained at least one subjective account of an individual's experience of mental distress	Included not sufficiently detailed accounts e.g. info about groups rather than individual cases
Featured accounts from culturally diverse individuals	Described perceptions that were referring to psychotic illnesses
Incorporated many diverse perceptions	Did not comprehensively describe the patient's experience, focussing only on selected aspects of the experience i.e. in relation to identity or somatization or stigma as a consequence of distress

The literature accounts i.e. the sources of the material used in the analyses is summarised in table 3 below.

Table 3 Literature Accounts that were used to develop the cross-cultural framework of distress ordered by the name of the individual, the culture and gender, and a brief summary of the content of the article

Authors	Accounts name (age in years) Culture, gender indicated by m/f	Content
(Pandolfi, 1990)	Maria () Southern Italian f	Describes strategies how the body is used to communicate stories/ personal narrative/ distress.
(Migliore, 1994)	Zia Salonia (born in 1920s) Sicilian migrant f Zia Alfiaca (80y) Sicilian migrant f Zio Vol (ca 60ys) Sicilian migrant m	The idiom of nerves in Sicilian Canadian individuals is conceptualised and the ambiguity of the term is identified.
(Rethman, 1999)	Moite late 30s Russian Koriak f	By illustration of the story of Moite the social plight of Koriak lives is narrated as a bodily disease.
(Baarnhielm & Ekblad, 2000)	Sevgi (38y) Turkish f Hawa (45y) Turkish f	Describes the understanding of distress in the manifestation of back pain. Migrants did not find a psychiatric understanding as a helpful tool for recovery.
(Yilmaz & Weiss, 2000)	Mr Osman (22y) Turkish m	Case description of a young male immigrant in Basel, Switzerland describing the link between pain and distress.
(Jadhav, Weiss, & Littlewood, 2001)	Tom (39y) White British m Linda (26y) White British f Jane (23y) White British f	White Britons explanatory models of depression were explored in a epidemiological survey (3 cases are used as illustrations.
(Rasmussen, 1992)	? (40y) Nigerien Tuareg f	The experience of Tamazai an illness of the heart and the soul in the Nigerien tribe of the Tuareg.
(Ilechukwu-Sunny, 1999)	? (50y) Yoruba Nigerian housewife f (35y) Nigerian technician m (40y) Nigerian housewife f (40y) Yoruba Nigerian lawyer	Describes the use of psychodynamic psychotherapy in Lagos, Nigeria and challenges generalisations that have been made about African patients.
(Bilu & Witztum, 1993)	Ezra (young) ultra-orthodox Israeli m David (29y) ultra-orthodox Israeli m Sara (late 50s) ultra-orthodox Israeli f Avraham (35y) ultra-orthodox Israeli m	Describes the gap between medical reality and spiritual/ sacred reality of the Jewish ultra-orthodox cases. Advocates the use of temporary suspension of disbelief to work with individuals with a culturally sensitive therapy.
(Daie, Witztum, Mark, & Rabinowitz, 1992)	Rafik (19y) Israeli Druze m	Describes use of explanatory model, healing and hypnotic suggestions to alleviate severe anxiety reaction.

Authors	Accounts name (age in years) Culture, gender indicated by m/f	Content
(Young, 1982)	Sharona (?) Ethiopian f	Discusses different conceptualisations of explanatory models and illustrates the complexity of EMs by a case study and schematisation.
(Durst, Minuchin-Itzigsohn, & Jabotinsky-Rubin, 1993)	? (28y) Ethiopian immigrant	Describes the processes of transculturation in an Ethiopian Jewish immigrant who presents with symptoms of 'Brain Fog'.
(Witztum, Grisaru, & Budowski, 1996)	Yalganesh (43y) Ethiopian immigrant f	Culturally bound Ethiopian concept of Zar possession is analysed on the base of cases and an argument is made for it to be culturally derived illness behaviour rather than disease.
(Grisaru, Budowski, & Witztum, 1997)	Imebet (45y) Ethiopian f	The possession of Zar phenomenon is demonstrated by a case illustration and should be understood as a culturally bound syndrome.
(Schreiber, 2001)	? (31y) Ethiopian refugee f	Identifies problems associated with refugees, misdiagnosis and appropriate cultural treatment in the form of purification and traditional healing.
(Budman, Lipson, & Meleis, 1992)	Omar (17y) Iraqi Arab	Describes misdiagnosis and psychiatric hospitalisation of patient and ability of cultural consultants in health care.
(Dwairy, 1997)	Ahmad (18y) Palestinian Arab m Boshra (31y) Palestinian Arab f	The cultural appropriateness of self-actualisation of individual needs by therapy is critically examined in relation to Arabic values.
(Masalha, 1999)	Jamal (38y) Palestinian Arab m	The change of attitudes towards psychotherapeutic is described and an argument is made using the description of Jamal against the adoption of a too culturally oriented approach.
(Ilechukwu-Sunny, 1999)	Mr AC (34y) Nigerian m	On the basis of a case study the differences and similarities of oedipal anxiety are contrasted.
(Streit, LeBlanc, & Mekki-Berrada, 1998)	B (46y) Moroccan migrant f	A clinical case study of a Moroccan migrant in Canada where exploration of traditional models of illness <i>sorcellerie</i> was instrumental in efficient treatment.

Authors	Accounts name (age in years) Culture, gender indicated by m/f	Content
(Kleinman, 1982)	? (18y) Chinese student m ? (35y) Chinese physician f Etc	Discusses the distinction between disease and illness by relating a lay concept of neurasthenia to the Western diagnosis of depression.
(Ots, 1990)	? (38y) Cadre Chinese m ? (30y) Worker Chinese f ? (57y) Librarian German f Etc	Uses case studies to illustrate the usefulness of traditional Chinese understanding of bodily organs and their link with emotions. Anger with liver problems, anxiety with heart conditions and melancholy with problems of the spleen.
(Lu, Lee, Liu, Wing, & Lee, 1999)	Mrs D (26y) Sichuan Chinese migrant f Mr F (30) Hunan Chinese migrant m Etc	Mental health problems of Chinese economic migrants moving to the cities and towns. Hospitalisation mostly due to socially intolerable behaviour.
(Etsuko, 1991)	Michiko (43y) Japanese f	Describes the process of role transformation, from client to healer in a Japanese woman complaining of fox possession.
(LeVine & Matsuda, 2003)	M (28y) Japanese migrant f	A differential diagnosis is described and elaborated on with reference to cultural background and values of a Japanese migrant in Australia.
(Weiss, Desai, Jadhav, Gupta, Channabasavanna, Doongaji, & Behere, 1988)	Gopal (45y) Indian m Ramesh (50y) Indian m	Describe by use of case descriptions humoral traditions and illness perceptions of individuals that come to psychiatric hospital in India suffering from distress.
(Skultans, 1991)	Parubai (45y) Maharashtra (India) f Bapu (29y) Maharashtra (India) m Suman (25y) Maharashtra (India) f	Reports findings of fieldwork in a Manubhav healing temple. Afflictions of the residents differed by gender and hence social standing.
(Oquendo & Graver, 1997)	S (29y) Christian Punjabi f	Illustrates the cultural diversity and the problem of a Latina therapist in relation to the treatment of a Punjabi patient.
(Pang, 1990)	Mrs Yun (67y) Korean Immigrant f Mrs Baik (65y) Korean Immigrant f Mrs Kim (73y) Korean Immigrant f Etc	Examines the cultural construction of <i>hwa byung</i> – a Korean cultural illness that combines negative life events, distress and somatisation.
(Yi, 2000)	Anna (27y) Korean migrant f	Case description of a Korean woman living in the USA that suffers from <i>Shin-Bung</i> (divine illness).

Authors	Accounts name (age in years) Culture, gender indicated by m/f	Content
(Pang, 1998)	Mrs Cha (65y) Korean Immigrant f Etc	Psychologisation/ somatisation divide is analysed in elderly Korean immigrants to the US. It is asserted that the more self-directed individuals they psychologise, the more they are directed the more they somatise.
(Wikan, 1989)	A young lady Balinese f A woman Balinese f	<i>Kesambet</i> a cultural syndrome of Balinese people associated with what are generally seen as disallowed emotions.
(Dein & Sembhi, 2001)	Mr D (35y) Bangladeshi m Mrs B () Pakistani f	Use of traditional healing among South Asian psychiatric patient in the UK.
(Bose, 1997)	Zahra Begum (?) Bangladeshi f Ali Hussein (15y) Bangladeshi m	The Bangladeshi concept of possession is described in young Bangladeshi teenagers. Psychosocial problems are enacted in a form that is culturally understood.
(Barrett, 1997)	Nam (33y) Vietnamese migrant m	Combined traditional and medical treatment for a patient with a complain of <i>thúông mã phong</i> an illness associate with being struck by wind.
(Cheung & Lin, 1997)	Ms J Chinese Vietnamese migrant	Illustrates by the case of Ms J the problems of applying culturally bound syndrome to diagnoses as CFS and neurasthenia.
(Hinton, Hinton, Pham, Chau, & Tran, 2003)	Lê (54y) Vietnamese refugee f Mơ (50y) Vietnamese refugee f Hương (?) Vietnamese refugee f Hảo (?) Vietnamese refugee f Etc	Being 'hit by the wind' is phenomenologically analysed in a Vietnamese refugee sample of a psychiatric centre in the USA.
(Yeung & Chang, 2002)	Mr K (55y) Taiwanese migrant m	A clinical case description of a Taiwanese father who discipline his daughter physically. Illustrates problems of acculturation to the USA and differing intergenerational values.
(Chuengsatian sup, 1999)	Sopha (35y) Thai Kui f	Describes the occurrence of distress, in response to being exposed to sounds, symbols that have political significance. The body is understood as a cultural form of memory and the senses create a specific mode to relate Kui' sense of marginality.

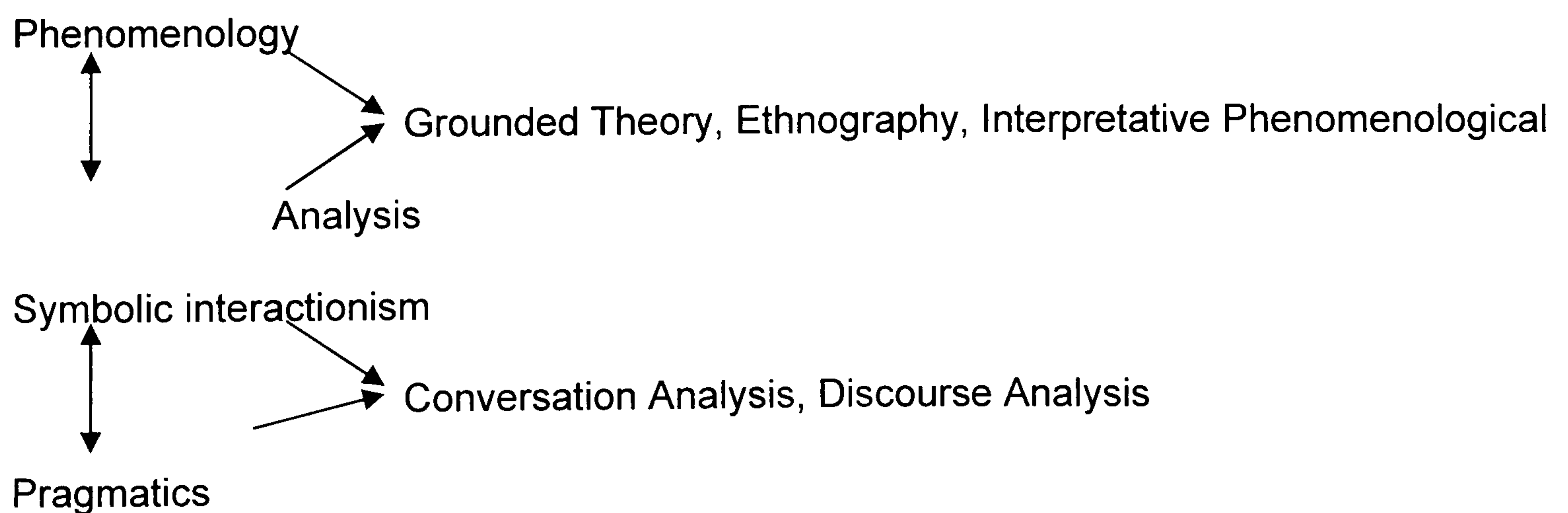
Authors	Accounts name (age in years) Culture, gender indicated by m/f	Content
(Rechtman, 2000)	Ms V (20y) Khmer refugee f	The manifestation of mental distress in a Cambodian refugee living in France and the resolution of distress by resolution of circumstances.
(Hinton, Um, & Ba, 2001)	San (44y) Khmer refugee f Sok (48y) Khmer refugee m Etc	The Khmer <i>Weak Heart Syndrome</i> characterised by palpitations and fear of dying is illustrated by three case descriptions.
(Hinton, Hinton, Um, Chea, & Sak, 2002)	Uy (?) Khmer refugee f Pich (?) Khmer refugee f	This article describes how certain cultural syndromes increase risk of panic attacks by example of <i>Kyol Goeu</i> (Wind Overload).
(Lemelson, 2003)	Pak Nengah (early 50s) Balinese m Pak Wayan (60y) Balinese m Pak Sudiasih (44y) Balinese m Etc	Describes the cultural shaping of obsessive-compulsive disorder in Bali, Indonesia.
(Seltzer, 1983)	D.L. (24y) Inuit m D.N. (19y) Inuit m A.K. (20y) Inuit m	Three cases were used to determine psychodynamic factors of spirit possession among the Inuit in Northwestern territories.
(Farias, 1991)	Omar (16y) Salvadorian refugee m Martin (26y) Salvadorian refugee m Mrs G (72y) Salvadorian refugee f Mrs P (34y) Salvadorian refugee f Mrs S (40y) Salvadorian refugee f Etc	Narrates the social origins and expressions of distress in Salvadorian Refugees in the US. Violence and trauma as predominant causes and resulting mental problems are patterned by gender differences.
(Oquendo, Horwath, & Martinez, 1992)	A (18y) Dominican F B (35y) Dominican F	Propose diagnostic criteria for <i>Ataques de Nervios</i> a culturally specific syndrome mainly observed in Spanish speaking people of the Caribbean and illustrates this by two cases.
(Lewis-Fernandez, 1996)	? (50s?) Puerto Rican migrant f	Another case of <i>Ataques de Nervios</i> in a clinical case presentation of diagnosis and treatment.
(Sobo, 1996)	Margaret (40y) Jamaican f	Tells of the link between feelings are linked in Jamaican traditions as physical. For example the description of "nerves" as physical rather than socially based disorder.
(Liggin & Kay, 1999)	Ms B (40y) African American woman f	Analyse the issue of cross-race interaction in the therapy, the internalisation of racial models and the possibility to provide effective cross-racial therapy.
(Hollan, 2004)	Ted (mid thirties) White American m Nene'na Tandi (early 60s) Toraja m	Outlines the development of idioms of distress in relation to one's personal social and cultural history.

Authors	Accounts name (age in years) Culture, gender indicated by m/f	Content
(Manson, 1996)	J (45y) American Indian m	A cultural clinical case assessment of a complex presentation with multiple problems: trauma, substance abuse, childhood abuse and bereavement.
(Storck, Csordas, & Strauss, 2000)	Eleanor (64y) Navajo f Rita (47y) Navajo f Jimmy (62y) Navajo m	Describes by the use of individual cases traditional, Navajo, Christian and Western biomedical healing their utilisation and helpfulness.
(Schieffelin, 1996)	? (young) Papa New Guinean m Wani (?) Papa New Guinean f Gasu (?) Papa New Guinean m Dibe (young) Papa New Guinean m	Evil Spirit Sickness is a newly emerging condition that emerged among Bosavi people of Papa New Guinea after a period of intense Christian evangelisation.

3.1.3. Qualitative Analyses

Each of the accounts was read and meaning was extracted from each account by qualitative analysis techniques. In qualitative social science research there are a variety of different techniques, which can be linked with different strands of philosophical thinking regarding the determination of truth and reality. A figure is provided to illustrate the links of methods with theories below.

Figure 4 Philosophical strands and social science techniques



As adapted from Jonathan Smith, Personal Communication in 1998

Phenomenology (Hegel, 1807) and more recently existential phenomenology (Husserl, 1901; Heidegger, 1927) advocate that *perceptions* and *interpretative processes* are leading the way in the assessment of what is truth and reality. The philosophical field of *pragmatics* evolved later in history and was advocated mainly by American metaphysical scholars (James, 1907; Dewey, 1929). They contended that only practical value indicates truth and reality – so "On pragmatist principles," James writes, "if the hypothesis of God works satisfactorily in the widest sense of the word, it is true" (James, 1907, p143). *Symbolic interactionism* (Mead, 1934); (Park, 1927) evolved under the influence of both but focussed on social actions rather than individual organisms; therefore knowledge about truth and reality are provided by the meanings given to items and meanings are the product of social interactions. Social research methodological techniques that support symbolic interactionism and pragmatism are conversation and discourse analysis. They examine the interaction between people, and also are firmly grounded in believing that the truth can only be ascertained by exploring exactly what people say and how they say it. Alternatively methods such as grounded theory, ethnography and interpretative phenomenological analysis are influenced by the way interpretation unravels truth – hence are linked to phenomenology and to symbolic interactionism by exploring interactions.

In grounded theory, meaning is provided by an evolving research strategy and continuous refinement of a theoretically evolving theory or construct that in the end should fit all the data. Ethnography involves observation and participating in a different culture and making notes about the way that things are done. Both require direct access to the population as the process is interactive and evolving. Interpretative phenomenological analysis (an offspring of discourse analysis) on the other hand has a different remit:

"The aim of IPA is to explore in detail the participant's view of the topic under investigation. Thus the approach is phenomenological in that it is concerned with an individual's personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or the event itself. At the same time, IPA recognizes that the research exercise is a dynamic process. One is trying to get close to

the participant's personal world to take, in Conrad's words, an 'insiders perspective; but one cannot do this directly or completely. Access depends on and is complicated by the researchers own conceptions and indeed these are required to make sense of that other personal world through a process of interpretative activity. Hence the term IPA is used to signal these two facets of the approach." (Smith, Jarman, & Osborn, 1999).

The source of the data in this thesis, i.e. secondary literature accounts, limited the use of more pragmatic methods such as discourse or conversation analysis and prohibited furthermore the use of grounded theory and ethnography as it was impossible to access the sample to observe, test and refine the results or the framework. It was therefore decided to use Interpretative Phenomenological Analysis (IPA) to make sense of the data. IPA contrasts with discourse and conversation analysis by being less sceptical of mapping 'verbal' reports on to underlying cognitions. IPA argues that to be able to say something about individuals' cognitions we must assume that cognitions are related to discourse. Through a careful examination of discourse one can learn about cognition; to rely on pragmatics alone to determine meaning and truth might not be always useful.

In IPA one begins with the coding of data. An example is provided to illustrate this process; in the first account of Gopal the account reads....

Items	Text
Sadness	Gopal [...] came to the psychiatric clinic [...] complaining of sadness,
Hopelessness	hopelessness,
Feeling run down	feeling run down,
Sleeping problems	and problems sleeping.
Disturbed sleep	He had been awakening early in the morning and could not get back to sleep.

According to IPA guidelines (Smith et al, 1999) the themes or items were first noted and it was then proceeded to look for connections, which were noted by developing diagrams or schematisations (Young, 1982) of the accounts. Young described explanatory models in

schematisations as it was easier to identify assumptions and I have adopted his approach to a) differentiate the lay from the author's perspective and b) enable easier comparison of accounts across cultures. The identification of perceptions to be categorised as consequences or symptoms of distress was made by examining the contextual links in which they were described. The schematisations were produced in pen and paper. Each perception was circled and the colour of the circle determined whether it was classified as a perception of identity, cause, consequence, course or control/ treatment. In addition, two colours were used to indicate the link between perceptions with each other to contextualise and identify associations. A distinction was made between assumed cognitive links (e.g. I am suffering from distress because ...) and behaviour or action connections – (e.g. because my distress is due to eating 'hot' foods, I will eat different foods instead). I have typed up the text excerpt for two accounts that I used and then displayed their schematisations in black and white below to illustrate this process. In order to show differences between lay and professional perceptions I have displayed the professional account as large proportions of the text referred to this.

Example 1 Gopal

Weiss MG, Desai A, Jadhav S, Gupta L, Channabasavanna SM, Doongaji DR *et al.* Humoral concepts of mental illness in India. *Soc.Sci.Med.* 1988; **27**:471-7.
45 year old Hindu Farmer 'Gopal' p. 473

Gopal [...] came to the psychiatric clinic [...] complaining of sadness, hopelessness, feeling run down, and problems sleeping. He had been awakening early in the morning and could not get back to sleep. He had no appetite and worried about several somatic symptoms: poor digestion, pains in his belly, belching, and alternating bouts of constipation and loose, frequent, mucous stools. Psychiatrists in the clinic diagnosed **major depression**, and a routine microscopic examination showed an **infection with several species of parasites**. [...] Financial hardship from staying in the city with his brother, physical disability from his symptoms, and the failure of his herbal self-treatment contributed to his despondent mood. Feeling helpless and disabled he missed his family very much. Doctors became concerned and referred him to **psychiatry**.

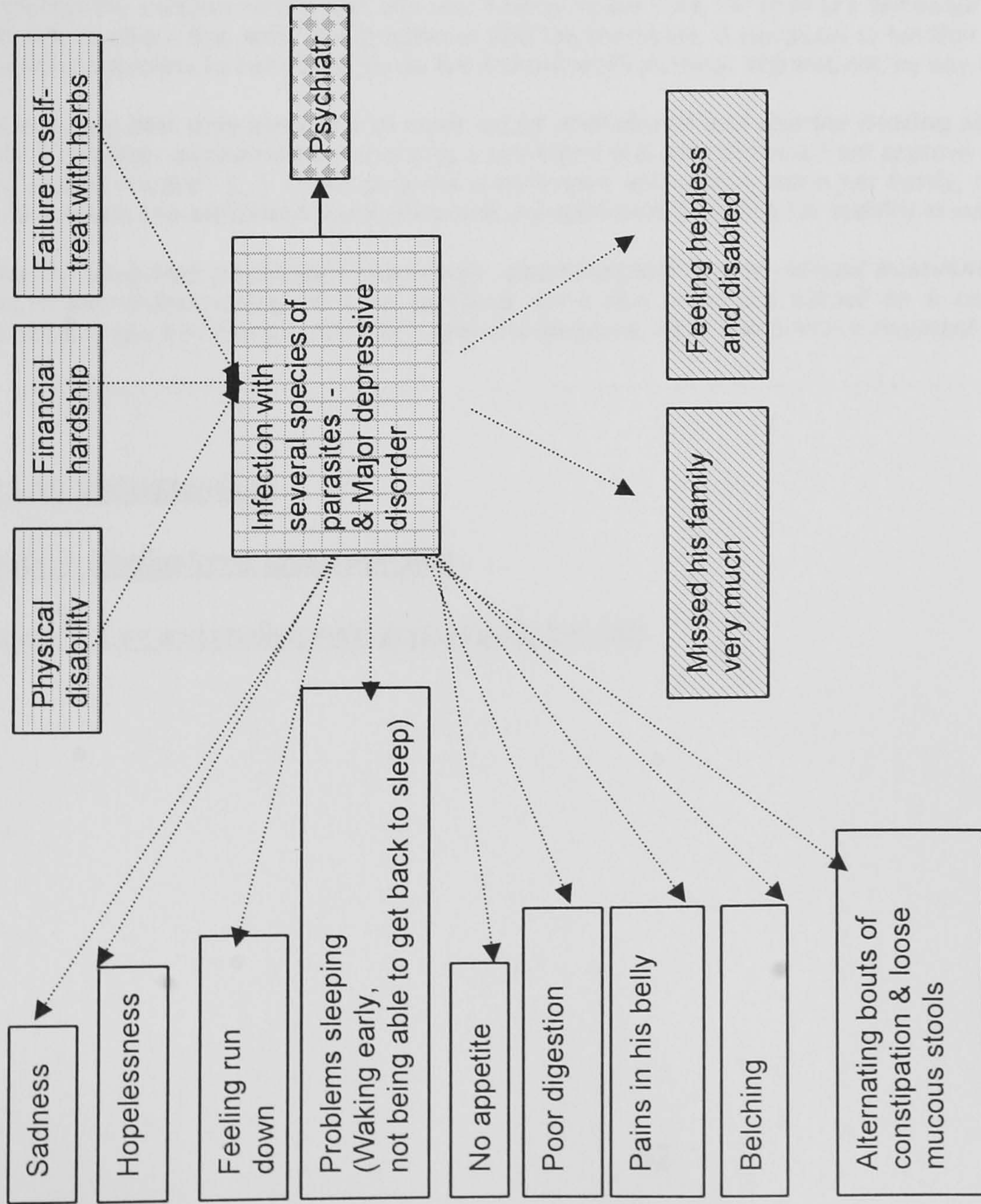
Gopal explained that he had a **physical illness** caused by **accumulation of bile (pitta)**. A **surgical procedure**, haemorrhoidectomy, 2 years earlier had caused the **excess bile**. [...] He also concluded from **tingling sensations** in addition to the excess *pitta*, a **lesser quantity of vāta had accumulated** in his extremities. He attributed his **sadness and other uncomfortable feelings to pitta reaching his brain**, but he was more concerned about his **physical problems** than his mental state; he insisted that even though he was in a psychiatric clinic, **he was not crazy (pāgal)**. **Ayurvedic medicine would help**, he thought, and he had read about them so he could treat himself with **herbs (tamarind and others)**. He had also **restricted his diet to avoid fried, spicy and fatty foods**. Despite his interest in Ayurvedic theory and his belief that it was relevant to his distress, he had not previously consulted an Ayurvedic healer. His attempts to treat himself having failed, but still maintaining that his problem was due to excess *pitta*, he presented for allopathic treatment and requested **abdominal surgery**, because he thought it would provide the fastest cure.

Bold = Lay understanding

Bold Italic = Professional understanding

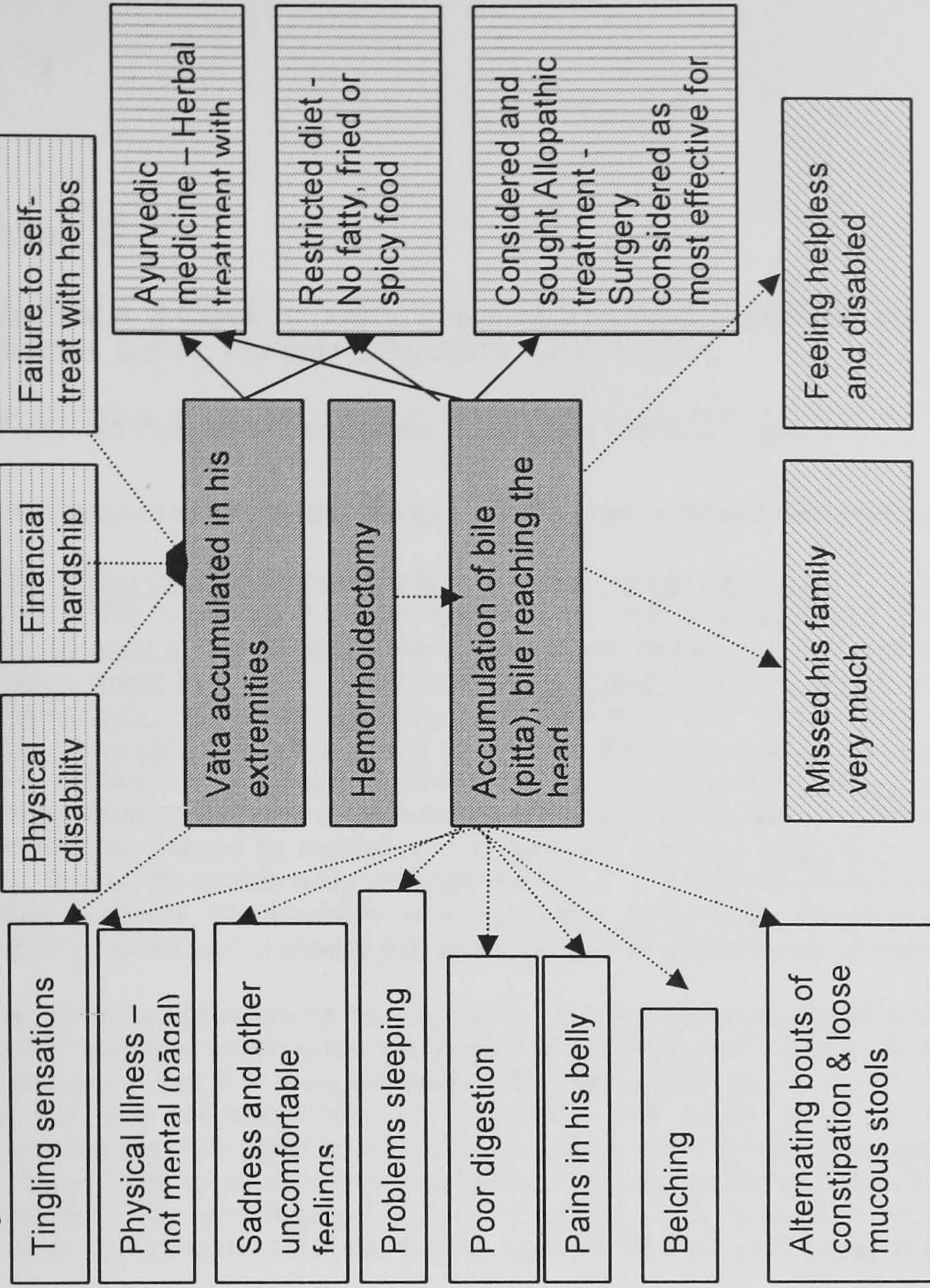
Underlined = Lay and professional perceptions/ Unclear

Professional understanding of Gopal's Distress



- = Complaints and Identity
- = Professional Identity & Cause
- = Unclear origin Cause
- = Professional Treatment

Lay Understanding of Gopal's Distress



- = Unclear origin Cause
- = Lay Cause
- = Lay Evaluation of Treatment (Preferred treatment and past treatment)
- = action link
- = cognitive link

Example 2 S

Oquendo, M.A. & Graver, R. (1997). Treatment of an Indian woman with major depression by Latina therapist: Cultural formulation. *Culture, Medicine & Psychiatry*, 21(1), 115-126

S 29 year old Punjabi woman, moved to UK age 5 and to US aged 11

She first presented for **psychotherapy** with the chief complaint "**My mother is driving me crazy**". [history build up]

As her mother became more persistent, S became more depressed. [...], she began worrying about her mother's opinion of her and her ability to tolerate the onslaught of phone calls and pages [...]. She would cry about her predicament and felt helpless about resolving it. She felt guilty about her parents' disapproval and was upset about disappointing them, but at the same time she felt enraged by them. [...] Gradually S developed difficulty sleeping and stayed up worrying about what would happen. She was constantly tired and had difficulty concentrating on her studies. Her grades started to drop. Her appetite increased and she gained 10 pounds over a two month period. She frequently thought that she might as well be dead since she could not imagine how to resolve her quandary. [...] She agreed to a treatment for **Major Depression which included medication and twice a week psychodynamically oriented supportive psychotherapy**. [...] Although S did not conceptualise her situation as one that could be helped by medicine, she agreed to a course of SSRIs. [...] S felt that her depression was a consequence of the **disruption in the relationship with her mother**. [...] In treatment, S focused on the **difficulty of integrating the standards for mother-daughter relationships in India versus in the USA, which she saw as dichotomous and which reinforced her conflict**. [...] Although S clearly identified herself as distressed and needing the help of a psychiatrist.

S identified her problem as **psychological** and therefore **contacted a psychiatrist for help**. She did not consider that her problem was one which could be helped by medication since she saw it as being strictly related to a family conflict. Although the therapist asked S to bring her mother for a family meeting, S's mother refused to attend. S's mother's remark to S about this was, "you are suffering from guilt, it is not I who needs to see a psychiatrist." Although S **expected treatment with psychotherapy**, she came to understand **some of her distress as being secondary to Major Depression**. She accepted a **trial of an SSRI**, to which she responded well. **Her acceptance of the medication was influenced by her wish to please the therapist**. S was very engaged in the [...] therapy which focused on elucidating the origins of the conflict and the ambivalent nature of the relationship with her mother. Later themes included issues of **low self-esteem and self-defeating patterns**. [...]

S's social supports were quite inadequate. She was isolated, in part of her conflict with her mother and other family members. The rift was distressing to both parties. Additionally, S felt that **telling others what was happening was too embarrassing**. S thought that the students with whom she was friendly would think her mother's behaviour crazy. She felt **the only person she could talk to about this were her boyfriend and the therapist**. S continued to function in her relationship with her boyfriend, but **noticed a decline in her ability to do her school work** although she was not, by any measure, failing. [...]

S **felt strongly that only someone of color could understand and tolerate hearing about her experience with racism**. [S rift with her mother originated from choosing a boy-friend that her mother did not approve of] Her mother was in S's own words, "racist against Hindus". [...] These personal experiences with racism within her family, made her quite sensitive to racism in general to which she **attributed much personal unhappiness**, including her inability to make friends with "non-minorities." [...]

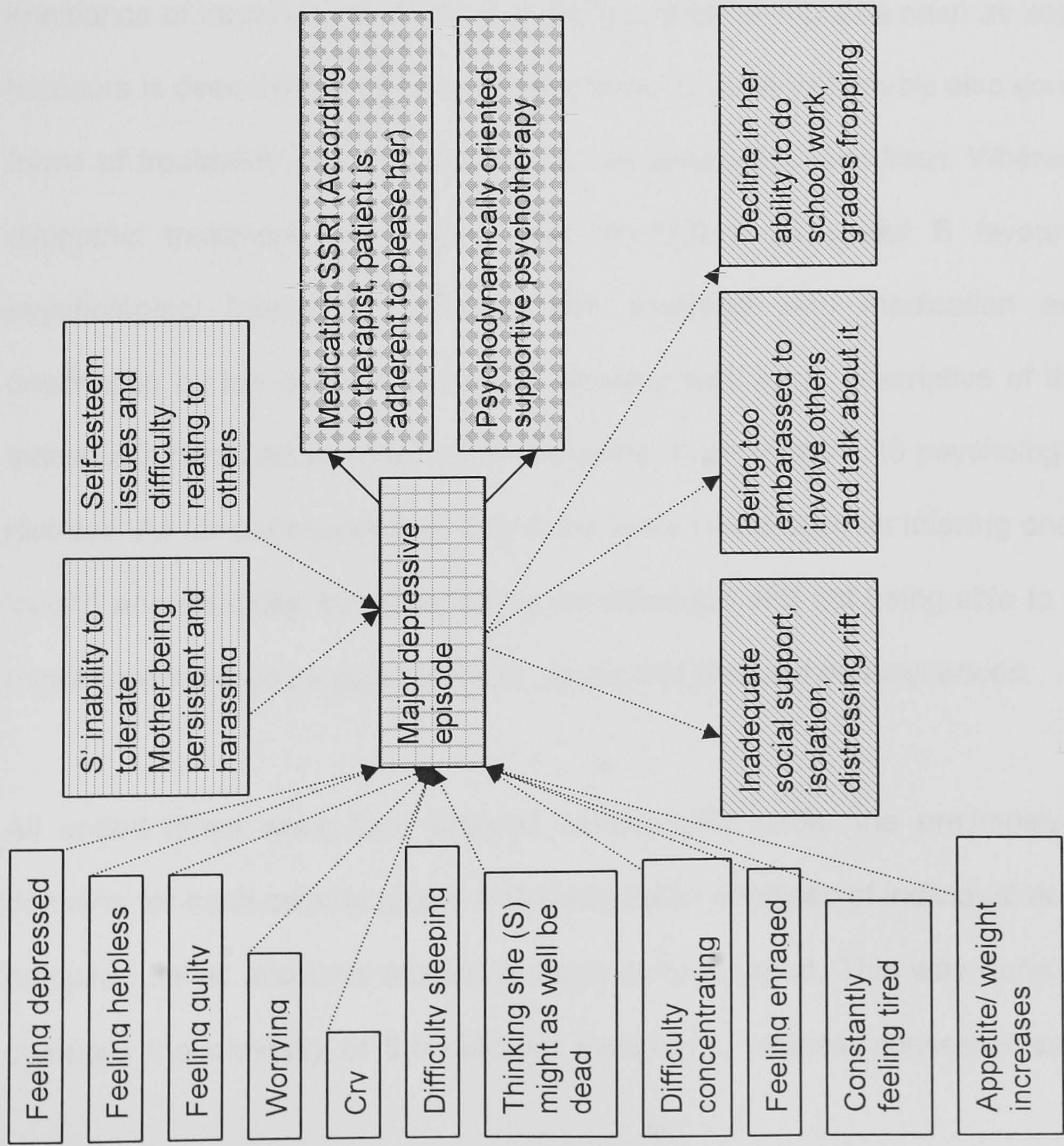
S's therapy integrated **psychopharmacologic, psychodynamic, and cultural interventions**. The cultural interventions were crucial in the understanding of S, in particular since she presented herself as a completely acculturated individual. Yet unconsciously she had many unresolved questions about the 'right' way to make important decisions in her life.

Bold = Lay understanding

Bold Italic = Professional understanding

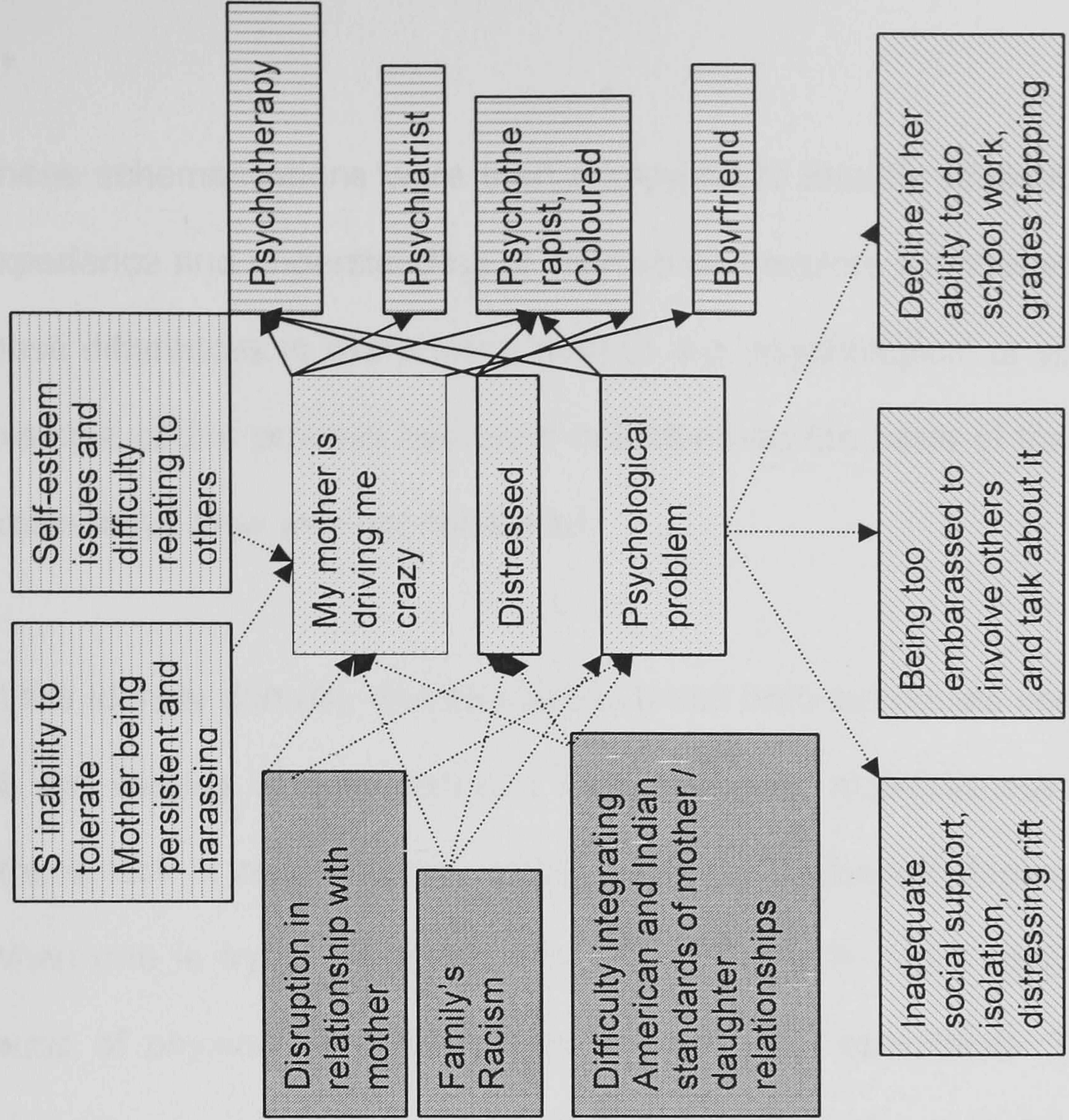
Underlined = Lay and professional perceptions/ Unclear

Professional understanding of S' Distress



- = Unclear origin Identity (Symptoms)
- = Professional Identity & Cause
- = Lay identity
- = Unclear origin cause

Lay understanding of S' Distress



- = Lay Cause
- = Unclear origin Consequence
- = Lay Evaluation of Treatment (Preferred treatment and healer)
- = Professional Preferred Treatment
- = action link
- = cognitive link

These schematisations were then compared to identify similarities and differences in the experience and understanding of distress and explore whether one can describe/document these differences in overarching themes e.g. psychological or spiritual causes - A detailed example of this process has been described on the basis of the two accounts below. The professional view was not compared.

In the identity domain, one can observe that both individuals considered different things to be the identity of their distress: Pain, sadness, hopelessness, feelings of guilt towards others, lack of concentration, crying, worrying, distressed, feeling enraged and indigestion. When one is trying to identify the differences, one might firstly differentiate variations in terms of *physical* complaints from *psychological* complaints. The comparison of causal perceptions also found no similarities, but showed variations from family problems to imbalance of humours. Whereas the family problems might be seen as *social*, imbalance of humours is describing a *physiological* imbalance. Both individuals also considered separate forms of treatment/ control as useful for alleviating their condition. Whereas Gopal viewed *allopathic* treatment i.e. surgery and medication as useful S favoured *non-medical/ psychological* treatment (although she complied with medication according to the description by her therapist). The terminology was again descriptive of the diversity here: individuals favoured medical/ pharmaceutical in comparison to psychological treatment for distress. As for consequences, only a few were noted such as missing one's family (feeling lonely) and disability, isolation, being embarrassed and not being able to study well; these might be described as *psychological, social and physical consequences*.

All coded items were then ordered conceptually under the previously determined five domains for each cultural group. Following these analyses of individual accounts, lists were compiled for all accounts studied in each cultural group. This was done to document and compare the diversity of the different symptoms, causes, consequences etc for cultural

groups rather than individuals. The next table shows the group analyses for Indian in comparison to Bangladeshi cultural groups.

Table 4 Group comparison

Indian (5 accounts)	Bangladeshi (3 accounts)	Domains Master Themes
Kampogal (unhappiness) Dil ghirda Hai Sink (Heartsink)	Upri Dosh	<i>Identity (Labels and symptoms/ complaints)</i>
Violence to others, conflicts with others, Social Isolation, Hallucinations, Possessions, Unhappiness in marriage, weight gain/loss, Insomnia, Rambling or Talking lots of nonsense, Bizarre behaviour, Suspiciousness, Neglect of personal Hygiene, substance abuse, seizures, suicide, fatigue, weakness, headache, pain, worrying, adverse feelings (hopelessness, sadness, rage & guilt), crying	Violence against relatives, swearing, violence against things, possessions i.e. seeing demonic shadows (shaitan), stopping to eat, stopping to talk, shouting, smoking, weeping/ lamenting, talk of 'injured liver', 'pain' as metaphors for mental distress, crying	Anti-social behaviour, isolation, Hallucinations, spiritual problems, diet, physical effects, behavioural effects, Cognitive and emotional effects <i>Cause</i>
Racism, possession, sociofamiliar conflict, conflict with others, loss, shock, substance abuse, physical illness, astrology, breaching taboos, sorcery, black magic, 'God', work, stress, injury & accident, exertion, humoral imbalance, toxin. Poison, ingestion, nerves, mind, worry, anatomy	Racism, possession, sociofamiliar conflict/ problem, substance abuse, evil eye, excessive brain activity, studying, stress.	Social Conflict with others, Trauma, Abuse, illness, spiritual / sorcery, stress, work problems, Physical imbalance, <i>Consequence</i>
Rejection stigmatisation, exclusion from activities, being alienated in the family, violence, fear for oneself, passive integration/ acceptance, tolerance and pity, being viewed as stubborn and as the real cause of illness	Role change, pity, acceptance, tolerance	Role change, social consequences, violence <i>Control/ Treatment</i>
Traditional healing (Ayurvedic, Una, Siddha), religious healing, praying, sacrificing, Panchayal (local counsellor) allopathic healing (medical doctors)/ mental hospital, vowing, fasting, controlling the temperature of one's diet (hot/cold)	Traditional healing, praying, exorcising, Allopathic healers (Casualty and psychiatrists), Violence incarceration	Traditional healing, spiritual healing, Medical healing, behavioural control, social control
Not described	Not described	<i>Timeline</i>

As can be seen in the domain level a master list of themes was produced that tried to convey perceptions in more abstract terms. When new themes emerged, they were checked against earlier transcripts to ensure that the themes were original and new.

The next stage of analysis was to conceptually compare and group the master list of themes to identify superordinate themes under which cultural variations could be noted and that would provide meaning. The terminology was aimed at providing thematic and categorical meaning to intra-cultural and cross-cultural differences observed in the literature.

3.1.4. Results of Qualitative Analyses

3.1.4.1 Identity Perceptions

The superordinate theme that was first identified for identity was called '*somatic events*' i.e. describing physical somatic events. The term 'event' was chosen as they seemed to refer to occurrences/events measurable without using interpretation. These bodily symptoms seemed to appear independent of mental problems/ perception; for example - sleep disturbance can simply be assessed whether someone does sleep through the night or not, nor is it necessary for an assessment to interpret whether someone eats more or less.

The second theme of identity domains was a category of physical symptomatology or labels that were physical manifestations that were dependent on perceptions. They describe 'a thing as it appears, as distinguished from its real nature as a thing in itself' (Kant). For example, pain was sometimes described, but it wasn't something that appeared independent of the patient's perceptions. Therefore symptoms were described as physical, but not necessarily measurable without using any form of interpretation of sensations. Therefore the cluster was called perceptual physical identity (symptoms and labels).

Non-bodily or mental symptoms were distinguished as all forms of emotions associated with distress (e.g. feeling irritable, down, sad or fearful) forming one cluster and impaired cognitive ability/ content of thoughts as another.

Beliefs surrounding the identity of distress also often manifested themselves in a behavioural format. This was particularly so among individuals who might communicate by doing something rather than talking about it (like children). Again it appeared that there was a gradient in different behaviours: a) Behaviour that affected other people directly i.e. interpersonal such as being violent or not talking and b) Behaviour that might be classed as personal behaviours such as rambling or smashing things.

Differences in those sub-themes were not identified in all accounts therefore these were subsumed under three overarching themes: 'mental', 'physical' and 'behavioural'. The findings are illustrated in table 5 below.

Table 5 Cultural variations in Perceptions regarding the Identity of Mental Distress described in Conceptual Themes

Complaints, perceived symptoms of distress	Sub-Themes	Themes
Sleep disturbance, Weight gain/ loss, Discharge, Visual deficiency	Somatic event	
Pain – Back pain, Heart pain, Chest pain, Headache & other aches/ soreness, Fatigue / Feel tired, Nerves / agitation, Crawling sensation, Heat or heaviness in head/stomach/chest, Bodily weakness, Nausea	Perceptual somatic	Physical/ Somatic
Dysphoria (feel down), Increased Irritability, Feel nervous/ anxious, Feeling frightened	Emotional	
Lack of concentration, Loss of interest, Worrying thoughts/ torment, Suicidal thoughts, Guilt towards others, Shame of self, Hearing voices, Seeing things	Cognition	Mental
Withdrawal from social life, Change in role – task fulfilment, Being Violent (towards others), Stopping to communicate/ talk	Interpersonal Behaviour	Behavioural
Crying, Screaming, Swearing, Substance (ab-)use (Smoking cigarettes, drinking alcohol), Stop eating, Being violent (towards thing), Obsessive cleaning etc, Neglect of personal hygiene, Irrelevant talk, Suicide attempts	Personal Behaviour	

3.1.4.2. Causal Perceptions

Among causal items, the first clusters that emerged were social versus physical themes, as noted in our first comparison of individual accounts. Interpersonal conflicts emerged as a theme as individuals identified problems with the family as the cause as well as the identity of the problem (e.g. Oquendo & Graver, 1997). Other people were also involved in a separate theme that featured items like sorcery and different forms of black magic. The two themes appear however distinct, since the belief that other people have the power to influence other people's spiritual wellness was advocated in some, but not all accounts. Spiritual power independent from people was another theme that emerged in the analyses.

Additional themes emerged regarding the recognition and interpretation of cognitions and attitudes towards work, identity and other characteristics of the self. Intra-personal behaviour such as worrying about drinking or eating the wrong things also emerged, although it was found that this was often prompted by researchers especially when the behaviour was socially stigmatised such as drug abuse.

Wind, weather or the stars formed an additional natural theme and when the body or bodily organs/ fluids were affected this was a separate theme. Bodily weakness emerged separately as a theme. Financial problems and deprivation were another theme as well as being exposed to traumatic situations. Findings are illustrated in table 6.

Table 6 Cultural variations in Perceptions of the Cause of Mental Distress described in Conceptual Themes

Causal perceptions of Distress	Sub-Themes	Themes
Stress/ overburdening mental capacities, Worrying, Guilt, Shame, Characteristics of the Self –Vulnerable due to... Gender, Age, Culture, Religion, Race	Perceptual Imbalance – Cognitive, attitudinal	
Emotions/Sensations (Excessive discharge of)	Emotional Imbalance	Psychosocial
Work / Family / Marital problem (s), Isolation, Loss/Bereavement, Racism – Prejudice/ Stereotype Trauma/Shock (e.g. Car crash, war)	Interpersonal conflicts - Social Imbalance	
'Destiny' – Fate (deliberate), Bad luck (random), Ancestors' spirits, Weakened spirit/ soul loss, Test of faith, Astrology	Spiritual imbalance	
Black magic/evil eye/ sorcery, Possession, Punishment for taboo breach	Spiritual ill will	Spiritual
Diet/Ingestion – Imbalance hot/cold, Substance abuse, Lack of or no sex	Behavioural imbalance	Behavioural
Wind/ weather, Climate	Natural imbalance	Natural
Illness and/or Disability, Semen loss, leukorrhoea, excess bile etc – Humoral imbalance, Bad blood, hot blood, poison, virus/ germs, genes	Physical imbalance	Physical
Financial	Lack of economical 'power'	Economical

3.1.4.3. Timeline perceptions

The issue of course or timeline of mental distress was not well reported in the literature. Since as only limited references were made, we adopted the categories that are used in physical illness perception assessment. They distinguished between acute and chronic in terms of the length of the illness and also included descriptions of the nature of the timeline as to whether it was linear or episodic/cyclical.

3.1.4.4. Consequence Perceptions

Consequence perceptions were not covered in the majority of literature accounts and this domain was also problematic because of the problems of trying to distinguish it from the identity of the illness. In most accounts, distress appeared to be a pertinent intrusion into

one's life rather than being limited in the impact like physical illnesses with sudden onset and potential for complete cure. Individuals reported for example that their role changed and that they were losing status, and it was difficult to note whether this was a consequence of being distressed or whether it was seen to be part of being distressed i.e. identity.

Some could be identified from the narrative e.g. 'Feeling helpless and disabled he missed his family very much'. This denotes that the helplessness and the disability from the experienced distress led to him missing his family and therefore was considered to be a direct consequence of distress. Reported consequences appeared to differ in terms of changes to characteristics of the self and direct influences on other important people. Initial sub-categories emerged that differentiated the perception of oneself/ personality and the effects on one's cognitive processes. Similarly among social effects it was possible to differentiate between one's interaction with others and the way it might affect individuals' perceptions of themselves. As these differentiations or sub-themes were not consistently observed across cultures, the final categories included only self and social. In further analyses, three additional clusters could be distinguished. Those were financial as they can involve personal and other people's lives, physical consequences that related to the items like pain but were mentioned in a narrative of physical suffering as a result of distress, and behavioural changes like drug abuse to cope with distress and stop partaking in activities. The results are displayed in table 7.

Table 7 Cultural variations in Perceptions regarding the Consequence of Distress described in Conceptual Themes

Perceived Consequences of Distress	Sub-domains	Themes
Increased attention to somatic symptoms/ illness, Go crazy/ Disruptive thoughts/ Interference, Aversive foreign Feelings, Lack of self esteem, Fear for oneself	Cognition Identity	Self
Sick role - role change, Exclusion from activities, Rejection, isolation, stigma not only for oneself but for whole family, loss of status (individ / family), Violence, Beatings, Incarceration	Interaction with others Social role	Social
Disability (dependent on welfare), Job Loss, Loss of financial security		Financial
Pain, Weight loss, weight gain		Physical
Substance abuse, Stop Sport and other social, religious activities		Behavioural

3.1.4.5. Control/ Cure

The first comparison shows that there were different treatments that were seen as appropriate and helpful. Generally the published literature reviewed mostly externalised, professional treatments, but in lay accounts often these came into play only when personal resources were exhausted and the social support network could not offer further help. There appeared little distinction between the healer as a person and the treatment that s/he offered although the person was more difficult to categorise especially if like traditional healers or psychiatrists they involve several aspects of treatment. It therefore seemed to make sense to collapse both characteristics of treatment into one with focus on treatment. So the final themes included self, social, medical, alternative and spiritual treatment. The results are displayed in table 8.

Table 8 Cultural variations in Perceptions regarding the Treatment of Mental Distress as described in Conceptual Themes

Table 6 Perceived Control/Cure/Treatment of Distress	Healer	Category
Change diet/ Fast Keep busy Substance (ab-) use	Self	Self/ Behavioural
Talk, Seek social support (SoS), Socialise	Family/friends/com munity	Family/friends/com munity
Medicine, diagnosis, medication Pharmaceuticals/ medication Medication + psychotherapy	GP Psychiatrist	Medical Bodily
Herbal therapy Acupuncture Relaxation/ massage Traditional herbal mixtures	Homeopath Acupuncturist Traditional healer	Alternative Bodily
Spiritual object (e.g. taveez) Exorcism Praying Chanting Ceremonial Dancing Lay hands	Faith healer Faith Healer/Priest Priest Traditional Healer (Medicine Man)	Spiritual

3.1.5 Triangulation

To triangulate the findings, it was decided to present the themes and the items to an independent psychologist colleague, who was not involved in the research process, was not trained in mental health and had no clinical professional knowledge of mental distress (Kate Hamilton-West). She was asked to group items according to the themes for each of the four domains and her ratings were then compared with my findings. Computing Cohen's Kappa for interrater reliability found that the conceptual themes were coded similarly above .8 for all themes.

3.1.6. Discussion of findings and comments on the process

Classification of perceptions appears useful to organise one's thinking, document diversity and guide assessment of lay perceptions. The process of categorisation can be a difficult one because of the nature of perceptions and the reliance on published accounts. The published accounts often made it difficult to code the data adequately and determine clearly what were the lay individuals' and the authors' perceptions. It was possible to find superordinate themes that fitted the entire data set, but this was not uncomplicated. Relations that are described in the text were often ambiguous, but crucial to guide this process. The processes described here offer some advice about how decisions between clusters are made, but some of the associations can only be hinted at in the schematisation as they were derived from subjective and often intuitive interpretation of the data. Access to secondary data also implied that one was at times too far removed from the experiences of the patient and inadvertently tempted to mix the professional perceptions with personal ones. Using secondary data not ideal as the researchers own conceptions and interpretations influence what data is presented and in which format. However, great care was taken by coding, illustrating and comparing the literature accounts to identify when the lay account could not be examined to overcome these limitations.

This thesis tried to find a new way of exploring the cross-cultural differences in the content of illness perceptions, since they could explain different cultural pathways to help-seeking, compliance and treatment outcome for individuals from diverse cultural background. The qualitative analyses of the accounts from the literature provided a number of themes that would need to be included in a comprehensive cross-cultural assessment. Since a framework has been developed in which qualitative accounts of perceptions can be situated and compared, this should help the interpretation of qualitative accounts and allows to investigate emic perspectives of distress across individuals and cultures.

Some themes (e.g. spiritual or traditional healing) were not as well reported in Western cultures, whereas psychological explanations and desire for psychiatric management was almost never described in Non-Western accounts. The prevalence of different themes in individual accounts was however not only dependent on the ethnic background of the lay person, but also on the cultures they had been exposed to and on their economic and educational background as the case study and schematizations of S illustrates.

3.2 The development of the BEMI

3.2.1. General considerations

In the review of the existing instruments (Chapter 2), it was established that each instrument had so many limitations that it was difficult to assess cultural variations of lay perceptions in the population. It was concluded that a new instrument was needed that allowed for a comprehensive assessment of an individual's perceptions from the emic perspective and also enabled documentation of cultural variations of perceptions in larger samples.

It seemed best to elicit subjective perceptions by asking individuals in open-ended questions as they allow individuals to talk uninhibitedly about the way they perceive distress. John Weinman and colleagues (1996) had previously argued that an open-ended enquiry was helpful to prime individuals for completing questionnaires. To be useful in clinical care or population research, one should be able to complete this interview within ten to twenty minutes and be able to interpret the elicited data quickly. Hence all the standardised EM interviews were either too long to administer (EMIC, SEMI) or to interpret (K8). It was thought that it might be useful to develop a new brief enquiry instrument similar to Kleinman's 8 questions, but with a data management guidelines that also included perceptions regarding the timeline, consequences of distress and associated help-seeking.

Weiss (1997) further identified that including structured/ direct questions to elicit specific perceptions (which might otherwise be omitted) might be useful for eliciting perceptions of distress. A questionnaire would enable a more detailed documentation of diversity in time-limited clinical circumstances; and it would also allow for inexpensive and time saving data collection and interpretation. A combination of both questionnaire and open-ended assessment would probably generate a better assessment of the lay perspective for two reasons. Firstly, it would allow the researcher to engage with patients / individuals and their concerns by asking them openly how they perceive their mental distress and then assess in detail how much the most common perceptions of the identity, causes, consequences and treatment of distress are endorsed. Secondly, such an inventory would circumvent the measurement bias that has been reported for individuals using questionnaire scales (French, 2004).

A new instrument was therefore developed that would meet the criteria set out above. This instrument was developed as an inventory that included a short semi-structured interview and a 'questionnaire' in the form of four checklists. In order to honour the sponsors of this research project, the new instrument was called Barts Explanatory Model Inventory.

3.2.2. Barts Explanatory Model Inventory – Interview (BEMI-I)

Firstly it was thought important to have a short introduction to the interview that made clear that the interviewee was not going to be judged on the information they provided and that participation in perception research was anonymous and confidential. Since there is no right or wrong way that individuals perceive the world, it was important to point this out to decrease defensiveness and suspicion. Answers need not be consistent or rationally related and individuals were asked to respond to each question independently from their previous answers. In order to advise individuals to be honest about their beliefs, they were told that the survey did not want to elicit beliefs from other individuals but their own. This short introduction was to build a level of rapport with the participant and has been adopted by many health

psychology questionnaires (E.g. Multi-dimensional locus of control scale (Wallston, Wallston, & DeVellis, 1978)).

To explore the genesis of mental distress in the general population of different cultural groups, it was determined that the new instrument should tap into different levels of distress. It seemed therefore necessary to identify a suitable question that allows some flexibility for individuals to narrate their distress, but that is not too vague (e.g. how are you?) and/or that will elicit people's perceptions of past or personally unrelated experiences (e.g. How have you been? How do you perceive mental distress?). Also there was a need to avoid the stigma associated with mental health problems so that certain questions such as 'how is your mental health?' had to be avoided.

To use the results in relation to other mental health assessment tools, it was decided to limit the elicitation to a set timeline. The General Health Questionnaire, a widely used measure for mental health screening, asks individuals to answer the question with regard to the last few weeks, so it seemed useful to cover the same time period and so to be able to link findings regarding perceptions with other mental health assessments. Mental health measures are often limited to the last week or the last month, so it seemed most useful to focus on the last month to be able to assess fluctuations for a greater time period. Hence the following question was formulated 'Did you experience something that stressed you in the past month?' to assess perceptions of distress. If individuals answered no, it was subsequently explored whether they experienced anything that worried or upset them, gave them emotional problems, made them depressed or difficult to function in their life, in the past month. If the answer to the original question or any of the subsequent questions was yes, individuals were then asked about the label that they give this experience (question 1) and how they would describe it (question 2) (This question was similar to Kleinman's question 1). In the original version of the BEMI-I, interviewers were advised to probe participants who focussed on relating experiences of a

physical nature about possible additional psychological and behavioural complaints. The individuals were asked in question 3 what they identified to be the cause of their problem. This open-ended question is the same as Kleinman's question 2, and again the interviewers were reminded to probe for different themes, if perceptions were not elicited spontaneously in the interview.

In the three questions of the interview, individuals were asked about their experienced and expected timeline (Acute/ chronic), and whether they went through cycles (times) when it has been better or worse in order to have a more detailed assessment of the timeline and the nature of its course (episodic/ constant). Question 7 was an open-ended item regarding the consequences that their distress had on their lives and what they perceived to be the biggest advantages and/or disadvantages that they experienced since having distress. Two structured questions followed that asked individuals whether it had a big or small impact on their life and whether the distress affected particular aspects of their life. These were evolved from the literature review, which found five different themes: self, social, physical, financial and behavioural. Self was further split according to the two sub-domains of personality and individuals' thinking. Social was similarly divided according to the sub-domains: how individuals perceive themselves in their community and whether distress actually affected their social life.

Following these structured questions individuals were finally asked open-ended questions about how they thought their distress might be resolved (question 10 a) or dealt with (question 10b). In the original design of the BEMI, the interviewer was asked to present different methods to them and rate whether a method had been considered, but not tried; tried, but not found helpful; or tried and found helpful. In question 11, individuals were also asked whether they talked with others about their distress and whether this was found helpful or not. Lastly, individuals were asked to describe why they found talking to others helpful or not

(question 12), in order to examine the appraisal process. After this question individuals were thanked and told that there would be three further checklists that needed to be completed to ensure that their experience was fully understood. A copy of the original measure is displayed below.

**Protocol for
Barts Explanatory Model Interview**

ALL INTERVIEWER INSTRUCTIONS ARE HIGHLIGHTED IN BOLD ITALIC CAPITALS

Record Time & Date of Interview Start :

Subject ID :

[Say]

This is a survey about how people perceive and understand illness and distress. It is totally anonymous and confidential. We will keep no reference to your name and your answers will be combined with others before they are analysed. We are very interested in **your personal beliefs**, which means there are no right or wrong answers to the questions we are going to ask you.

Please answer the questions carefully, but do not spend too much time on any one of the questions. As much as you can try to answer the question independently from your previous answers. Please be honest and try **not** to report what you think we or other people might want to hear, but what **you** actually believe in.

I would like to start interviewing you about your understanding of illness and distress.

A) Have you experienced something that distressed you in the past month?

[IF YES – NEXT QUESTION

IF NO – PROBE WITH WORRIED YOU, MADE YOU UPSET, DEPRESSED, EMOTIONAL PROBLEMS, DIFFICULT TO FUNCTION IN YOUR LIFE?]

1) Could you tell me what you call this problem?

[WRITE DOWN ALL THE ANSWER – IF PERSON SAYS DON'T KNOW OR NOT SURE PROBE UNTIL NAME IS FOUND]

2) Could you please describe to me what**[FILL WITH NAME ESTABLISHED IN 1]** is?

[WRITE DOWN OR RECORD INITIAL RESPONSE, THEN PROBE FOR DIFFERENT SUB-DOMAINS – FOR INTERVIEWERS' REFERENCE FULL LIST OF SYMPTOMS REPORTED IN THE LITERATURE IS ATTACHED IN APPENDIX 1 OF THIS PROTOCOL. MAIN DOMAINS ARE SOMATIC – PHENOMENAL; PERCEPTUAL, MENTAL – COGNITIVE, EMOTIONAL; AND BEHAVIOURAL – INTERPERSONAL, PERSONAL UNTIL YOU HAVE ASSESSED BELIEFS OF ALL SUB-DOMAINS]

Spontaneous

[PROBE EXAMPLES - MENTAL - DO YOU EXPERIENCE ANY MENTAL PROBLEMS LIKE LACK OF CONCENTRATION OR FEELING LOW AND OUT OF SINK? SOMATIC – DO YOU EXPERIENCE ANY PHYSICAL OR BODILY PROBLEMS LIKE PALPITATIONS OR FATIGUE? BEHAVIOURAL - DO YOU EXPERIENCE ANY BEHAVIOURAL PROBLEMS LIKE CRYING, SMOKING OR DRINKING MORE THAN YOU USED TO?]

3) I would also like to know from you what do you think has caused**[FILL IN NAME ESTABLISHED IN 1]**?

[RECORD INITIAL RESPONSE – THEN PROBE AGAIN FOR ANSWERS ON DIFFERENT SUB-DOMAINS – FULL LIST OF SUBDOMAINS & CATEGORIES IS AGAIN ATTACHED IN APPENDIX 2 OF THIS PROTOCOL: PSYCHOSOCIAL – PERCEPTUAL, EMOTIONAL. INTERPERSONAL, SUPERNATURAL – SPIRITUAL IMBALANCE AND SPIRITUAL ILL-WILL, BEHAVIOURAL, AND SITUATIONAL – NATURAL, PHYSICAL, IMMUNOLOGICAL, GENETIC, ECONOMICAL AND SITUATIONAL]

Spontaneous

[PROBE EXAMPLES: PSYCHOSOCIAL - DO YOU THINK YOUR PROBLEMS WERE CAUSED BY STRESS OR PROBLEMS WITH PEOPLE? SUPERNATURAL – DO YOU THINK YOUR PROBLEMS WERE CAUSED BY HIGHER FORCES OR BLACK MAGIC? BEHAVIOURAL – DO YOU THINK YOUR PROBLEM WAS CAUSED BY DRINKING TOO MUCH OR EATING THE WRONG THINGS? – SITUATIONAL – DO YOU THINK YOUR PROBLEMS WERE CAUSED BY THE WEATHER, ILLNESS OR FINANCIAL PROBLEMS?]

4) How long has lasted so far?

Less than a day	<input type="checkbox"/>	1-2 months	<input type="checkbox"/>
1 day	<input type="checkbox"/>	3-6 months	<input type="checkbox"/>
2-3 days	<input type="checkbox"/>	7-12 months	<input type="checkbox"/>
4-6 days	<input type="checkbox"/>	2-5 years	<input type="checkbox"/>
1-2 weeks	<input type="checkbox"/>	5-10 years	<input type="checkbox"/>
3-4 weeks	<input type="checkbox"/>		

5) How long do you expect it to last?

- | | | | |
|-----------------|--------------------------|-------------|--------------------------|
| Less than a day | <input type="checkbox"/> | 1-2 months | <input type="checkbox"/> |
| 1 day | <input type="checkbox"/> | 3-6 months | <input type="checkbox"/> |
| 2-3 days | <input type="checkbox"/> | 7-12 months | <input type="checkbox"/> |
| 4-6 days | <input type="checkbox"/> | 2-5 years | <input type="checkbox"/> |
| 1-2 weeks | <input type="checkbox"/> | 5-10 years | <input type="checkbox"/> |
| 3-4 weeks | <input type="checkbox"/> | Forever | <input type="checkbox"/> |

6) Do you go through cycles when gets better or worse? Yes No

7) How has having affected your life? What are the main difficulties and advantages you experience since having.....?

[RECORD INITIAL RESPONSE. THEN PROBE FOR OTHER SUBDOMAINS. FULL LIST OF REPORTED CONSEQUENCES IS AGAIN ATTACHED IN APPENDIX 3. SUBDOMAINS ARE SELF, SOCIAL, FINANCIAL, PHYSICAL AND BEHAVIOURAL]

Spontaneous

[PROBE EXAMPLES SELF – WHAT HAS HAPPENED TO YOURSELF AS A RESULT OF THE PROBLEM? SOCIAL – WHAT HAS HAPPENED TO YOUR FAMILY OR RELATIONSHIP AS A RESULT OF THE PROBLEM? PHYSICAL – WHAT HAS HAPPENED TO YOUR HEALTH AS A RESULT OF THE PROBLEM? FINANCIAL – WHAT HAS HAPPENED TO YOU FINANCIALLY AS A RESULT OF YOUR PROBLEM? BEHAVIOURAL – HAVE YOU CHANGED YOUR BEHAVIOUR AS A RESULT OF YOUR PROBLEM?]

8) Generally, would you say that having has had a big or small impact on your life?

[TICK] Big Small

9) Has having **[FILL IN NAME ESTABLISHED IN 1]** affected your

[TICK] Physical Ability Personality
Social life Behaviour
Financial security Status

[IF THIS QUESTION ELICITS ANYTHING MORE THAN MENTIONED IN 7. RECORD ANSWER BELOW]

10) How do you think should **[FILL IN NAME ESTABLISHED IN 1]** be best dealt with?

How can **[FILL IN NAME ESTABLISHED IN 1]** be best resolved?

[RECORD ANSWER – NO PROBING]

11) I would like to ask you to tell me whether you have tried or considered any of the following methods to resolve your problem? **[RECORD UNDER CONSIDERED]**

	Considered	Tried
Dieting/Fasting	<input type="checkbox"/>	<input type="checkbox"/>
Exercising	<input type="checkbox"/>	<input type="checkbox"/>
Using alcohol, tobacco or illicit drugs	<input type="checkbox"/>	<input type="checkbox"/>
Keeping busy	<input type="checkbox"/>	<input type="checkbox"/>
Talking to somebody	<input type="checkbox"/>	<input type="checkbox"/>
Socialising	<input type="checkbox"/>	<input type="checkbox"/>
Taking medication	<input type="checkbox"/>	<input type="checkbox"/>
Using herbal remedies	<input type="checkbox"/>	<input type="checkbox"/>
Relaxation/massage	<input type="checkbox"/>	<input type="checkbox"/>
Seeing	<input type="checkbox"/>	<input type="checkbox"/>
(APPROPRIATE TRADITIONAL HEALER e.g. HAKEEM)		
Praying	<input type="checkbox"/>	<input type="checkbox"/>
Chanting	<input type="checkbox"/>	<input type="checkbox"/>
Dancing	<input type="checkbox"/>	<input type="checkbox"/>
Thinking	<input type="checkbox"/>	<input type="checkbox"/>

12 a) Who did you talk to about this problem? **[RECORD ANSWER UNDER A]**

b) Was talking to **[FILL IN NAME OF PEOPLE CONSULTED]** helpful?

A)	B)		
1) _____	YES	NO	
2) _____	YES	NO	
3) _____	YES	NO	
4) _____	YES	NO	
5) _____	YES	NO	

13) Why-why not? OPEN -ENDED

[RECORD ANSWER – NO PROBING]

[SAY]

This means we have finished with this interview. However I would also like you to fill in the following three checklists and am happy to assist you if you need any help. We have included the checklists as we want to be sure that we can truly understand what the problem is and what it means to you.

3.2.3. Barts Explanatory Model Inventory-Checklist

After the interview phase was ended, individuals were given three checklists to complete which have been attached below. Each checklist (1 - identity, 2 - causes, 3 - consequences) was domain specific and contained items that were previously elicited in the literature review. The instruction for the 'perceived identity' checklist (1) was to tick any items that applied (Complaints), when individuals believed they were part of their problem. For the 'perceived caused checklist' (2), they were asked to tick any of the items that they believed contributed to their problem. The instruction for the 'perceived consequences' checklist was to indicate whether they experienced any of the listed consequences. The psychometric evaluation and further development of the scale will be explored in the following chapter.

Please tick any of the following boxes if you believe that the symptoms are part of your problem.

- CRYING
- DISTURBED SLEEP
- CHANGE OF EATING PATTERNS
- PALPITATIONS
- INDIGESTION
- UNUSUAL SKIN SENSATIONS
- VISUAL DEFICIENCY
- LOSS OF BODILY FLUID
- PAIN
- ACHES
- FATIGUE
- NERVES- AGITATION
- HEAT OR HEAVINESS IN ANY PART OF THE BODY
- BODILY WEAKNESS
- NAUSEA
- DYSPHORIA (FEEL DOWN)
- IRRITABILITY
- FEEL NERVOUS- ANXIOUS
- FEEL FRIGHTENED
- LACK OF CONCENTRATION
- LOSS OF INTEREST
- WORRYING THOUGHTS/TORMENT
- SUICIDAL THOUGHTS/PLANS
- FEEL GUILTY
- FEEL ASHAMED
- WITHDRAWAL FROM OTHERS
- CANNOT COMPLETE TASKS
- BE VIOLENT TOWARDS PEOPLE
- BECOME MUTE
- SCREAM
- SWEAR
- SUBSTANCE USE
- TOBACCO, ALCOHOL, MEDICINES, DRUGS
- BE VIOLENT TOWARDS THINGS
- OBSESSIVE BEHAVIOUR
- NEGLECT OF HYGIENE
- HALLUCINATIONS
- RAMBLING
- SUICIDE PLANS

OTHER

Have any of the following causes contributed to your illness? Tick the boxes if you believe that this might have contributed to developing your illness.

- STRESS.....
- YOUR AGE.....
- YOUR GENDER.....
- YOUR CULTURE.....
- YOUR RELIGION.....
- YOUR ETHNICITY.....
- WORRY.....
- GUILT/SHAME.....
- EMOTIONS (EXCESSIVE).....
- WORK PROBLEMS.....
- FAMILY PROBLEM.....
- MARITAL PROBLEM.....
- LONELINESS/ISOLATION.....
- LOSS/BEREAVEMENT.....
- RACISM – PREJUDICE/ STEREOTYPE.....
- FATE/ DESTINY' (DELIBERATE).....
- BAD LUCK (RANDOM).....
- ANCESTORS' SPIRITS.....
- WEAKENED SPIRIT/ SOUL LOSS.....
- TEST OF FAITH.....
- BLACK MAGIC/EVIL EYE/SORCERY.....
- PUNISHMENT (GOD) – TABOO BREACH.....
- DIET/INGESTION.....
- SUBSTANCE (AB-) USE (ALCOHOL, TOBACCO, DRUGS).....
- LACK OF OR NO SEX.....
- WIND/ WEATHER.....
- CLIMATE.....
- ASTROLOGY.....
- ILLNESS AND/OR DISABILITY.....
- IMBALANCE OF BODILY FLUIDS.....
- BLOOD, (BAD BLOOD, HOT BLOOD ETC).....
- POISON.....
- VIRUS/GERM.....
- HEREDITY (GENES).....
- FINANCIAL PROBLEMS.....
- ANY KIND OF TRAUMA/SHOCK (E.G. CAR CRASH, WAR).....

OTHER

Finally we would also like to know whether you experienced any of the following consequences?

- INCREASINGLY FOCUS ON YOUR BODY/ THE ILLNESS
- BEING TORMENTED BY INTERFERING THOUGHTS
- FEELING BAD
- FEELING SAD
- FEELING IRRITABLE
- FEELING AGGRESSIVE
- LOWERED SELF-ESTEEM
- FEAR.....
- YOUR ROLE (IN YOUR FAMILY, COMMUNITY ETC HAS CHANGED
- BEING EXCLUDED FROM SOCIAL ACTIVITIES.....
- BEING REJECTED OR ISOLATED.....
- BEING STIGMATISED OR LOSS OF STATUS
- BEING PHYSICALLY ABUSED.....
- BEING LOCKED UP
- LOSING YOUR JOB
- BECOMING DISABLED.....
- LOSING YOUR FINANCIAL SECURITY
- PAIN
- LOSING WEIGHT
- GAINING WEIGHT.....
- ABUSING ALCOHOL, TOBACCO, MEDICATION OR ILLEGAL DRUGS
- STOP PARTAKING IN ACTIVITIES THAT YOU ENJOY.....

OTHER

I would like to take the time to thank you very much for spending the time talking to me and filling in these checklists, your answers are very important to us.
Thank you very much !!!

Chapter 4 Validating the BEMI – Pilot Study and further development

4.1. Background

The new assessment tool of perceptions (Barts Explanatory Model Inventory) was developed on the basis of a review of the existing instruments. This chapter reports on the face and concurrent validity and test-retest reliability of the BEMI and examined three hypotheses.

The three hypotheses (as outlined in chapter 2) were going to be tested.

- H1) Perceptions of distress are associated with individuals' cultural (ethnic) background.
- H2) Perceptions of distress are associated with acculturative processes. With greater exposure to host culture, perceptions will adjust towards those of the host culture.
- H3) Perceptions of distress are associated with the absence or presence of mental distress (psychiatric caseness).

4.2. Methods 2

4.2.1. Design

The study was devised using a two-phase design to examine cultural variations in lay perceptions in the general population. This sample was chosen to explore the diversity within the population rather than specific sections of the population (i.e. GP attendees) whose perceptions might have underlying 'ideological themes'. For example, individuals in health settings are likely to have a preponderance of medical/bodily explanations; likewise in religious settings individuals are likely to show a bias towards religious explanations and healing methods. Hence, to assess cultural variations and be able to generalise them to the cultural groups it was necessary to sample from the general population and eliminate any envisaged biases by using probability sampling methods. The two-phase

design was chosen to ensure that the proportion of distressed individuals would be sufficiently represented in the sample. The survey used interviews and questionnaires.

Ethics approval was sought from the East London and the City Health Authority Ethics committee and was granted (Ref # DO/SG/N/02/023).

4.2.2. Sampling location and desirable characteristics of the sample

Individuals who identified themselves as belonging to three ethnic groups (A) Black Caribbean; B) Bangladeshi and C) White British) were included to evaluate cultural variations in perceptions of mental distress. The ethnic groups were chosen according to their size within the boroughs of Hackney and Tower Hamlets and it was aimed for including groups with one cultural heritage. For example the ethnic category Black African can include individuals from many different countries and cultural backgrounds (in terms of language, history, religion and traditions) so that the group is heterogeneous in terms of cultural influences. However one could argue by choosing ethnic groups which seem confined to nationalities, one might be able to draw better conclusions about cultural influences – therefore it was decided to select Bangladeshi and Caribbean. Even though the Caribbean is also quite diverse in terms of history and language, in Britain the majority of individuals come from former English Speaking Colonies e.g. Jamaica, Barbados, Trinidad and Tobago. It is understood that ethnic categories are at most arbitrary concoctions as they seem to order individuals by skin colour (Black), geographical (Asian) and nationality (Chinese) and therefore comprise individuals from fairly heterogeneous background.

In Tower Hamlets, the Bangladeshi form the largest ethnic group with 65,533 (33%) of the entire population of the Tower Hamlets 196,106 (100%). In Hackney, the Black Caribbean 20,879 (10%) formed the second largest ethnic minority after Black African 24,290 (12%)

of the entire population of Hackney 202,824 (100%) (Office for National Statistics, 2001). As over 99% are registered with a GP the sample was drawn from two GP registers in East London: Jubilee Street Practice in Tower Hamlets and Lower Clapton Practice in Hackney. The sample was determined by using a function on the general practice routine software EMIS, which allows to draw a random sample of a specified size.

4.2.3. Materials

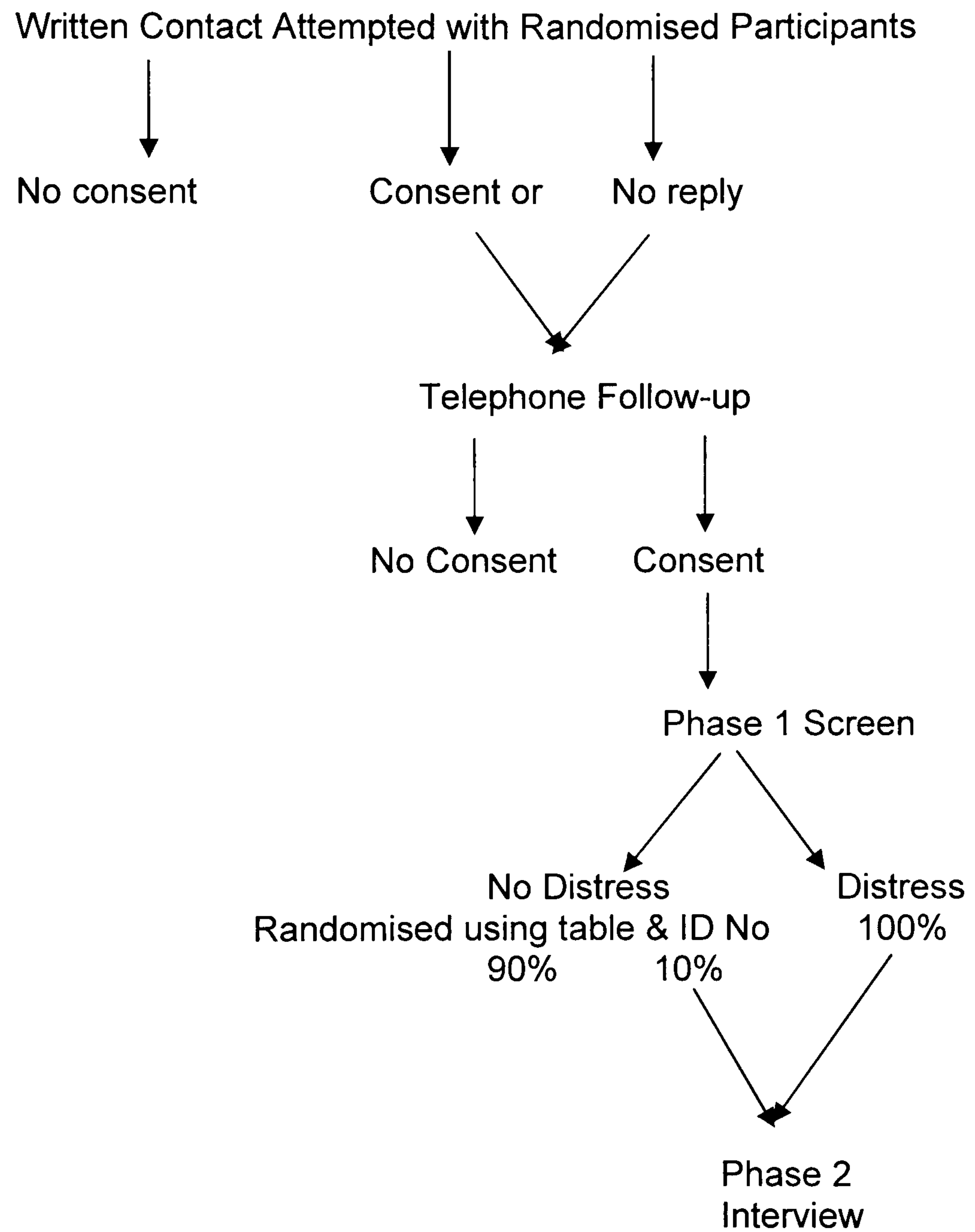
Phase 1 The Screening instrument (Appendix 2) measured cultural information (including ethnic background and migration history) and mental distress (with the General Health Questionnaire (GHQ-12), (Goldberg, 1992) and the Bradford Somatic Inventory (BSI- 21), (Mumford, Tareen, Bajwa, Bhatti, Pervaiz, & Ayub, 1991). Both mental distress screening measures were included so that variations that have been reported for individuals from South Asian background could be detected. Prior research found that South Asian individuals report more physiological than psychological problems when experiencing distress and psychological screening tools (such as the GHQ) might not be sensitive enough. Additional socio-demographic information as well as details about how to contact and follow-up individuals was also collected.

Phase 2 Bartholomew's Explanatory Model Inventory (Original Version – see Appendix 1) was included to assess perceptions of distress. The IPQ-R (Appendix 3) was included to assess concurrent validity. We also included an acculturation scale (see Appendix 4) and the Clinical Interview Schedule Revised as an assessment for distress (see Appendix 5).

4.2.4. Procedure

During the first phase, individuals were screened for distress on the telephone. All distressed cases and 10% of the non-distressed participants were invited to take part in Phase 2 interviews at the respective GP practice.

Flowchart of Study design for Pilot Study



The initial assumptions about recruitment of individuals are outlined in table 9 below.

Table 9 Planned Recruitment

Procedure	n per ethnic group
Written Invitation to participate letter (Randomly selected from patient registers of Lower Clapton and Jubilee practice)	100
Estimated 8% letter refusal (Prior survey research suggests that between 5-10% do write in that they do not consent to participate) – Telephone contact with individuals who have not refused or from whom no written response was obtained.	90-95
Refusal to give oral consent during telephone call, inaccurate contact details will reduce numbers (Prior research suggested that final consent participation rate might be between 60-70%) Phase 1-screening telephone interview.	60-70
Distressed positive (BSI distress prevalent in 20% of the general population (Mumford, Tareen, Bhatti, Bajwa, Ayub, & Pervaiz, 1991), GHQ distress prevalent in 26-30% of general population (Goldberg & Huxley, 1980) Distressed negative control	12-20 48-50
Assuming a further 25% drop out between phase 1 and 2 Phase 2 Interview Distressed 100% Phase 2 Interview Control 10%	8-15 4-5

Possible participants were derived by random sampling from the two general practice records. The White British and Caribbean sample were totally randomly determined, whereas we tried to filter Bangladeshi individuals out of the register in order to be able to send them a translated invitation in Bengali. Bangladeshi names were pre-selected from the Jubilee practice by using a naming program '*Nam Pehchan*'. The program identifies South Asian names by the name stem - differentiating between Hindi, Urdu, Bengali, Punjabi, Gujarati and common South Asian names - and also identifies religious affiliation by name as Hindi, Muslim or Sikh. After running the program, I found only a small number of names identified as Bengali and consulted the GP practice (Sally Hull and Salma Ahmed) as they developed their own Bangladeshi/ Bengali name bank. Comparing the name bank results with the *Nam Pehchan* results, it became clear that the names identified by *Nam Pehchan* as having an Urdu stem were indeed mostly Bengali names. Since the naming program was developed in Bradford, Sally Hull suggested that the naming program's validity might be limited to the local setting and hence affected by the

prevalence of different ethnic groups. Another explanation would be that among the Bangladeshi population there is a mix of Pakistani (Urdu) and Bangladeshi (Bengali) names as the separation and emancipation of Bangladesh (formerly called East Pakistan) is relatively recent (1979). In the random sample, we identified 81 Bengali names based on the local naming bank.

Individuals were firstly sent a written invitation to participate in a research project, and if they did not respond or their response letter said that they were happy to participate, we (myself and Nilufar Ahmed, a Bengali/ Sylheti researcher) followed them up by telephone. If they gave consent during the phone call, we proceeded with phase 1 screening interviews. After screening, we invited every individual who screened positive, and planned to recruit 10% of those who screened negative as control subjects.

4.3. Results

4.3.1. Recruitment

It became apparent that it was very difficult to recruit individuals for this study and recruitment by probability sampling alone was unlikely to produce a representative sample of the general population. The actual recruitment numbers are given in Table 10 below.

Table 10) Actual Recruitment in Numbers of Participants

	Jubilee	Jubilee Subset White & Caribbean	Jubilee Subset Bengali	Lower Clapton White & Caribbean		
Complete sample Contact with letter (Randomised from GP lists)	130 (100%)	50 (100%)	80 (100%)	200 (100%)		
Contact details wrong	33 (25.4%)	13 (26%)	20 (25%)	113(56.5%)		
Missing – could not be reached	29 (22.3%)	15 (30%)	14 (17.5%)	16 (8%)		
Contactable for participation Max Possible Sample Size = N – Wrong Contact etails and missing	68 (100%)	22 (100%)	46 (100%)	71 (100%)		
Refusal	30 (44.1%)	15 (68.2%)	15 (32.6%)	33 (46.5%)		
Consent	38 (55.9%)	7 (31.8%)	31 (67.3%)	38 (53.5%)		
Individuals who belong to specified ethnic groups (% of Consenting) Phase 1	34 (50%)	BC	WB	BC	WB	
		-	3 (13.6%)	31 (67.4%)	7 (9.9%)	14(19.7%)
Distressed pos (% of specified ethnic consent part.)	13 (38.2%)	-	1 (33.3%)	12 (38.7%)	4 (57.1%)	7(50%)
Distressed negative control	21 (61.8%)	-	2 (66.6%)	19 (61.3%)	3 (42.9%)	7 (50%)
BEMI Interview Phase 2	6 (8.8%)	-	1 (4.5%)	5(10.8%)	1(1.4%)	5(9.7%)

4.3.2. Descriptive information

Socio-demographic information is presented for those who participated in table 11 below.

Table 11 Socio-demographic information of participants

		White British (n =17)	Caribbean (n =7)	Bangladeshi (n = 31)
Age in Years Mean (SD)		48.00 (SD 17.38)	53.85 (SD 15.76)	38.01 (SD 14.85)
Gender	Male	10 (58.8%)	4 (57.1%)	8 (25.8%)
	Female	7 (41.2%)	3 (42.9%)	23 (74.2%)
Education (Age left school) Mean (Standard Deviation)		18.02 (SD 2.76)	15.79 (SD 1.14)	15.53 (SD 3.85)
Occupation	Employed	10 (58.8%)	2 (28.6%)	4 (12.9%)
	Retired	3 (17.6%)	1 (14.3%)	1(14.3%)
	Not employed	4 (23.5%)	4 (57.1%)	26(83.9%)
Housing	Owned	8 (47.1%)	1 (14.3%)	6 (19.4%)
	Private Rent	5 (29.4%)	2(28.6%)	
	Council	4 (23.5%)	4 (57.1%)	25 (80.6%)
Received Benefits		9 (52.9%)	3 (42.9%)	26 (83.9%)
Born in the UK		17 (100%)	1 (14.3%)	4 (12.9%)
Attended Primary school in Britain		16 (94.1%)	2 (28.6%)	7 (22.6%)
First Language English		17(100%)	7(100%)	1 (3.3%)

Deprivation was measured in terms of education, employment, housing and receipt of benefits. Both ethnic groups appeared more deprived in terms of education, employment rates and housing (Owned) than the White British group. In terms of benefits, the Caribbean and British were not observably different, but a higher proportion of the Bangladeshi group received one or more than one benefit.

To examine the representativeness of the sample, it was firstly decided to compare individuals with whom contact was made with those who could not be reached on the contact list. As I did not have access to patient files, I could only examine age as a possible confounding factor. There was a small but significant age difference between people who were available for interview and those we could not reach. Those who were not contactable were significantly younger (n = 202; mean age in years = 38.20) than the people we could not reach (n = 138; mean age in years = 42.36; t= 2.98 (261), p = .022).

I then compared individuals who agreed to participate with those who did not, to investigate whether either group had a significant age bias. An independent t-test confirmed that there was no significant difference in age between consenting individuals (n=75, mean age 41.68 years) and non-consenting individuals (n=63, mean age 43.17 years; $t = -.501 (136), p = .617$).

Mental health status was first assessed in Phase 1 by the GHQ and the BSI and in phase 2 with the CIS-R.

Table 12 Mental health status of participants

	White British (n =17)	Caribbean (n =7)	Bangladeshi (n = 29)
GHQ-12 Case	7 (41.2%)	4 (57.1%)	11 (37.9%)
BSI Case	4 (23.5%)	2 (28.6%)	7 (23.3%)
CISR different subject numbers as indicated	4/ 6 Ph2 interviews (66.7%)	1/ 1 Ph2 interview (100%)	5 / 5 Ph 2 interviews (100%)

Mental health was dichotomised into case and non-case according to cut off specification reported for the general population (Hardy, Shapiro, Haynes, & Rick, 1999; Mumford et al, 1991; Hardy et al, 1999; Jenkins, Lewis, Bebbington, Brugha, Farrell, GILL, & Meltzer, 1997). The GHQ identified higher levels of distress in all groups than has been quoted in the general population (30%), the BSI identified fewer as it identified some cases that scored positive on the BSI, but negative on the GHQ.

Cultural variations in perceptions of mental distress

Two independent 'raters' coded whether perceptions were present or not present in the narrative of the open-ended data. Due to the small numbers of spontaneously elicited perceptions, probed perceptions and perceptions elicited by checklist were aggregated according to the previously elicited themes. The mean scores are given in table 13 below.

Table 13 Preliminary findings of the BEMI means and standard deviations on aggregated scores

	White British (N=6)	Bangladeshi (N=5)	Caribbean (N=1)
Somatic Identity	6.5 (SD 3.44)	12.60 (SD 2.3)	17
Mental identity	7.16 (SD 4.36)	6.60 (SD 3.21)	12
Behavioural identity	1.67 (SD 1.36)	2.60 (SD 3.21)	4
Psychosocial cause	5.67 (SD 2.87)	6.00 (SD 1.87)	9
Supernatural cause	.67 (SD .82)	1.20 (SD .84)	1
Behavioural Cause	1.17 (SD 1.60)	0 (SD 0)	0
Situational cause	3.33 (SD 1.97)	2.20 (SD 1.30)	1
Psychological consequen.	3.00 (SD 1.67)	3.40 (SD 2.07)	6
Social consequences	1.83 (SD 1.47)	4.40 (SD 1.81)	5
Physical consequences	.50 (SD .84)	1.4 (SD .89)	1
Financial consequences	.50 (SD .84)	.60 (SD .89)	0
Behavioural consequen.	1.67 (SD 1.37)	1 (SD 1)	1
Self treatment	3.17 (SD 1.33)	1.2 (SD .84)	2
Social treatment	2.33 (SD 1.37)	.4 (SD .55)	3
Medical treatment	2.50 (SD 1.23)	1.4 (SD 1.14)	0
Spiritual treatment	.83 (SD .98)	1 (SD .71)	0
Psychological treatment	.67 (SD .82)	.80 (SD .45)	0

The number of participants makes it unfortunately too low to conduct any meaningful statistical analyses of the data. On first sight of the data, it appears that the BEMI could tap into ethnic differences regarding the content of perceptions of distress although these deductions/ findings are of course only exploratory due to small numbers of interviewees. Preliminary comparisons between Bangladeshi and White British subjects suggest that they differed in a number of themes. Bangladeshi reported almost double the number of somatic complaints in comparison to White British, but did not differ in neither perceived behavioural nor mental symptomatology. Bangladeshi also suffered from more negative social consequences (e.g. being excluded from activities, role change etc). Fewer of them would describe how they themselves could control their distress and/or relate any helpful interventions from their immediate social environment (talking to friends and family).

4.4. General Discussion of the Pilot Study and the Research Protocol

4.4.1. Sampling and comparison of planned to actual recruitment

In the original plan, it was estimated that 19 individuals would be interviewed in Phase 2, but this was not possible. Following are a number of factors that might have contributed to the low recruitment.

Firstly, the possibility of contact details being inaccurate was not initially taken into consideration. Contact details were inaccurate in 25% of all patients in the Jubilee practice and over 50% in the Lower Clapton Practice. There were also many individuals who could not be followed up, as they did not register their phone number with their GP. It was also noted that some individuals even after 10 telephone calls, at different times of the day, could not be contacted at all. Actively seeking interviewees (i.e. contacting individuals and their relatives frequently and assertively) did, however, reduce drop-out numbers greatly (in both practices) so that concerted pursuit was needed to keep missing numbers low.

Refusal was around 40%, which was almost correctly estimated, but consent was greatly overestimated in the plan and given by only 40.2% of the entire sample. Discussion with experts, found that terms like 'mental health' and 'distress', were laden with negative and stigmatising connotations, so that changes to the title of the study were advised in the invitation to participate. The Jubilee practice subset analysis showed individuals in the Bangladeshi group were very forthcoming with consent. Indeed more individuals from Bangladeshi background agreed to participate than any other group, while the White British & Caribbean subsets in the same practice had the lowest percentage of consenting individuals. The reasons for the greater consent among Bangladeshi might include conducting culture-matched interviews, pre-selecting individuals on the basis of their ethnic background and sending Bengali invitations. This might have induced greater motivation to participate as individuals might have felt that a special effort was made to

recruit them into the study. It was decided to try to recruit culture matched interviewers for the Caribbean group to increase the response rates. In the invitation it was specified which ethnic groups were to be included in the study, to try to make participation more appealing and relevant to people of all selected ethnic groups.

The most disappointing result was that instead of keeping a minimum of 75% of the participants from phase 1 to 2, we were able to retain less than 30% of individuals. Language/culture matched interviewing had no effect how many individuals would turn up for interview, but on first impressions it seemed that those who had higher scores and were more severely distressed on the GHQ did not show. Offering to conduct phase 2 interviews over the telephone was identified as a further option to increase response rates.

4.4.2. Problematic issues in the administration of the BEMI, IPQ-R and the acculturation scale

4.4.2.1. BEMI

The BEMI appeared initially the most easy to administer instrument in the research protocol, because it allows individuals to talk freely about their experience. My collaborating interviewer and I found that the prompting for non-described 'themes' caused considerable problems in the administration of the tool. As a researcher, one had to remember what the different themes were for each domain, and also make a decision about whether themes had been mentioned and therefore did require further prompting or not. This was a difficult decision to make during a time-pressured interview, but inclusion of specific probing questions for each domain would have lengthened the administration time considerably. Furthermore participants reacted to prompting questions often with defensiveness. So, if for example, we enquired whether social or spiritual factors might have contributed to their developing distress, some would answer: 'I've told you what I

think is the cause of my problem! Why are you still asking me questions about it?' and would not progress from the initial statement. If for example individuals perceived the cause of their distress to be their social environment, but were then asked about other influences (e.g. the weather) they felt as if they had not been heard. The general idea of 'probing' seemed to be associated with too much structure to the elicitation of respondents' perceptions and it was felt that this process was imposing too many predefined ideas, which kind of perceptions were going to be elicited. In a sense this was contradicting the aim to eliciting an *emic* lay view. In response it seemed advisable to remove the probing sections from the instrument and reduce it to have only open-ended questions in the interview only and plus detailed perceptions in the checklist.

A second problem emerged with the treatment methods section at the end of the interview. It was difficult to change from open-ended to closed questions about particular treatment methods, without individuals talking about their experiences in more detail. Although this might have been useful it also considerably lengthened the enquiry process. Therefore it seemed advisable to make the structured treatment methods section a part of the questionnaire assessment. The changes led to an adaptation of the BEMI outline and have been illustrated in table 14 below. The adapted version of the BEMI is attached in Appendix 6.

Table 14 Changes from BEMI Draft to Main Survey BEMI

BEMI Development	BEMI Draft	BEMI – Suggested adaptations for Main survey
Identity	<p>2 questions & 1 Checklist</p> <p>BEMI-I 1 Label or name</p> <p>BEMI-I 2 Open-ended Description of the experience with Probes reminding of all 6 sub-domains</p> <p>BEMI-C Identity Checklist including 39 items describing 'symptoms'</p>	<p>2 questions & 1 Checklist</p> <p>BEMI-1 Label or name</p> <p>BEMI-2 Description of the experience without any probes</p> <p>BEMI Identity Checklist including 42 'symptoms'</p> <ul style="list-style-type: none"> • Change of eating patterns was divided into 3 items eating less, more or different foods, • Pain and aches were subsumed under 1 item • Inclusion of two new items that emerged in the pilot study: 1 being restless and continuously moving about, 2 not doing things or avoiding to do things <p>The remaining items were explained more and simple terms were used to aid understanding e.g. Fatigue/ Tiredness, suicidal thoughts for example 'life is not worth it'</p>
Cause	<p>1 Question & 1 Checklist</p> <p>BEMI-I 3 Open-ended question followed by Probes</p> <p>BEMI-C Cause including 36 items</p>	<p>1 Question and 1 Checklist</p> <p>BEMI-I 3 Open-ended question</p> <p>BEMI-C Cause including 39 items</p> <ul style="list-style-type: none"> • Prejudice and Racism was divided as 2 separate-items • Inclusion of two new items that emerged in the pilot study 1 being abused, 2 problem with the bones
Course	<p>3 structured questions no checklist</p>	<p>3 structured questions no checklist</p> <ul style="list-style-type: none"> • Adding don't know as possible option
Consequence	<p>4 questions and 1 checklist</p> <p>BEMI-I 7 a & b open-ended questions followed by probes, BEMI-I 8 & 9 structured questions</p> <p>BEMI-C Consequence Checklist including 23 items</p>	<p>4 questions and 1 checklist</p> <p>BEMI-I 7 a & b open-ended questions, BEMI-I 8 & 9 structured question</p> <ul style="list-style-type: none"> • Added Decision Making/ Thinking as Option for 9 <p>BEMI-C Consequence Checklist including 27 items</p> <ul style="list-style-type: none"> • Added 4 new items that emerged in the pilot study 1 feel like crying, 2 having little concentration or memory, 3 losing your friends, 4 losing your partner/ children
Treatment	<p>5 questions</p> <p>BEMI-I 10 a & b open-ended questions, BEMI-I 11 structured questions about 14 different treatment methods whether they were considered or tried, BEMI-I 12 a open-ended b structured, BEMI-I 13 open-ended</p>	<p>4 questions and 1 checklist</p> <p>BEMI-I 10 a & b open-ended questions, BEMI-I 11 a open-ended b structured, BEMI-I 12 open-ended</p> <p>1 checklist asking individuals whether 18 different 'treatment methods' have been considered, tried and if tried whether they were found helpful</p> <ul style="list-style-type: none"> • Talking to somebody was differentiated between according to recipient to examine help-seeking in more detail. It was differentiated between talking to family, friends or GP/ nurse • Added two new items that emerged in the pilot study 1 Yoga and 2 Spending time on a hobby

4.4.2.2. IPQ-R

The IPQ-R was very difficult to use among individuals from Bangladeshi background. Despite the fact that we had translated the version into Bengali - the official language and writing of Bangladesh, none of the individuals could read the scale and fill it in themselves. The majority came from a region in Bangladesh called Sylhet, which has its own language, but no written form. It also appeared that the Sylheti dialect, which is estimated to contain only 20,000 words, was limited in its ability to convey variations in meaning compared to English, which is estimated to contain over 500,000 words. The IPQ-R contains 4-5 statements for each of the following domains: consequence, treatment, timeline and coherence. The items are differently worded, but mean quite similar things (e.g. IP24 'The symptoms of my condition are puzzling to me'; IP25 'My illness is a mystery to me'; IP26 'I don't understand my illness'; IP27 'My illness doesn't make any sense to me'). Therefore the researcher sometimes had to simply repeat a previous statement, because there were not enough expressions to communicate the differences, and participants would reasonably say 'I have already answered this question'. Also the IPQ-R considerably lengthened phase 2 when the questionnaire had to be read out. Since at the time there was no published shortened version of the IPQ-R, it was decided to exclude the measure from the main survey.

4.4.2.3. *Acculturation scale*

The acculturation scale (Appendix 4) was included to provide some information about individual's acculturative processes and was used only once by myself during the study. Participant #71 from West Indian background and her friend Mr M told me that some of the items were not applicable to her cultural background or acculturation processes (i.e. clothes and language). I showed the scale to other individuals from Black Caribbean background and found likewise non-favourable responses from individuals from the English speaking countries in the Caribbean. Questions about language, food and clothes

were, they felt, not appropriate and a little offensive. This made me doubt the generalisability of the scale to the Black Caribbean population in East London, the majority of which came from English speaking countries of the British Commonwealth. As the usefulness, generalisability and interpretation of the findings could not be established for all acculturation processes, it seemed likely that the scale would probably produce unreliable scores and might not possess good consequential validity. I have therefore exchanged this scale with selected more generalisable items from the 'subjects' loyalty scale' and the 'ethnic minority stress scale' by (Mena, Padilla, & Maldonado, 1987) (Appendix 7).

4.5. Reliability of the Barts Explanatory Model Inventory

After completing the pilot study, it was clear that the number of individuals was too small to determine internal consistency of the scales. More reliability analyses including inter-rater reliability of classifying open-ended data onto the data management form, inter-item correlations and Cronbach's Alpha have hence been produced with the results of the main survey and are therefore presented in Chapter 5 (p.119). However, in order to be able to determine reliability prior to the main survey, it was decided to administer the new BEMI (Appendix 6) at two different time points to examine test-retest reliability. Reliability of the BEMI was measured for both open-ended and checklist items one day apart (a) n=5) and one week apart (b) n=5) in two independent voluntary samples of mixed ethnic background. Pearson correlation was significant and varied between .914-.988; $p < .001$ for the subjects in study a) and between .775- .948; $p < .001$ in study b). The BEMI asks whether individuals experience something that has stressed them in the past month, and it was not appropriate to extend the test-retest analyses much further, because individuals would then be asked to evaluate different time periods.

4.6. Validity of the Barts Explanatory Model Inventory

Most psychological researchers like to establish content, criterion and construct validity of instruments, despite research and convincing arguments for extending this list. Messick has described this most competently.

'The conventional view (content, criterion, construct) is fragmented and incomplete, because it fails to take into account both evidence of the value implications of score meaning as a basis for action and the social consequences of score use.' (Messick, 1995)

Messick further asserts that validity is not only the property of an assessment, but rather evaluates the **meaning** of the test scores and argues that the examination of an instrument should be extended to include the following 6 domains.

- **Content**--evidence of content relevance, representativeness, and technical quality
- **Substantive**--theoretical rationale
- **Structural**--the fidelity of the scoring structure
- **Generalizability**--generalization to the population and across populations
- **External**--applications to multitrait-multimethod comparison
- **Consequential**--bias, fairness, and justice; the social consequence of the assessment to the society

The validity for all six domains was examined as it was seen more comprehensive and also sensible when conducting cross-cultural research as the meaning might not be transferable and have negative consequences for particular cultural groups.

The content of the BEMI emerged from a qualitative literature review of a selection of culturally diverse accounts regarding perceptions of mental distress suggesting that the content is cross-culturally relevant and representative. Since the instrument was also conceptually developed out of a review of the different instruments, it also seems to have substantive validity. The structural validity of the BEMI should have been demonstrated by interrater reliability of the scoring of individual accounts and internal consistency of the questionnaire scales. This will be subsequently presented in chapter 5. The instrument was developed for general population use and has cross-cultural validity and should

therefore be generalizable across a variety of populations. Its external or concurrent validity was determined in relation to scores of the CISR and the IPQR below. The consequential validity of the assessment is important and has been the core of anthropological and sociological critiques on cross-cultural quantitative research. It is assumed that since the qualitative component needs careful coding, the likelihood of careless interpretation is reduced, but it also poses some risk of bias and unfairness in the assessment. However, if the interviews are coded carefully by a minimum of two individuals and difficult responses are resolved by 'expert' input of indigenous individuals, the instrument's consequential validity is demonstrated as it is designed to facilitate patient centred culturally appropriate clinical care.

I have described three case studies to illustrate the interview process and to firstly demonstrate the findings elicited by the BEMI to establish face and content validity from a qualitative perspective:

1) # 61 White British Male – 49 years old

Born in Bristol, married with 3 children, in paid employment, architect, left school at 18, went on to study, lives in owned accommodation and suffers from depression (elicited from the screening question about presence of chronic conditions).

61 scored positive on the GHQ (7) and just below the threshold on the BSI (12).

On the CIS, 61 scored 19 he was particularly high on depression and fatigue, and also on somatic symptoms, concentration, irritability, depressive ideas and phobia. His phobia was mostly about work and social situations. During the interview he showed markedly slowed behaviour and an inability to make decisions about things. He would not answer for sometimes minutes, and I would have to repeat the questions.

With the BEMI he called his distressing problem 'feeling tired, exhausted and having no energy'. When he was asked to describe it, he said that it was not being able to get up, needing to do things, but not being able to do it, deciding, he said 'it feels very physical, there ought to be a pill to make things normal'. '[my] worries stem from not having the energy to deal with problems and worries, not getting round to dealing with them and then worrying about it'. He mentioned on the somatic level fatigue, on the mental level a lack of concentration and that it does get him down at times. After probing for behavioural complaints he mentioned 'Not having the energy to do things he used to enjoy, like reading a paper/ magazines' which he now just glances through'.

When asked what he thought had caused the problem, he spontaneously mentioned that his 41 year-old dad died, when he was 13 and that he had not dealt with it. When he was approaching 41 himself, he thought his time was up. After probing for social problems, he said, he generally did not have many friends, but it had not changed his relationships. He did not believe in supernatural or behavioural causes. He said that being out of work might have contributed. He thinks that it is a chronic weakness in his make up, made worse by situational factors. Maybe to do with genetics, as his father died of heart problems and the fatigue is always brought on by aches in the chest. He

said that it might be caused by cognitive or perceptual factors, but that he did not believe in this before. His perceptions started to change, because he had just started a CBT following the advice of his GP and was now being exposed to the idea of perceptual control.

He said that it lasted 20 years so far, but the last 6 months were more severe, he expected it to last forever, if he would not do something about it and said that it was cyclical. When asked about consequences, he initially said that everything he does is a chore, even enjoying himself was hard work. I probed to tell me about social consequences, he said that he can't be bothered to see anyone, he also changed his behaviour doing less exercise, and his personality, he supposes, but it has been around for so long that he does not know his 'real' personality. There were no financial problems. He said that his low level of energy has had a big impact on his life, affecting his physical ability, social life, financial security, personality, behaviour and status. He believed that the best way, it should be resolved is either by a pill, physical examination to reveal the physical origin or CBT. He considered exercising and herbal remedies, and tried talking to somebody, taking medication and relaxation/ massage. He talked to his GP, therapist and his wife about it and it was always helpful. He found it helpful to talk to his GP, because he assured him that there was nothing physical and encouraged him to seek therapy. Talking to his wife he said was more for general moral support and the therapist just started to explore a new way of thinking and how to deal with it.

He filled in the checklist himself and ticked crying, disturbed sleep, indigestion, pain, aches, fatigue, nerves agitation, bodily weakness, nausea, dysphoria, irritability, feeling nervous or anxious, lack of concentration, loss of interest, feel guilty, withdrawals from others and not being able to complete tasks as part of his problem. He believed that it was caused by stress, guilt/shame, work problems, loss/bereavement, heredity. He added further that seasons played a part in it as it got worse in the winter. As consequence, he had an increase focus on his body/ the illness, feeling irritable, lowered self-esteem, fear, being excluded from social activities and stop partaking in activities that he enjoyed.

This detailed account showed that the individual had a strong perception that his illness was of a physical nature, but interaction with his GP led him to change his perceptions to a more psychological identity. In consequence, he was keen to mention his father as the result of the problem, but also included a number of other items, such as stress and work-problems. He spontaneously mentioned a pill to relieve his problems and a physical examination that would identify the underlying physical origin, but later also talked about CBT as a possible remedy. His perceptions were associated with his scores on the clinical interview schedule, and were intricately linked with information he had received from health professionals. It seemed that the interview was able to tap into important perceptions that clinicians might want to address, such as the timeline and the belief in physical origins of his distress.

I have selected a second case description to relate the experience of a more severely distressed individual whose perceptions of distress appeared to have been formed with little input from health professionals.

2) #71 Black Caribbean woman – 65 year old

Born in Jamaica, 71 lived in the UK for 40 years and had 6 children. She now lives separated from husband on her own, is permanently disabled, worked previously in manual jobs, left school at 16, did not go to primary school in Britain, lives in privately rented accommodation, receives disability benefits and had hip and knee replacement.

71 screened positive on both the GHQ (6) and the BSI (19), when I said that I wanted to interview her, she asked question about whether the GP knows about this. I said that it was completely confidential and she said that she wanted me to tell her GP, as she had a good relationship with him.

She arrived at the GP practice alone, but her friend Mr M came in 10 minutes after the beginning of the conversation. She scored positive on all scales of CISR, but anxiety, contributing to an overall score of 37. Her highest scores were on somatic symptomatology, fatigue, worry and panic. She scored also considerably high on concentration and forgetfulness, sleep problems, irritability, depression, depressive ideas and moderately on phobias, compulsions and obsessions. Her obsessions were mostly about her son being not there, hand hygiene and her compulsions were hand washing and checking. She was mostly phobic about other people, she felt embarrassed about her disability. The interview lasted quite a long time as she was describing her pain etc in detail and was very distressed, at times she was crying.

In the BEMI, she called her problem 'loneliness and not being able to see her children and grandchildren'. When asked to describe what it was, she said that everything was gone and there was no hope. Her son died last year of cancer and the others don't come to visit as much as she would like them too. Mr M added that she had 3 sons, one with schizophrenia – so we don't expect too much of him (his words), the one who died and another one who not as much rejected, but neglected her. When prompted, she said that she was feeling low, not being able to concentrate, loneliness, nervous, tense and sick. She suffered from heart palpitations and fatigue on the somatic level and mentioned crying and drinking more water as behavioural aspects. When asked spontaneously what had caused her problem she said that she felt this way, because her children are not coming, her son dying of cancer and loneliness. When I tried to prompt about problems with people or stress, she spontaneously mentioned what she had done to deserve this and started to cry. She said her husband and her are still good friends, he beat her up in the past and that's why they are separated, but they are still talking. There were no situational causal factors initially. However, she mentioned that her flat had been broken into, which traumatised her and which also was the last time, she saw her son and that she has had ongoing problems with her neighbours and noise. She said her problem had lasted for 2-5 years and she was hoping it to last for another 1-2 months. She said that it went through cycles of getting better or worse. When asked how it affected her life, she said that it made her feel terrible. When prompted she said that she had not got many friends anymore, problems with the neighbours and that she changed her behaviour and does not visit anyone anymore. Financially there were no repercussions. She said however that it had a big impact on her life and said that it affected her physical ability, her social life, personality, behaviour and status. When asked how it could be best resolved, she said, that seeing her children and grandchildren would help, socialising and exercising. She tried to socialise and exercise and talks sometime to her doctor and her friend Mr M. She said that talking to her doctor helped, but talking to her friend helped only sometimes, because sometimes he does not listen. Again this section lasted quite a long time as she had a lot to say and sometimes Mr M had a different opinion and they would argue. When this happened 71 would turn her head away from him and signal that he did not understand.

In the checklist assessment, I had to read out the items, because she wasn't sure whether she could understand them. She checked for identity crying, disturbed sleep, palpitations, indigestion,

unusual skin sensations, visual deficiency, loss of bodily fluid, pain, aches, fatigue, nerves/agitation, heat or heaviness in part of the body, bodily weakness, nausea, dysphoria, irritability, feel nervous, feel frightened, lack of concentration, loss of interest, worrying thoughts, feeling guilty, feeling ashamed, withdrawal from others, becoming mute, screaming, violent towards things, obsessive behaviour and rambling. As causes she checked stress, age, worry, family problems, marital problems, loneliness, loss/ bereavement, bad luck, illness and disability. Consequences checked were an increased focus on her body/ illness, being tormented by interfering thoughts, feeling bad, feeling sad, feeling irritable, feeling aggressive, lowered self-esteem, fear, role change, being excluded from social activities, pain and gaining weight. Additionally she mentioned neglect.

As can be seen, 71 had a long list of perceived symptoms and complaints. She mentioned double the number of causal attributions and perceived a larger number of negative consequences. Her perceptions about the treatment focussed mainly on personal and behavioural aspects and she did not mention any possible psychological help as part of the BEMI. She did however tell me at the end of the interview that it was nice to talk to someone who would listen and understand, which suggests that she might find benefit in counselling. The comparison of the two distressed individuals suggests that perceptions appear to be able to differentiate between more distressed and less distressed cases.

Unfortunately, there were only two control cases in phase 2 and one of them said that nothing had stressed him in the past month. This meant that only one control case was available for a qualitative comparison.

3)# 52 White British Female – 24 years old

Born in London, no children, lives with mother, brother, sister, brothers' girlfriend, and her boy boyfriend, in paid employment, in fashion magazine advertising, left school at 18 and did degree, Lives in privately rented accommodation, suffers from menstrual problems.

52 scored below the threshold on both screening scales, but only narrowly so GHQ (2) and BSI (8).

On the CIS, she scored 13 i.e. one above caseness. Her highest score was in worry and anxiety. She also scored moderately in somatic symptoms, fatigue, irritability, and depressive ideas and phobias.

With the BEMI, she identified her problem was getting very upset and depressed. When asked what that meant, she said crying a lot, feelings of self-doubt or not liking herself, not being able to stop crying or doing something about it. Prompted about somatic problems, she said, that when she had menstrual problems, she did have more pain. Listening to her interview afterwards, I think she did not understand the question correctly. On the behaviour domain, she said that doing not a lot was associated with it and being preoccupied with the way she feels. This can change very rapidly and all of a sudden, no feelings of depression are left.

When she was asked to say spontaneously, what she thinks causes it, she said that it's usually set off by smaller things, then once she gets upset she then worries about bigger things. 'It's kind of

like a progression' the more she thinks, she will focus on things that make her feel worse. Prompted about people or work she said that stress in the job affects it, but not people. They are individual worries that she likes to keep to herself, occasionally gets worse after drinking. Situational things were causing it, but she felt more, that it was the way she handled situational things. She felt that she was getting too stressed out when the situation does not warrant it.

She said that it lasted for 5-10 years and will last for another 2-5 years. She also goes through cycles, when it gets better or worse. As consequences, she mentioned spontaneously not being as socially active as she would like to be, affecting other people with her feelings, not getting many things done. As an advantage, she voiced that after she has been very upset and depressed, she feels a lot better for about a week or so. She obsessed about checking the time constantly, to ensure that she was on time for meetings and appointments. She said that the advantage of that was that she was prepared for all eventualities. I prompted for social consequences and she said that she was left alone, but on her own request. The only person, she lets close is her boyfriend, who sometimes gets very frustrated about not being able to help. She said that she stopped smoking and drinking, but that this was not necessarily related to the distress. She decided that distress had a big influence on her life, but it was difficult for her to quantify the impact as she learnt how to deal with it, more so than other people notice. She said that it affected her social life, her personality and her behaviour. Counselling rather than medication was her best resolution of the problem. Her father has been taking antidepressant and she said it helped him, but for her talking to someone would be preferable. She considered substance abuse, keeping busy, talking to somebody, using herbal remedies, relaxation massage and seeing a traditional healer. She tried relaxation/ massage, using alcohol and talking to somebody and added yoga to the list of therapies. She said talking to her boyfriend and mother was helpful and said that it was helpful 'because when you are thinking about something yourself, it helps to have other people's opinion to rationalise things that you are thinking about and be reassured about my worries'. She said that just explaining to somebody the way, she has been feeling makes her feel better, and also to know that someone is feeling the same. To her relating to other people was important.

She filled in the forms by herself and sent them later with the post. She checked on the symptom list crying, change of eating patterns, fatigue, nerves-agitation, nausea, dysphoria, irritability, feeling nervous-anxious, worrying thoughts/ torment, feeling guilty, feeling ashamed, withdrawal from others, substance abuse and being violent towards things. As causes she checked stress, her gender, worry, emotions (excessive), work problems, wind/weather, illness/ disability and heredity. As consequences she stated feeling bad, feeling sad, feeling irritable, feeling aggressive, being excluded from social activities and losing weight.

52 scored below caseness during the screening interview, but scored just above caseness during the more detailed phase 2 psychiatric interview. Her account has been described as she was the only available Control subject if one considers the screening GHQ outcome, who said that something distressed her in the previous month. As 52 scored on the borderline of distressed and non-distressed, it seemed likely that her thoughts were not clearly differentiable from perceptions of distressed cases. 52 went through phases of feeling well and phases of distress. Contrary to the other cases she was able to mention a number of positive consequences as well as negative ones. She preferred non-drug treatment and thought that talking to her family/ partner was a helpful remedy for her

distress. Contrary to distressed cases, she also did not perceive the need for medical intervention.

Exploring these case studies suggested that there is a link between objective measures of distress and the level of perceived distress, its causes, consequences and preferred treatment. As there were some qualitative differences in perceptions of distress and treatment evaluation between severely distressed and non-cases, this would suggest that the new tool should have face, content and possibly criterion validity although the number is obviously too small to state this with confidence.

External or Concurrent Validity

The instrument's external or concurrent validity was examined by correlating scores of the BEMI with scores on the IPQ-R. The IPQR assesses the identity of the illness similarly to the BEMI as it lists symptoms/ complaints and asks individuals whether they are related to the illness/ problem or not. As the majority of symptoms listed in the IPQ-R appeared not to be related to mental health, I could only select a few IPQ-R items that had overlap with mental distress (Fatigue, Pain, Nausea, Sleep Problems and Loss of Strength). IPQ-R Fatigue was significantly correlated to checklist item fatigue ($n=12$, $R= .671$, $p<.025$); but no correlation with probed questioning or spontaneous reports. IPQ-R Pain had a similar correlation with the pain item on the checklist ($R=.632$), but was not significant as only 6 individuals reported this feeling. IPQR Nausea was perfectly correlated with spontaneously mentioned nausea ($R=1$,) but not related to any of the other measures. Bodily weakness was reported by Bangladeshi individuals on the BEMI, but not as loss of strength on the IPQR. This could be related to linguistic differences in the translation of this item.

Causes are differently assessed on the IPQ-R, as the individual has to say how much (on a 5-point Likert scale) they agree or disagree that listed causes were causes for their illness. The IPQ-R causal item 'Chance or bad luck' was significantly correlated with the same item on the BEMI checklist item ($n = 12$, $R = .614$, $p < .05$); likewise the IPQR item 'Stress or Worry' was significantly correlated with BEMI checklist item Worry ($n = 12$; $R = .631$, $p < .05$). IPQ-R Family problems or worries was almost significantly correlated with the BEMI probed item family problems ($n = 12$, $R = .575$, $p = .051$) and IPQ-R Ageing was almost significantly correlated with BEMI item Age ($n = 12$; $r = .566$, $p = .055$).

The IPQ-R items for timeline, consequence, treatment, emotion and coherence were assessed by evaluating how much (on a 5-point Likert scale) they agreed with statements. For the consequence domain, I found also a significant correlation between the IPQR and the BEMI consequence list ($n = 12$, $R = .664$, $p < .05$). For the domains of timeline, treatment, emotional response or coherence, no correlation was found between these IPQ scales and the BEMI possibly due to the diversity in the content of the items. The BEMI does not directly measure coherence or insight into distress quantitatively, but one might be able to determine this information indirectly, by assessing how often an individual responds with 'don't know' to the questions. The emotional response on the IPQ was not correlated with any of the emotional consequences stated by the BEMI, but this was not unexpected due to the different remit of the instruments. The treatment component of the IPQ-R measures whether people believe that a) they personally or b) medication or others can influence the outcome of their illness. Adding all treatment methods that involved personal or external control on the BEMI did not correlate significantly with scores of the IPQ-R.

This analysis showed that the IPQ-R and the BEMI are very different instruments particularly in their assessment of timeline, cause and consequence. As the IPQ-R is mainly designed for physical illness it might be argued that finding any significant

correlations is encouraging. It was further established that there were significant associations between some but not all symptoms that are commonly identified as the identity of mental distress and perceptions of causes for mental distress such as worry, bad luck etc. The small numbers of participants however significantly undermined eliciting a huge set of diverse perceptions, which could be associated with the IPQ-R. The results however seem to suggest that the BEMI had concurrent validity with another measure of illness perceptions although this needs to be established in further research.

4.7. Conclusions from the pilot study and implications for the main survey

Probability sampling from the general practice register was not a useful way to obtain a representative general population sample. Recruitment from general practice registers was difficult as 30–60% of individual contact details were out of date, possibly due to the high level of mobility in the East End of London. Also when contact was made, there were low levels of participation in the study particularly among Black Caribbean people. Consultations with experts revealed that the terminology employed particularly the term 'mental' was likely to be problematic and stigmatising, and advised us to rephrase the invitation to participate to include less stigmatised terminology. Sampling should be extended to a variety of locations in the community to ensure better response rates. Furthermore screening results suggested that the sample contained a much higher proportion of distressed cases (38-52%) than had been previously observed in the general population (20-30%). This was interpreted as that the study seemed to attract distressed individuals to share their experience. Maybe especially because they were distressed we also had a large attrition rate and large numbers of willing interviewees were lost between phase 1 and 2. Therefore the rationale for using a two-phase survey was compromised, and it seemed advisable to change the design into a simple survey design to increase response rates. It was decided to therefore go ahead with a simple survey design, under the premise that if the initial proportion of distressed cases would have been too less than

is usually observed in the populations alternative sampling methods might have been considered. It was also identified that it might be useful to offer telephone interviews, to ensure that individuals were not lost due to practical reasons such as time when the practice was open, child care, working hours, and mobility problems.

The small number of participants limited statistical analyses, but it seemed that the BEMI was useful. The management of probed questions in the original scale was very problematic in the interview situation and it was difficult to switch from open to closed questions when assessing treatment and help-seeking. As a result an adapted version of the scale was produced in which the treatment section formed a fourth checklist and the probed questions were dropped. The new BEMI version (see Appendix 6) had acceptable test-retest reliability and the results of the pilot study also found content, substantive, generalisability, external and consequential validity for the original BEMI. Preliminary analyses of the pilot study suggested that the BEMI was useful for assessing cultural variations in perceptions. White British (n=5) were significantly different from Bangladeshi (n=5) in a number of items. Bangladeshi individuals had significantly more somatic symptoms, experienced more social consequences, described fewer self or social treatment methods than White British and did not speak to anyone about their distress.

The IPQ-R was translated into standard Bengali on paper, but could not be utilised as few Bangladeshi individuals could read Bengali. As it therefore needed to be administered by reading out the questions the inclusion of the IPQ-R also lengthened the administration of the detailed interview considerably. It seemed therefore advisable to exclude the IPQ-R from the research protocol. The acculturation scale was not applicable to all cultural groups, and to accommodate all groups, I have exchanged this scale with selected items from the 'subjects' loyalty scale' and the 'ethnic minority stress scale' to measure acculturative stress by Mena et al. 1987.

Chapter 5 Main study – A survey of perceptions of distress in three cultural groups of the East London population

In order to test and apply the adapted assessment tool (BEMI, see Appendix 6) in an epidemiological survey, individuals' perceptions of distress were examined in three ethnic groups in East London. The three ethnic groups were chosen according to local concentrations, and included Bangladeshi, Black Caribbean and White British.

5.1.1. Study Design

The design of this study was changed from a two-phase design to a cross-sectional questionnaire / interview survey in which all subjects were interviewed. A general population sample was selected for the following reasons a) to explore the effects of culture on perceptions of mental distress in the population by comparing different ethnic groups and acculturation processes and b) to explore how much perceptions are affected by current levels of distress. In order to be able to generalise findings to the population of all three groups, it was necessary to draw a representative sample of the general population. The pilot study showed that recruiting individuals from the general practice register via invitation did not ensure sufficient participation from all ethnic groups. Hence supplementary recruitment from a range of different community sites was included.

Ethics approval was sought from the East London and the City Health Authority Ethics committee and was granted (Ref # Do/ SG/ 02/ 145). After it was decided to expand the research to recruit more Caribbean participants from community organisations to Lambeth, a request was put forward to ethics at King's College and they granted approval as long as recruitment remained in the voluntary community organisations.

5.1.2. Hypotheses

The following research hypotheses were explored in the survey:

- H1) Perceptions of distress are associated with individuals' cultural (ethnic) background.
- H2) Perceptions of distress are associated with acculturative processes. With greater exposure to host culture, perceptions will adjust towards those of the host culture.
- H3) Perceptions of distress are associated with the absence or presence of mental distress (psychiatric caseness).

5.1.3. Research team and interrater reliability

The interviews were conducted by a research team of five researchers (Deba Choudhury (British Bangladeshi), Cecilia Faduola (Mixed British Black African and Caribbean), Louise Harding (British Black Caribbean), Katja Rüdell (White German/European) and Farah Suraiya (Bangladeshi)). Deba Choudhury was born and reared in Britain and was a postgraduate psychology researcher. Louise Harding and Cecilia Faduola were also both born and reared in Britain and were final year sociology students from Brunel University. Farah Suraiya was a medical doctor from Bangladeshi, who came to the UK in the past year. I was brought up in Germany, but have been living and studying Psychology in the UK since September 1995. I was trained as a counsellor for a student support nightline and my main research background is in health psychology. All researchers were fluent in English and DC and FS were also fluent in standard Bengali and Sylheti.

Researchers had been selected on the basis of their training, language skills and cultural background to ensure high quality interviews and to match interviewers with interviewees for participants from ethnic minorities. This was done to increase recruitment and to minimise flaws in the culturally diverse encounter between interviewer and interviewee. DC and FS interviewed the Bangladeshi sample and most of the interviews (95%) were conducted in Sylheti/ Bengali. As Sylheti is a spoken language with no written equivalent, the data had to be managed according to

previously agreed rules. DC translated the questions and wrote Sylheti pronunciation (for English speakers) on top of each question. FS learnt these by heart and both interviewers administered their questions in Sylheti, but translated answers immediately to record them in English only. CF and LH interviewed 75% of the Caribbean interviewees during the time of their placement. This was the most difficult group to engage in research as previously shown in the pilot. I therefore also interviewed Caribbean participants in the community sites to supplement the sample. My interviews accounted for about 25% of the Caribbean sample and 100% of the individuals in the White British group. The data collection for the White British was not ethnically matched under the assumption that British and German cultures evolved under the influence of similar factors. The Caribbean interviews that were not culture matched were compared with the culture matched interviews and no qualitative differences were observed. All interviewers were trained for two weeks in the administration of the research protocol by mock and taped interviews. Interrater reliability was established in English prior to data collection on ten interviews. Kappa was established on elicited perceptions and subsection scores on the CISR: .93 -.95; suggesting that it was 'near perfect' interrater agreement (Landis & Koch, 1977).

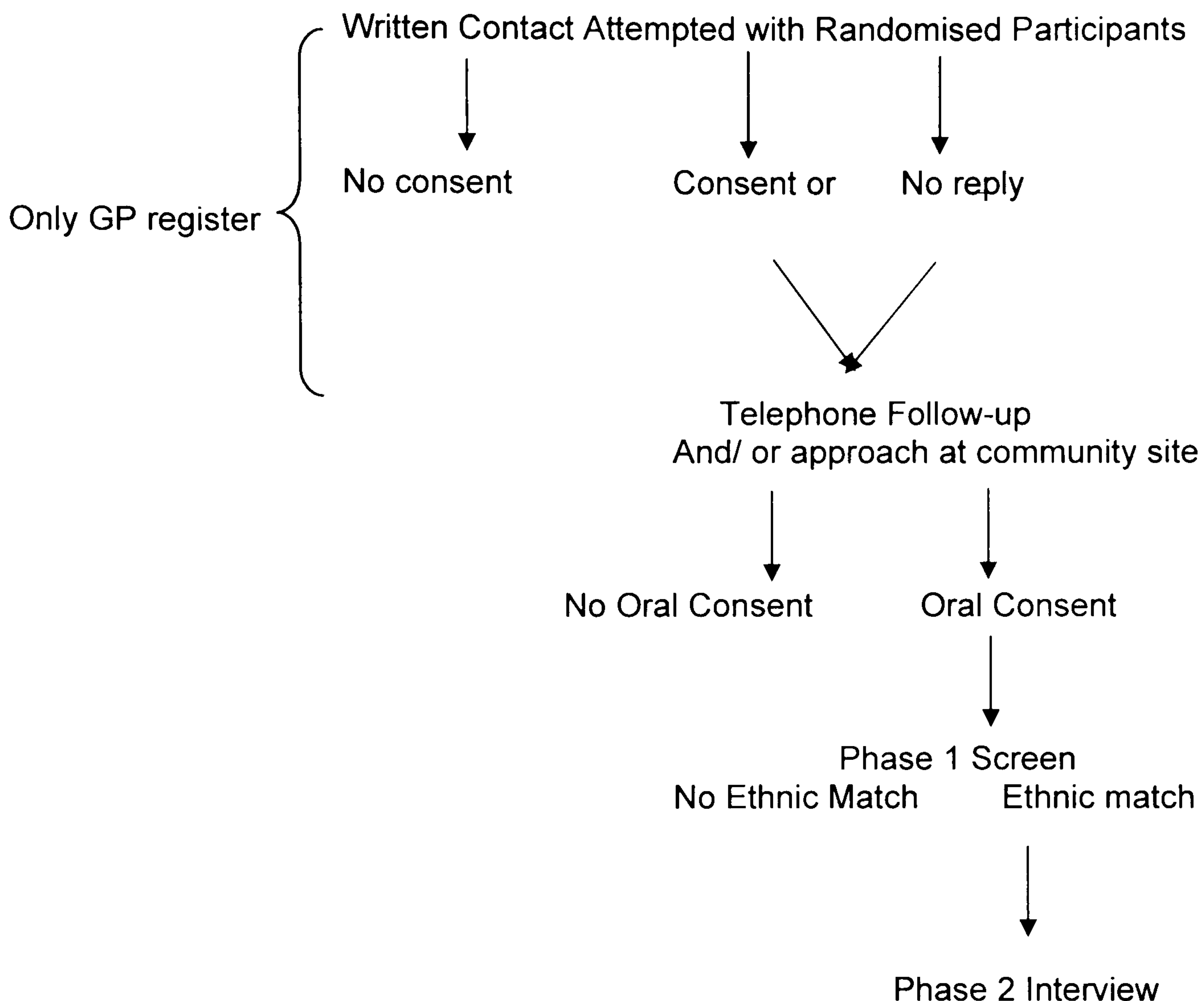
5.1.4. Sample

The pilot study found a low uptake from general practice registers, which raised questions about how to ensure representativeness of a general population sample when exclusively sampling from the general practice register. A new recruitment strategy was therefore adopted to ensure that a more representative community sample was obtained. Half of the sample was gathered from general practices and the other half from non-health community organisations. Four GP practices were involved (Lower Clapton, Statham Grove, Jubilee Street & Albion Health Centre) and fifteen Community organisations (Groundwork, Idea Store, Tower Hamlets College, Haggerston Community Centre, Hackney College, Family Welfare Association, Bangladeshi Welfare Association, Jagonari, Brixton Carer, Ujima, Hackney Caribbean

Elderly Organisation, Hibiscus, Lofthill Community Group, Piermont Community Group, Brixton Sheltered Project). The remit of these organisations is described in Appendix 9)

5.1.5. Procedure

Flowchart of Study design for Pilot Study



5.1.5.1. General practice

In the general practice sub-sample, two practices per ethnic group were included (Lower Clapton and Statham Grove in Hackney for White British and Black Caribbean; Jubilee Street and Albion Health Centre in the Tower Hamlets for Bangladeshi). In both Hackney practices, a random sample was drawn from individuals, who registered their ethnic background as White British or Caribbean. The number of individuals who recorded their background as White British was below the two hundred envisaged in the sampling strategy. This group was therefore complemented by a group of randomly selected individuals with no assigned ethnic background. Bangladeshi

patients were identified on the basis of the name register developed by Sally Hull and colleagues at the Jubilee practice (see Chapter 4 for reasoning) and a random sample was determined using the random sample selection option on the EMIS menu. EMIS was the general practice routine software for all four GP practices.

All randomly identified individuals were firstly contacted with a written invitation. Enclosed was a response slip to indicate whether they would like to participate or not. All individuals who did not object to participating were contacted with a follow up phone call. Those who agreed to participate orally during the follow up call were shortly 'screened' on the phone. If they were eligible for the study (i.e. over 18 years old and identified themselves as White British, Caribbean or Bangladeshi), they were invited for a detailed interview at the respective practice and/ or over the telephone.

5.1.5.2. Community organisations

Individuals who were interviewed in community settings were approached in their community organisation. They were informed about the study, screened to assess eligibility and then interviewed at the community centre in more detail. The sampling in this group was not probability based, for two reasons a) the sampling frame was unknown and b) it seemed that probability sampling alone would produce such low response rates that it would not give an accurate representation of the population.

Data collection started in March 2003 and was completed in January 2004.

5.2. Materials

The materials used in this survey are detailed below:

5.2.1. Screening instrument

The same screening questionnaire was used as in the pilot study (Appendix 2). This measured information about ethnic background and age to assess eligibility for the

study. In addition, socio-demographic information was collected to control for possible confounding variables (age, gender, education and socio-economic status).

5.2.2. BEMI

Both parts of the amended version were used in this study (i.e. the semi-structured interview and questionnaires, see Appendix 6). The open-ended data of the semi-structured interviews were independently coded by two interviewers (KR and either DC, CF, LH) and documented in data management scoring sheets (see Appendix 8). The processes for managing the open-ended data, particularly in relation to new perception items, are outlined below.

5.2.2.1. BEMI Findings – Management of BEMI interview data and issues surrounding coding

Before results are presented, the way that open-ended responses were managed will be described. The open-ended data of semi-structured BEMI interviews were independently coded by two interviewers (KR and DC for White British and Bangladeshi, KR and CF or LH for Caribbean) and documented in data management scoring sheets (see Appendix 8). The BEMI management guidelines advise the coder to classify perceptions as either absent or present, and to differentiate between spontaneously elicited perceptions by interview and by checklist. There were few disagreements as to how open-ended data should be coded, but if these did occur they were resolved by discussing the alternatives and deciding jointly which one might be a better option or entering present for both options. Interrater-reliability was established for a selection of 5 BEMI Interviews for each cultural group and was acceptable (.85-.98).

As expected, similar problems were encountered to those in the literature analyses described in Chapter 3. Not all individuals were able to differentiate clearly between perceptions regarding the identity of distress, its causes and consequences. Coding of

open-ended data was fairly straightforward, when individuals were describing perceptions in language that was previously identified as conceptual perception items. Words or terminology that appeared to refer to additional perceptions were added to a list of 'new' perceptions and similar procedures were utilised to those in the literature analysis. Perceptions were compared, and perceptions with similar meaning were aggregated and paraphrased using a generic term. For example abuse, harassment, bullying and domestic violence were aggregated and described under a new item 'abuse, violence'. Perceptions that were conceptually disparate were introduced individually as new items e.g. 'tension'. I have described the emergence of new items individually for each domain below. I have used case examples (coded WB for White British, BC for Black Caribbean and BA for Bangladeshi plus their ID code) to illustrate coding problems and findings in the paragraphs below.

5.2.2.2. Perceptions about the identity of distress

Perceptions regarding the identity of distress were described separately according to the questions regarding the label and the description of distress.

BEMI-I 1) What would you call this problem [the experience]?/ What names would you give it?

The majority of individuals were able to reify their experience and label it - WB RD41 'anxiety', WB RD110 'similar to an irritable bowel [syndrome], but with panic attacks', BC BCCB6 'physical pain' and more than half of BA referred to it as 'Worrying' (e.g. BAWA 22). Some individuals extended the list of labels/complaints, but would still treat the experience as a coherent bodily or mental condition which they described with a label e.g. WB WBSG81 'stress', WB THC5 'post menstrual tension', BA BAWA23 'tension' and BC GW23 'pregnancy'. Some would talk more about the cause of their distress BC GW27 'noisy neighbours', BA BAWA4 'family problem', WB WB50 'marital dysfunction' rather than the experience of distress itself. To stay near to the subject's experience, the list of items had to be extended to accommodate the new items and furthermore an additional 'theme' emerged called 'social identity'. Some Bangladeshi

individuals also talked of an additional theme, a 'spiritual identity' BA 171 'God's wish'. An additional phenomenon among individuals of Bangladeshi background was that 16 (20%) found it impossible to reify the experience and describe it with a name, so that the researchers were forced to note individual 'can't think of a name'.

BEMI-I 2) Could you please describe to me what... is?

All individuals were able to describe what their distress in the past month had been. Some descriptions were straightforward to code for example WB WBSG21: 'not sleeping too well' coded as 'having disturbed sleep', 'start worrying about other things', coded as 'worrying'; 'when it got really bad I lost my appetite' coded as 'eating behaviour change'. The list of items was extended to capture previously unidentified problems such as WB WBSG 100 'missing something you don't have anymore/ grieving' coded as 'grief/ bereavement', BA AL6 'housing damp and overcrowded, physical illness' coded as 'conditions, you live in' and 'illness/ physical condition'. Caribbean and Bangladeshi people would describe how cultural differences made them feel BC LCBC19 'I sometimes feel restricted. Jamaica is very different you know more people and get out and about more. Here is very different. Still not used to it here, even after 6 years.' and BA 132 'The culture, in which I was born and brought up, the culture which I expect is not present now. I have to cope with a different culture. This to me is cultural stress'. This was coded as a separate item 'feeling culturally restricted/inadequate'.

5.2.2.3. Perceptions regarding the cause of distress

BEMI-I 3 What do you think has caused ...?

It was found that causal perceptions were the least difficult to code as they had been well represented in the BEMI framework and only a few new items and one extra

theme emerged. Individuals were often reporting problems with their immediate social environment: 'work', their 'family' and 'marital or partner problems'. WB IDST2 'Normal husband and wife arguments, [I have to look after] my daughter's children and we do not always agree [about their education and upbringing]' was coded as family and relationship problems. BA BA56 'Husband's physical health, my physical health, my children' was coded as 'marital and family problems' as partner problems included physical problems that happened to a partner. BC BCCB5 'health, my children stress me and I get headache as result, it's all interrelated [and has a] knock on effect. Housing, children bugging me, I get headache and then don't feel like visiting my friends' were coded as 'family problems', 'housing', 'illness' and 'isolation from other people'.

Individuals would also say things that were related to their personality and showed them to be responsible for their distress. Example WB WBSG35 'it's me, embarking on something I'm not suited for, it's difficult to answer, not really knowing what I'm doing [in my new business] and working with a business partner who's not very supportive' which was coded as 'me' and 'work problems'. Further examples are BA THBA8 'because I don't speak up' which was coded under 'communication problems' and 'me'. BC BC68 [I am] very considerate and generous, [I] always think about others' and BC PCBC5 'it's me, being silly and naive, trusting someone who I thought [would] care about me' which were both coded under 'me'.

Individuals would further talk about situations that were out of their control WB WBSG90 'unavoidable circumstances', LCBC23 'not knowing, if I got the [exam] results I want'. WBSG 88 'the worry about not knowing what the outcome [of my friend's cancer treatment] will be that's when I get worried'. As these items all related to uncertainty in relation to a specific situation and not having control, they were aggregated as a new item 'situation that is out of your control'.

5.2.2.4. Perceptions regarding the consequences of distress

The BEMI-I questions contained two questions about consequences:

BEMI 7a) How has this affected your life?

BEMI 7b) What are the main difficulties/ disadvantages and advantages that you experienced since having...?

This was the most difficult domain to code, since the literature review had not rendered many consequence items. Advantages and disadvantages were coded separately. For example: WB IDSTWB1 'Disadvantages: feeling tired, run down and lethargic, lack of motivation, not seeing friends as much, Advantages: 'Makes you more aware, draws attention to issues and problems, and makes me talk to my husband whereas we might not have talked before'. Disadvantages were coded separately under 'fatigue', 'having no energy/ feeling powerless', 'no motivation and less outgoing', and advantages were identified as 'become more considerate / aware' and 'have more interaction'.

Individually, people spontaneously reported many items that referred to their psychological state, how it made them feel and how it affected how they viewed the world etc. The BEMI coding only featured a small list of 'Aversive feelings' - 'feeling sad/ bad/ unpleasant/ irritable/ like crying/ aggressive', and individuals reported a number of additional emotions and psychological effects. Therefore new items needed to be generated that would accommodate these notions. It was difficult to cluster quite diverse descriptions into meaningful items, and to the outside viewer the coding terminology might at times appear arbitrary, but I have tried to explain my coding procedures and the differences between the items below. Some individuals reported feeling a 'loss, sense of disappointment' in relation to their distress. WB HACWB4 'I lost my career, livelihood, physical health, mental, physical and emotional health, am unable to concentrate, read and write and all my skills and abilities have been erased'; BA THBA8 'I have wasted years doing nothing.'; BC BCCB3 'My mobility and ability to

work has been affected, [am] dependent, [have] no financial independence, all this takes away my dignity’.

Other individuals reported problems with their mental health and an increase of symptoms or conditions that are commonly referred to as mental health problems, such as suicidality, anxiety, depression and other conditions. These were coded under ‘increased nervousness, anxiety, emotional/ mental health affected’, and further examples are given below. BA BA51 ‘have weakness in body, want to always cry, so irritable that I want to die, tried overdosing with Paracetamol 2 or 3 times’. WBSG8 ‘at certain points it affected me hugely and other points not very much, after my dad died I had CFS, [...], RD41 ‘It’s prevented me from returning to work, am anxious about being anxious to go back to work, I would like anxiety to disappear’.

The perceptions described above were differentiated from casual reports of ‘ruminations and increased doubt’. For example WBSG53 ‘not massively, just constantly there, but has not affected me doing things, constantly in the back of my mind’, WBSG 100 ‘I find it difficult to think about other things, wasting mental energy, [...]’.

It was further attempted to differentiate between the feeling of irritability (coded under Aversive feelings) and acting on these feelings. Feelings were coded under ‘feeling irritable’ THC7 ‘uneasiness and restless’, ‘SGWB 35 ‘doing many things and not doing them very well’ and RD34 ‘am less patient with my own children’. Outward actions were called ‘outward anger’ and included HC2 ‘get very short tempered, shout at my daughter when I shouldn’t’, BC BCCB5 ‘I make irrational decisions, angry in my tone of voice, and I make other people angry too’, SGWB35 ‘being impatient, moody or rude with people’.

Some individuals just reported a general effect of their distress such as making them feel stressed or upset, which was coded as 'feeling stressed'.

All reports that mentioned being stopped from engaging in certain activities were coded as being 'prevented from doing things'. Some reported small effects WB IDSTWB1 'I seem to have a lot less energy than I should have' and some exclaimed drastic effects: BC HCEO1 'Greatly...I can't do the things that I want to do and I don't have the confidence, because of that'.

Individuals who said that their entire life was changed as a result of their distress had their perceptions separately coded under 'hopelessness'. BC BCCB6 'Not working, completely rendered my life. Can't go shopping, can't do long journeys. Am very dependent on my daughter' WB12 'It destroyed my life, am depressed, feel like shite everyday, everything's gone awful, I am living in council house! I never thought I'd have to live in council housing...' BAWA27 'I have no life. I'm just breathing and physically there, I'm not who I was 6 weeks ago. I cannot motivate myself to do anything. I can't eat or sleep. I have no identity, I don't know who I am anymore.'

Individuals who reported that their life was mostly determined by their distress had perceptions coded under 'lacking or losing control'. For example WB RD110 said with regard to his perception of distress 'It makes it difficult to plan in advance, anything that you are taking in, comes up again, left my full-time job, because I couldn't cope and was making me depressed, vicious circle was feeling very low at times, couldn't cope then I could not plan ahead.'

All descriptions that featured perceptions that referred to perceived 'changes of their personality' and perceived 'changes about the world' around them were coded respectively under each item.

Coding the number of advantages cited by individuals was also quite difficult. Some reported that they 'learnt from the experience' IDSWB48 'You get to look at yourself and learn from the experience', and that it 'motivated them to change' GW15 'It gives you more purpose, anything better than boredom, it pushes you to achieve, physically mentally, [...]. There were also a number of individuals who cited 'support from others' as helpful, which was coded as an individual item. Some individuals reported a generic effect without specifying further how it affected their life, which was coded as 'in a good way'. If individuals reported advantages, because of the measures they had taken to deal with distress, this was coded under 'feel pleased with yourself'. For example: SGWB92 [after the change of my career I] can forget knowledge that is no longer relevant'. IDWB2 'People feel better once you cleared the air', WBSG65 'I have taken a firm stance'.

5.2.2..5. Perceptions regarding treatment

BEMI-I 10a) how, do you think, should this be best resolved? 10b) how could this be best dealt with?
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The coding of individuals' suggestions or perceptions about their illness was more straightforward as their content was easily differentiable. New items emerged as individuals reported, for example, increase in leisure time, more holidays and 'resting' as possible treatments; WB WBSG106 'time off and a bit more pay'. Some also talked about 'acknowledgement' of distress; WBSG108 'recognising what it is, accepting it, knowing it won't last,' and some talked about 'taking on responsibility' BC PCBC13 'I think we need to be a bit more responsible, but we've always been like this so it's hard'. Some argued that it was 'other people' who needed to change and provide help e.g. BC GW25 'We need to sit down, talk and discuss with my 12 year old son, [...] I need help from my family', which was coded as talk to family. Two people said that others should make them feel secure, but did not say how this was to be achieved. Change of career and working hours was also a common solution to distress. Few

individuals talked of 'counselling' and 'time' as a healing agent. 'Money' (WB WBSG67 'Winning the lottery') and the 'resolution of outside circumstances' were also often mentioned (BC HCCB7 'if I get my half of the house', BA BA85 'If I got a better house then people would come and make me feel better').

5.2.3. CIS_R

The revised clinical interview schedule was included to determine whether individuals' distress fulfilled criteria for psychiatric caseness (see Appendix 5).

5.2.4. Acculturation

Individuals were asked in which country they were born, and to say how long they had been living in the UK, as part of the socio-demographic questions in the screening questionnaire. To be able to test acculturation processes further, these questions were augmented by selected items from the 'subjects loyalty scale' and the 'ethnic minority stress scale' by (Mena, Padilla, & Maldonado, 1987) (Appendix 7)

5.3. Results

The analytical strategies were testing socio-demographic, acculturation, mental distress and perceptions first with univariate and secondly multivariate analyses. Univariate analyses for continuous data included T-tests, One Way ANOVAs, for categorical data χ^2 tests and associations were determined in the main with Pearson's correlation as well as partial correlations. For the χ^2 tests, it was firstly explored whether the three groups differed significantly from each other (noted in the left hand column of each table) and then 2x2 analyses were employed to determine whether all or only specific groups were different from each other (if only specific differences were found these were noted within the tables in each of the cells). Multivariate analyses included multiple regressions for continuous and logistic regression for categorical data.

5.3.1. Sample

As envisaged from the findings of the pilot study, the response rates varied between ethnic groups in terms of general practice recruitment, a mixed sample (n = 159) of predetermined White British (n=135) and randomly assigned general practice registrants (n=24) were approached, and 99 (62.3%) gave consent to participate in the short telephone screening interview. 73 (45.9%) agreed to do the detailed interview at the general practice or on the phone. Likewise from 129 predetermined Caribbean individuals 52 (44.3%) gave consent to the short telephone interview and 31 (24%) agreed to be interviewed in detail. From 130 predetermined Bangladeshi individuals 84 (64.6%) agreed to participate in the short telephone interview, from which 57 (43.8%) agreed to be interviewed in detail.

GP Register Probability sampling				
Recruitment	Random	White British	Caribbean	Bangladeshi
Identified as eligible	24 + 159	135	129	130
Consent Screening	99 (62.3%)		52 (44.3%)	84 (64.6%)
Consent Full Interview	73 (45.9%)		31 (24%)	57 (43.8%)

Further recruitment was undertaken at various community sites to attain a sample that had characteristics as close as possible to the population. In the community organisation, response rates varied between 60% and 100%. Details of the sampling locations and recruitment are presented in table 15 below.

Table 15 Participants who completed detailed interviews by general practice and community location

Site	White British n=125	Caribbean n=115	Bangladeshi n=122
Lower Clapton	32	23	-
Statham Grove	39	8	-
Jubilee Street	-	-	46
Albion Health Centre	-	-	11
Groundwork	11	9	-
Idea Store	28	1	19
Jagonari	-	-	12
Bangladeshi Welfare Association	-	-	24
Tower Hamlets College	5	-	8
Hackney College	2	3	-
Haggerston Community Centre	1	-	-
Tower Hamlets Family Welfare Association	1	-	2
Brixton Sheltered Project	6	2	-
Lambeth Carers	-	5	-
Lofthill Community Centre	-	20	-
Piermont Community Centre	-	34	-
Hibiscus (Caribbean Elderly)	-	6	-
UJIMA	-	3	-
Hackney Caribbean Elderly Organisation	-	2	-

5.3.2. Descriptive statistics

5.3.2.1. Sociodemographic information

To contextualise the influence of ethnicity in association with other variables; e.g. education, occupational status, housing, welfare and illness (Hesse, 1988), socio-demographic information was obtained. SES was not determined. Census data characterises Tower Hamlets as the 4th most deprived borough in the country and Hackney as 5th most deprived (Office for National Statistics, 2001). Sociodemographic information was assessed in the screening questionnaire (Appendix 2) and the sample characteristics are summarised in Table 16 below. This showed that the groups were not statistically different in terms of age and school leaving age. It was tested firstly whether there were statistical differences in socio-demographic characteristics across the group as a whole (significance levels are indicated in the column furthest to the left) and then χ^2 differences are presented for each group individually (significance levels are noted within the cells). The groups

were statistically different in their distribution of gender ($\chi^2 (2)=23.54, p<.001$), proxy indicators for social class (in terms of occupation ($\chi^2 (2)=41.47, p<.001$) and receiving welfare benefits ($\chi^2 (2)= 43.23, p<.001$), access location ($\chi^2 (2) 22.86, p<.001$) and accommodation $\chi^2 (4)=38.80, p<.001$). Differences within groups were further tested by χ^2 test and ANOVA and statistical differences were indicated in the table. Further details have been provided in the text below. The White British, despite having a significantly higher proportion of illness and chronic conditions ($\chi^2 (2)=6.32, p<.05$), seemed in most aspects the least deprived; significantly more WB individuals had further education ($\chi^2 (1) 17.67, p<.001$), most WB were in paid non-manual employment ($\chi^2 (1)=42.63, p<.001$), most WB had significantly less dependent children than the Caribbean and the Bangladeshi (One Way ANOVA $F(2,359) = 47.3, p<.001$, Bonferroni post hoc tests $p>.001$) and lived in owned accommodation ($\chi^2 (2)=7.50, p<.05$) The Bangladeshi were on the contrary, the most deprived of the groups: they had the smallest proportion of individuals in paid employment ($\chi^2 (2)=18.70, p<.001$) and those the smallest proportion of employed people in non-manual employment ($\chi^2 (1)=7.98, p<.05$). They also had the largest number of dependant children (see above Bonferroni, $p<.001$) and the majority lived in statutory accommodation ($\chi^2 (2)=38.57, p<.001$) The Caribbean had the lowest number of male participants ($\chi^2 (1)=51.5, p<.001$), both in general practice and community settings, and the largest number of individuals living in council housing ($\chi^2(2)=78.54, p<.001$), the result of large recruitment from Lofthill and Piermont community groups, who were located between two large council estates in Hackney.

Table 16 Socio-demographic characteristics of the sample

Demographic Characteristics		White British (n=125)	British Caribbean (n=116)	British Bangladeshi (n=122)
Age range (y)		19-92	19-92	18-77
	Median (mode)	38 (30)	38 (31)	37.50 (31)
Gender ***	Female	72 (42.4%) ***BC	97 (83.6%) ***WB & BA	70 (57.4%) ***BC
	Male	53 (57.6%)	19 (16.4%)	52 (42.6%)
Access location ***	GP	71 (56.8%) ***WB	31 (26.7%) ***WB & **BA	57 (46.7%) **BC
	Community	54 (43.2%)	85 (73.3%)	65 (53.3%)
Age range (y) left school		14-19	14-21	6-24
	Median (Mode)	16 (16)	16(16)	16 (16)
Further education ***	Yes	86 (68.8%) ***BA & BC	53 (46.5%) ***WB	40 (33.6%) ***WB
	No	39 (31.2%)	61 (53.5%)	79 (66.4%)
Number of Children***	Range	0-6	0-7	0-10
	Median (Mode)	0(0)	2(2)	3(3)
Employment status***	In Paid Employment	62 (49.6%) ***BA & BC	40 (34.5%) **WB ***BA	21 (17.2%) ***WB & BC
	Homemaker	7 (5.6%)	16 (13.8%)	41 (34.2%)
	Other/ unemployed, retired, disabled	31 (44.8%)	60 (51.7%)	60 (48.3%)
Form of occupation ***	Manual	26 (20.8%) ***BA & BC	44 (43.1%) ***WB&BA	53 (65.4%) ***WB&BC
	Non-manual	99 (79.2%)	58 (56.9%)	28 (34.6%)
Receives Benefits***	Yes	40(32.5%) ***BA & BC	73 (62.9%) ***WB & BA	90 (76.3%) ***WB&BC
	No	83 (67.5%)	43 (37.1%)	28 (23.7%)
Accommodation***	Owned	54 (43.2%) ***BA & BC	20 (17.4%) ***WB * BA	40 (33.1%) ***WB *BC
	Rented	29 (29.6%)	13 (11.3%)	13 (10.7%)
	Statutory/ Council	42 (27.2%)	82 (71.3%)	68 (56.2%)
Chronic Illness	Yes	76 (61.3%)* ^{BA}	61 (52.6%)	67 (55.4%)
	No	48 (38.7%)	55 (47.4%)	54 (44.3%)

p<.05, ** p<.01, *** p<.001

5.3.2.2. Acculturation/ Cultural Information

Information was also gathered about individuals' acculturative processes (enculturation – i.e. learning about the new culture's language, exposure and desire to maintain one's cultural traditions) and perceptions about acculturative stress (Berry & Sinha, 1992), which was detailed in Table 17 below. The groups were very different. Among Bangladeshi 93.3% were born outside this county, the majority identified themselves as Bangladeshi and the majority spoke Sylheti to their friends. Although the majority of Caribbean individuals were born outside the UK, individuals lived for longer in the UK, and identified themselves as British, and most indicated no preference to be with people of their own ethnic origin. White British in the majority were born within the UK but a fifth had lived outside the UK and was the least likely of all three groups to be offended by insults.

Table 17 Cultural information for each group

Acculturation Items		White British (n=125)	Caribbean British (n=116)	Bangladeshi British (n=122)
Place of Birth	UK	120 (96%) ^{***BA & BC}	35 (30.2%) ^{***WB & BA}	6 (5%) ^{***WB & BC}
	Caribbean		81 (69.8%)	
	Bangladesh			112 (93.3%)
	Other	5 (4%)		2 (1.7%)
Lived outside UK	No	97 (77.6%) ^{***BA & BC}	34 (29.3%) ^{***WB & BA}	6 (5%) ^{***WB & BC}
	Yes	28 (22.4%)	82 (70.7%)	115 (95%)
Only for migrants	How long in UK (y)	1.5-66	.8-63	.04-42
	Median (Mode)	30 (23)	23 (40)	17 (17)
	Migration age (y) (Range)	8.5 (2-39.5)	22.39 (1-66)	23.67 (.5-63.75)
First Language	English	123 (98.4%) ^{***BA}	112 (96.6%) ^{***BA}	2 (2.5%) ^{***WB & BC}
	Other	2 (1.6%)	4 (3.6%)	121 (97.5%)
Primary Education	In Britain	117 (93.6%) ^{***BA & BC}	50 (44.6%) ^{***WB & BA}	21 (19.6%) ^{***WB & BC}
	Elsewhere	8 (6.4%)	62 (55.4%)	72 (67.3%)
	Neither	0	0	14 (11.5%)
What is the ethnic background of your closest friend?	Same	85 (74.5%) ^{*BA}	84 (75.7%) ^{*BA}	105 (87.5%) ^{*WB & BC}
	Other	27 (23.7%)	20 (18%)	12 (10%)
	Both	1 (.9%)	4 (3.6%)	0
	Neither	1 (.9%)	3 (2.7%)	3 (2.5%)
What is the ethnic group of your preferred date?	Same	43	54	24 ⁺
	Other	13	9	5 ⁺
	Both	46	36	1 ⁺
	Neither	0	2	0 ⁺
How would you identify yourself? ***	British	103 (90.4%) ^{***BA&BC}	27 (24.1%) ^{***WB & BA}	4 (3.4%) ^{***WB & BC}
	Other	4 (3.5%)	49 (43.8%)	81 (68.6%)
	Both	6 (5.3%)	36 (32.1%)	33 (28%)
	Neither	1 (.9%)	0	0
If someone were to insult the British would you feel offended?	Yes	35 (30.4%) ^{***BA & **BC}	57 (50.9%) ^{***WB & BA}	89 (75.4%) ^{***WB & **BC}
	No	75 (65.2%)	55 (49.1%)	24 (20.3%)
	Don't know	5 (4.6%)		5 (4.2%)
Do you prefer to be with those that share your cultural heritage?	Yes	32 (28.8%) ^{***BA & *BC}	40 (35.7%) ^{*WB & ***BA}	106 (88.3%) ^{***WB & BC}
	No	59 (53.2%)	66 (58.9%)	13 (10.8%)
	Don't know	20 (18%)	6 (5.4%)	1 (.8%)
In what language do you speak to the majority of your friends?	English	114 (99.1%) ^{***BA & *BC}	97 (93.3%) ^{*WB & ***BA}	16 (13.3%) ^{***WB & BC}
	Other	0	4 (3.8%)	101 (84.2%)
	Both	1 (.9%)	3 (2.9%)	3 (2.5%)
What language (s) is/are spoken where you live?	English	102 (88.7%) ^{***BA & *BC}	94 (91.3%) ^{*WB & ***BA}	9 (8.3%) ^{***WB & BC}
	Other	2 (1.7%)	3 (2.9%)	80 (66.7%)
	Both	11 (9.6%)	6 (5.8%)	30 (25%)

⁺ This question was seen as culturally inappropriate by interviewers

5.3.2.3. Mental distress/ Psychiatric caseness information

As can be deduced from table 18 below, the prevalence of psychiatric caseness varied significantly between the ethnic groups ($F(2, 357) = 10.13, p < .001$). Bonferroni post hoc analyses found that the Caribbean were significantly lower on CIS-R scores than White British ($p < .025$) and Bangladeshi ($p < .001$) but that Bangladeshi and White British were not significantly different from each other. When the distribution of cases across ethnic groups was tested by χ^2 test, the number of cases changed significantly across ethnic groups ($\chi^2 = 20.161, p > .001$).

Table 18 Mental Distress information by ethnic group

Mental health assessments		White British (n=125)	Caribbean British (n=116)	Bangladeshi British (n=122)
CISR	Mean (Range)	9.43 (0-38)	6.20 (0-33)	11.68 (0-42)
	Mode	0	0	0
	Median	7	2	9.5
	No of Cases Sum>12 (%) ***	37 (29.6%) ^{**BA & *BC}	22 (19%) ^{*WB & ***BA}	54 (44.3%) ^{**WB & ***BC}

* $p < .05$, ** $p < .01$, *** $p < .001$

5.3.3. Inferential statistics

5.3.3.1. H1 Perceptions of distress will vary significantly between diverse ethnic groups

Ethnic variations for each item are listed systematically for each domain and assessment method (BEMI-I or BEMI-C) in tables and graphs below. As can be seen there were slight variations in the number of the interview and the checklist participants for the Black Caribbean (n=86/85) and the White British (n=105/97). This was a result of individuals, who were interviewed over the telephone, not sending their checklists back as instructed.

Hypothesis 1 was firstly evaluated by presenting descriptive data on how many individuals reported perceptions in interview and checklist, and then by statistically testing those with univariate analyses. The frequencies of absence or presence of perceptions were tested using χ^2 tests for individual perceptions items. To test whether ethnic differences could be found in relation to the previously identified themes, items

were then aggregated for each conceptual theme. The aggregated score was then transformed into a binary variable describing the absence of perceptions regarding this conceptual theme versus the presence. The frequencies of absence and presence of perceptions were again statistically compared using χ^2 tests.

The results of the BEMI-I and BEMI-C are displayed for each domain identity, cause, course, consequence and treatment in tables and graphs below. The information presented in graphs shows differences between all three groups and information presented in tables specifies which groups were significantly different from another. Firstly the results for perceptions elicited in the interview are shown then the respective items in the respective checklist are displayed. Structured questions of the BEMI-I regarding consequences are shown after the open-ended and checklist items are displayed.

BEMI-I 1) What would you call this problem [the experience]? What names would you give it?

5.3.3.1.1. Findings regarding ethnic differences in perceptions of the identity of distress

a) Perceived mental symptoms

'Mental' symptoms were spontaneously reported in the interview by over 70% of the sample and formed the most commonly reported theme regarding the perceived identity of distress in both assessments BEMI-I and BEMI-C. Significant ethnic differences were found for items such as 'worrying' ($\chi^2 = 18.233$, $p < .001$), 'stress' ($\chi^2 = 10.070$, $p < .01$) 'tension' ($\chi^2 = 11.319$, $p < .01$), 'irritability' ($\chi^2 = 6.120$, $p < .05$), 'feeling culturally restricted' ($\chi^2 = 14.200$, $p < .001$) and 'nervousness' ($\chi^2 = 17.527$, $p < .001$), which suggested that lay terminology was culturally determined. Worrying and tension were significantly more reported by individuals from the Bangladeshi group, whereas stress, nervousness and irritability were significantly more frequently reported in the White British sample. After all items that described mental symptoms were aggregated and compared, however, the significant ethnic differences disappeared. This seems to

indicate that distress is universally associated with mental problems, but the particular language terminology differs culturally. This finding was replicated in the assessment by checklist, which found greater endorsement of mental perceptions (over 80% of the sample). Significant ethnic differences were found for items 'dysphoria' ($\chi^2 = 48.069$, $p < .001$), 'irritability' ($\chi^2 = 11.184$, $p < .01$), 'anxiety' ($\chi^2 = 12.856$, $p < .01$), 'lack of concentration' ($\chi^2 = 41.281$, $p < .001$), 'loss of interest' ($\chi^2 = 13.356$, $p < .01$), feeling culturally restricted' and 'feeling ashamed' ($\chi^2 = 25.750$, $p < .001$). But when these were aggregated according to the previously identified theme and it was tested whether any of the group had a higher level of perceived mental symptoms, no statistical difference was found.

b) Perceived Somatic Symptoms

Somatic perceptions were the third most commonly spontaneously described theme, but made up the most common perception theme of the identity of distress by checklist assessment. Spontaneously, significant ethnic differences were only reported with regard to 'physical illness' ($\chi^2 = 9.767$, $p < .01$) and 'pain' ($\chi^2 = 9.461$, $p < .01$). When perceptions that were elicited by interview were aggregated for the physical theme, a significant difference between the three groups was evident ($\chi^2 = 13.573$, $p < .001$). The White British group had the lowest endorsement of somatic perceptions when reporting spontaneously about the identity of distress (16.2%). Taking this result in isolation from the other assessment suggests that WB dissociate physical problems from their mental distress. This finding was however not replicated by the checklist perception assessment. Here, it was found that over 90% of White British view physical symptoms as part of their distress. Perceptions regarding the physical nature of distress increased also twofold in individuals from ethnic minorities. Significant ethnic differences were reported for the following perceptions 'sleep disturbance' ($\chi^2 = 7.179$, $p < .05$), 'palpitations' ($\chi^2 = 16.939$, $p < .001$), 'pain' ($\chi^2 = 26.078$, $p < .001$), 'fatigue'

($\chi^2 = 14.322$, $p < .001$), 'nerves' ($\chi^2 = 21.079$, $p < .001$) and 'bodily weakness' ($\chi^2 = 46.854$, $p < .001$).

c) Behavioural perceived symptoms

The least commonly voiced theme regarded behavioural issues and there were no significant ethnic differences in the aggregated score in either assessment. One behavioural perception item that was associated with significant ethnic differences in both BEMI-I and BEMI-C was 'substance abuse'. Bangladeshi individuals were the only group that spontaneously reported 'substance abuse' as part of their distress ($\chi^2 = 7.335$, $p < .05$). Although this was a statistically significant difference, the number of cases who held this view was very small ($n=3$). A larger significant ethnic difference was found in the checklist assessment of 'substance abuse' ($\chi^2 = 18.519$, $p < .001$), when 45% of White British individuals reported 'substance abuse' as an indicator of distress, but only 20% of the ethnic minorities shared that view. Another significant item was 'being restless' which was identified by White British and Bangladeshi as associated with distress, but not by the Caribbean ($\chi^2 = 8.880$, $p < .05$).

d) Perceived Social Identity

In the assessment by interview, the second most commonly reported theme of perceptions regarding the identity of distress was social identity. Significant differences between the three groups were found for individual items and the aggregated theme score ($\chi^2 = 7.448$, $p < .05$). Caribbean and Bangladeshi reported more social complaints such as 'financial/ money' ($\chi^2 = 11.849$, $p < .01$), 'family' ($\chi^2 = 23.879$, $p < .001$), 'environmental (housing)' ($\chi^2 = 6.430$, $p < .05$) problems and 'cultural restrictions' ($\chi^2 = 14.200$, $p < .001$). Money, housing and cultural restriction differences were to be expected due to the different levels of deprivation and acculturation/ cultural identity between individuals from ethnic minority status and the host culture. Family problems were often identified as problems among both ethnic minorities for different reasons. Bangladeshi spoke of family problems related to larger households and greater levels

of family obligations for example: BA210 'my sister lives with her husband and sister in law. My sister doesn't like living with her sister in law. This has caused me great stress in the past month'; BAWA23 'family worries, husband relationship, he has 3 wives in B'desh and doesn't give me any money. He always questions where I go. He'll shout at me when I'm late. My son's wife can be mean to me. In my heart and mind I feel sad, but I try not to show it to people'. They would also talk of problems related to having dispersed families as BA 112 'I worry about my parents in Bangladesh. I send them money. I don't know how they are keeping up'. Caribbeans described more commonly the breakdown of family structures: LCBC 5 'coping with 3 kids on your own'; LCBC4 'my husband's family don't accept me, because I'm black'; PCBC1 'my daughter is getting in a lot of trouble, she got kicked out of school, I don't know what to do'. As social items were not part of the checklist under identity, there was no further formal way to examine these ethnic differences.

A significant difference was also found regarding the spiritual identity of distress ($\chi^2 = 7.335, p < .05$), but again there was a small number of individuals who held this view ($n=3$). The results are displayed in table 19 for spontaneous and 20 for checklist assessment and figure 7 and 8 respectively.

Table 19 Spontaneously elicited perceptions of distress in response to questions BEMI-I1 What do you call your problem and BEMI-I2 Could you please describe to me what it is?

COMPLAINTS/PERCEIVED SYMPTOMS	Them	White British N=105	Bangladeshi N=79	Black Caribbean N=86
HAVING DISTURBED SLEEP		4 (3.8%)	4 (5.1%)	3 (3.5%)
PALPITATIONS (HEART POUNDING)		1 (1%)	1 (1.3%)	0
INDIGESTION		0	0	0
UNUSUAL SKIN SENSATIONS (CRAWLING UNDER THE SKIN ETC)		0	0	0
VISUAL DEFICIENCY		0	0	0
LOSING BODILY FLUIDS		1 (1%)	0	1 (1.2%)
PAIN/ ACHES		4 (3.8%) ^{*BA}	11 (13.9%) ^{*BC &WB}	3 (3.5%) ^{*BA}
FATIGUE OR TIREDNESS		4 (3.8%)	1 (1.3%)	6 (7%)
NERVES OR BEING AGITATED OR RESTLESS		2 (1.9%)	2 (2.5%)	2 (2.3%)
HEAT OR HEAVINESS IN ANY PART OF THE BODY		0	0	1 (1.2%)
BODILY WEAKNESS		0	2 (2.5%)	3 (3.5%)
NAUSEA OR FEELING SICK		0	0	1 (1.2%)
+ ILLNESS/ PHYSICAL CONDITION		8 (7.6%) ^{**BA & *BC}	19 (24.1%) ^{**WB}	16 (19.6%) ^{*WB}
Total Cases with one or more Somatic Perception (%)	Somatic	17 (16.2%)^{***BA & *BC}	32 (40.5%)^{***WB}	25 (29.1%)^{*WB}
DYSPHORIA OR FEELING DOWN)		11 (10.5%)	16 (20.3%)	12 (14%)
FEELING IRRITABLE OR FED UP BORED		12 (11.4%) ^{*BA}	2 (2.5%) ^{*WB &BC}	11 (12.8%) ^{*BA}
FEELING NERVOUS, ANXIOUS OR PARANOID		24 (22.9%) ^{*BA & **BC}	7 (8.9%) ^{*WB}	3 (3.5%) ^{***WB}
FEELING FRIGHTENED OR FEARFUL		6 (5.7%)	1 (1.3%)	4 (4.7%)
LACK OF CONCENTRATION OR FORGETFULNESS		4 (3.8%)	2 (2.5%)	2 (2.3%)
LOSS OF INTEREST OR NOT BEING ABLE TO ENJOY THINGS		2 (1.9%)	0	1 (1.2%)
WORRYING OR OBSESSIVE THOUGHTS		32 (30.5%) ^{**BA}	40 (50.6%) ^{***WB & ***BC}	17 (19.8%) ^{***BA}
SUICIDAL THOUGHTS (E.G. LIFE'S NOT WORTH IT)		2 (1.9%)	2 (2.5%)	1 (1.2%)
FEELING GUILTY		1 (1%)	2 (2.5%)	0
FEELING ASHAMED		0	0	1 (1.2%)
HALLUCINATIONS		0	1 (1.3%)	0
FEELING LONELY		3 (2.9%)	4 (5.1%)	3 (3.5%)
PREFER TO BE ALONE OR NO SOCIAL LIFE		2 (1.9%)	1 (1.3%)	3 (3.5%)
+ TENSION		0 ^{**BA}	6 (7.6%) ^{**WB & *BC}	1 (1.2%) ^{*BA}
+ FEELING OUTRAGED/ RESENTFUL		6 (5.7%)	2 (2.5%)	9 (10.5%)
+ STRESS, SENSE OF NOT ENOUGH TIME		24 (22.9%) ^{**BA}	4 (5.1%) ^{***WB & *BC}	17 (19.8%) ^{**BA}
+ UNCERTAINTY		10 (9.5)	5 (6.3%)	6 (7%)
+ SENSE OF SHOCK, LOSS, GRIEF		6 (5.7%)	2 (2.5%)	1 (1.2%)
+ HOPELESSNESS, DESPONDANCE, FEELING INVISIBLE NO POWER		10 (9.5)	5 (6.3%)	4 (4.7%)
Total Cases with one or more Mental Perception (%)	Mental	80 (76.2%)	63 (79.7%)	63 (73.3%)
NOT BEING ABLE TO COMPLETE TASKS		1 (1%)	1 (1.3%)	0
BEING VIOLENT TOWARDS PEOPLE		1 (1%)	0	0
BECOMING MUTE OR STOP TALKING		0	1 (1.3%)	0
CRYING		3 (2.9%)	0	2 (2.3%)
SCREAMING		1 (1%)	0	0
SWEARING		1 (1%)	0	0
BEING RESTLESS OR CONTINUALLY MOVING ABOUT		1 (1%)	0	0
NOT DOING A LOT OF THINGS OR AVOIDING TO DO THINGS		1 (1%)	3 (3.8%)	1 (1.2%)
USING SUBSTANCES – TOBACCO, ALCOHOL, MEDICINES, DRUGS		0	3 (3.8%)	0
VIOLENT TOWARDS THINGS (THROWING OR SMASHING THINGS)		1 (1%)	1 (1.3%)	0
OBSESSIVE BEHAVIOUR (CHECKING, WASHING, COUNTING THINGS)		1 (1%)	1 (1.3%)	0
NEGLECT OF HYGIENE (STOP WASHING YOURSELF, WEARING FRESH CLOTHES)		1 (1%)	0	0
EATING BEHAVIOUR CHANGE		3 (2.9%)	3 (3.8%)	0
RAMBLING OR TALKING NONSENSE		0	0	0
MAKING PLANS FOR SUICIDE		0	0	0
Total cases one or more behavioural perception	Behavioural	11 (10.5%)	9 (11.4%)	3 (3.5%)
+ FAMILY / CHILDREN PROBLEMS		1 (1%) ^{***BA & **BC}	19 (24.1%) ^{***WB & *BC}	11 (12.8%) ^{***WB & *BA}
+ RELATIONSHIP PROBLEMS		9 (8.6%)	12 (15.2%)	5 (5.8%)
+ INTERPERSONAL CONFLICT		9 (8.6%)	2 (2.5%)	4 (4.7%)
+ CULTURALLY INADEQUACY/ RESTRICTIONS		0 ^{***BC}	3 (3.8%)	10 (11.6%) ^{***WB}
+ PROBLEMS DEALING WITH AUTHORITIES		4 (3.8%)	0	2 (2.3%)
+ ABUSE, BULLYING, VIOLENCE		5 (4.8%)	0	1 (1.2%)
+ EMPATHY, TAKING ON OTHER PEOPLE'S PROBLEMS		6 (5.7%)	5 (6.3%)	5 (5.8%)
+ MONEY PROBLEMS		2 (1.9%)	11 (13.9%)	13 (15.1%) ^{**}
+ WORK PROBLEMS		7 (6.7%)	6 (7.6%)	8 (9.3%)
+ ENVIRONMENTAL PROBLEMS, CONDITIONS YOU LIVE IN		3 (2.9%) ^{*BA & *BC}	9 (11.4%) ^{*WB}	10 (11.6%) ^{*WB}
Total Cases with one or more social perception	Social ++	39 (37.1%)^{*BA & *BC}	44 (55.7%)^{*WB}	45 (52.3%)^{*WB}
+ RELIGIOUS SPIRITUAL PROBLEMS	+	0	3 (3.8%)	0

+ extra items, ++ new domains, significant χ^2 at *p<.05, ** p<.01, *** p<.001 level

Figure 7 Perceptions about identity of distress (BEMI-I1 What would you call it? BEMI-I2 How would you describe it?)

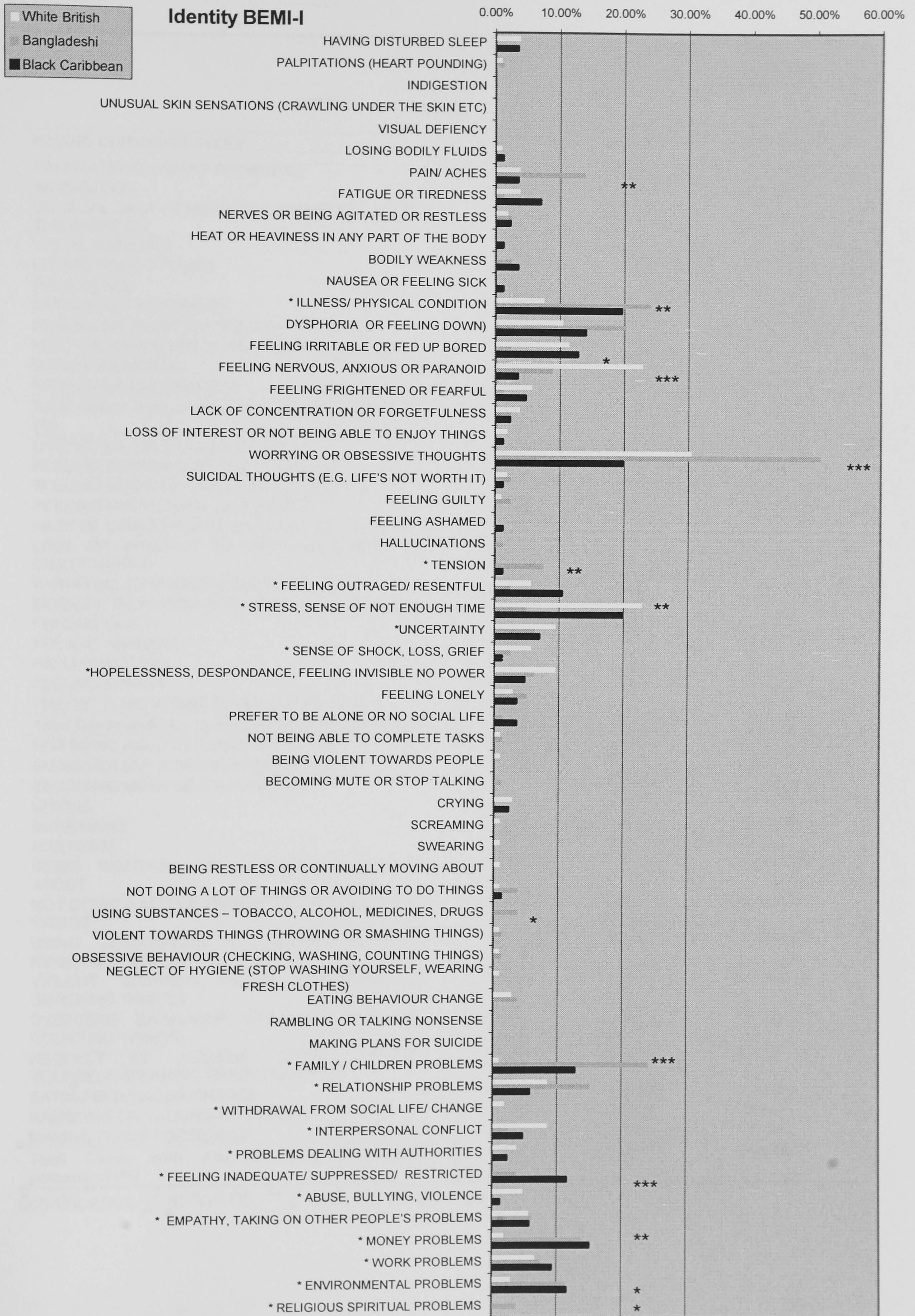
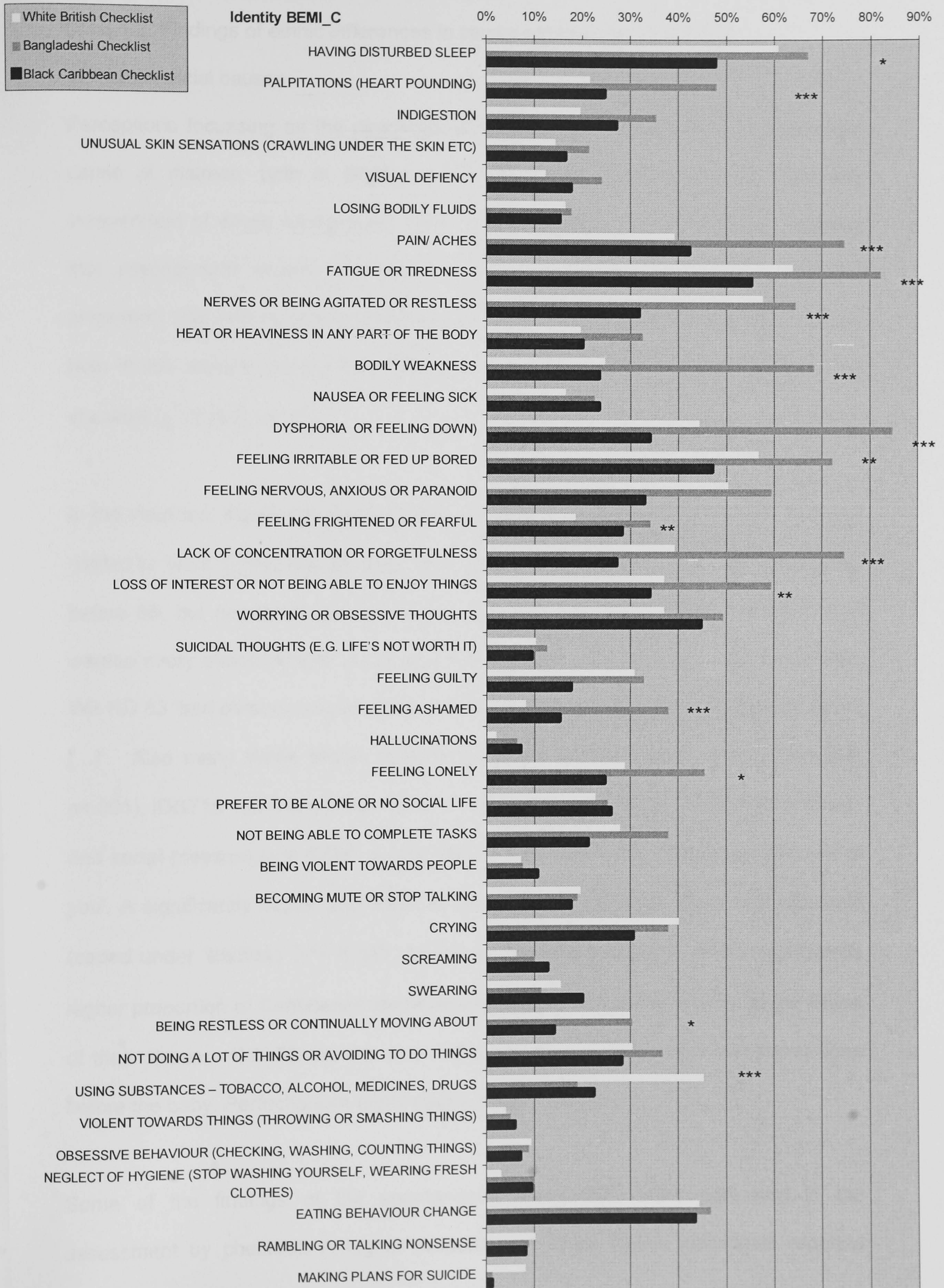


Table 20 Perceptions of the identity of distress in BEMI-C 1- Identity
Please tick any of the following boxes if you believe that the results are art of your problem.

	White British N=97	Bangladeshi N=79	Black Caribbean N=85
<i>Themes</i>			
HAVING DISTURBED SLEEP	59 (60.8%) ^{***BA}	53 (67.1%) ^{***WB & **BC}	41 (47.7%) ^{***BA}
PALPITATIONS (HEART POUNDING)	21 (21.6%) ^{***BA}	38 (48.1%) ^{***WB & BC}	21 (24.7%) ^{***BA}
INDIGESTION	19 (19.6%)	28 (35.4%)	23 (27.1%)
UNUSUAL SKIN SENSATIONS (CRAWLING UNDER THE SKIN ETC)	14 (14.4%)	17 (21.5%)	14 (16.5%)
VISUAL DEFICIENCY	12 (12.4%)	19 (24.1%)	15 (17.6%)
LOSING BODILY FLUIDS	16 (16.5%)	14 (17.7%)	13 (15.3%)
PAIN/ ACHES	38 (39.2%) ^{BA}	59 (74.7%) ^{***WB & BC}	36 (42.4%) ^{***BA}
FATIGUE OR TIREDNESS	62 (63.9%) ^{***BA}	65 (82.3%) ^{***WB & ***BC}	47 (55.3%) ^{***BA}
NERVES OR BEING AGITATED OR RESTLESS	56 (57.7%) ^{***BC}	51 (64.6%) ^{***BC}	27 (31.8%) ^{***WB & BA}
HEAT OR HEAVINESS IN ANY PART OF THE BODY	19 (19.6%)	25 (31.6%)	17 (20%)
BODILY WEAKNESS	24 (24.7%) ^{***BA}	54 (68.4%) ^{***WB & BC}	20 (23.5%) ^{***BA}
NAUSEA OR FEELING SICK	16 (16.5%)	18 (22.5%)	20 (23.5%)
Total Cases with one or more Somatic Perception (%)	89 (91.8%)	75 (94.9%)	62 (72.9%)^{**}
<i>Somatic</i>			
DYSPHORIA OR FEELING DOWN)	43 (44.3%) ^{***BA}	67 (84.8%) ^{***WB & BC}	29 (34.1%) ^{***BA}
FEELING IRRITABLE OR FED UP BORED	55 (56.7%) ^{BA}	57 (72.2%) ^{WB & ***BC}	40 (47.1%) ^{***BA}
FEELING NERVOUS, ANXIOUS OR PARANOID	49 (50.5%) ^{**BC}	47 (59.5%) ^{***BC}	28 (32.9%) ^{***WB & ***BA}
FEELING FRIGHTENED OR FEARFUL	18 (18.6%) ^{BA}	27 (34.2%) ^{WB}	24 (28.2%)
LACK OF CONCENTRATION OR FORGETFULNESS	38 (39.2%) ^{***BA & *BC}	59 (74.7%) ^{***WB & BC}	23 (27.1%) ^{WB & ***BA}
LOSS OF INTEREST OR NOT BEING ABLE TO ENJOY THINGS	36 (37.1%) ^{***BA}	47 (59.5%) ^{***WB & **BC}	29 (34.1%) ^{BA}
WORRYING OR OBSESSIVE THOUGHTS	36 (37.1%)	39 (49.4%)	38 (44.7%)
SUICIDAL THOUGHTS (E.G. LIFE'S NOT WORTH IT)	10 (10.3%)	10 (12.7%)	8 (9.4%)
FEELING GUILTY	30 (30.9%)	26 (32.9%)	15 (17.6%)
FEELING ASHAMED	8 (8.2%) ^{***BA}	30 (38%) ^{***WB & **BC}	13 (15.3%) ^{***BA}
HALLUCINATIONS	2 (2.1%)	5 (6.3%)	6 (7.1%)
FEELING LONELY	28 (28.9%) ^{BA}	36 (45.6%) ^{WB & **BC}	21 (24.7%) ^{***BA}
PREFER TO BE ALONE OR NO SOCIAL LIFE	22 (22.7%)	20 (25.3%)	22 (25.9%)
Total Cases with one or more Mental Perception (%)	82 (84.5%)	73 (92.4%)^{BC}	69 (81.2%)^{BA}
<i>Mental</i>			
NOT BEING ABLE TO COMPLETE TASKS	27 (27.8%)	30 (38%)	18 (21.2%)
BEING VIOLENT TOWARDS PEOPLE	7 (7.2%)	6 (7.6%)	9 (10.6%)
BECOMING MUTE OR STOP TALKING	19 (19.6%)	15 (19%)	15 (17.6%)
CRYING	39 (40.2%)	30 (38%)	26 (30.6%)
SCREAMING	6 (6.2%)	8 (10.1%)	11 (12.8%)
SWEARING	15 (15.5%)	9 (11.4%)	17 (20%)
BEING RESTLESS OR CONTINUALLY MOVING ABOUT	29 (29.9%) ^{**BC}	24 (30.4%) ^{**BC}	12 (14.1%) ^{***WB & **BA}
NOT DOING A LOT OF THINGS OR AVOIDING TO DO THINGS	32 (30.5%)	29 (36.7%)	24 (28.2%)
USING SUBSTANCES – TOBACCO, ALCOHOL, MEDICINES, DRUGS	44 (45.4%) ^{***BA & **BC}	15 (19%) ^{***WB}	19 (22.4%) ^{***WB}
VIOLENT TOWARDS THINGS (THROWING OR SMASHING THINGS)	4 (4.1%)	4 (5.1%)	5 (5.9%)
OBSESSIVE BEHAVIOUR (CHECKING, WASHING, COUNTING THINGS)	9 (9.3%)	7 (8.9%)	6 (7.1%)
NEGLECT OF HYGIENE (STOP WASHING YOURSELF, WEARING FRESH CLOTHES)	3 (3.1%)	8 (10.1%)	8 (9.4%)
EATING BEHAVIOUR CHANGE	43 (44.3%)	37 (46.8%)	37 (43.5%)
RAMBLING OR TALKING NONSENSE	10 (10.3%)	7 (8.9%)	7 (8.2%)
MAKING PLANS FOR SUICIDE	8 (8.2%)	1 (1.3%)	1 (1.2%)
Total Cases with one or more behavioural perception (%)	77 (79.4%)^{BC}	55 (69.6%)	52 (61.2%)^{WB}
<i>Behavioural</i>			

Significance χ^2 at *p<.05, ** p<.01, *** p<.001 level

Figure 8 Perceptions of the identity of distress in BEMI-C 1- Identity
 Please tick any of the following boxes if you believe that the results are part of your problem.



BEMI-I 3 What do you think has caused ...?

5.3.3.1.2. Findings of ethnic differences in causal perceptions of distress

a) Psychosocial causes

Perceptions focussing on the psychosocial theme were the most frequent perceived cause of distress, both in BEMI-I and BEMI-C assessments, for all individuals independent of ethnic background. When the proportion of individuals who believed that psychosocial causes contributed to their problem was compared with the proportion, that had no psychosocial causes, significant ethnic differences were found both in the assessment by interview ($\chi^2= 21.041, p<.001$) and the assessment by checklist ($\chi^2=7.623, p<.05$).

In the interview, significant ethnic differences were found in relation to items that were related to 'work' ($\chi^2=42.907, p<.001$). For example WB IDST31 'I was made redundant before 65, but needed to get a new job, got work from an American firm and they wanted every ounce of work out of you, that is why I got stress and [had] the stroke'. WB RD 83 'bad personal organisation, nature of the work, taking on unnecessary work [...]'. Also many White British complained of not having enough time ($\chi^2=14.544, p<.001$), IDST15 'too many things to do in too little time, so that it feels I'm not coping'; and social pressure ($\chi^2= 6.380, p<.05$) WBSG 102 'Want other people to think well of you'. A significantly higher proportion of Bangladeshi individuals described accidents (coded under 'trauma') ($\chi^2= 6.853, p<.05$) as a cause of distress, and a significantly higher proportion of Caribbeans identified themselves ($\chi^2= 9.718, p<.01$) as the cause of their distress. GW 23 'I'm the sort of person who wants to have everything done before the baby. Perfectionism might cause anxiety'.

Some of the findings of the spontaneous assessment were replicated in the assessment by checklist. A higher proportion of White British individuals reported

'stress' ($\chi^2=14.111$, $p<.001$), 'worry' ($\chi^2= 9.351$, $p<.01$) and 'work problems' ($\chi^2= 16.839$, $p<.001$) as the cause of their distress. Additionally, Black Caribbean individuals described their 'ethnic background' ($\chi^2= 6.124$, $p<.05$) significantly more often for their distress, than either of the other two groups, and also reported more 'family problems' ($\chi^2=7.194$, $p<.001$).

b) Spiritual Causes

In the BEMI-I assessment, spiritual causes were not endorsed by White British individuals, but significantly more so by Caribbean and Bangladeshi ($\chi^2=5.997$, $p<.05$). There were no significant ethnic differences between specific items, but when the items were aggregated the level of endorsement differed significantly although numbers were quite small. In the assessment by checklist, there were marked differences in the endorsement of spiritual causal perceptions between ethnic groups ($\chi^2=65.312$, $p<.001$). A significantly higher proportion Bangladeshis believed that it was their fate to have this distress ($\chi^2= 94.305$, $p<.001$) and saw it as a test of their faith ($\chi^2=71.909$). Over 40% of Bangladeshi also believed it was due to bad luck ($\chi^2= 32.543$, $p<.001$) and a punishment by god for breaching a taboo ($\chi^2=65.595$, $p<.001$). 20% of Caribbean individuals also quoted bad luck as a reason for their distress, and 15% believed it was a test of their faith. A further 15% of Bangladeshi believed that their distress was due to black magic and sorcery by others ($\chi^2=18.677$, $p<.001$). Only a very small proportion of White British held these perceptions. When all spiritual items were aggregated, it was found that the proportion of individuals who endorsed spiritual perceptions was twice as high among the Caribbean as White British, and almost five times as high among the Bangladeshi ($\chi^2=65.312$, $p<.001$). It was the second most common perceived cause of distress among Bangladeshi.

c) Behavioural Causes

A significant difference was found in the spontaneous assessment for 'dietary intake' ($\chi^2= 6.491$, $p<.05$) among the behavioural items, but the number of cases was small ($n=3$). When spontaneously elicited perceptions were aggregated, the distribution was found to be not significantly different across groups. Among the checklist assessment, it was found that 20% White British identified 'substance abuse' to be the reason for their distress in significant contrast to 2.5% of Bangladeshi and 14% of Caribbean ($\chi^2=11.714$, $p<.01$). When behavioural checklist items were aggregated, it was found that there were significant ethnic differences ($\chi^2=9.438$, $p<.01$). It was identified to be the second most common theme to cause distress among the White British, but it was only seen to be 4th and 5th among the Caribbean and Bangladeshi respectively.

d) Weather causes

No ethnic differences were found in the attribution of distress to the individual weather items and the aggregated theme. This cause was the least endorsed perception of distress.

e) Physical Causes

Significant ethnic differences were found in terms of 'illness', as a significantly higher proportion of Bangladeshi individuals saw illness as the reason for their distress. This finding was found both in spontaneous assessment ($\chi^2=23.417$, $<.001$) as well as by checklist ($\chi^2= 19.292$, $p<.001$). On the checklist, it was found that significantly more Bangladeshi individuals attributed their problem to 'problems with their bones' ($\chi^2=21.041$, $p<.001$). This might be to do with a higher level of physical problems with their bones (e.g. osteoporosis), but could also be related to what the researchers identified as a common saying in Bengali loosely translated as 'don't fight it, it's in your bones' – referring to destiny. Finally also significant ethnic differences (most striking differences between White British and Bangladeshi) were found for perceptions related

to 'blood' ($\chi^2= 7.057$, $p<.05$) and 'imbalance of fluids in the body' ($\chi^2=6.721$, $p<.001$), though the number of people who endorsed these perceptions was small.

e) Situational/ economic causes

There were no significant ethnic differences in the attribution of distress to situational effects. These perceptions were shared by the same proportion of individuals in the spontaneous assessment and by checklist. However, it was found that a higher proportion of individuals of White British background would describe a 'situation that was out of their control' as the reason for their distress. One example WBSG21 'exams, boyfriend not being happy, he's at a different university, so it's upsetting you can't be with them, I was also worrying about what I was going to do in the summer and money'. As situations were not assessed by checklist there was no further validation of this ethnic difference.

f) Unknown Causes

Further significant differences were found in the 'don't know' category where higher percentages of the ethnic minority groups (about 20%) reported spontaneously that they had no idea what the cause of their distress was in contrast to only 4% of the White British ($\chi^2= 13.048$, $p<.001$) . However all respondents could attribute their illness to at least one cause when they were probed in the checklist assessment.

The results are presented and illustrated in table 21 for spontaneous responses and table 22 for checklist responses, and figure 9 and 10 respectively.

Table 21 Perceptions regarding the cause of distress BEMI-13 What do you think has caused...?

	THE MES	White British N=105	Bangladeshi N=79	Black Caribbean N=86	
STRESS		5 (4.8%)	1 (1.3%)	4 (4.7%)	
YOUR AGE		2 (1.9%)	3 (3.8%)	4 (4.7%)	
YOUR GENDER		1 (1%)	1 (1.3%)	1 (1.2%)	
YOUR CULTURE		0	2 (2.5%)	2 (2.3%)	
YOUR RELIGION		1 (1%)	1 (1.3%)	0	
YOUR ETHNICITY OR RACE		0	0	0	
WORRY		4 (3.8%)	3 (3.8%)	4 (4.7%)	
GUILT OR SHAME		1 (1%)	0	1 (1.2%)	
EMOTIONS (EXCESSIVE)		4 (3.8%)	1 (1.2%)	0	
WORK PROBLEMS (INCLUDING LACK OF WORK)		44(41.9%) ^{***BA & BC}	5 (6.3%) ^{***WB}	9 (10.5%) ^{***WB}	
FAMILY PROBLEMS		13 (12.4%)	18 (22.8%)	16 (18.4%)	
MARITAL OR PARTNER PROBLEMS		21 (20%)	14 (17.7%)	8 (9.3%)	
LONELINESS OR ISOLATION FROM OTHER PEOPLE		3 (2.9%)	3 (3.8%)	0	
BEREAVEMENT OR LOSS		7 (6.7%)	2 (2.5%)	4 (4.7%)	
RACISM , PREJUDICE/ STEREOTYPE		1 (1%)	0	0	
+ CONFLICT WITH COLLEAGUES, INDIVIDUALS OF EQUAL STATUS		4 (3.8%)	1 (1.2%)	1 (1.2%)	
+ CONFLICT WITH AUTHORITIES, COMPANIES		7 (6.7%)	0	3 (3.5%)	
+ SOCIAL PRESSURE		3 (2.9%)	0	0*	
+ FRIENDS' TRAUMA ILLNESS		1 (1%)	0	1 (1.2%)	
+ COMMUNICATION PROBLEMS		2 (1.9%)	1 (1.3%)	2 (2.3%)	
+ NEW CHILD		0	0	2 (2.3%)	
+ NOT ENOUGH TIME (TO DO THINGS)		9 (8.6%) ^{***BA & BC}	0 ^{***WB}	0 ^{***BC}	
+ CHILDHOOD ISSUES, THINGS THAT HAPPENED IN THE PAST	PSYCHOSOCIAL	3 (2.9%)	2 (2.5%)	1 (1.2%)	
ANY KIND OF TRAUMA OR SHOCK (CAR CRASH, WAR)		2 (1.9%)	5 (6.3%) ^{BA}	0 ^{BC}	
ABUSE		0	1 (1.3%)	0	
+ ME, MY CHARACTER, PERSONALITY, CONDITION		14 (13.3%)	5 (6.3%) ^{BC}	20 (23.3%) ^{***BA}	
Total cases with one or more psychosocial cause		92 (87.6%)^{***BA & BC}	46 (58.2%)^{***WB}	58 (68.2%)^{***WB}	
FATE/ DESTINY (DELIBERATE)		0	0	0	
BAD LUCK (BY CHANCE)		0	2 (2.5%)	3 (3.5%)	
ANCESTORS' SPIRITS		0	1 (1.3%)	1 (1.2%)	
WEAKENED SPIRIT SOUL LOSS		0	1 (1.3%)	0	
TEST OF FAITH		0	1 (1.3%)	1 (1.2%)	
BLACK MAGIC OR EVIL EYE SORCERY	SPIRITUAL	0	1 (1.3%)	0	
PUNISHMENT (GOD) – TABOO BREACH		0	2 (2.5%)	1 (1.2%)	
ASTROLOGY OR STARS		0	0	1 (1.2%)	
Total Cases with one or more spiritual cause			0^{BA & BC}	4 (5.1%)^{WB}	5 (5.8%)^{WB}
DIET OR FOOD INTAKE		0	0	3 (3.5%)	
SUBSTANCE ABUSE (ALCOHOL, TOBACCO & DRUGS)	BEHAVIOURAL	5 (4.8%)	0	1 (1.2%)	
LACK OF OR NO SEX		0	1 (1.3%)	0	
Total Cases with one or more behavioural causes		5 (4.8%)	1 (1.3%)	4 (4.7%)	
THE WIND	WEATHER	0	0	0	
CLIMATE OR WEATHER		1 (1%)	0	1 (1.2%)	
Total Cases with one or more weather cause		1 (1%)	0	1 (1.2%)	
ILLNESS OR DISABILITY OR HANDICAP	PHYSICAL	5 (4.8%) ^{***BA}	21(26.6%) ^{***WB& BC}	6 (7%) ^{***BA}	
IMBALANCE OF BODILY FLUIDS (TOO MUCH OR TOO LITTLE BLOOD SEMEN, BILE)		1 (1%)	0	1 (1.2%)	
BLOOD (BAD BLOOD OR HOT BLOOD ETC)		0	0	0	
PROBLEM WITH THE BONES		0	0	0	
POISON		0	0	1 (1.2%)	
VIRUS OR GERMS		0	0	0	
HEREDITY (GENES)		2 (1.9%)	0	1 (1.2%)	
+ MEDICATION		1 (1%)	0	1 (1.2%)	
Total Cases with one or more physical cause			8 (7.6%)^{***BA}	21(26.6%)^{***WB&BC}	9 (10.5%)^{***BA}
FINANCIAL PROBLEMS		SITUATIONAL	11 (10.5%)	8 (10.1%)	11 (12.8%)
+ MIRCATION, MOVING	4 (3.8%)		1 (1.2%)	4 (4.7%)	
+ HOUSING, NOISE, LONDON	8 (7.6%)		6 (7.6%)	9 (10.5%)	
+ SITUATION THAT'S OUT OF YOUR CONTROL	14 (13.3%) ^{BA}		1 (1.2%)	4 (4.7%)	
Total cases with one or more situational causes		19 (18.1%)	13 (16.5%)	23 (26.7%)	
+ JUST THE WAY IT IS / LIFE	NON DESCRIPTIVE	0 ^{***BC}	1 (1.2%)	4 (4.7%) ^{WB}	
+ DON'T KNOW		4 (3.8%) ^{***BA & BC}	16 (20.3%) ^{***WB}	15 (17.4%) ^{***WB}	
Has one or more non-descriptive cause/ don't know		4 (3.8%)	16 (20.3%)	18 (20.3%)^{***}	

+ extra items, ++ new domains, significant χ^2 at *p<.05, ** p<.01, *** p<.001 level

Figure 9 Perceptions about the cause of distress (BEMI-I3 What do you think has caused ...?)

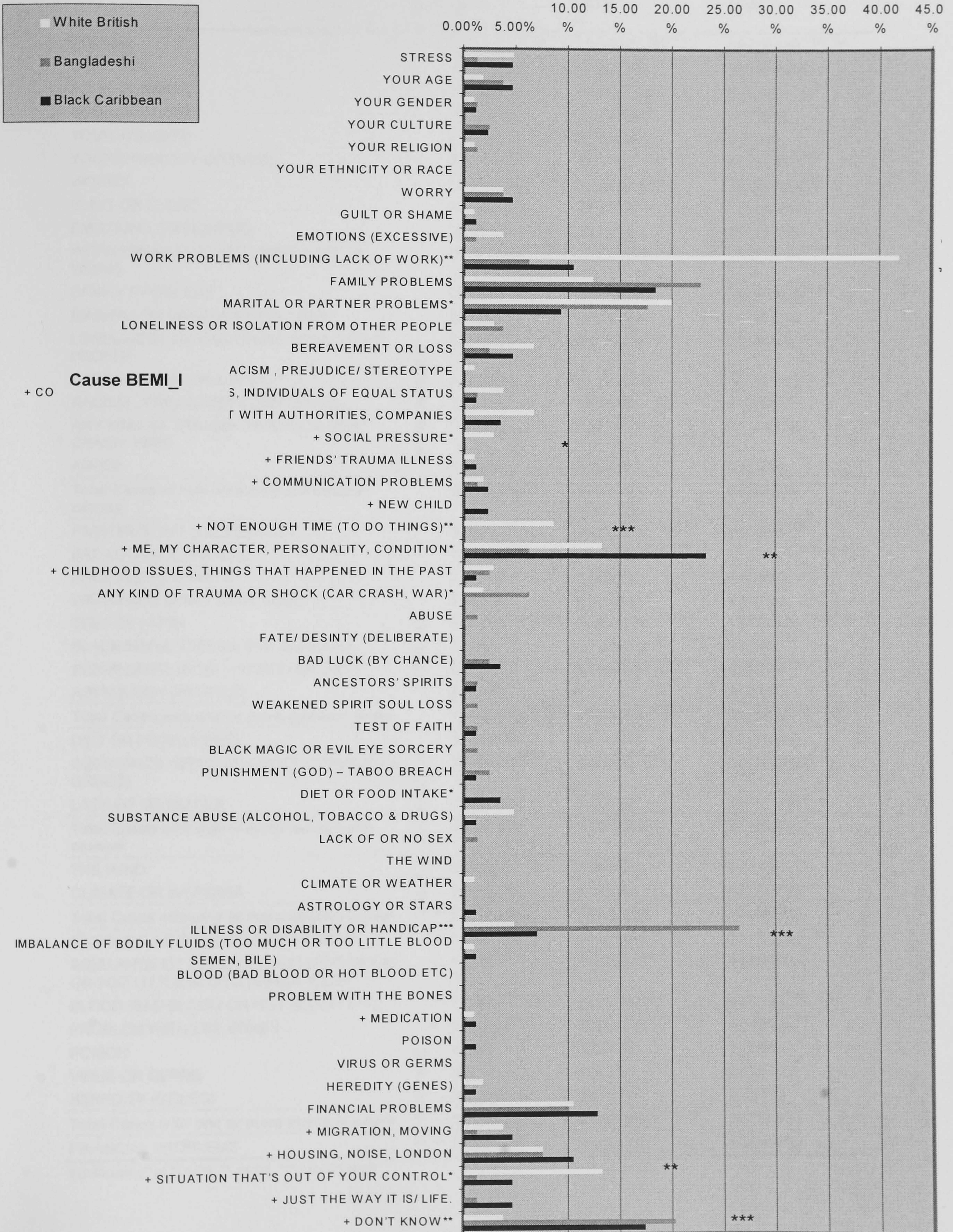
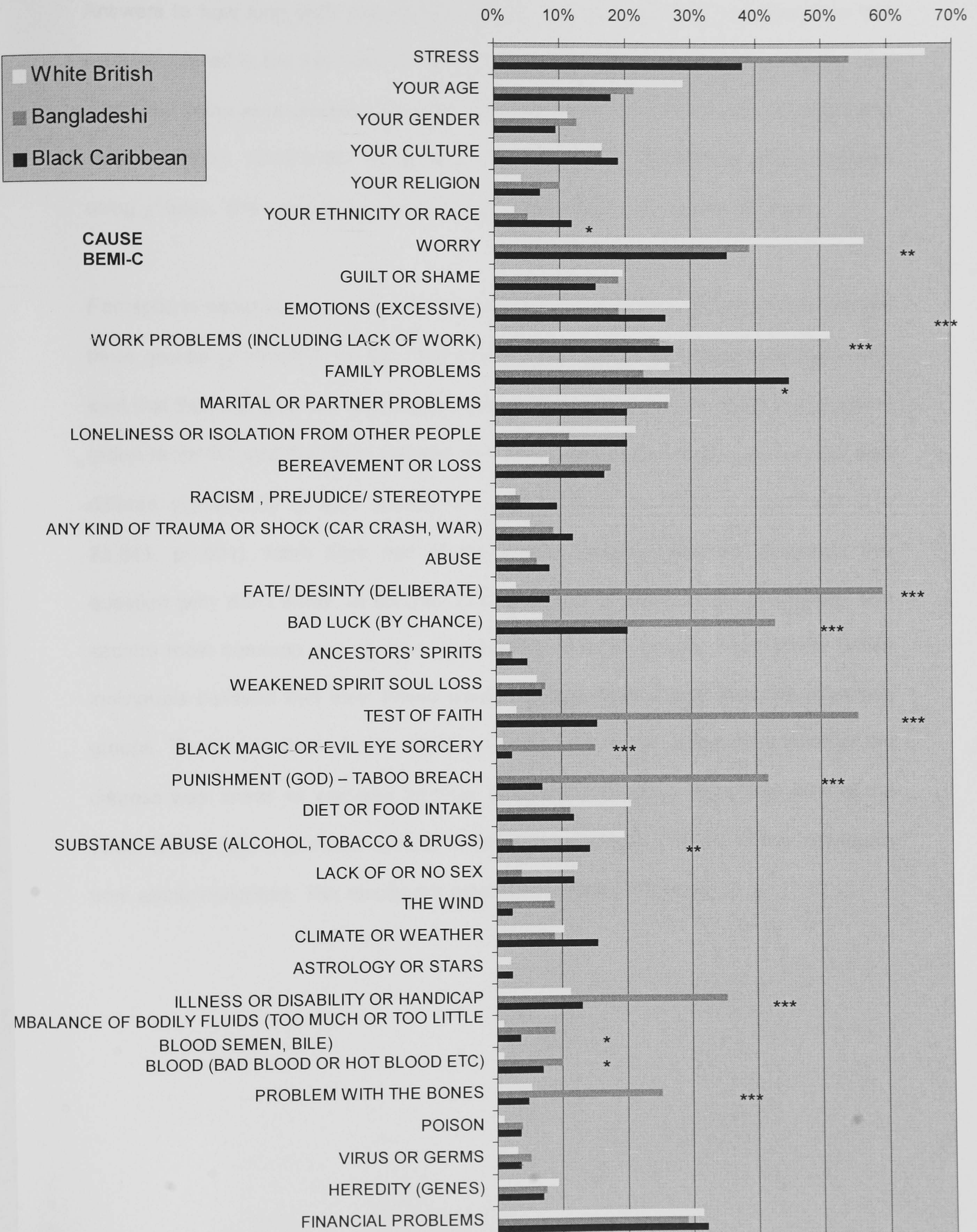


Table 22 Perceptions about the Cause of Distress BEMI-C 2 Have any of the following causes contributed to your problem. Tick the boxes if you believe that they contributed to your problem.

CAUSES	The mes	White British N=97	Bangladeshi N=79	Black Caribbean N=85
STRESS		64 (66%) ^{***BC}	43 (54.4%) ^{*BA}	32 (38.1%) ^{***WB*BA}
YOUR AGE		28 (28.9%)	17 (21.5%)	15 (17.9%)
YOUR GENDER		11 (11.3%)	10 (12.7%)	8 (9.5%)
YOUR CULTURE		16 (16.5%)	13 (16.5%)	16 (19%)
YOUR RELIGION		4 (4.1%)	8 (10.1%)	6 (7.1%)
YOUR ETHNICITY OR RACE		3 (3.1%) ^{*BC}	4 (5.1%)	10 (11.9%) ^{*WB}
WORRY		55 (56.7%) ^{*BA**BC}	31 (39.2%) ^{*WB}	30 (35.7%) ^{**WB}
GUILT OR SHAME		19 (19.6%)	15 (19%)	13 (15.5%)
EMOTIONS (EXCESSIVE)		29 (29.9%)	15 (19%)	22 (26.2%)
WORK PROBLEMS (INCLUDING LACK OF WORK)		50 (51.5%) ^{***BA & BC}	20 (25.3%) ^{***WB}	23 (27.4%) ^{***WB}
FAMILY PROBLEMS		26 (26.8%) ^{**BC}	32 (22.8%)	38 (45.2%) ^{**WB}
MARITAL OR PARTNER PROBLEMS		26 (26.8%)	21 (26.6%)	17 (20.2%)
LONELINESS OR ISOLATION FROM OTHER PEOPLE		21 (21.6%)	9 (11.4%)	17 (20.2%)
BEREAVEMENT OR LOSS		8 (8.2%)	14 (17.7%)	14 (16.7%)
RACISM, PREJUDICE/ STEREOTYPE		3 (3.1%)	3 (3.8%)	8 (9.5%)
ANY KIND OF TRAUMA OR SHOCK (CAR CRASH, WAR)		5 (5.2%)	7 (8.9%)	10 (11.9%)
ABUSE		5 (5.2%)	5 (6.3%)	7 (8.3%)
Total Cases of one or more psychosocial causes		90 (92.8%)^{**BC}	68 (86.1%)	66 (78.6%)^{**WB}
FATE/ DESTINY (DELIBERATE)		3 (3.1%) ^{***BA}	47 (59.5%) ^{***BC & WB}	7 (8.3%) ^{***BA}
BAD LUCK (BY CHANCE)		7 (7.2%) ^{***BA & **BC}	34 (43%) ^{**BC & ***WB}	17 (20.2%) ^{***BA & **BC}
ANCESTORS' SPIRITS		2 (2.1%)	2 (2.5%)	4 (4.8%)
WEAKENED SPIRIT SOUL LOSS		6 (6.2%)	6 (7.6%)	6 (7.1%)
TEST OF FAITH		3 (3.1%) ^{***BA & **BS}	44 (55.7%) ^{***BA & BC}	13 (15.5%) ^{***BA & **BC}
BLACK MAGIC OR EVIL EYE SORcery		1 (1%) ^{***BA}	12 (15.2%) ^{**BC & ***WB}	2 (2.4%) ^{**BA}
PUNISHMENT (GOD) – TABOO BREACH		0 ^{***BA & **BC}	33 (41.8%) ^{***WB & BC}	6 (7.1%) ^{***BA & **WB}
ASTROLOGY OR STARS		2 (2.1%)	0	2 (2.4%)
Total Cases with one or more spiritual cause		16 (16.5%)^{***BA & **BC}	58 (74.7%)^{***WB & BC}	26 (31%)^{***BA & **WB}
DIET OR FOOD INTAKE		20 (20.6%)	9 (11.4%)	10 (11.9%)
SUBSTANCE ABUSE (ALCOHOL, TOBACCO & DRUGS)		19 (19.6%) ^{***BA}	2 (2.5%) ^{***WB}	12 (14.3%) ^{**}
LACK OF OR NO SEX		12 (12.4%)	3 (3.8%)	10 (11.9%)
Total Cases with one or more behavioural causes		36 (37.1%)	13 (16.5%)	22 (26.2%)^{**}
THE WIND		8 (8.2%)	7 (8.9%)	2 (2.4%)
CLIMATE OR WEATHER		10 (10.3%)	7 (8.9%)	13 (15.5%)
Total Cases with one or more weather cause		12 (12.4%)	12 (15.2%)	13 (15.5%)
ILLNESS OR DISABILITY OR HANDICAP		11 (11.3%) ^{***BA}	28 (35.4%) ^{***WB & BC}	11 (13.1%) ^{***BA}
IMBALANCE OF BODILY FLUIDS (TOO MUCH OR TOO LITTLE BLOOD SEMEN, BILE)		1 (1%) ^{*BA}	7 (8.9%) ^{*WB}	3 (3.6%)
BLOOD (BAD BLOOD OR HOT BLOOD ETC)		1 (1%) ^{**BA & *BC}	8 (10.1%) ^{**WB}	6 (7.1%) ^{*WB}
PROBLEM WITH THE BONES		5 (5.2%) ^{***BA}	20 (25.3%) ^{***BA & **BC}	4 (4.8%) ^{***BA}
POISON		1 (1%)	3 (3.8%)	3 (3.6%)
VIRUS OR GERMS		3 (3.1%)	4 (5.1%)	3 (3.6%)
HEREDITY (GENES)		9 (9.3%)	6 (7.6%)	6 (7.1%)
Total Cases with one or more physical cause		24 (24.7%)^{***BA}	40 (50.6%)^{***WB & BC}	19 (22.6%)^{***BA}
FINANCIAL PROBLEMS		33 (31.4%)	23 (29.1%)	27 (32.1%)

significant χ^2 at *p<.05, ** p<.01, *** p<.001 level

Figure 10 Perceptions about Causes of Distress BEMI-C 2 Have any of the following causes contributed to your problem. Tick the boxes if you believe that they contributed to your problem.



5.3.3.1.3. Findings of ethnic differences in perceptions regarding the timeline of distress

Answers to how long their distress had lasted and how long they expected it to last were structured in the interview as categories of duration (days, months, years). Two additional items were provided 'don't know and 'forever', to assess level of insight and catastrophising. Additionally items were aggregated as percentiles and compared using χ^2 tests. The episodic question was structured 'yes', 'no' and 'don't know'.

Perceptions about how long the distress had lasted did differ significantly between the three groups ($\chi^2=23.842$, $p<.01$). The White British group had more individuals who said that their distress had lasted less than two months, while among the Bangladeshi group more thought that their distress had been present for longer. The groups also differed significantly in their assessment of how long the distress would last ($\chi^2=23.841$, $p<.001$). More than half of the ethnic minority members answered this question with 'don't know', in contrast to only a third of White British individuals. The second most common answer was 'forever' for all three groups. More White British individuals believed that their illness would last less than a year than the other two groups. There was also a highly significant difference in the assessment whether the distress was 'linear' or 'episodic /cyclical' ($\chi^2=28.060$, $p<.001$). More than 80% of the White British said that it was cyclical in contrast to 50% and 58.8% of the individuals from ethnic minorities. The results are presented in table 23 below.

Table 23 Perceptions about the Course of Distress BEMI-I 4) how long has ... lasted so far?
 BEMI-I 5) how long do you expect it to last?
 BEMI-I 6) do you go through cycles when the distress get better or worse?

	White British N=105	Bangladeshi N=79	Black Caribbean N=86
How long has it lasted so far?	***BA	***WB & *BC	*BA
Less than a day	4 (3.8%)	1 (1.3%)	1 (1.2%)
1 day	2 (1.9%)	0	0
2-3 days	5 (4.8%)	1 (1.3%)	2 (2.3%)
4-6 days	0	0	1 (1.2%)
1-2 weeks	4 (3.8%)	1 (1.3%)	3 (3.5%)
3-4 weeks	5 (4.8%)	1 (1.3%)	1 (1.2%)
1-2 months	18 (17.1%)	3 (3.8%)	12 (14.0%)
Less than 2 months (~25% of complete sample)	38 (36.2%)	7 (8.9%)	20 (23.3%)
3-6 months	12 (11.4%)	11 (13.9%)	12 (14.0%)
7-12 months	5 (4.8%)	4 (5.1%)	4 (4.7%)
13-23 months	5 (4.8%)	10 (12.7%)	10 (11.6%)
Less than 2 months, but more than 2 years (~50% of complete sample)	22 (21%)	25 (31.6%)	26 (30.2%)
2-5 years (~75% of complete sample)	18 (17.1%)	22 (27.8%)	22 (25.6%)
6-10 years	12 (11.4%)	8 (10.1%)	7 (8.1%)
11-20 years	7 (6.7%)	11 (13.9%)	2 (2.3%)
21 years or more	4 (3.8%)	4 (5.1%)	4 (4.7%)
More than 5 years (~96% of complete sample)	23 (21.9%)	23 (29.1%)	13 (15.1%)
Don't know	4 (3.8%)	2 (2.5%)	5 (5.8%)
How long do you expect it to last?	***BA & BC	***WB	***WB
Is finished	3 (2.9%)	4 (5.1%)	1 (1.2%)
Less than a day	8 (7.6%)	0	2 (2.3%)
1 day	1 (1.0%)	0	1 (1.2%)
2-3 days	3 (2.9%)	0	1 (1.2%)
4-6 days	0	1 (1.3%)	0
1-2 weeks	7 (6.7%)	0	3 (3.5%)
3-4 weeks	2 (1.9%)	1 (1.3%)	1 (1.2%)
1-2 months	8 (7.6%)	0	0
3-6 months	8 (7.6%)	1 (1.3%)	3 (3.5%)
7-12 months	2 (1.9%)	3 (3.8%)	3 (3.5%)
Less than one year	42 (40.2%)	10 (12.8%)	15 (17.4%)
13-23 months	0	2 (2.6%)	1 (1.2%)
2-5 years	6 (5.7%)	1 (1.3%)	2 (2.3%)
6-10 years	0	0	2 (2.3%)
11 years and more	1 (1.0%)	0	0
Forever	20 (19.0%)	21 (26.9%)	16 (18.6%)
More than one year	27 (25.7)	24 (30.8%)	21 (24.4%)
Don't know	36 (34.3%)	44 (56.4%)	50 (58.1%)
Is it cyclical? Yes	87 (82.9%) ***BA & BC	38 (50%) ***WB	50 (58.8%) ***WB

5.3.3.1.4. Findings regarding perceptions about consequences of distress

BEMI 7a) How has this affected your life?

BEMI 7b) What are the main difficulties/ disadvantages and advantages that you experienced since having...?

a) Psychological Consequences

Perceptions about psychological consequences were the most commonly reported consequence perception for all individuals, independent of ethnic background and were reported by 67-96%. In the BEMI-I, significant ethnic differences were found among specific items, but not for the aggregated score. The items were 'increased levels of fatigue' ($\chi^2=7.735$, $p<.05$), 'aversive feelings (feeling down, irritable etc)' ($\chi^2=9.533$, $p<.01$), 'having increased doubt' ($\chi^2=9.413$, $p<.01$), 'feeling powerless' ($\chi^2=20.719$, $p<.001$), 'hopelessness' ($\chi^2=6.547$, $p<.05$) and 'changes to one's personality' ($\chi^2=10.900$, $p<.01$). A significantly higher proportion of White British individuals than ethnic minority individuals reported that they were fatigued (WB=11%, BA=3%, BC=4%) and had aversive feelings (WB=32%, BA=15%, BC=17%). E.g. WBSG31 'feeling more tired, and not well, sometimes a bit depressed; whereas I am not [usually] a person to get depressed, sometimes a bit powerless'. Some reported increased doubt (WB=16%, BA=3%, BC=9%) - WBSG65 'It created sadness about my future, hope about my future, questioning what went wrong, re-evaluating what had happened and trying to get some positive out of it'. A larger proportion of ethnic minority individuals would say that their life had been destroyed by their distress and reported that they had no energy to do anything (WB=8%, BA=19%, BC=23%). For example, BAWA 11 'I am very, very hurt. I feel that my life is ruined. I didn't think this could happen to me at this stage in my life'. BA97 'I keep feeling almost breathless even as I'm talking to you now. I can't always cook nor do housework, so my husband helps me out'. A similarly high proportion would voice this concern in the Caribbean population, e.g. BC44 'stops me from doing things, can't stick at things like courses'.

In the BEMI-C assessment there were significant ethnic differences for selected items and the aggregated theme (WB=86%, BA=96%, BC=75%) ($\chi^2=14.670$, $p<.001$). Higher proportions of Bangladeshi reported aversive feelings (WB=76%, BA=95%, BC=64%) ($\chi^2=22.634$, $p<.001$) as a result of their distress, having little concentration (WB=36%, BA=71%, BC=27%) ($\chi^2=35.084$, $p<.001$), being tormented by thoughts that interfered with thinking (WB=25%, BA=41%, BC=25%) ($\chi^2=6.459$, $p<.05$) and focussing on their illness (WB=31%, BA=57%, BC=30%) ($\chi^2=16.436$, $p<.001$).

b) Social Consequences

Individuals also reported a number of social consequences, but there were no significant ethnic differences in the assessment by interview (BEMI-I). In the assessment by checklist, significant differences were reported for 'changes to role and status in the community' (WB=14%, BA=34%, BC=25%) ($\chi^2=8.054$, $p<.05$), 'stigmatisation' (WB=8%, BA=23%, BC=6%) ($\chi^2=12.975$, $p<.01$) and 'relationship with partner or kids' (WB=6%, BA=3%, BC=13%) ($\chi^2=6.994$, $p<.05$). Higher proportions of Bangladeshi individuals reported that they had been stigmatised and that their role was affected by their distress. A larger proportion of Caribbean individuals said that they lost their partner or their children as a result of their distress. When all items were aggregated, however, significant differences disappeared.

c) Economic/ Situational Consequences

There were no significant ethnic differences in perceptions of financial/ situational problems, apart from a higher proportion of Bangladeshi individuals spontaneously reporting that distress affected their living conditions, in terms of housing (WB=1%, BA=9%, BC=4%) ($\chi^2=7.325$, $p<.05$).

d) Physical Consequences

When all physical items were aggregated, the difference in the distribution of individuals who perceived spontaneously reported physical consequences to their distress was statistically significant (WB=21%, BA=38%, BC=20%) ($\chi^2=8.554$, $p<.05$). More Bangladeshi individuals talked about how their distress affected their health and physical ability (WB=11%, BA=27%, BC=13%) ($\chi^2=8.726$, $p<.05$), e.g. BA113 'my physical illness is increasing' and more White British reported losing weight (WB=4%, BA=0%, BC=0%) ($\chi^2=6.381$, $p<.05$). In the checklist assessment it was found that significantly more Bangladeshi reported 'pain' (WB=13%, BA=42%, BC=21%) ($\chi^2=19.564$, $p<.001$). However when all physical items were aggregated, no statistically significant ethnic differences were found.

e) Behavioural Consequences

There was no statistically significant difference in perceptions of behavioural consequences in the BEMI-I assessment. In the BEMI-C assessment, it was found that the proportion of White British who reported that they abused substances as a result of distress was twice the proportion of the ethnic minorities, which was a significant difference (WB=31%, BA=51%, BC=37%) ($\chi^2=8.977$, $p<.05$). When behavioural items were aggregated, both Bangladeshi and White British had significantly higher proportions of individuals who believed that the distress affected their behaviour than Caribbean (WB=44%, BA=38%, BC=25%) ($\chi^2=7.450$, $p<.001$).

f) Advantageous Consequences

The majority of individuals did not perceive any benefits to their distress. It was evident, however, that the proportion of White British who could describe advantages was significantly higher for most items, apart from 'getting support' and in consequence the aggregated theme (WB=49%, BA=17%, BC=16%) ($\chi^2=32.402$, $p<.001$). A significantly higher proportion of White British said that they 'learned

something from it' (WB=23%, BA=1%, BC=8%) ($\chi^2=21.781$, $p<.001$), that it 'motivated them to change' (WB=15%, BA=3%, BC=2%) ($\chi^2=15.364$, $p<.001$), that they have 'become more considerate' (WB=4%, BA=0%, BC=0%) ($\chi^2=6.380$, $p<.05$) and that they dealing with distress [successfully] 'increased their confidence' (WB=8%, BA=1%, BC=0%) ($\chi^2=9.999$, $p<.01$) As many of the WB perceptions regarding the identity of distress were associated with 'work problems' and 'having too little time', it was easier to identify advantages. Examples include THC8 'felt pleased with myself, when I got the work done, and value my [free] time'. WBSG 43 'makes me get things done, is impetus to action, if I get worried makes me think to do something about it, get well organised,' and WBSG26 'sometimes it gives me a kick up the arse to do something, pushes you on, maybe pursue my career, find new ways'. A significantly higher proportion of Bangladeshi individuals reported getting help and support from their family (WB=0%, BA=11%, BC=1%) ($\chi^2=18.690$, $p<.001$).

g) Unknown Consequences

Finally, it was found that significantly more individuals from a Bangladeshi background reported not knowing what advantages or disadvantages were nor how distress affected their life (WB=0%, BA=11%, BC=1%) ($\chi^2=18.690$, $p<.001$). When this latter item was aggregated with other items that said that life was not affected, the difference between groups was not statistically significant.

The results are presented and illustrated in table 24 for spontaneous responses and table 25 for checklist responses, and figure 11 and 12 respectively.

Table 24) Perceptions about the consequences of distress BEMI-I 7aHow has this affected your life? BEMI 7b) What are the main difficulties/ disadvantages and advantages that you experienced since having... ?

CONSEQUENCES		White British N=105	Bangladeshi N=79	Black Caribbean n=86
+ INCREASED TIREDNESS/FATIGUE		12 (11.4%) ^{*BA & *BC}	2 (2.5%) ^{*WB}	3 (3.5%) ^{*WB}
INCREASINGLY FOCUS ON YOUR BODY THE ILLNESS		4 (3.8%)	4 (5.1%)	0
BEING TORMENTED BY INTERFERING THOUGHTS		8 (7.6%)	11 (13.9%)	6 (7%)
AVERSIVE FEELINGS		34 (32.4%) ^{**BA & *BC}	12 (15.2%) ^{**WB}	15 (17.4%) ^{*WB}
HAVING LITTLE CONCENTRATION OR MEMORY		9 (8.6%)	2 (2.5%)	4 (4.7%)
LOSING CONFIDENCE AND SELF ESTEEM		12 (11.4%)	2 (2.5%)	8 (9.3%)
NO MOTIVATION AND LESS OUTGOING		13 (12.4%)	13 (16.5%)	11 (12.8%)
FEAR		8 (7.6%)	1 (1.3%)	3 (3.5%)
+ FEEL OF LOSS, DISAPPOINTMENT, DISILLUSIONMENT		13 (12.4%)	5 (6.3%)	12 (14%)
+ INCREASED ANXIETY & MENTAL HEALTH AFFECTED		11 (10.5%)	5 (6.3%)	3 (3.5%)
+ INCREASED OUTWARD ANGER		6 (5.7%)	0	4 (4.7%)
+ INCREASED DOUBT/ UNCERTAINTY, RUMINATIONS		17 (16.2%) ^{**BA}	2 (2.5%) ^{**WB}	8 (9.3%)
+ FEELING STRESSED, UPSET, DAUNTED		8 (7.6%)	10 (12.7%)	12 (14%)
+ FEELING POWERLESS, PARALYSED, PREVENTED FROM DOING ANYTHING, NO ENERGY		8 (7.6%) ^{*BA & ***BC}	15 (19%) ^{*WB & *BC}	29 (22.7%) ^{***WB & *BA}
+ HOPELESSNESS, NOT ENJOYING LIFE, LIFE IS DESTROYED		7 (6.7%)	11 (13.9%) ^{*BC}	3 (3.5%) ^{*BA}
+ LACK OF CONTROL, LOOSING CONTROL, UNEASINESS		6 (5.7%)	2 (2.5%)	2 (2.3%)
+ CHANGED PERCEPTIONS, BELIEFS OF THE WORLD		2 (1.9%)	1 (1.3%)	5 (5.8%)
+ CHANGING YOUR PERSONALITY		2 (1.9%)	2 (2.5%)	5 (5.8%)
Total cases with one ore more psychological consequences		85 (81%)	53 (67.1%)	61 (70.9%)
ROLE/ STATUS (IN YOUR FAMILY, COMMUNITY)		12 (11.4%)	9 (11.4%)	9 (10.5%)
BEING EXCLUDED FROM SOCIAL ACTIVITIES		2 (1.9%)	0	0
BEING REJECTED OR ISOLATED		8 (7.6%)	2 (2.5%)	4 (4.7%)
BEING STIGMATISED OR LOSS OF STATUS		3 (2.9%)	1 (1.3%)	0
BEING PHYSICALLY ABUSED		1 (1%)	0	0
BEING LOCKED UP		2 (1.9%)	0	0
JOB/ WORK		19 (18.1%)	11 (13.9%)	8 (9.3%)
RELATIONSHIP WITH PARTNER/KIDS		20 (19%)	17 (21.5%)	12 (14%)
RELATIONSHIP WITH FRIENDS		7 (6.7%)	3 (3.8%)	6 (7%)
+ WITHDRAWAL, LESS INTERACTION		15 (14.3%)	9 (11.4%)	6 (7%)
+ HAVING LACK OF COMMUNICATION, ABILITY TO COMMUNICATE		7 (6.7%)	4 (5.1%)	5 (5.8%)
Total cases with one ore more social consequences		45 (42.9%)	25 (36.7%)	33(38.4%)
BECOMING DISABLED		3 (2.9%)	4 (5.1%)	1 (1.2%)
FINANCIAL SECURITY		15 (14.3%)	11 (13.9%)	18 (20.9%)
+ AFFECTED MY LIVING CONDITIONS		1 (1%) ^{*BA}	7 (8.9%) ^{*WB}	3 (3.5%)
Total cases with one or more financial/situational consequences		18 (17.1%)	17 (21.5%)	21 (24.4%)
PAIN		6 (5.7%)	8 (10.1%)	4 (4.7%)
LOSING WEIGHT		4 (3.8%) ^{*BC & BA}	0 ^{*WB}	0 ^{*WB}
GAINING WEIGHT		1 (1%)	0	2 (2.3%)
+ SLEEP PROBLEMS		2 (1.9%)	8 (10.1%)	2 (2.3%)
+ ILLNESS, PHYSICAL HEALTH AFFECTED		12 (11.4%) ^{**BA}	21 (26.6%) ^{**WB & *BC}	11 (12.8%) ^{*BA}
Total cases with one or more physical consequences		23 (21.9%)^{*BA}	30 (38%)^{*WB & **BC}	17 (19.8%)^{**BA}
USING ALCOHOL TOBACCO MEDICATION OR ILLEGAL DRUGS TO COPE		4 (3.8%)	0	2 (2.3%)
STOP DOING ACTIVITIES THAT YOU ENJOY		8 (7.6%)	5 (6.3%)	5 (5.8%)
+ EATING PROBLEMS		0	3 (3.8%)	2 (2.3%)
Total cases with one or more behavioural consequences		11 (10.5%)	7 (8.9%)	9 (10.5%)
+ HAS NOT AFFECTED MY LIFE, DOES NOT STOP ME FROM DOING ANYTHING		21 (20%)	13 (16.5%)	21(24.4%)
+ DON'T KNOW		0 ^{***BA}	9 (11.4%) ^{***WB & **BC}	1 (1.2%) ^{**BA}
Total cases with no known consequences		21 (20%)	20 (25.3%)	22 (25.6%)
+ LEARNED SOMETHING FROM IT		24 (22.9%) ^{***BA & **BC}	1 (1.3%) ^{***WB & *BC}	7 (8.1%) ^{**WB & *BA}
+ MOTIVATED ME TO CHANGE		16 (15.2%) ^{***BA & **BC}	2 (2.5%) ^{***WB}	2 (2.3%) ^{***WB}
+ BECOME MORE CONSIDERATE, EMPATHIC, AWARE OF OTHERS		4 (3.8%)	0	0
+ INCREASED CONFIDENCE, FEEL PLEASED WITH YOURSELF**		8 (7.6%) ^{*BA & **BC}	1 (1.3%) ^{*WB}	0 ^{**WB}
+ AFFECTED LIFE IN A GOOD WAY		7 (6.7%)	0	4 (4.7%)
+ GETTING SUPPORT IN RESPONSE		0 ^{***BA}	9 (11.4%) ^{***WB & **BC}	1(1.2%) ^{**BA}
+ HAVE MORE INTERACTION, INCREASED STATUS, BETTER SOCIAL LIFE		3 (2.9%)	1 (1.3%)	3 (3.5%)
Total cases with one or more positive consequences		51 (48.6%)^{***BA & ***BC}	13 (16.5%)^{***WB}	14(16.3%)^{***WB}

+ extra items, ++ new domains, significant χ^2 at *p<.05, ** p<.01, *** p<.001 level

Figure 11 Spontaneously elicited perceptions BEMI-I 7a How has this affected your life? BEMI 7b What are the main difficulties/ disadvantages and advantages that you experienced since having...?

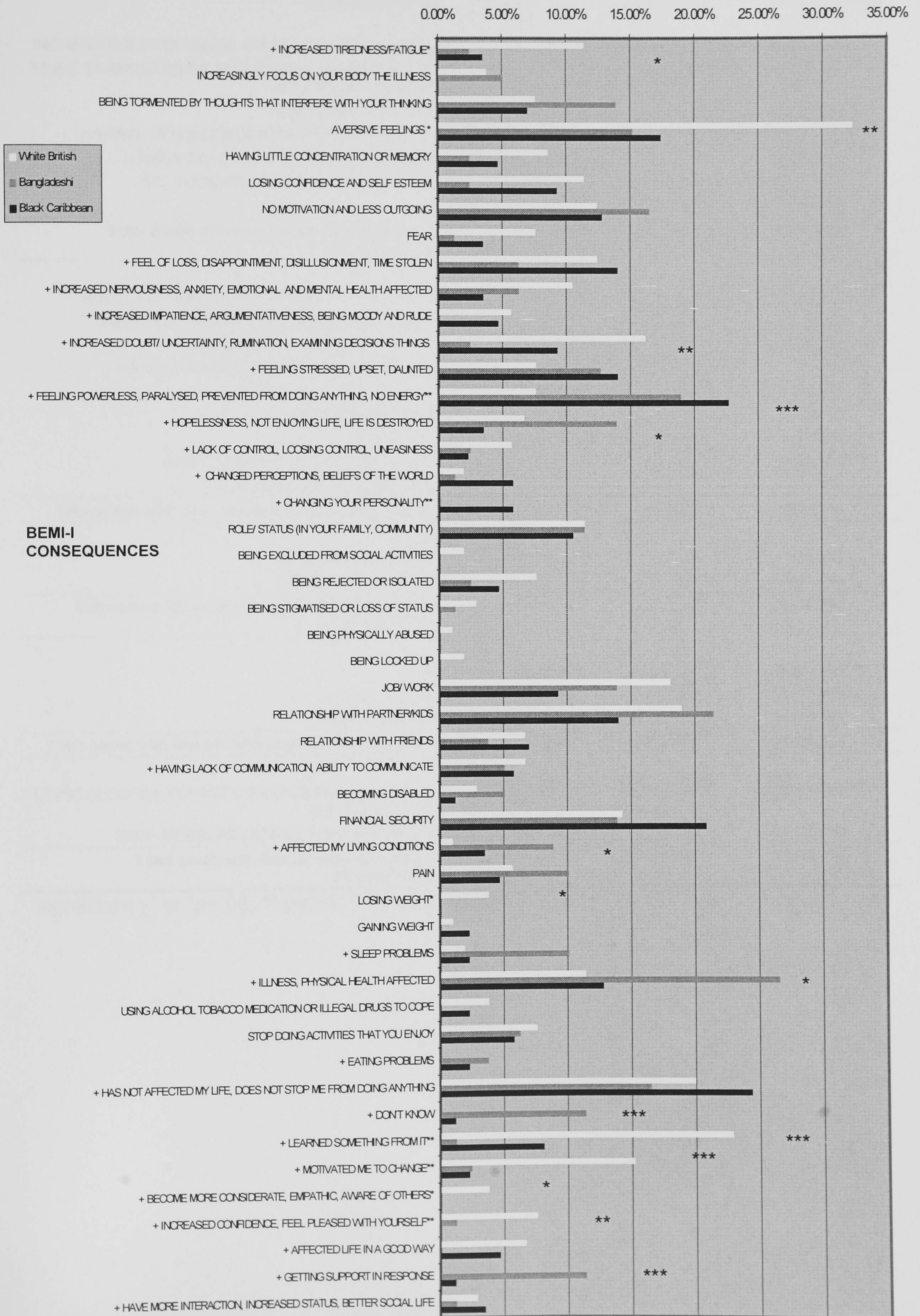
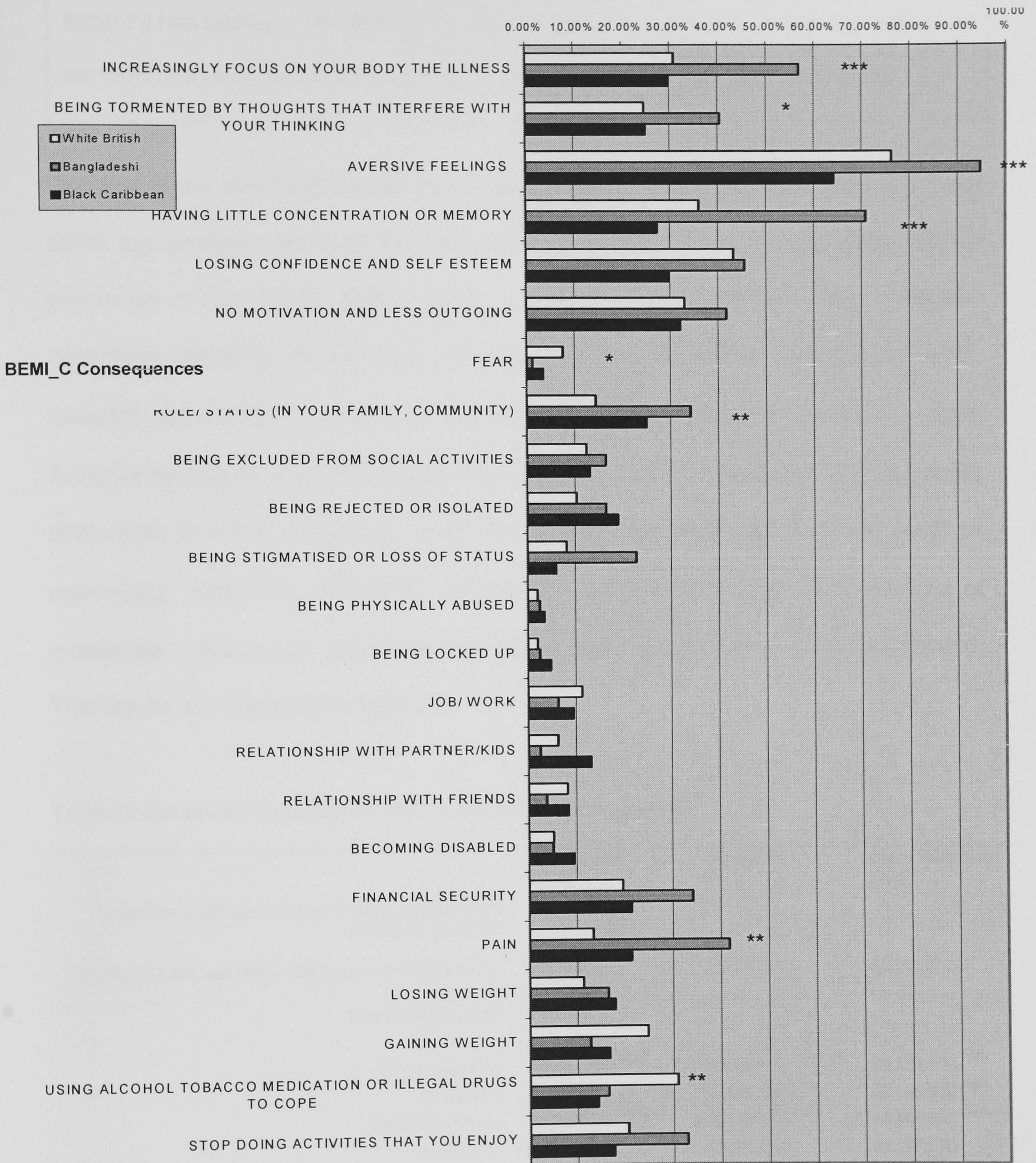


Table 25 Perceptions about the Consequences of distress - BEMI-C 3 We would also like to know if you experienced any of the following consequences, please tick the box if you have experienced them as a result of having your problem?

CONSEQUENCES	The mes	White British N=97	Bangladeshi N=79	Black Caribbean N=85
INCREASINGLY FOCUS ON YOUR BODY THE ILLNESS		30 (30.9%) ***BA	45 (57.0%) ***WB & BC	25 (29.8%) ***BA
BEING TORMENTED BY THOUGHTS THAT INTERFERE WITH YOUR THINKING		24 (24.7%) *BA	32 (40.5%) *WB & BC	21 (25.0%) *BA & BC
AVERSIVE FEELINGS	SELF/PSYCHOLOGICAL	74(76.3%) ***BA	75 (94.9%) ***WB & BC	54 (64.3%) ***BA
HAVING LITTLE CONCENTRATION OR MEMORY		35 (36.1%) ***BA	56 (70.9%) ***WB & BC	23 (27.4%) ***BA
LOSING CONFIDENCE AND SELF ESTEEM		42(43.3%)	36 (45.6%)	25 (29.8%)
NO MOTIVATION AND LESS OUTGOING		32 (33%)	33 (41.8%)	27 (32.1%)
FEAR		8(7.6%) *BA	1(1.3%) *WB	3 (3.5%)
Total cases with one ore more psychological consequences		83 (85.6%) *BA	76 (96.2%) *WB & ***BC	63 (75.0%) ***BC
ROLE/ STATUS (IN YOUR FAMILY, COMMUNITY)	SOCIAL	14 (14.4%) **BA	27 (34.2%) **WB	21(25.0%)
BEING EXCLUDED FROM SOCIAL ACTIVITIES		12 (12.4%)	13 (16.5%)	11(13.1%)
BEING REJECTED OR ISOLATED		10 (10.3%)	13 (16.5%)	16(19.0%)
BEING STIGMATISED OR LOSS OF STATUS		8 (8.2%) **BA	18 (22.8%) **WB & BC	5 (6%) **BA
BEING PHYSICALLY ABUSED		2 (2.1%)	2 (2.5%)	3 (3.5%)
BEING LOCKED UP		2 (2.1%)	2 (2.5%)	4 (4.8%)
JOB/ WORK		11 (11.3%)	5 (6.3%)	8 (9.5%)
RELATIONSHIP WITH PARTNER/KIDS		6 (6.2%)	2 (2.5%) *BC	11(13.1%) *BA
RELATIONSHIP WITH FRIENDS	8 (8.2%)	3 (3.8%)	7 (8.3%)	
Total cases with one ore more social consequences		39 (40.2%)	39 (49.4%)	38 (45.2%)
BECOMING DISABLED	FIN/SIT	5 (5.2%)	4 (5.1%)	8 (9.5%)
FINANCIAL SECURITY		19 (19.6%)	27 (34.2%)	18 (21.4%)
Total cases with one or more financial/situational consequences			22 (22.7%)	29 (36.7%)
PAIN	PHYSICAL	13 (13.4%) ***BA	33(41.8%) ***WB & **BC	18 (21.4%) **BA
LOSING WEIGHT		11 (11.3%)	13 (16.5%)	15 (17.9%)
GAINING WEIGHT		24 (24.7%)	10 (12.7%)	14 (16.7%)
Total cases with one or more physical consequences		37 (38.1%)	40 (50.6%)	31 (36.9%)
USING ALCOHOL TOBACCO MEDICATION OR ILLEGAL DRUGS TO COPE	BEHAVIOURAL	30 (30.9%) *BA & **BC	13 (16.5%) *WB	12 (14.3%) **WB
STOP DOING ACTIVITIES THAT YOU ENJOY		20 (20.6%)	26 (32.9%)	15 (17.6%)
Total cases with one or more behavioural consequences		43 (44.3%) **BC	30 (38.0%)	21 (25.0%) **WB

significant χ^2 at *p<.05, ** p<.01, *** p<.001 level

Figure 12 Perceptions about consequences of distress BEMI-C 3 We would also like to know if you experienced any of the following consequences, please tick the box if you have experienced them as a result of having your problem?



Structured questions about consequences of BEMI-I

BEMI-I 8 Generally would you say that ... has had a big or small influence on your life?

BEMI-I 9 Has having ... affected your a) physical ability, b) behaviour, c) decision making, d) personality, e) financial security, f) status in their family/ community and g) social life?

Findings in the structured questions produced similar results to those from the other BEMI assessments and can be understood to validate them. A significantly higher proportion of the White British group said that distress affected their behaviour (WB=68%, BA=47%, BC=47%) ($\chi^2=11.375$, $p<.01$) and decision making (WB=65%, BA=46%, BC=47%) ($\chi^2=9.031$, $p<.05$) than in the Caribbean or Bangladeshi groups. A higher proportion of the Bangladeshi sample said that it affected their physical ability (WB=36%, BA=70%, BC=29%) ($\chi^2=31.461$, $p<.001$) and their status in their family or community (WB=31%, BA=47%, BC=30%) ($\chi^2=6.231$, $p<.05$). The majority of individuals evaluated the effects on their life as 'big', irrespective of ethnic background. The results are displayed in table 26.

Table 26 Structured questions of BEMI-I regarding consequences

	White British N=105	Bangladeshi N=79	Black Caribbean N=86
Generally would you say that it had a big or a small impact on your life?			
Cases (%) who said the influence on their life was big	67 (63.8%)	61 (77.2%)	56 (67.5%)
Has it affected your			
Physical ability	38 (36.2%) ^{***BA}	55 (69.6%) ^{***WB & BC}	25 (29.1%) ^{***BA}
Behaviour	71 (67.6%) ^{**BA & BC}	37 (46.8%) ^{**WB}	40 (46.5%) ^{**WB}
Decision making	68 (64.8%) ^{**BA & BC}	36 (45.6%) ^{**WB}	40 (46.5%) ^{**WB}
Personality	65 (61.9%)	47 (59.5%)	41 (47.7%)
Financial security	43 (41%)	37 (46.8%)	38 (44.2%)
Status in your family/ community	33 (31.4%) ^{*BA}	37 (46.8%) ^{*WB & BC}	26 (30.2%) ^{*BA}
Social life	60 (57.1%)	50 (63.3%)	43 (50%)

5.3.3.5.) Perceptions regarding control and cure/ treatment of distress

BEMI-I 10a) how, do **you** think, should this be best resolved?

10b) how could this be best dealt with?

a) Self-directed interventions

It was found that there were many significant ethnic differences in individuals' perceptions about how their distress should be best dealt with. Statistically significant differences were found with regards to 'thinking' ($\chi^2=6.380$, $p<.05$), 'holidays' ($\chi^2=10.803$, $p<.01$) and 'acknowledging it' ($\chi^2=15.057$, $p<.001$), which was advocated by a much higher proportion of White British individuals. In probed assessments, ethnic differences were found for the following methods: 'exercising' ($\chi^2=16.329$, $p<.001$), 'substance abuse' ($\chi^2=7.709$, $p<.05$), 'dancing' ($\chi^2=9.658$, $p<.01$), 'thinking' ($\chi^2=7.804$, $p<.05$) and 'spending time on a hobby' ($\chi^2=25.592$, $p<.001$). Individuals from White British background reported spontaneously significantly more self-treatment methods than any other group when all self-treatment methods were aggregated ($\chi^2=16.159$, $p<.001$).

b) Social interventions

Social interventions were spontaneously seen as helpful by large proportions of the sample, but significant ethnic differences were only found for the item 'talking to your friends' A higher proportion of White British reported this spontaneously ($\chi^2=12.925$, $p<.01$) and on checklist ($\chi^2=21.821$, $p<.001$) to be helpful in contrast to the ethnic minorities. When social treatment perceptions were aggregated, a significant difference between individuals from different ethnic groups was found in the interview ($\chi^2=8.959$, $p<.05$) and in the checklist ($\chi^2=26.893$, $p<.001$).

c) Medical Interventions

'Medical' treatment was neither mentioned spontaneously nor in the checklist by the majority of individuals as helpful in resolving distress. A significantly higher proportion of Bangladeshi reported that it was to be helped by medication in both assessments (BEMI-I ($\chi^2=9.381$, $p<.01$) and BEMI-C ($\chi^2=13.814$, $p<.05$)). In the assessment by checklist, when all medical items were aggregated it was found that the distribution was significantly different ($\chi^2=6.597$, $p<.05$).

d) Alternative Interventions

Among the White British a higher proportion perceived alternative treatments as helpful as the other groups. Here, significant ethnic differences were reported for the items 'Yoga' (BEMI-I $\chi^2=6.380$, $p<.05$) and BEMI-C ($\chi^2=23.949$, $p<.001$) and 'Relaxation' BEMI-I $\chi^2=11.571$, $p<.01$) and BEMI-C ($\chi^2=14.462$, $p<.001$). A significant proportion of Bangladeshi found 'chanting helpful' when assessed by checklist ($\chi^2=8.331$, $p<.05$). When alternative items were aggregated, a significant difference was found between ethnic groups in open-ended ($\chi^2=18.209$, $p<.001$) and checklist assessment ($\chi^2=12.035$, $p<.01$).

e) Spiritual Interventions

Spiritual healing was much more endorsed by Caribbean and Bangladeshi in contrast to White British. Spontaneously a significantly higher proportion of individuals from ethnic minorities reported 'god or a miracle' as the only solution to their problem ($\chi^2=10.898$, $p<.01$), and more Caribbean individuals said that 'praying' was helpful for them both in spontaneous ($\chi^2=6.491$, $p<.05$) and checklist assessment ($\chi^2=21.369$, $p<.001$). When spiritual items were aggregated, it was found that both in the BEMI-I ($\chi^2=7.915$, $p<.05$) and BEMI-C assessment ($\chi^2=17.916$, $p<.001$), there were significant ethnic differences.

f) No treatment/ additional intervention items

Additional items that were found included the perception that there was no treatment method available (cannot be resolved), which was endorsed by a significantly larger proportion of White British individuals ($\chi^2=7.994$, $p<.05$). Perceptions that efficient treatment was only brought about by the 'resolution of outside circumstances' were endorsed by significantly higher proportions of both ethnic minorities ($\chi^2=11.935$, $p<.01$). A higher proportion of the Caribbean sample thought that an adequate diagnosis of the problem would help them treat it better ($\chi^2=13.129$, $p<.01$). Individuals from ethnic minorities were more commonly found to say that they did not know how their illness could be best dealt with or resolved ($\chi^2=10.825$, $p<.001$).

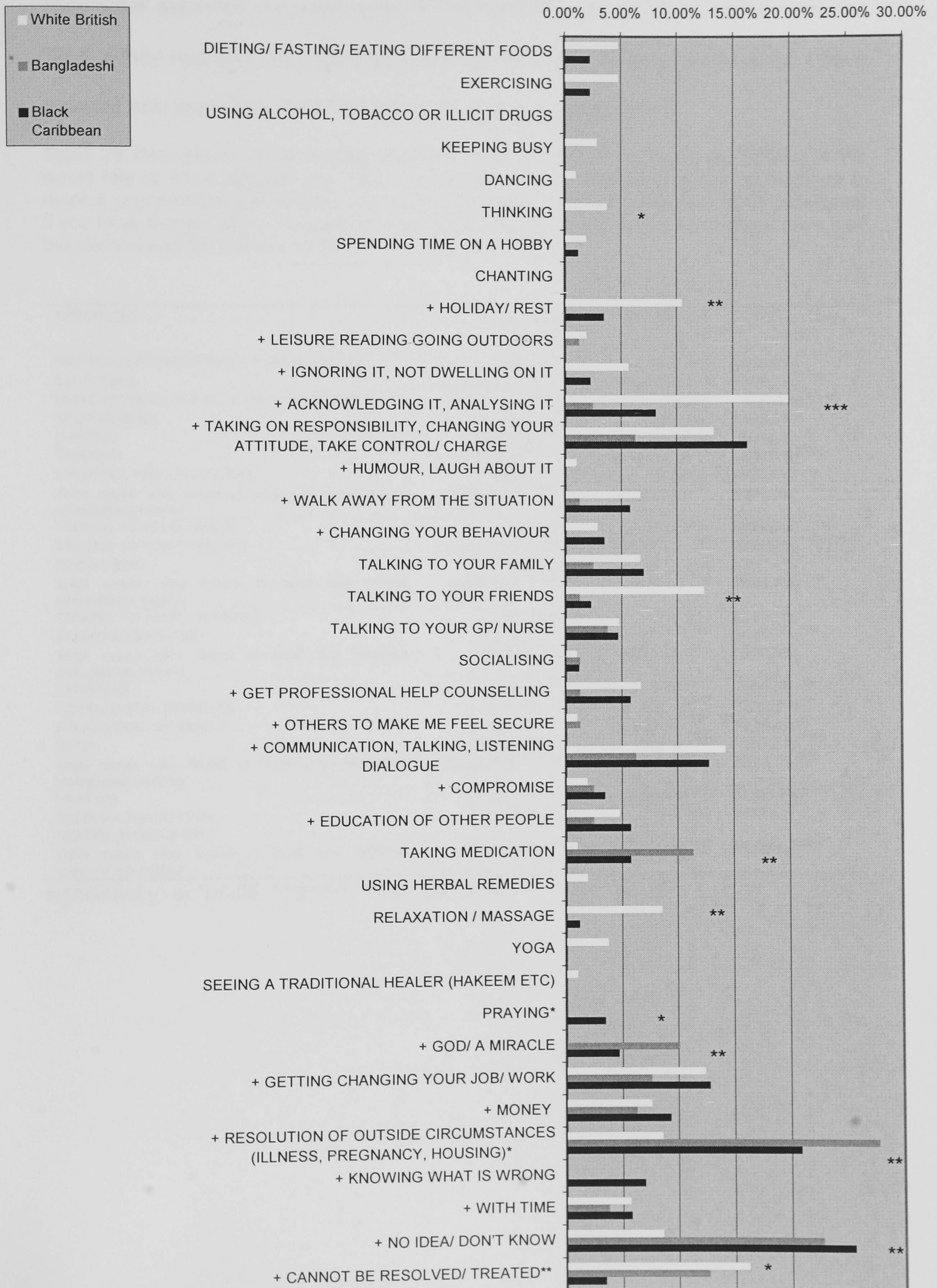
The results are presented and illustrated in table 27 for spontaneous responses and table 28 for checklist responses, and figure 13 and 14 respectively.

Table 27 Perceptions of treatment of distress BEMI-I10a) how do you think should this be best dealt with, BEMI-I 10b) how can this be best resolved?

TREATMENT	TH	White British N=105	Bangladeshi N=79	Black Caribbean n=86
DIETING/ FASTING/ EATING DIFFERENT FOODS		5(4.8%)	0	2(2.3%)
EXERCISING		5(4.8%)	0	2(2.3%)
USING ALCOHOL, TOBACCO OR ILLICIT DRUGS		0	0	0
KEEPING BUSY		3(2.9%)	0	0
DANCING		1(1%)	0	0
THINKING		4(3.8%)	0	0
SPENDING TIME ON A HOBBY		2(1.9%)	0	1(1.2%)
+ HOLIDAY/ REST		11(10.5%) ^{**BA}	0 ^{**WB}	3(3.5%)
+ LEISURE READING GOING OUTDOORS		2(1.9%)	1 (1.3%)	0
+ IGNORING IT, NOT DWELLING ON IT		6(5.7%)	0	2(2.3%)
+ ACKNOWLEDGING IT, ANALYSING IT		21(20%) ^{***BA *BC}	2 (2.5%) ^{***WB}	7(8.1%) ^{**WB}
+ TAKING ON RESPONSIBILITY, CHANGING YOUR ATTITUDE, TAKE CONTROL/ CHARGE		14(13.3%)	5 (6.3%)	14(16.3%)
+ HUMOUR, LAUGH ABOUT IT		1(1%)	0	0
+ WALK AWAY FROM THE SITUATION	SELF	7(6.7%)	1 (1.3%)	5(5.8%)
+ CHANGING YOUR BEHAVIOUR		3(2.9%)	0	3(3.5%)
Total cases who thought best resolved by self treatments		55(52.4%)^{***BA & *BC}	7 (8.9%)^{***WB & ***BC}	32 (37.2%)^{**WB & ***BA}
TALKING TO YOUR FAMILY		7(6.7%)	2 (2.5%)	6 (7%)
TALKING TO YOUR FRIENDS		13(12.4%) ^{**BA & BC}	1 (1.3%) ^{**WB}	2 (2.3%) ^{**WB}
SOCIALISING		1(1%)	1 (1.3%)	1(1.2%)
+ GETTING CHANGING YOUR JOB/ WORK		13(12.4%)	6 (7.6%)	11(12.8%)
+ OTHERS TO MAKE ME FEEL SECURE		1(1%)	1 (1.3%)	0
+ COMMUNICATION, TALKING, LISTENING DIALOGUE		15(14.3%)	5 (6.3%)	11(12.8%)
+ COMPROMISE	SOCIAL	2(1.9%)	2 (2.5%)	3(3.5%)
+ EDUCATION OF OTHER PEOPLE		5(4.8%)	2 (2.5%)	5(5.8%)
Total cases who thought it was best resolved socially		44 (41.9%)^{**BA}	17 (21.5%)^{**WB & *BA}	33(38.4%)^{*BA}
TAKING MEDICATION		1(1%) ^{**BA}	9 (11.4%) ^{**WB}	5(5.8%)
TALKING TO YOUR GP/ NURSE		5(4.8%)	3 (3.8%)	4(4.7%)
+ GET PROFESSIONAL HELP COUNSELLING	MEDICAL	7(6.7%)	1 (1.3%)	5(5.8%)
Total cases who thought it was best resolved by professional/ medical help		13(12.4%)	13 (16.5%)	12 (14.0%)
USING HERBAL REMEDIES		2(1.9%)	0	0
RELAXATION / MASSAGE		9(8.6%)	0	1(1.2%) ^{**}
CHANTING		0	0	0
YOGA		4(3.8%)	0	0 [*]
Total cases who thought it was best resolved alternatively	ALTERNAT	13(12.4%)^{**BA **BC}	0^{WB}	1(1.2%)^{**WB}
SEEING A TRADITIONAL HEALER (HAKEEM ETC)		1(1%)	0	0
PRAYING		0	0	3(3.5%)
+ GOD/ A MIRACLE	SPIRITUAL	0 ^{***BA}	8 (10.1%)	4(4.7%) ^{**WB}
Total cases who thought it was best resolved spiritually		1(1%)	8 (10.1%)	7(8.1%)*
+ MONEY		8(7.6%)	5 (6.3%)	8(9.3%)
+ RESOLUTION OF OUTSIDE CIRCUMSTANCES (ILLNESS, PREGNANCY, HOUSING)		9(8.6%) ^{**BA & *BC}	22 (27.8%) ^{**WB}	18(20.9%) ^{**WB}
+ KNOWING WHAT IS WRONG		0 ^{**BC}	0 ^{BC}	6 (7%) ^{**WB & *BA}
+ WITH TIME		6(5.7%)	3 (3.8%)	5(5.8%)
+ NO IDEA/ DON'T KNOW		9(8.6%) ^{**BA & BC}	18 (22.8%) ^{**WB}	22(25.6%) ^{**WB}
+ CANNOT BE RESOLVED/ TREATED		17(16.2%) ^{**BC}	10 (12.7%) ^{WB}	3(3.5%) ^{**WB & *BA}

+ extra items, ++ new domains, significant χ^2 at *p<.05, ** p<.01, *** p<.001 level

Figure 13 Perceptions elicited in response to question BEMI-I10a) how do you think should this be best dealt with, BEMI-I 10b) how can this be best resolved?



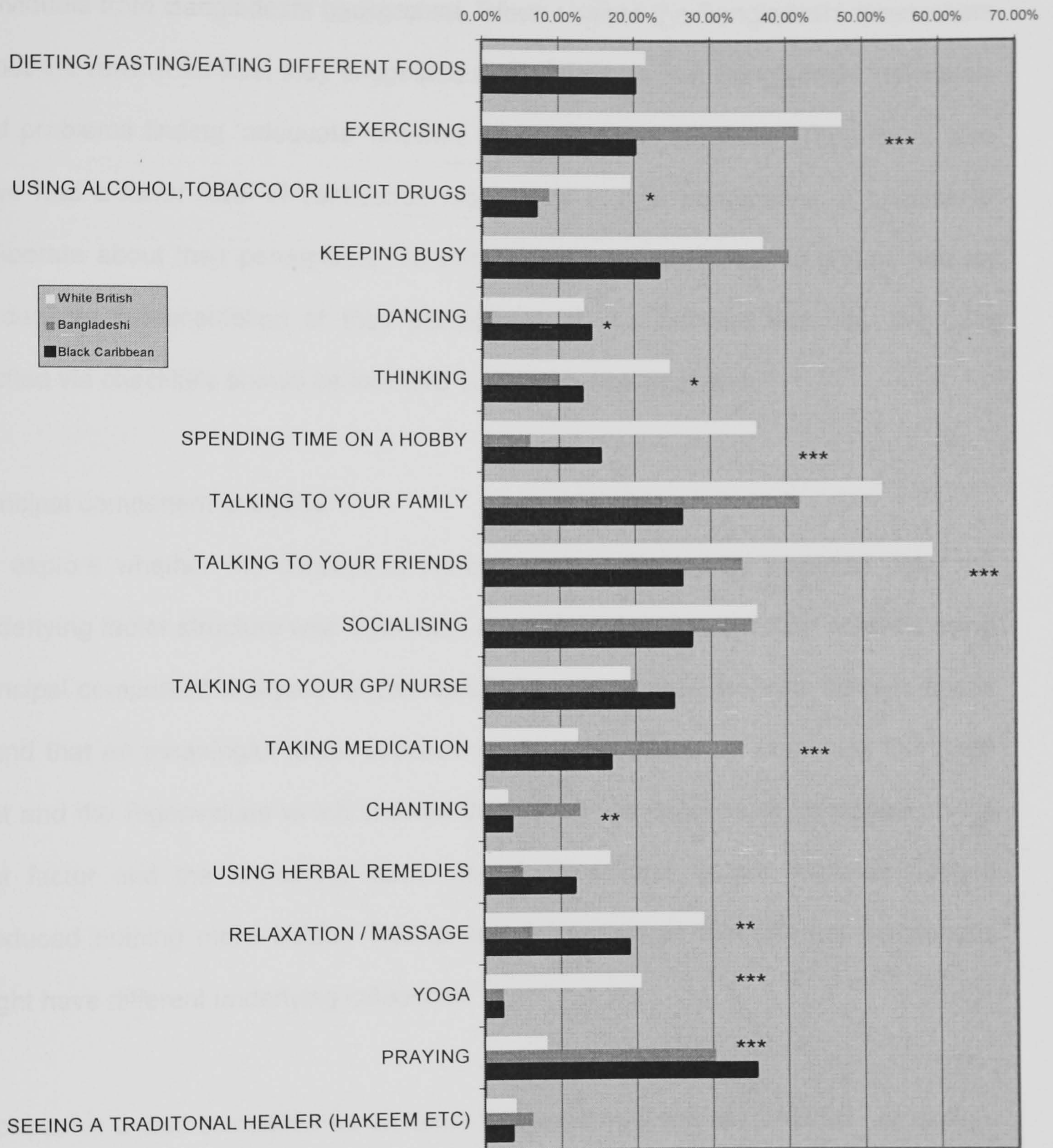
Assessment of treatment perceptions by checklist BEMI-C 4 asked individuals to tick, if they had considered or tried an intervention and if so whether they had found it helpful. They were asked to tick 'considered' if they had thought about an intervention and 'tried' if they had tried the intervention and tick 'helpful' if they found it helpful. I have reported only items that were considered helpful in Table 27 below.

Table 28 Perceptions about **helpful** treatment interventions as assessed by BEMI-C 4 We would like to know whether you have considered or tried any of the following methods to resolve your problem and whether you found them helpful. Please tick the boxes for considered if you have thought about the method, **and/ or** tick the box in the tried column if you have tried the method and tick the box for helpful if you found it helpful.

TREATMENT	White British N=105	Bangladeshi N=79	Black Caribbean n=86
DIETING/ FASTING/EATING DIFFERENT FOODS	21(21.6%)	8(10.1%)	17(20.2%)
EXERCISING	46(47.4%) ^{**BA & ***BC}	22(41.8%) ^{**WB}	17(20.2%) ^{***WB}
USING ALCOHOL, TOBACCO OR ILLICIT DRUGS	19(19.6%) ^{***BA & *BC}	7(8.9%)	6 (7.1%) ^{*WB}
KEEPING BUSY	36(37.1%)	32(40.5%)	20(23.3%)
DANCING	13(13.4%) ^{**BA}	1(1.3%) ^{**WB&BC}	12(14.3%) ^{**BA}
THINKING	24(24.7%) ^{*BA & BC}	8(10.1%) ^{*WB}	11(13.1%) ^{*WB}
SPENDING TIME ON A HOBBY	35(36.1%)	5(6.3%)	13(15.5%) ^{***}
Total cases who found at least one self-directed intervention helpful	74(70.5%)^{**BA & ***BC}	46(58.2%)^{**WB}	40(46.5%)^{***WB}
TALKING TO YOUR FAMILY	51(52.6%)	22(41.8%)	22(26.2%)
TALKING TO YOUR FRIENDS	58(59.2%) ^{***BA & BC}	27(34.2%) ^{***WB}	22(26.2%) ^{***WB}
SOCIALISING	35(36.1%)	28(35.4%)	23(27.4%)
Total cases who found at least one social intervention helpful	80(76.2%)^{***BA & BC}	44(55.7%)^{***WB}	38(44.2%)^{***WB}
TALKING TO YOUR GP/ NURSE	19(19.4%)	16(20.3%)	21(25.0%)
TAKING MEDICATION	12(12.4%) ^{***BA}	27(34.2%) ^{***WB & **BC}	14(16.7%) ^{**BA}
Total cases who found at least one medical intervention helpful	24(22.9%)^{**BA}	33(41.8%)^{**WB}	26(30.2%)
CHANTING	3(3.1%) ^{*BA}	10(12.7%) ^{*WB & BC}	3(3.6%) ^{*BA}
USING HERBAL REMEDIES	16(16.5%) ^{*BA}	4(5.1%) ^{*WB}	10(11.9%)
RELAXATION / MASSAGE	28(28.9%) ^{***BA}	5(6.3%) ^{***WB & *BC}	16(19.0%) ^{*BA}
YOGA	20(20.6%) ^{***BA & BC}	2(2.5%) ^{***WB}	2(2.3%) ^{***WB}
Total cases who found at least one alternative intervention helpful	40(38.1%)^{**BA & *BC}	15(19%)^{**WB}	20(23.3%)^{*WB}
PRAYING	8(8.2%) ^{***BA & BC}	24 (30.4%) ^{**WB}	30 (35.7%) ^{**WB}
SEEING A TRADITIONAL HEALER (HAKEEM ETC)	4(4.1%)	5 (6.3%)	3 (3.6%)
Total cases who found at least one spiritual intervention helpful	11(10.5%)^{***BA & BC}	26 (32.9%)^{***WB}	31 (36%)^{***WB}

significant χ^2 at *p<.05, ** p<.01, *** p<.001 level

Figure 14 BEMI-C 4 We would like to know whether you have considered or tried any of the following methods to resolve your problem and whether you found them helpful. Please tick the boxes for considered if you have thought about the method, **and/ or** tick the box in the tried column if you have tried the method and tick the box for helpful if you found it helpful.



The statistical exploration of the differences in perceptions found that there were some similarities between cultures, but also that there were many significant differences in perceptions of distress. These could be seen as support for hypothesis 1.

Further analyses with the BEMI

The research with the BEMI-I found that not all individuals were able to answer open-ended questions about perceptions of distress. This was particularly pronounced for individuals from Bangladeshi background. When I asked the Bangladeshi researchers about the reason for this, they suggested that it might be that Bangladeshi individuals had problems finding 'adequate' answers to open-ended questions. They might also have had a lower level of confidence, coherence in their perceptions or practice to deliberate about their perceptions. To ensure that none of the ethnic groups had an inadequate representation of their perceptions, it was decided that only the data elicited via checklists should be included in the statistical analyses.

Principal component analyses

To explore whether the conceptual themes were supported by empirical data, the underlying factor structure was examined. In an initial exploratory factor analysis using principal component analyses, all perceptions were examined for each domain. It was found that no meaningful factor structure could be extracted by examining the scree plot and the Eigenvalues which showed that 95% of perceptions items loaded on the first factor and the remaining items loaded on several factors. Varimax rotation produced nothing more fruitful. This is understandable as the different perceptions might have different underlying influences.

Cronbach's α was calculated for all items that were conceptually ordered - to explore the themes internal reliability. The results are displayed in table 29 below.

Table 29 Internal Reliability of the Clusters

Theme (number of items)	Cronbach's α		Theme (number of items)	Cronbach's α	
Physical perceived symptoms (12)	.84		Psychological Consequences (7)	.75	.79
Mental perceived symptoms (13)	.84		Physical Consequences (3)	.34	
Behavioural perceived symptoms (15)	.82		Behavioural Consequences (2)	.21	
			Economic Consequences (2)	.21	.70
			Social Consequences (9)	.68	
Psychosocial causal attributions (17)	.80	.82	Self-directed Treatment (7)	.66	.81
Physical causal attribution (7)	.63		Social Treatment (3)	.50	
Behavioural causal attribution (3)	.45		Alternative Treatment (4)	.54	
Financial problems (1)	n.a.				
Weather causal attribution (2)	.34	.77	Medical Treatment (2)	.51	.61
Spiritual causal attribution (8)	.78		Spiritual Treatment (2)	.19	

Nunnally (1978) suggests that internal consistency is satisfactory when Cronbach's α is above .70 (Nunnally, 1978). As α is also dependent on the number of items (> 10), it was decided to aggregate items further to more superordinate themes. Causal perceptions were clustered for 'internal' (i.e. under one's influence) and 'external' (outside one's influence) causal attributions, and consequences were aggregated under 'affecting the self consequences' and 'affecting others consequences'. For intervention/ treatment 'informal' (self-directed and family) and 'formal' external agents were differentiated. All clusters produced acceptable internal reliability scores (except formal treatment) which might be considered acceptable as the cluster contained only four items. Scales with acceptable internal consistency sum scores were used and explored in relation to psychiatric caseness and acculturation.

5.3.3.2. H 2 Perceptions of distress are influenced by acculturation. With greater exposure to the host culture, perceptions will adjust towards that of the host culture.

This hypothesis was difficult to test by statistical analyses as acculturation is multidimensional construct that can be measured in a variety of ways. Initial thoughts explored the idea of using migration or generation characteristic status as a measure of acculturation. It was assumed that individuals who were born in their host country would be closer to the host culture than first generation migrants. However, only 46 individuals from the second or third generation ethnic minority background took part in the BEMI, which was insufficient to explore pathways statistically. It was also assumed that different factors would be involved in acculturation for individuals from different ethnic background, so that it was important to control for ethnic background. Secondly it was assumed that perceptions would be different in individuals who were from birth exposed to a complex array of culturally diverse perceptions. To explore the genuine effect of 'acculturation', or changes in perceptions due to time of exposure to host culture, it was decided to contrast only perceptions of first generation migrants with those of non-migrating White British individuals (see table 30). To explore the effects of exposure by length of stay descriptively it was decided to split the group by the median time of exposure, 22 years.

Table 30 Perceptions endorsed by different acculturation groups split by median years of exposure to British culture

	Non migrated White British n=74	White British living in UK for 0-21.99 years n=3	White British living in UK for 22 + years n=19	Bangladeshi living in UK for 0-21.99 years n=44	Bangladeshi living in UK for 22+ years n=31	Black Caribbean living in UK for 0-21.99 years n=28	Black Caribbean living in UK for 22 + years n=30
CISR cases	28 (35%)	3 (100%)	8 (40%)	32 (72.7%)	21 (67.7%)	4 (14.3%)	7 (26.9%)
Has somatic perceived symptoms (identity)	69 (93.2%)	3 (100%)	17 (89.5%)	41 (93.2%)	30 (96.8%)	18 (64.3%)	20 (80%)
Has mental perceived symptoms (identity)	64 (86.5%)	3 (100%)	15 (78.9%)	42 (95.5%)	27 (87.1%)	23 (82.1%)	19 (76%)
Has behavioural perceived symptoms (identity)	60 (81.1%)	3 (100%)	14 (73.7%)	31 (70.5%)	21 (67.7%)	16 (57.1%)	16 (64%)
Attributes distress to self or others	68 (91.9%)	3 (100%)	18 (94.7%)	42 (95.5%)	30 (96.8%)	23 (82.1%)	24 (96%)
Attributes distress to external agents	34 (45.9%)	2 (66.7%)	2 (10.5%)	34 (77.3%)	23 (74.2%)	7 (25%)	10 (40%)
The timeline is cyclical/ coming and going	68 (84%) _{n=81}	3 (100%)	15 (75%)	24 (57.1%)	12 (40%)	16 (64%)	15 (57.7%)
Experienced consequences to self	68 (91.9%)	3 (100%)	15 (78.9%)	42 (95.5%)	30 (96.8%)	22 (78.6%)	19 (76%)
Experienced social consequences	32 (43.2%)	2 (66.7%)	10 (52.6%)	24 (54.5%)	19 (61.3%)	17 (60.7%)	12 (48%)
Found informal treatment helpful	64 (86.5%)	3 (100%)	18 (94.7%)	24 (54.5%)	25 (80.6%) ($\chi^2=5.470, p<.05$)	11 (39.3%)	18 (72%) ($\chi^2=5.705, p<.05$)
Found formal treatment helpful	42 (56.8%)	1 (33.3%)	13 (68.4%)	25 (56.8%)	20 (64.5%)	12 (42.9%)	17 (68%)

5.3.3.2.1. Descriptive statistics and univariate analyses

It was found that among the Bangladeshi individuals who came to this country less than 22 years ago there were a higher proportion of CISR cases compared with those who had been here for 22 years or longer. Caribbean individuals, on the other hand, had a higher proportion of psychiatric cases in the group that stayed in the UK for longer. The distribution however was not significantly different in either of the groups when assessed by means of a χ^2 test.

There were few significant differences in perceptions, and they focussed on viewing informal treatment as useful. A correlation matrix relating perceptions to length of stay also only found informal treatment perceptions to be significantly associated with distress. The lack of an effect might have been produced by the small numbers, a true lack of association, or by a confounding influence affecting the relationship between exposure to host culture and perceptions. Age was examined as one possible confounding variable as individuals, who have lived for 22 years or longer in the UK were likely to be older than individuals who have been here for less time:

Age → Exposure to Host Culture (Length of Stay in UK) → Perceptions

According to this proposed pathway, older individuals have higher levels of physical morbidity, and are more likely to talk about different perceptions as a consequence. Individuals, who have lived in this country for longer, also seem to have established more helpful self-treatment methods and social networks. To explore whether exposure to host culture would affect perceptions of distress after controlling for age, it was decided to compute partial correlations. The partial correlation matrix is displayed in Appendix 10 and shows that three perception themes were correlated with exposure to host culture when controlling for the effects of age. Attributing illness to an external cause was negatively associated with length of exposure; viewing support from informal sources such as family and friends as helpful was positively associated with length of exposure. These findings

support the hypothesis as fewer White British attributed their distress to external causes and most find informal support helpful. Reporting internal consequences was almost significantly negatively associated with length of stay.

5.3.3.1. Multivariate Statistics

To explore the association between acculturation in terms of exposure (length of stay) and perceptions, it was decided to conduct a hierarchical multiple regression analysis that would allow one to control for the effects of age. The perception variables included were those that were significantly or almost significantly associated with distress in the partial correlation matrix (see above).

In the first step, when only age was entered into the regression it was found that the model was highly significant at predicting length of stay ($R^2 = .48$, $p < .001$). In the second step perceptions were entered and it was found that they added significantly perceptions were adding to the model. The final regression model was highly significant and explained 58% of the variance ($\text{Adj } R^2 = .58$, $p < .001$). The standardised coefficients (Beta) showed that 3 of the 4 included variables were also significant. The standardised regression coefficients were highest for age (.718, $p < .001$), second highest for attributing distress to an external cause (-.235, $p < .015$) and third highest for finding informal treatment helpful (.226, $p < .001$). Reporting internal consequences was not useful in predicting exposure of stay (-.043, $p = .137$).

5.3.3.3. *H3 Perceptions of distress will vary significantly between psychiatric cases and non-cases.*

Psychiatric Caseness

The Clinical Interview Schedule (Revised) was used to assess distress. It determines scores of clinical significance for a variety of different aspects of psychiatric conditions and is designed to assign psychiatric diagnoses in epidemiological studies. Items were scored for each of the fourteen sections (according to CIS-R guidelines) and a sum score was obtained by aggregating all sections together. If individuals scored 12 and above, they were considered to be a case, and if they scored below they were not. In the case of missing data on two or three sections, the score was computed manually and a conservative evaluation was made: If individuals scored above the threshold on the sum of the remaining sections, they were considered to be a case. If individuals scored so far below that even with a maximum score on the remaining sections they would not be able to go over the threshold of the CIS-R for psychiatric caseness, they were considered not to be a case. If missing data was reported on four or five sections on the CIS-R and/ or a decision about caseness could not be made, they were classed as missing data. This affected only two (1 WB & 1BC) individuals in the sample.

268 (74.4%) of the sample (n=362) said that they had experienced something that stressed them in the past month and therefore qualified themselves for the survey about their perceptions/ explanatory models. From these, 151 (41.9%) did not fulfil the criteria for psychiatric caseness (CIS-R \geq 12), but 117 (32.5%) did. Table 31 breaks down the number of individuals per ethnic group.

Table 31 Experienced Stress by CISR caseness and ethnic group

Experienced stress in the past month		Absent	Present	Total
White British	No case	20(16.1%)	65 (52.4%)	85 (68.5)
	Case	0	39 (31.5%)	39 (31.5%)
	Total	20 (16.1%)	104 (83.9%)	124 (100.0%)
Bangladeshi	No case	42 (34.4%)	22 (18.0%)	64 (52.5%)
	Case	1 (.8%)	57 (46.7%)	58 (47.5%)
	Total	43 (35.2%)	79 (64.8%)	122 (100%)
Black Caribbean	No case	27 (23.7%)	64 (56.1%)	91 (79.8%)
	Case	2 (1.8%)	21 (18.4%)	23 (20.2%)
	Total	29 (25.4%)	85 (74.6%)	114 (100%)

Only 3 of the 92 individuals who said that they had not experienced distress in the past month met the criteria for psychiatric caseness. This suggests that the starter question of the BEMI had a high level of sensitivity to different levels of distress, but low levels of specificity in filtering out severely distressed individuals.

When the distribution of psychiatric cases was examined in association with ethnicity it was found that the distribution of cases was not equal among the ethnic groups ($\chi^2= 20.161$, $p<.001$) and particularly not equally distributed among individuals who said yes to the starter problem ($\chi^2= 40.091$, $p<.001$). Among the Bangladeshi a higher proportion of cases said yes to the question whether they experienced stress in the past month whereas in the other groups the majority of those who experienced stress were non-cases.

Ethnic differences in perceptions of distress were stratified by CIS-R caseness in table 32 and table 33 below. Initially significant differences in the distribution of perceptions were explored by computing χ^2 tests for cases and non-cases for each ethnic group. In table 32 all perception items were aggregated according to the previously determine scales in table 29, and univariate analyses (independent t-tests) were used to determine whether the number of perceptions was significantly different between cases and non-cases.

Table 32 Content of Perceptions of distress stratified by psychiatric caseness and ethnic background

	White British			Bangladeshi			Black Caribbean		
	Non-Case N=61	Case N= 36	Statistical test χ^2	Non-Case N=22	Case N=57	Statistical test χ^2	Non -Case N=63	Case N=20	Statistical test χ^2
Reports somatic perceived symptom	53 (86.9%)	36 (100%)	$\chi^2 = 5.146, p < .05$	18 (81.8%)	57 (100%)	$\chi^2 = 10.916, p < .001$	40 (63.5%)	20 (100%)	$\chi^2 = 10.101, p < .001$
Reports mental perceived symptom	47 (77%)	35 (97.2%)	$\chi^2 = 7.048, p < .01$	16 (72.7%)	57 (100%)	$\chi^2 = 16.823, p < .001$	48 (76.2%)	20 (100%)	$\chi^2 = 5.812, p < .05$
Reports behavioural perceived symptom	41 (67.2%)	36 (100%)	$\chi^2 = 14.869, p < .001$	10 (45.5%)	45 (78.5%)	$\chi^2 = 8.419, p < .01$	31 (49.2%)	20 (100%)	$\chi^2 = 16.533, p < .01$
Attributes distress to self or others	55 (90.2%)	36 (100%)	$\chi^2 = 3.774, p = .052$	21 (95.5%)	55 (96.5%)	$\chi^2 = .047, n.s.$	53 (84.1%)	20 (100%)	$\chi^2 = 3.609, p = .057$
Attributes distress to external agents	8 (13.1%)	14 (38.9%)	$\chi^2 = 8.576, p < .01$	11 (50%)	48 (84.2%)	$\chi^2 = 9.826, p < .01$	13 (20.6%)	15 (75%)	$\chi^2 = 20.071, p < .001$
The timeline is cyclical/ coming and going	53 (81.5%)	33 (84.6%)	$\chi^2 = 1.868, n.s.$	8 (36.4%)	30 (52.6%)	$\chi^2 = 5.053, n.s.$	36 (56.3%)	14 (66.7%)	$\chi^2 = .826, n.s.$
Lasted more than 1 year	21 (33.9%)	24 (63.2%)	$\chi^2 = 8.165, p < .01$	12 (54.5%)	43 (78.2%)	$\chi^2 = 4.302, p < .05$	36 (56.3%)	12 (57.1%)	$\chi^2 = .670, n.s.$
Experienced internal consequences	50 (82%)	36 (100%)	$\chi^2 = 7.332, p < .01$	19 (86.4%)	57 (100%)	$\chi^2 = 8.080, p < .01$	49 (77.8%)	20 (100%)	$\chi^2 = 5.436, p < .05$
Experienced external consequences	18 (29.5%)	26 (72.2%)	$\chi^2 = 16.665, p < .001$	8 (36.4%)	39 (68.4%)	$\chi^2 = 6.769, p < .01$	30 (47.6%)	13 (65.0%)	$\chi^2 = 1.837, n.s.$
Found informal treatment helpful	53 (86.9%)	33 (91.7%)	$\chi^2 = .515, n.s.$	13 (59.1%)	39 (68.4%)	$\chi^2 = .614, n.s.$	31 (49.2%)	17 (85.0%)	$\chi^2 = 7.975, p < .01$
Found formal external treatment helpful	35 (57.4%)	22 (61.1%)	$\chi^2 = .130, n.s.$	9 (40.9%)	39 (68.4%)*	$\chi^2 = 5.039, n.s.$	30 (47.6%)	13 (65.0%)	$\chi^2 = 1.837, n.s.$

Table 33 Number of Perception (means) stratified by ethnicity and psychiatric caseness

	White British			Bangladeshi			Black Caribbean		
	Non-Case N=61	Case N= 36	ANOVA	Non-Case N=22	Case N=57	ANOVA	Non-Case N=63	Case N=20	ANOVA
Mean of somatic perceived symptoms	2 (2)	6 (3)	F (1, 95)=58.453, p<.001	3 (2)	7 (3)	F (1, 78)=36.754, p<.001	2 (3)	7 (3)	F (1, 82)=42.095, p<.001
Mean of mental perceived symptoms	2 (2)	6 (3)	F (1, 95)=61.063, p<.001	3 (3)	7 (3)	F (1, 78)=39.460, p<.001	2 (3)	7 (3)	F (1, 82)=48.182, p<.001
Mean of behavioural perceived symptoms	2 (2)	4 (3)	F (1, 95)=35.122, p<.001	1 (1)	3 (3)	F (1, 78)=15.578, p<.001	1 (2)	5 (4)	F (1, 82)=28.406, p<.001
Mean number of perceived symptoms (SD)	7 (5)	17 (7)	F (1, 95)=73.939, p<.001	6 (5)	17 (7)	F (1, 78)=43.402, p<.001	6 (7)	19 (9)	F (1, 82)=45.958, p<.001
Mean of attribution to self or others	4 (3)	8 (4)	F (1, 95)=38.598, n<.001	4 (3)	5 (3)	F (1, 78)= 4.674, n<.05	3 (3)	10 (7)	F (1, 82)=49.494, n<.001
Mean of attribution to external agents	0 (1)	1 (1)	F (1, 95)=6.111, p<.05	1 (1)	1 (1)	F (1, 78)=5.556, p<.001	0 (1)	1 (1)	F (1, 82)=36.547, p<.001
Mean of causal attributions (SD)	4 (3)	8 (4)	F (1, 95)=33.418, p<.001	4 (4)	8 (4)	F (1, 78)=13.094, p<.001	3 (3)	12 (9)	F (1, 82)=45.421, p<.001
Mean of internal consequences	3 (2)	6 (2)	F (1, 95)=42.069, p<.001	3 (2)	6 (3)	F (1, 78)=29.921, p<.001	2 (2)	6 (3)	F (1, 82)=62.011, p<.001
Mean of external consequences	1 (2)	1 (1)	F (1, 95)=4.538, p<.05	1 (1)	2 (2)	F (1, 78)=8.353, p<.01	1 (1)	3 (3)	F (1, 82)=21.612, p<.001
Mean sum of experienced consequences	3 (3)	7 (3)	F (1, 95)=29.975, p<.001	3 (3)	8 (3)	F (1, 78)=30.680, p<.001	3 (3)	10 (5)	F (1, 82)=54.463, p<.001
Mean sum of preferred informal treatment	3 (2)	3 (2)	F (1, 95)=.242, n.s.	2 (2)	2 (2)	F (1, 78)=.041, n.s.	1 (2)	4 (3)	F (1, 82)=25.780, p<.001
Mean sum of preferred external/ formal treatment	1 (1)	1 (1)	F (1, 95)=.068, n.s.	1 (1)	1 (1)	F (1, 78)=3.619, n.s.	1 (1)	2 (2)	F (1, 82)=10.361, p<.01
Number of helpful treatments for distress	2 (1)	2 (1)	F (1, 95)=.506, n.s.	2 (2)	2 (1)	F (1, 78)=1.701, n.s.	1 (2)	3 (2)	F (1, 82)=11.494, p<.01

5.3.3.3. Results

5.3.3.3.1. Univariate analyses

5.3.3.3.1.1. Distribution of Perception Themes

Individuals who scored higher than the cut-off for psychiatric caseness on the CISR (cases) and those who scored lower (non-cases) had differing perceptions across all domains. Almost all cases reported either a behavioural, somatic and mental perceived symptom, in contrast to varying proportions among non-cases. It was also found that a significantly higher proportion of cases (independent of ethnic background) attributed their distress to external agents. For cases and non-cases there were significant differences concerning the length of time their distress had lasted in the Bangladeshi and White British group, but not the Black Caribbean group. There were also significant differences between cases and non-cases for psychological consequences and financial consequences.

Differences between cases and non-cases were also examined by considering the number of perceptions people held about their distress. Individuals who scored higher than the cut-off for psychiatric caseness on the CISR (cases) described more perceived symptoms of distress. Cases also attributed their distress to a significantly larger number of causes and reported a significantly higher number of consequences. These findings were found to hold across ethnic backgrounds. It was found that Black Caribbean cases reported more symptoms, more causal attributions and more consequences. In the Caribbean group there was a significant difference between the number of interventions that was seen as helpful between cases and non-cases, but no significant differences were found in the other ethnic groups or when considering specific kinds of treatment.

In order to examine the relationships further, the predictive power of the perception scales on psychiatric caseness was explored through logistic regression. A correlation matrix was first produced to evaluate whether perception scales, ethnicity and CISR caseness were significantly correlated for each ethnic group and then for the overall sample (see Appendix

11). It was found that all perception scale and ethnic background were significantly correlated with CIS-R caseness.

5.3.3.3.2. Multivariate analyses

A logistic regression analysis was chosen to determine whether perceptions predicted caseness. Green (1991) provided a detailed overview of the procedures used to determine regression sample sizes (Green, 1991). He suggests $N > 50 + 8m$ (where m is the number of IVs) for examining multiple correlations. Hence, the number in each group was insufficient to permit conducting individual analyses per ethnic group, but did allow including ethnicity as an indicator variable. A hierarchical logistic regression was conducted, in which ethnic background was included as a first step, perception scores were entered second to explore how much they added to the variance explained. Ethnic background was found to explain a significant proportion of the variance (Nagelkerke $R^2=.200$, $p<.0001$). In comparison with White British, the odds for being a case were significantly different only for individuals of Bangladeshi background (OR 4.39, CI 2.3 - 8.3), but not Black Caribbean (OR .54, CI .28-1.03). When perceptions were added, a much larger proportion of the variance was explained (Nagelkerke $R^2=.577$, $p<.0001$). Still individuals from Bangladeshi background had significantly higher odds of being a psychiatric case (OR 4.38, CI 1.663-11.560). Also individuals who reported one or more mental perceived symptom had significantly higher odds for being a psychiatric case (OR 11.541, CI 1.85-112.451). Similarly, individuals who cited one or more behavioural items had higher odds for being a psychiatric case (OR 5.812, CI 2.11-16.015). Individuals who reported that external agents had contributed to their distress had significantly higher odds for being a psychiatric case (OR 2.809, CI 1.34 – 5.91) and finally individuals who reported external consequences were also at higher odds for being a psychiatric case (OR 2.14, CI 1.05 -4.26).

Chapter 6 Discussion

The discussion of the PhD is divided into three main sections. The first section discusses the development of the Barts Explanatory Model Inventory including the qualitative analyses of subjective literature accounts. The second section reviews evidence regarding cultural association with distress i.e. whether the influence of ethnic background on perceptions could be demonstrated and whether acculturative processes affect perceptions of mental distress. The third section discusses the association between perceptions of distress and absence or presence of distress (psychiatric caseness). Each section contains a brief summary and discussion of the main findings, determines strengths and limitations of the findings in relation to prior knowledge, and considers implications for clinical practice and past research. The conclusion describes how the findings might enhance our general understanding of perceptions and culture and identifies areas for future research.

6.1. Barts Explanatory Model Framework Development – the conceptualisation and assessment of cultural variations in perceptions of distress

6.1.1. Summary of Findings

This thesis first explored how cultural/ ethnic variations in lay perceptions of mental distress can be best conceptualised and assessed.

Medical anthropological literature and health psychological literature was considered to inform how distress has been conceptualised and assessed in the past. Theories of illness perceptions (explanatory model and illness representation approach) previously focussed assessment on five domains. These domains were identity, cause, consequence, course and treatment and form the conceptualisation of the lay perceptions (Lau and Hartman, 1983; Kleinman, 1980). A transdisciplinary approach was adopted to review the conceptualisation of distress in relation to cultural variations and identified additional issues that extended the current conceptualisations (see

Chapter 2a p32). It was considered how suitable currently available assessment tools (Kleinman's 8 questions, EMIC, SEMI, MDMEQ, IPQ and IPQ-R) are to conduct comparative research on perceptions in different cultural groups (Chapter 2b). The review concluded that these were not useful for assessing cultural variations in perceptions comprehensively. In the main, interview methods appeared too lengthy to administer and analyse, and questionnaires were problematic in cultural comparative research. Cross-cultural research using questionnaires must determine that a) the constructs within the perception assessment are valid in each of the populations studied, b) the assessment method produces comparable results in each of population studied and c) they are also sensitive enough to detect 'emic' conceptualisations of distress (Canino, Lewis-Fernandez, & Bravo, 1997). The review concluded that a comprehensive cross-cultural assessment of perceptions needs to be able to assess perceptions on an 'etic' as well as an 'emic' level and should therefore combine different assessment methods to ensure the validity of the assessment.

A literature review used subjective literature accounts to identify common perception themes. Many different perceptions and themes were found that could be used to cluster perceptions (items) to examine cultural differences in a broader sense. An assessment inventory was developed from the findings that contained Barts Explanatory Model Inventory - Interview and Checklist and a data management tool. The BEMI-I contains 9 open-ended questions and 3 structured questions, to determine an emic perspective and validate the research. The interview is supplemented by detailed 4 page questionnaire in a concrete checklist format (BEMI-C). The data management tool records the absence or presence of perceptions in interview and or checklist and also allows for clustering items under common themes.

The tool had good test-retest reliability (.78-.99) and empirical research also established that there was sufficient internal consistency for the majority of the identified conceptual themes. The pilot study established that the BEMI had good face,

content and external validity. Also there were significant correlations between the identity and the causal items of the BEMI and the IPQ, suggesting that some concurrent validity appears to be apparent although this needs further validation. Lastly the empirical work conducted after the pilot study further validated that the content was appropriate as over 95% of the listed perceptions were endorsed by individuals in the survey.

6.1.2. Strengths and Weaknesses of the BEMI

6.1.2.1 Strengths

The BEMI is short and easy to administer in different situations i.e. medical and community settings, with demographically diverse individuals and enabled an assessment of cultural variations in perceptions. The limited examination of the psychometric properties of the tool suggests that the tool has adequate internal consistency, reliability and validity.

The BEMI adds to the existing tools in terms of its brevity and cross-cultural validity, and offers a conceptual data management framework, which can be used to interpret open-ended emic data quickly. In contrast to IPQ assessment, the BEMI assesses the consequence, timeline and treatment perceptions in a conceptually different way. The BEMI asks individuals about their perceived consequences, their perceived past as well as expected course (timelines) and requests individuals to evaluate their help-seeking process by judging treatment options in terms of preferred, tried and helpful treatments. The IPQ on the other hand assesses agreement with certain beliefs regarding the controllability of the illness and the seriousness and the length of time the illness is expected to last. In terms of perceptions regarding identity and cause the IPQ and the BEMI are similar organised, but the items within the BEMI describe more mental symptoms than the IPQ. The BEMI might therefore add to the IPQ assessment when assessing perceptions of mental distress. The BEMI extends the MDEMQ assessment by including other perception domains, therefore granting a more

comprehensive assessment of the patient perspective. The BEMI further extends the currently available explanatory model interviews (K8, SEMI, EMIC) in providing a more structured approach for data elicitation and management, and reducing the risk of omitting important perceptions by including checklists.

The use of an assessment inventory using mixed methods has benefits as one can explore perceptions comprehensively and unravel conceptual differences in perception communication and understanding. French et al reported in their study of non-patient and patient attribution of myocardial infarction that differences in attributions were more likely to be explained by measurement similarities than actor-observer correlations, recommending that a combination of diverse assessment methods might therefore produce more robust findings (French, Marteau, Weinman, & Senior, 2004).

The items included in the checklist and the data management tool, were endorsed by 95% of individuals within our study and newly identified items fitted mostly under pre-existing themes. In the open-ended interviews 82 additional items were identified, but most items could be easily categorised under the pre-existing structure. Only two additional themes were identified: social identity and positive consequences. In the treatment section, resolution of outside circumstances, money and time were not subsumed as they were referring to general effects. Similarly individuals said 'Don't know' across all domains in the open-ended interview. The framework underlying the tool is hence flexible and adaptable to new items and can be easily adapted to new data.

6.1.2.2. Weaknesses

The BEMI's is based on qualitative analyses of *secondary* data such as qualitative case studies and literature accounts as the closest available analogue to individuals' experience of distress. Some might say it is impossible to analyse secondary data qualitatively as the data has already been analysed and is presented to support the

analyses. Qualitative analyses (in particular IPA) also would consider the subjective aspect of interpreting the data. Following these critique, it seems that the instrument would have benefited from talking to individuals from across the globe about their experience of distress. With greater time, researchers and funding this undoubtedly would have been a preferred and more thorough approach to the development of a cross-culturally valid tool on lay perceptions. However, one would have had to learn a multitude of languages and recruit a research team that spent years coding and interpreting the interviews before producing a new assessment tool. When this was attempted in the area of quality of life, the most culturally appropriate tool, the World Health Organisation's Quality of Life Scale (WHOQOL), was developed with immense care and input from all over the world (Kuyken et al, 1994). Nevertheless, although the WHOQOL overcomes the majority of problems as far as construct validity is concerned the questionnaire still has problems in cross-cultural application (Collinge, Rüdell, & Bhui, 2002). To sample from literature accounts was therefore seen as appropriate, even though they offered only a small window on patients' perception of distress. Nevertheless, it was possible to draw on material from all over the world and develop expertise in cultural variations in perceptions of distress.

An exploratory factor analysis did not replicate the conceptual theme structure, but this might be because perceptions, unlike other psychological attributes, cannot possess construct validity.

The strengths of the BEMI in terms of brevity might also be interpreted as a weakness as it reduces the need to immerse in other cultures, increasing the risk of uncritical application. However, in order to ensure comparability and validity across cultures I would strongly recommend researcher to use both parts of the instrument when applying it in a culture in which it has not been validated.

The validity of the tool was examined in three ethnic groups in two languages (Sylheti and English), but it is still unclear how the BEMI might perform in other languages or in other settings (i.e. outside the UK). Further studies are necessary to determine a universal applicability and cross-cultural validity. More data regarding the psychometric properties should be gathered in relation to test and re-test reliability and construct validity of the tool.

The predictive value has not been demonstrated as the funding proposal for this PhD specified a cross-sectional study. The predictive value is best demonstrated in longitudinal studies, where the influences of cause and effect can be identified. I describe in the next section how one might best determine the tool's predictive value in future studies.

6.1.3. Implications for Clinical Practice and Future Research

The theoretical and conceptual development of the scale has little direct effect on clinical practice. However, an indirect effect might be associated with the adopted transdisciplinary approach (integrating knowledge from different disciplines) and the outcome of the development - the BEMI, which could be used in clinical practice. The transdisciplinary approach supports and transcends Kleinman's ideas surrounding clinical practice, described as 'clinical social science' by arguing that health problems need the input from a variety of disciplines (e.g. epidemiology, medicine, psychology, biology, ecology etc) and need input from different methodological approaches (e.g. Emic and etic, qualitative and quantitative).

Comparative research with the BEMI will be contentious as at this moment in time, whilst it has not been determined whether the research tool is comparable with other tools (EMIC, SEMI), to elicit an individuals' emic perspective. More comparative research with different tools is needed to examine where the main strengths and

weaknesses are and how one might be able to assess both intra-ethnic and inter-ethnic variation better.

Within Kleinman and colleagues' 'clinical social science' model of clinical practice, the clinician elicits the patient EM, compares it with the physician model and then via careful communication develops an integrated model, leading to better treatment adherence and outcome (Kleinman, Eisenberg, & Good, 1978). Research has shown that elicitation can be complex and time consuming (Jadhav et al, 2001). Additional knowledge from other disciplines (in particular cultural psychology) has facilitated the development of a comprehensive, but less time-consuming assessment which might make a comprehensive formal assessment within clinical practice possible.

The BEMI was designed to explore cultural variations in perceptions of distress however there are other areas in which the tool might be useful. The BEMI-I is a fairly generic tool which could easily accommodate not only perceptions of mental distress, but also perceptions of a variety of physical illnesses and chronic conditions. The BEMI-C can be used to support clinicians and researchers to comprehensively assess how lay people construct their illness in time-limited circumstances.

The existence of the BEMI might attract more researchers to conduct more comparative descriptive research into ethnic and cultural variations in patients' perception of their illness. The BEMI could also be used to compare perceptions across different socio-demographic categories such as different socio-economic status, geographical region and/ or individuals suffering from distinct psychopathological conditions etc. Surveys on the patient perspective in individuals at different stages of a disorder might also inform more epidemiological questions regarding the incidence of *disease* by underpinning it with knowledge regarding the incidence of *illness*.

The predictive validity of the instrument might therefore be demonstrated by associating perceptions with outcome factors (e.g. subjective perceptions of related areas quality of life, ability to function, service use, physical and psychological morbidity, physiological effects and mortality). For example, it seems useful to examine perceptions' association with the development of illness as well as the development of disease. In psychiatric conditions in which indicators for disease severity are less discernible physiologically, this could be problematic, but other indicators could be used. Experimental psychological and neurological research exploring the lay experience of distress and linking it with attention spans, reaction times, neurological associations and immunological functions would also allow evaluating the importance of perception and appraisal further.

6.2. Researching cultural variations in perceptions of mental distress

The impact of culture on perceptions was derived by associating perceptions with ethnic background and examining perceptions' associations with the exposure to host culture. In general it appeared that the groups were probably more similar in their perceptions than they were different. However there also some significant ethnic differences could be observed, which means that the study found partial support for the first hypothesis. It is important to stress that the differences refer to group variations and that 'ethnic' groups are a heterogeneous group of individuals who have been exposed to different cultural influences.

In relation to the second hypothesis, it was found that some perceptions changed in relation to exposure but many remained the same, which partially supports the second hypothesis also.

6.2.1.1. Brief Summary of Findings – H 1 Ethnic variations in perceptions of distress

6.2.1.1.1) Identity

In the identity domain, variations in perceptions of the mental, physical and social theme were found. In the behavioural domain only substance abuse showed notable cultural variations and will therefore be discussed in detail. Perceptions regarding mental theme were the most commonly spontaneously voiced symptom across all cultures suggesting that individuals report similar mental concerns across cultures. There were however culturally diverse preferences for particular words describing the experience of distress. For example White British favoured certain terms 'stress', 'nervousness' and 'anxiety', while Bangladeshi preferred 'worries' and 'tension'.

A significantly higher proportion (>50%) of individuals of Bangladeshi and Caribbean background reported spontaneously that social problems were the identity of their distress than White British (37%). It is difficult to determine whether a focus on social problems is a culturally accepted non-stigmatising form to communicate distress in these groups, or whether individuals of these groups have an alternative holistic experience of distress.

White British lay individuals included social factors in their perceptions of distress in spontaneous narrative, but they were seen as more important in the causes of distress. The large majority of individuals from White British background (over 90%) spontaneously attributed their distress to at least one psychosocial cause.

A significantly smaller proportion of White British individuals (16%) described spontaneously physical problems than the other groups (BA = 40%; BC = 29%), but when assessed by checklist it was found that over 90% of White British regarded physical complaints as symptoms of their distress.

Finally, the number of individuals who spontaneously reported substance abuse to be a symptom of distress compared to the number who ticked it on the checklist was also significantly different. Less than 4% Bangladeshi individuals spontaneously reported as part of the identity in the spontaneous assessment and none of the other groups did. But on the checklist assessment over 40% of the White British population and 20% of both ethnic minorities identified it as an indicator of their mental distress.

6.2.1.1.2.) Cause

Among causal perceptions, the main findings for discussion were considerable ethnic differences in the proportions of people who answered 'don't know' in the interview (BA & BC =20%; WB= 4%) and ticked 'spiritual' items in the checklist (BA=75%; BC=31%; WB=17%). For each ethnic group specific attributions were also observed: more White British reported work to be the cause of their distress (WB=42%, BA=6%; BC=11%) spontaneously and (WB=52%, BA=25%, BC=27%) by checklist. More Caribbean attributed mental distress spontaneously to their personality than did any other group (BC=23%, WB=13%, BA=6%) and to their ethnic group by checklist (BC=12%; BA=5%, WA=3%). Bangladeshi had significantly higher proportions who attributed their distress to illness spontaneously (BA=27%, BC=7%, WB=5%) and by checklist (BA=35%, BC =13%; WB=11%).

6.2.1.1.3) Timeline

The timeline analysis showed that the distribution of specific past and expected timeline perceptions was significantly different across ethnic groups and that the various groups also had different perceptions regarding the nature of the timeline. It seemed that Bangladeshi and White British perceptions were placed at the extreme ends in this domain and Caribbean were located in the middle. The majority of White British believed that their illness had lasted less than two years, while the majority of Bangladeshi believed that their distress had lasted longer than two years. When individuals were asked about the length of time they expected their distress to last, the

majority higher among ethnic minorities (BC=58.1%, BA=56.4%) and 34.3% among the White British had no idea, the Chi² analysis showed that this was a significant difference. Only 12-17% of ethnic minority groups said it would last less than a year in contrast to 40% of White British. As there were significantly fewer individuals among the ethnic minorities (BA=50%, BC=59%), who said that their illness was episodic than among the White British group (83%), this suggests that individuals from ethnic minorities have a longer lasting constant effect. In addition, between a fifth (WB and BC=19%) and a quarter (BA=27%) of the sample thought that it could not be helped and would therefore last forever.

6.2.1.1.4) Consequences

The main ethnic variations were associated with psychological effects, as well as social and physical consequences and substance abuse. A significantly higher proportion of White British reported spontaneously more doubt (WB=16% versus BA=3%; BC=9%) and aversive feelings (i.e. feeling angry, sad, irritable, depressed) (WB =33% versus BA=15%, BC=17%). A significantly larger proportion of Black Caribbean and Bangladeshi reported the consequence of 'feeling powerless' (BC =23%; BA=19% versus WB=8).

Significantly more individuals from a Bangladeshi noted in the structured part of the interview that their status had changed (BA=47% versus WB=31%, BC 30%) and said that their distress influenced their physical ability (BA=70% versus WB=36%, BC=29%) as a consequence of their distress. A significantly higher proportion also reported pain in the checklist assessment (BA=42% versus BC=21% and WB=13%).

Finally a higher proportion of White British reported substance abuse as the consequence of distress in the checklist assessment (WB=31% versus BA=17%; BC=14%).

6.2.1.1.5.) Treatment

The largest cultural variations in perceptions of mental distress were found for evaluation of treatments. These variations might also have important implications for help-seeking and will therefore be elaborated for each assessment method separately.

In the spontaneous assessment, significantly more WB spontaneously associated holidays (11% versus BC=3%; BA=0%), relaxation (WB=9% versus BC=1%, BA=0%) and acknowledging the problems (WB=20% versus BC=8%, BA=3%) as the best method to resolve or deal with distress. Significantly more Bangladeshi reported taking medication (BA=11% versus BC=6%, WB=1%) and a miracle (BA=10% and BC=5% and WB=0%) as the best possible cure. Significantly more Caribbean individuals wanted to have an accurate diagnosis of the problem (BC=7% versus WB and BA=0%). A higher proportion of individuals from ethnic minorities again reported that they did not know how the problem might be resolved (BC= 26%; BA=23% versus WB=9%) or that it could only be resolved by resolution of outside circumstances (BA=28%, BC=21% and WB=9%).

In the assessment by checklist, it was found that the proportion of White British who preferred self directed treatment i.e. spending time on a hobby, thinking, yoga, substance abuse and talking to their friends, was double to triple the number among ethnic minorities. Only relaxation was seen as a helpful intervention by a higher number of Black Caribbean, but the distribution was found to be highly significant different (WB=29% versus BC=19%, BA=6%). Among the Bangladeshi on the other hand a significantly higher proportion viewed taking medication as helpful (BA=34% versus BC=17%, WB=12%). A much lower proportion of Caribbean found exercising helpful (BC=20% versus WB=47%, BA=42%) and also a much lower proportion of Bangladeshi (BA=1% versus BC=14%; WB=13) found dancing a useful method to resolve distress. White British had much lower proportions of individuals who found praying useful to resolve their distress (WB=8% versus BC=36%, BA=30%).

6.2.1.2. Brief summary of findings – H2 Perceptions of distress are influenced by acculturation. With greater exposure to host culture, perceptions will adjust towards those of the host culture.

It was examined whether perceptions are subject to acculturative processes. The hypothesis was derived from research on general cognitive processes (Bartlett, 1932) and cultural psychology (Berry, 1990). Bartlett's experimental studies showed that our memory and perceptions change 'unconsciously' according to exposure as experiences are integrated into existing cognitive structures thereby producing an autobiographical perspective. Additionally Berry's model of acculturation differentiates that acculturation can be described as a process of a) contact/ exposure and b) the desire to maintain cultural influences. It was assumed that contact dimension would be more crucial to explain semi-conscious changes in perceptions rather than the desire to maintain. Using Berry's terminology, individuals from ethnic minorities would either 'integrate' or 'assimilate' their perceptions according to those of the host culture.

To test this hypothesis, it was firstly necessary to reduce the number of overall items to a more manageable number whose effects could be explored statistically. The psychometric properties of the BEMI were explored and it was tested whether they allow subsuming items under the previously identified conceptual themes. It was found that although the majority of themes were internally consistent, a few (e.g. causal theme 'weather') were not. All items regarding cause, consequence and treatment were therefore aggregated under even larger themes.

Associations between perceptions and exposure to host culture were tested, and surprisingly low correlations between perceptions and length of stay were found. It was then examined how far age might confound the effects of migration, as individuals who were in this country for longer were also likely to be older. A partial correlation matrix

was computed that allowed examining associations independent of age, and significant correlations between perceptions and length of stay in the UK were revealed.

It was then proceeded to conduct multivariate regression analyses to separate the influence of age and length of stay on perceptions. In view of the bi-directionality of the relationship it was decided to use length of stay as the dependent variable. In a hierarchical regression analyses, it was shown that when age was added to the model it could explain 48% of the variance in length of stay. However, adding perceptions in a second model added significantly towards the explained variance. The final model of both age and perceptions explained 58% of the variance in length of stay. The perceptions that were significantly associated were - attributing distress to an external cause and perceiving informal treatment as helpful. The longer individuals had stayed in the UK, the less they attributed stress to an external cause and the more they saw informal treatment as helpful - similar to the White British population. However the remainder of perceptions was not significantly associated with length of stay.

These results partially support the second hypothesis in the notion that first generation migrants seem more likely to integrate and assimilate specific perceptions of the host culture. However, the majority of perception themes were not correlated with length of stay so that more research is necessary to explore why certain perceptions appear to be affected by exposure.

6.2.2. Strengths and Weaknesses

6.2.2.1. Strengths

The research supported that cultural variations in perceptions of distress can be assessed by means of the BEMI. The study explored the views of the general population adding to evidence about the clinical population (e.g. Bhui et al 2000, 2002, McCabe & Priebe, 2004).

Examining the influence of ethnic background and culture on the content of perceptions is a novel and original research area, which could be considered a strength of this research. Ethnic variations in perceptions were found regarding a) the identity of distress, b) the causes that individuals attributed for their distress and c) the consequences. Further, there were significant differences in how individuals from diverse ethnic groups perceived the course and the length of distress, and most importantly strong variations in the evaluation of different treatment interventions.

The combined structured and unstructured assessment of perceptions enabled one to examine cultural factors in the elicitation and communication of perceptions. During the interview, 'don't know' responses to questions were common, particularly among individuals from ethnic minority status, but that these uncertainties were not observed in the assessment by checklist. This research identified clearly that an assessment based on interviews alone is influenced more by the problems of communication in the elicitation of perceptions.

The research also supported both hypotheses partially. Firstly ethnic differences were found with regard to some perception items as well as themes and secondly selected perceptions could be used to explain length of stay in the UK. There was however a large number of perceptions that were not different between ethnic groups and that were also not affected by exposure to host culture.

6.2.2.2. Weaknesses

The non-random sampling procedure in community sites might have introduced bias and limited the generalisability of the findings. Indeed the randomly sampled participants from the general practice register had different demographic characteristics from those of the individuals recruited from community organisations. However, it seemed that the community sampling helped to increase recruitment from

the lower social classes, particularly among the White British group, which would have otherwise been underrepresented in the sample.

Another methodological and conceptual problem was the examination of ethnic differences based on self-classification. This was arbitrary in a small number of cases. For example one elderly Jewish individual, who lived throughout his entire life in the UK, identified himself as White Other whereas another recently migrated young South African individual classed himself as White British even though he only lived in this country for a couple of months. One person identified herself as British, but did not want to be classed according to her ethnic Caribbean background, because of a strong sentiment as belonging to Britain and the Commonwealth. Although the majority would assign themselves a status that was based on their personal and cultural history, this might become a bigger problem for future research as more complex ethnic identities emerge.

Future epidemiological and psychological research must be cautious of grouping individuals by ethnic background as this serves to highlight differences between groups of people (Hillier, 1997). The grouping variable 'ethnic' background is an increasingly arbitrary construct and describes a very mixed group of people. As the research only found some significant ethnic differences, this could be an indicator of greater intra-ethnic variations than inter-ethnic differences. It could be that individuals have more in common with individuals from a different ethnic group, but who have a similar cultural (i.e. language, religion, education) or demographic (i.e. age, gender, geographical location) background. Therefore consensual appreciation of the move from race to ethnic background and most recently to culture is important for epidemiology and cultural psychology and new ideas need to be developed how to conceptualise and assess culture more adequately.

The sample size of this study was determined by power analyses of the hypotheses and therefore only allowed to examine differences between individuals from different ethnic background, but did not allow us to examine cultural and socio-demographic influences. The ethnic groups were very different in their socio-demographic characteristics, their linguistic ability, their education and their migration history including their push and pull factors that motivated the move to the UK. A larger sample size would have allowed exploring the influences of these factors on the content of perceptions in greater detail.

The majority of the Bangladeshi sample was interviewed in Sylheti of which there is no written equivalent. We had translated the materials into standard Bengali, but this was only spoken by few Bangladeshi's living in Tower Hamlets. The interviewers were therefore trained in writing information down in English on their notepads. The interviewees were carefully trained in the process and used tapes to verify their notes at the end of the interview. A few tapes were used to check the data independently, but the absence of independent forward and back translation is considered a weakness.

6.2.3. Implications for Clinical Practice and Future Research

The finding that individuals share many perceptions regarding distress independent of their ethnic background identified that whilst ethnic background might be important it is necessary to evaluate each patient individually. Ethnicity appears to be a very heterogeneous and arbitrary concept, and future perception research should try to consider sample size on the basis of 'cultural' variables in conjunction with ethnicity to learn more regarding 'ethnicity' and 'culture' and identify better grouping variables.

The findings of this research might help health professionals understand ethnic differences in help-seeking and outcome of care in local settings better and treat individuals in more culturally appropriate ways. The research found that despite many

similarities in perceptions of distress across ethnic groups, there were also ethnic differences in the conceptualisation and communication of distress, causal attribution, assessment of timeline and appraisal of help-seeking. More research is necessary to replicate these findings in further studies.

The research tool could be used in conjunction with further research to train health professionals to recognise variations in communication patterns of individuals in mental distress. For example, as individuals from Caribbean and Bangladeshi background were more likely to refer to their distress as part of their social problems, health professionals could be trained in recognising lay narrative that embeds mental health problems. Training health professionals in variations of perceptions and communication of distress could lead to a better recognition of mental health problems in primary care among ethnic minorities.

Furthermore the findings might lead to a better understanding of the ethnic variations in pathways to care, by exploring what type of help is seen as useful by patients of different cultural background. For example, individuals from Bangladeshi background might approach medical services more as they view this sort of treatment helpful, whereas Caribbean and White British seem to prefer for example relaxation. It would be important to determine whether actual help-seeking follows individuals' evaluation of health care and other services in longitudinal studies. Research on psychological models such as theory of planned behaviour (Ajzen, 1972) have been shown to disentangle the effects of attitudes, social norms and perceived behavioural control on health behaviour and could guide such research.

Clinical research could explore whether preferred treatments are also related to better outcome, which in turn might lead to improve services for patients. Ethnic variations in appraisal of treatment could also affect adherence to treatment and thereby indirectly influence variations in outcome between ethnic groups.

The research also identified that what is seen to be distressing varies widely between individuals both within and between ethnic groups. Further research would need to demonstrate how much individual (micro) influences as well as social/ ethnic (macro) influences influence the content of perceptions.

The findings offer also important insights into theories of illness perceptions and cognition. The findings established that perceptions change by exposure to host culture and time suggesting that perceptions might be accessible for interventions.

Findings from the BEMI-I showed the importance of the starting point in the elicitation process as it strongly determined the content of subsequently elicited perceptions. As individuals from White British background would more commonly identify time management and mental health problems as the identity of their distress, they describe work issues and worry as the reason for their distress. In contrast, when individuals from ethnic minorities report social problems as the identity of their distress, it is more coherent to answer 'don't know' to the question as to what caused it or 'me'. This seems to suggest that the starting point appears to determine how and when different links are activated. This might be also important for clinical interviews as it might be the starting point of the interview the initial complaint that precludes pursuing a dialogue about mental distress.

Research should explore the influence of socio-demographic and cultural influences on perceptions in conjunction with ethnic background in cross-sectional and longitudinal studies. This would allow one to unpack the concept ethnic background further and allow one to identify how our background determines our perception of distress and how this might change over time.

Future research should also explore the difference between the assessment by checklist or interview further. How much does the assessment affect the quality of the data and is the difference mainly in the expression or the experience of distress. Particularly language and ability to communicate using one's language might be an important confounding factor when exploring cultural and ethnic differences on various assessment methods. Future studies should therefore examine the influence of language in more detail. Firstly it might be necessary to examine the influence of language more crudely by focusing on individuals who speak the same language and examine where and how the assessment produces different results and why this might be the case. Secondly individuals who speak a different language could be studied to determine whether same effects apply and whether there are differences. Another set of studies might look at individual's verbal ability and differences in the assessment process.

The research on acculturative processes also found partial support for the hypotheses as selected perceptions could be used to predict length of stay in the UK and perceptions adjusted towards those of the host culture. Although these are only cross-sectional data, this could be interpreted that exposure rather than the desire to maintain cultural influences was influencing the content of perceptions. On the other hand, other perceptions were not associated with length of stay. Future longitudinal research should explore whether all or only few perceptions change over time. Following Berry's theory one would expect adaptive changes to occur mainly in perceptions which cause 'conflict' between different cultural / ethnic groups and it would be important to determine the consequences of conflicting views which are not resolved.

6.3. H3 -Perceptions of Distress are associated with absence or presence of mental distress (psychiatric caseness).

6.3.1. Brief Summary of Findings

The research found partial support for the hypothesis that perceptions were associated with absence or presence of mental distress.

Analyses by ethnic group showed that independent of ethnic background almost all cases described somatic, mental and behavioural symptoms and were much more likely to attribute their distress to external (i.e. spiritual, weather, financial causes) than non-cases. When items were aggregated it was also found that psychiatric cases have more 'complex' models of mental distress than non cases. They report almost three times the number of perceived symptoms than non cases, in all ethnic groups. The number of perceptions elicited was also almost double (WB, BA) to triple (BC) in terms of attributions, consequences and helpful treatments received than in non cases. There were no significant differences for the expected course of distress, but for experienced length of distress - as the majority of the cases reported that they suffered from their distress for more than six months.

Additional correlations were computed to determine whether psychiatric caseness was significantly associated with perceptions and other confounding variables. It was found that perceptions and ethnicity were significantly associated with psychiatric caseness.

Multivariate analyses were conducted to determine whether associated perceptions of distress could be determined by caseness, and whether caseness could be predicted by perceptions. A hierarchical logistic regression entered ethnic background as a first explanatory block and then perception variables to test how much they added to the variance explained. It was found that a significant amount of the variance in caseness could be explained by ethnic background (15%), but perceptions explained a much larger proportion of the variance (58%). In terms of ethnic background, this research

found that the odds of being a psychiatric case was four times higher among the Bangladeshi than White British (OR=4.4). Individuals who reported either a mental (OR =11.5) or a behavioural symptom (OR=5.8), who attributed their distress to external causes (OR=2.8) and who reported external consequences (OR=2.1) had significantly higher odds for being a psychiatric case.

The univariate and multivariate results suggest that the majority of perceptions are affected by absence or presence of distress. Perceptions differed in number and in content between psychiatric cases and non-cases and selected perceptions were so strongly associated with mental distress that they could be used to predict caseness in a logistic regression. However as some perceptions (in particular surrounding the helpfulness of help-seeking) were not associated with mental distress, it is concluded that the evidence only partially supports this hypothesis.

6.3.2. Strengths and Weaknesses

6.3.2.1. Strengths

A strength of this finding is that it revealed a close link between the assessment of lay perceptions of 'illness' and professional 'disease'. Selected types of perceptions were associated with caseness, which suggests that perceptions are an important addition of predictor variables that can be associated with mental distress.

It was also shown that individuals' perceptions varied both qualitatively i.e. by the *content* of the attributions (e.g. more external attributions, a wider variety of different symptoms), as well as quantitatively i.e. by looking at the *number* of perceptions that cases held in contrast to non-cases.

6.3.2.2. Weaknesses

The cross-sectional research design unfortunately prohibited any causal inferences of the relationship between perceptions and the development of mental distress, but this could be considered in further research.

A further weakness of the research was the small sample size, which did not allow for detailed analyses assessing perceptions and distress within each of the ethnic groups individually. Here it would have been beneficial to establish whether there are particular perceptions in each ethnic group that could be used as indicators for psychiatric caseness.

6.3.3. Implications for clinical practice and future research

The findings indicate that an assessment of perceptions or the patients' perspective on their illness might not only be useful to do research, but it might also help clinicians identify mental health problems better. Individuals who reported a mental health or a behavioural problem to be associated to their distress, who attributed their distress to external causes and who reportedly experienced external consequences were more likely to be psychiatric cases. A quicker recognition might support primary care physicians to provide more appropriate care.

It would be important to examine the effect of perceptions in longitudinal studies to determine whether perceptions might act as risk indicators for mental illness or mental illness causes variations in the perceptions. It would also be important to determine whether specific perceptions are associated with specific psychiatric disorders facilitate easier recognition of disorder.

It would also be important to examine whether the same perceptions are associated with disorder across cultural/ ethnic groups or whether there are differences.

The findings have also important implications for the theory of illness perception and health psychological research. Individuals who can be classified as psychiatric cases reported a much larger number and a different content of perceptions regarding distress. Whereas some might say the level of distress is simply more severe and has been endured for longer time, leading to more complex perceptions and models, it could also be that psychiatric cases are experiencing an increased level of cognitive processing and more ideas competing for attention. More experimental and clinical research in this area would be warranted to examine the relationships between mental distress, perception and behaviour further.

6.4. Conclusions and implications of this research

The work presented in this PhD examined the assessment of ethnic variations in perceptions of mental distress. The theoretical background of illness perceptions and the currently available instruments were reviewed and a new transdisciplinary approach and new instrument was deemed necessary. This tool was subsequently developed as an inventory (BEMI) that combined a short open-ended interview with checklists and complemented the assessment of cultural variations in perceptions. When the BEMI's suitability to assess cultural variations was examined, it was found to be useful and have internal reliability and validity.

The empirical research found partial support for all hypotheses. Some significant ethnic differences were found in selected perceptions and certain perceptions were affected by acculturative processes and distress. The results only provide partial support as there were also many non-significant findings which point towards a greater intra-ethnic than inter-ethnic variation in perceptions.

Future research studies are necessary to substantiate the usefulness of the new tool and determine the psychometric properties of the scale in additional cultural groups and also among individuals with different mental distress conditions. Comparative

studies with other assessment tools might be useful to delineate the similarities and differences between them in empirical research. After the reliability and validity of the BEMI has been established by independent research the predictive value of perceptions should be explored. Longitudinal studies would be useful to assess whether perceptions cause mental distress or mental distress causes different perceptions. Neuropsychological studies might explore whether mental distress produces more diverse and animated cognitive functioning and perceptions. The finding that perceptions changed with level of exposure to British culture in migrants suggests that perceptions can be changed and it seems vital to explore how this change occurred. Is change in perception only visible after individuals have been exposed to a totally different culture for a number of years or can this be achieved in controlled manner in a much shorter time-span? Experimental studies would be useful to isolate the influences of different factors. Health service research is needed to see how perceptions can be assessed and if including them in health care is of benefit to the patient in terms of outcome and satisfaction with health care. Health psychological research might benefit from exploring the link between emotions, mental state and cognitions further to derive more comprehensive models of health behaviour.

This research has tried to identify the influences of culture and ethnicity on perceptions and has determined that researching these influences is an extremely complex endeavour. This PhD is a starting point to examine the cultural aspects of illness and disease further and has tackled many controversial issues surrounding cross-cultural research including different methodologies, interdisciplinary or transdisciplinary knowledge and application of theory. Despite controversial nature of cross-cultural and cross-ethnic research on perceptions, it seems a necessary and worthwhile pursuit and will be challenging researchers for many years to come.

References

- Ajzen, I. (1972). Attitudes and normative beliefs as factors influencing behavioral intentions. *Journal of Personality & Social Psychology*, **Vol. 21**, 1-9.
- Albrecht, G., Freeman, S., & Higginbotham, N. (1998). Complexity and Human Health: The Case for A Transdisciplinary Paradigm. *Culture, Medicine & Psychiatry*, **22**, 55-92.
- Andrews, M. M. & Boyie, J. S. (1995). *Transcultural Concepts in Nursing Care*. (2nd edition ed.) Philadelphia: Lippincott
- Baeaernhielm, S. & Ekblad, S. (2000). Turkish migrant women encountering health care in Stockholm: A qualitative study of somatization and illness meaning. *Culture, Medicine & Psychiatry*, **24**, 431-452.
- Baer, R. D., Weller, S. C., de Alba Garcia, J. G., Glazer, M., Trotter, R., Pachter, L., & Klein, R. E. (2003). A Cross-Cultural Approach to the Study of the Folk Illness "Nervios". *Culture, Medicine and Psychiatry*, **27**, 315-337.
- Bandura, A., Adams, N. E., & Beyer, J. (1977). Cognitive processes mediating behavioral change. *J Pers.Soc.Psychol.*, **35**, 125-139.
- Bandura, A., Pastorelli, C., Barbaranelli, C., & Caprara, G. V. (1999). Self-efficacy pathways to childhood depression. *J Pers.Soc.Psychol.*, **76**, 258-269.
- Barrett, R. J. (1997). Cultural formulation of psychiatric diagnosis. Death on a horse's back: adjustment disorder with panic attacks. *Culture, Medicine & Psychiatry*, **21**, 481-496.

- Barrowclough, C., Lobban, F., Hatton, C., & Quinn, J. (2001). An investigation of models of illness in carers of schizophrenia patients using the Illness Perception Questionnaire. *British Journal of Clinical Psychology*, **40**, 371-385.
- Bartlett, F. C. (1932). *Remembering: A study in experimental and social psychology*. New York: Cambridge University Press
- Baumann, L. J., Cameron, L. D., Zimmerman, R. S., & Leventhal, H. (1989). Illness representations and matching labels with symptoms. *Health Psychol.*, **8**, 449-469.
- Baumann, L. J. & Leventhal, H. (1985). I Can Tell When My Blood-Pressure Is Up, Cant I. *Health Psychology*, **4**, 203-218.
- Baumann, L. J., Zimmerman, R. S., & Leventhal, H. (1989). An experiment in common sense: education at blood pressure screening. *Patient.Educ.Couns.*, **14**, 53-67.
- Berry, J. W. (1989). Imposed Etics Emics Derived Etics - the Operationalization of A Compelling Idea. *International Journal of Psychology*, **24**, 721-735.
- Berry, J. W. (1997). Immigration, acculturation, and adaptation. *Applied Psychology-An International Review-Psychologie Appliquee-Revue Internationale*, **46**, 5-34.
- Berry, J. W. & Sinha, D. (1992). Psychological Acculturation - the Generalizability of Theories and Findings. *International Journal of Psychology*, **27**, 656.
- Berry, J.-W. (1969). On cross-cultural comparability. *International Journal of Psychology*, **4**, 119-128.

- Berry, J.-W. (1990). Psychology of Acculturation: Understanding individuals moving between cultures. In R.W.Brislin (Ed.), *Applied Cross-cultural Psychology* (pp. 232-253). Newbury Park, CA: Sage.
- Berry, J.-W. & Kim, U. (1988). Acculturation and Mental Health. In P.R.Dasen, J.-W. Berry, & N. Sartorius (Eds.), *Health and Cross-cultural Psychology Toward Applications* (pp. 207-236). Newbury Park, CA: Sage Publications.
- Berry, J.-W., Poortinga, Y. H., Segall, M. H., & Dasen, P. R. (2002). *Cross-cultural Psychology Research and Applications*. (Second ed.) Cambridge: Cambridge University Press
- Bhui, K. & Bhugra, D. (2003). Explanatory models in psychiatry. *The British Journal of Psychiatry*, **183**, 170.
- Bhui, K. & Bhugra, D. (2001). Explanatory models for mental distress: implications for clinical practice and research. *Br.J.Psychiatry*, **181**, 6-7.
- Bhui, K., Stansfeld, S., Hull, S., Priebe, S., MOLE, F., & FEDER, G. (2003). Ethnic variations in pathways to and use of specialist mental health services in the UK. Systematic review. *The British Journal of Psychiatry*, **182**, 105-116.
- Bhui, K. S. (2000). *Common mental disorders among Punjabi Asians : prevalence, explanatory models and the general practitioner's assessment / Kamaldeep Singh Bhui*. London : University of London, 2000.
- Bilu, Y. & Witztum, E. (1993). Working with Jewish ultra-orthodox patients: Guidelines for a culturally sensitive therapy. *Culture, Medicine & Psychiatry*, **17**, 197-233.
- Bose, R. (1997). Psychiatry and the Popular Conception of Possession among the Bangladeshis in London. *Int.J.Soc.Psychiatry*, **43**, 1-15.

- Boynton, P. M., Wood, G. W., & Greenhalgh, T. (2004). Reaching beyond the white middle classes. *BMJ*, **328**, 1433-1436.
- Brewer, W. F. (2000). Bartlett's Concept of the schema and its impact on theories of knowledge representation in contemporary cognitive psychology. In A. Saito (Ed.), *Bartlett, Culture and Cognition* (pp. 69-89). Guildford: Psychology Press.
- Budman, C. L., Lipson, J. G., & Meleis, A. I. (1992). The Cultural Consultant in Mental Health Care. *Am.J.Orthopsychiatry*, **62**, 359-370.
- Canino, G., Lewis-Fernandez, R., & Bravo, M. (1997). Methodological challenges in cross-cultural mental health research. *Transcultural Psychiatry*, **34**, 163-184.
- Cheung, F. & Lin, K. M. (1997). Neurasthenia, depression and somatoform disorder in a Chinese-Vietnamese woman migrant. *Culture, Medicine & Psychiatry*, **21**, 247-258.
- Chuengsatiansup, K. (1999). Sense, Symbol, and Soma: Illness Experience in the Soundscape of Everyday Life. *Culture, Medicine & Psychiatry*, **23**, 273-301.
- Ciampi, L. (1991). Affects as Central Organising and Integrating Factors
A New Psychosocial/ Biological Model of the Psyche. *Br.J.Psychiatry*, **159**, 97-105.
- Cohen, M. Z., Tripp-Reimer, T., Smith, C., & Sorofman, B. (1994). *Explanatory models of diabetes: Patient practitioner variation*. United Kingdom: Elsevier Science Ltd.
- Collinge, A., Rüdell, K., & Bhui, K. (2002). Quality of life assessment in non-Western cultures. *International Review of Psychiatry*, **14**, 212-218.

- Colman, A. M. (1972). "Scientific" racism and the evidence on race and intelligence. *Race*, 137-153.
- Daie, N., Witztum, E., Mark, M., & Rabinowitz, S. (1992). The belief in the transmigration of souls: Psychotherapy of a Druze Patient with severe anxiety reaction. *Br.J.Med.Psychol.*, **65**, 119-130.
- David, D., Miclea, M., & Opre, A. (2004). The information-processing approach to the human mind: Basics and beyond. *Journal of Clinical Psychology*, **60**, 353-368.
- Dein, S. & Sembhi, S. (2001). The Use of Traditional Healing in South Asian Psychiatric Patients in the U.K.: Interactions Between Professional and Folk Psychiatrists. *Transcultural Psychiatry*, **38**, 243-257.
- Dewey, J. (1929). *Experience and Nature*. New York: Dover
- Diefenbach, M. A. & Leventhal, H. (1996). The common-sense model of illness representation: Theoretical and practical considerations. *Journal of Social Distress & The Homeless*, **5**, 11-38.
- Durst, R., Minuchin-Itzigsohn, S., & Jabotinsky-Rubin, K. (1993). 'Brain-Fag' Syndrome: Manifestation of Transculturation in an Ethiopian Jewish Immigrant. *Isr.J.Psychiatry Relat.Sci.*, **30**, 223-232.
- Dwairy, M. (1997). Addressing the Repressed Needs of the Arabic Client. *Cultural Diversity & Mental Health*, **3**, 1-12.
- Eisenberg, L. (1977). Disease and illness. Distinctions between professional and popular ideas of sickness. *Culture, Medicine & Psychiatry*, **1**, 9-23.

- Eisenbruch, M. (1990). Classification of natural and supernatural causes of mental distress. Development of a Mental Distress Explanatory Model Questionnaire. *J.Nerv.Ment.Dis.*, **178**, 712-719.
- Eisenbruch, M. & Handelman, L. (1990). Development of a Cambodian Mental Distress Explanatory Model Questionnaire. *Journal of Refugee Studies*.
- Ekman, P. (1993). Facial Expression and Emotion. *American Psychologist*, **48**, 384-392.
- Etsuko, M. (1991). The interpretations of fox possession: Illness as metaphor. *Culture, Medicine & Psychiatry*, **15**, 453-477.
- Farias, P. J. (1991). Emotional distress and its socio-political correlates in Salvadoran refugees: analysis of a clinical sample. *Culture, Medicine & Psychiatry*, **15**, 167-192.
- Fernando, S. (1991). *Mental Health, Race and Culture*. London: Macmillan
- Fischhoff, B. (1975). Hindsight-foresight: The effect of outcome knowledge on judgments under uncertainty. *Journal of Experimental Psychology: Human Perception and Performance*, **1**, 288-299.
- Foster, G. M. (1976). Disease Etiologies in Non-Western Medical Systems. *American Anthropology*, **78**, 773-776.
- French, D. P., Marteau, T. M., Senior, V., & Weinman, J. A. (2002). Eliciting causal beliefs about heart attacks: A comparison of implicit and explicit methods. *Journal of Health Psychology*, **7**, 433-444.

- French, D. P., Marteau, T. M., Weinman, J., & Senior, V. (2004). Explaining differences in causal attributions of patient and non-patient samples. *Psychology, Health & Medicine, 9*, 259-272.
- Giosan, C., Glovsky, V., & Haslam, N. (2001). The Lay Concept of 'Mental Disorder': A Cross-Cultural Study. *Transcultural Psychiatry, 38*, 317-332.
- Goldberg, D. 1992. General Health Questionnaire (GHQ-12). Windsor, NFER-NELSON
- Goldberg, D. & Huxley, P. (1980). *Mental illness in the community: the pathway to psychiatric care*. London: Tavistock Press
- Green, S. B. (1991). How many subjects does it take to do a regression analysis? *Multivariate Behavioral Research, 26*, 499-510.
- Grisaru, N., Budowski, D., & Witztum, E. (1997). Possession by the "Zar" among Ethiopian immigrants to Israel: Psychopathology or culture-bound syndrome? *Psychopathology, 30*, 223-233.
- Guarnaccia, P. J., Rivera, M., Franco, F., & Neighbors, C. (1996). The experiences of ataques de nervios: Towards an anthropology of emotions in Puerto Rico. *Culture, Medicine & Psychiatry, 20*, 343-367.
- Hagger, M. S. & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology & Health, 18*, 141-184.
- Hardy, G. E., Shapiro, D. A., Haynes, C. E., & Rick, J. E. (1999). Validation of the General Health Questionnaire-12 Using a Sample of Employees From England's Health Care Services. *Psychological Assessment, 11*, 159-165.

- Hegel, G. W. F. 1807. *Phänomenologie des Geistes*. Bamberg und Würzburg
- Heidegger, M. (1927). *Sein und Zeit*. Tübingen: Max Niemeyer Verlag
- Helfrich, H. (1999). Beyond the dilemma of cross-cultural psychology: Resolving the tension between etic and emic approaches. *Culture & Psychology*, **5**, 131-153.
- Henley, A. & Schott, J. (1999). *Culture, Religion and Patient Care in a Multi-Ethnic Society A Handbook for Professionals*. London: Age Concern
- Hesse, H. G. (1988). Methodische Probleme des Kulturvergleichs psychometrischer Daten und Moeglichkeit ihrer Bearbeitung durch Strukturgleichungsmodelle. *Zeitschrift fuer internationale erziehungs und sozialwissenschaftliche Forschung*, **8**, 119-140.
- Higginbotham, N., Albrecht, G., & Connor, L. (2001). *Health Social Science A transdisciplinary and Complexity Perspective*. South Melbourne: Oxford University Press
- Hillier, S. (1997). The Health and Health Care of Ethnic Minority Groups. In G.Scambler (Ed.), *Sociology as Applied to Medicine* (4th Edition ed., pp. 135-147). London: W.B. Saunders Company Ltd.
- Hinton, D., Hinton, S., Pham, T., Chau, H., & Tran, M. (2003). 'Hit by the wind' and temperature-shift panic among Vietnamese refugees. *Transcult.Psychiatry*, **40**, 342-376.
- Hinton, D., Hinton, S., Um, K., Chea, A. S., & Sak, S. (2002). The Khmer "weak heart" syndrome: Fear of death from palpitations. *Transcultural Psychiatry*, **39**, 323-344.

- Hinton, D., Um, K., & Ba, P. (2001). Kyol goeu ('wind overload') Part I: A cultural syndrome of orthostatic panic among Khmer refugees. *Transcultural Psychiatry*, **38**, 403-432.
- Hollan, D. (2004). Self systems, cultural idioms of distress, and the psycho-bodily consequences of childhood suffering. *Transcult.Psychiatry*, **41**, 62-79.
- Holtgraves, T. (2004). Social desirability and self-reports: Testing models of socially desirable responding. *Personality & Social Psychology Bulletin*, 161-172.
- Horne, R., James, D., Petrie, K., Weinman, J., & Vincent, R. (2000). Patients' interpretation of symptoms as a cause of delay in reaching hospital during acute myocardial infarction. *Heart*, **83**, 388-393.
- Husserl, E. (1901). *Logische Untersuchungen. Zweiter Teil: Untersuchungen zur Phänomenologie und Theorie der Erkenntnis*. Tübingen: Max Niemeyer Verlag
- Ilechukwu-Sunny, T. C. (1999). Oedipal anxiety and culture variations in the incest taboo: A psychotherapy case study in the Nigerian setting. *Transcultural Psychiatry*, **36**, 211-225.
- Jaber, R., Steinhardt, S., & Trilling, J. (1991). *Explanatory models of illness: A pilot study*. US: Families Systems and Health Inc.
- Jadhav, S., Weiss, M. G., & Littlewood, R. (2001). Cultural experience of depression among white Britons in London. *Anthropology & Medicine*, **8**, 47-69.
- Jahoda, G. (1977). In pursuit of the emic-etic distinction: Can we ever capture it. In Y.H.Poortinga (Ed.), *Basic Problems in Cross-cultural Psychology* (Lisse: Swets and Zeitlinger).

James, W. (1907). *Pragmatism*. Cambridge: Harvard University Press

Jenkins, R., Lewis, G., Bebbington, P., Brugha, T., Farrell, M., GILL, B., & Meltzer, H. (1997). The National Psychiatric Morbidity Surveys of Great Britain – initial findings from the Household Survey (Psychiatric morbidity survey – initial findings). *Psychological Medicine*, **27**, 775-789.

Joel, D., Sathyaseelan, M., Jayakaran, R., Vijayakumar, C., Muthurathnam, S., & Jacob, K. S. (2003). Explanatory models of psychosis among community health workers in South India. *Acta Psychiatr.Scand.*, **108**, 66-69.

Keesing, R. M. (1981). *Cultural Anthropology - a contemporary perspective*. (2nd Edition ed.) New York. London:

Kirmayer, L. J. (1989). Cultural variations in the response to psychiatric disorders and emotional distress. *Social Science & Medicine*, **29**, 327-339.

Kleinman, A. (1980b). *Patients and Healers in the Context of Culture*. Berkeley and Los Angeles: University of California Press

Kleinman, A. (1987a). Anthropology and psychiatry. The role of culture in cross-cultural research on illness. *British Journal of Psychiatry*, **151**, 447-454.

Kleinman, A. (1980a). Ethnicity and clinical care: the Chinese patient. *Physician Assist.Health Pract.*, **4**, 60-68.

Kleinman, A. (1981). On illness meanings and clinical interpretation: not 'rational man', but a rational approach to man the sufferer/man the healer. *Culture, Medicine & Psychiatry*, **5**, 373-377.

- Kleinman, A. (1982a). Neurasthenia and depression: a study of somatization and culture in China. *Culture, Medicine & Psychiatry*, **6**, 117-190.
- Kleinman, A. (1982b). Selected issues in treating the Chinese patient. *Hosp.Physician*, **18**, 58-61, 65, 71.
- Kleinman, A. (1983). The cultural meanings and social uses of illness. A role for medical anthropology and clinically oriented social science in the development of primary care theory and research. *J.Fam.Pract.*, **16**, 539-545.
- Kleinman, A. (1977a). Culture, and illness: a question of models. *Culture, Medicine & Psychiatry*, **1**, 229-231.
- Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Ann.Intern.Med.*, **88**, 251-258.
- Kleinman, A. & Gale, J. L. (1982). Patients treated by physicians and folk healers: a comparative outcome study in Taiwan. *Culture, Medicine & Psychiatry*, **6**, 405-423.
- Kleinman, A. & Kleinman, J. (1991). Suffering and its professional transformation: toward an ethnography of interpersonal experience. *Culture, Medicine & Psychiatry*, **15**, 275-301.
- Kleinman, A. M. (1977b). Depression, somatization and the "new cross-cultural psychiatry". *Soc.Sci.Med.*, **11**, 3-10.
- Kleinman, A. M., Ravitz, L. J., & Koran, L. M. (1972). Psychiatry in mainland China: additional sources. *Am.J.Psychiatry*, **129**, 482-484.

- Kleinman, A. (1978). Clinical relevance of anthropological and cross-cultural research: Concepts and strategies. *Am.J.Psychiatry*, **135**, 427-431.
- Kleinman, A. (1982c). *Neurasthenia and depression: A study of somatization and culture in China*. Netherlands: Kluwer Academic Publishers.
- Kleinman, A. (1987b). Explanatory models in health-care relationships: A conceptual frame for research on family-based health-care activities in relation to folk and professional forms of clinical care. In Ed (Ed.), *Stoeckle, John D* (pp. 273-283). MA,US: The MIT Press: Cambridge.
- Kleinman, A. (1988b). *A window on mental health in China*. US: Society of the Sigma Xi.
- Kleinman, A. (1988a). *The illness narratives: Suffering, healing, and the human condition*. New York, NY, US: Basic Books, Inc. (1988). xviii, 284 pp.
- Kleinman, A. (1992). *Local worlds of suffering: An interpersonal focus for ethnographies of illness experience*. US: Sage Publications, Inc.
- Kleinman, A. E., Kunstadter, P. E., Alexander, E. R. E., & Gate, J. L. E. (1978). *Culture and healing in Asian societies: Anthropological, psychiatric and public health studies*. Cambridge, Mass., Schenkman. (1978). 462 pp.
- Kleinman, A. M. (1977c). *Depression, somatization and the new cross-cultural psychiatry*. United Kingdom: Elsevier Science Ltd.
- Klonoff, E. A. & Landrine, H. (1994). Culture and gender diversity in commonsense beliefs about the causes of six illnesses. *J.Behav.Med.*, **17**, 407-418.

- Krause, I. B. (1989). Sinking heart: a Punjabi communication of distress. *Soc.Sci.Med.*, **29**, 563-575.
- Landis, J. R. & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, **33**, 159-174.
- Landy, D. (1983). Medical Anthropology: A critical appraisal. In J.L.Ruffini (Ed.), *Advances in Medical Social Science (Vol 1)* (New York: Gordon and Breach.
- Lau, R. R. & Hartman, K. A. (1983). Common sense representations of common illnesses. *Health Psychology*, **2**, 167-185.
- Lawson, V. L., Bundy, C., Lyne, P. A., & Harvey, J. N. (2004). Using the IPQ and PMDI to predict regular diabetes care-seeking among patients with Type 1 diabetes. *Br J Health Psychol.*, **9**, 241-252.
- Leak, G. K. (2004). Clarification of the link between socially desirable responding and the social interest index. *Journal of Individual Psychology*, 94-99.
- Lee, S. & Kleinman, A. (1997). Mental illness and social change in China. *Harv.Rev.Psychiatry*, **5**, 43-46.
- Lemelson, R. (2003). Obsessive-compulsive disorder in Bali: the cultural shaping of a neuropsychiatric disorder. *Transcult.Psychiatry*, **40**, 377-408.
- Leventhal, E. A., Hansell, S., Diefenbach, M., Leventhal, H., & Glass, D. C. (1996). Negative affect and self-report of physical symptoms: two longitudinal studies of older adults. *Health Psychol.*, **15**, 193-199.
- Leventhal, H. (1971). Fear appeals and persuasion: the differentiation of a motivational construct. *Am.J.Public Health*, **61**, 1208-1224.

- Leventhal, H. (1970). Findings and theory in the study of fear communications. *Advances in Experimental Social Psychology*, **5**, 119-186.
- Leventhal, H., Benyamini, Y., Brownlee, S., Diefenbach, M., Leventhal, E., Patrick-Miller, L., & Robitaille, C. (1997). Illness Representations: Theoretical Foundations. In K. Petrie & J. Weinman (Eds.), *Perceptions of Health & Illness* (pp. 19-49). London: Harwood Academic.
- Leventhal, H., Diefenbach, M., & Leventhal, E. A. (1992). Illness Cognition - Using Common-Sense to Understand Treatment Adherence and Affect Cognition Interactions. *Cognitive Therapy and Research*, **16**, 143-163.
- Leventhal, H. & Singer, R. P. (1966). Affect arousal and positioning of recommendations in persuasive communications. *Journal of Personality & Social Psychology*, **4**, 137-146.
- Leventhal, H. & Watts, J. C. (1966). Sources of resistance to fear-arousing communications on smoking and lung cancer. *Journal of Personality*, **34**, 155-175.
- Leventhal, H., Watts, J. C., & Pagano, F. (1967). Effects of fear and instructions on how to cope with danger. *Journal of Personality & Social Psychology*, **6**, 313-321.
- LeVine, P. & Matsuda, Y. (2003). Reformulation of diagnosis with attention to cultural dynamics: case of a Japanese woman hospitalized in Melbourne, Australia. *Culture, Medicine & Psychiatry*, **27**, 221-243.
- Lewin, K. 1951. Field theory in social science; selected theoretical papers. Cartwright, D. New York, Harper & Row

- Lewis-Fernandez, R. (1996). Cultural formulation of psychiatric diagnosis. Case No. 02. Diagnosis and treatment of Nervios and Ataques in a female Puerto Rican migrant. *Culture, Medicine & Psychiatry*, **20**, 155-163.
- Lewis-Fernandez, R. & Kleinman, A. (1994). Culture, personality, and psychopathology. *J.Abnorm.Psychol.*, **103**, 67-71.
- Liggan, D. Y. & Kay, J. (1999). Race in the room: Issues in the dynamic psychotherapy of African Americans. *Transcultural Psychiatry*, **36**, 195-209.
- Littlewood, R. & Lipsedge, M. (1988). Psychiatric illness among British Afro-Caribbeans. *BMJ*, **297**, 135-136.
- Lloyd, K. R., Jacob, K. S., Patel, V., St Louis, L., Bhugra, D., & Mann, A. H. (1998). The development of the Short Explanatory Model Interview (SEMI) and its use among primary-care attenders with common mental disorders. *Psychol.Med.*, **28**, 1231-1237.
- Logan, B. & Semmes, C. (1986). Culture and ethnicity. In B.Logan & C. Dawkins (Eds.), *Family-centered nursing in the community* (pp. 97-126). Menlo Park , CA: Addison-Wesley Publishing Company.
- Lu, Y. W., Lee, S., Liu, M. L., Wing, Y. K., & Lee, T. S. (1999). Too costly to be ill: Psychiatric disorders among hospitalized migrant workers in Shenzhen. *Transcultural Psychiatry*, **36**, 95-109.
- Macrae, C. N. & Bodenhausen, G. V. (2000). Social Cognition: Thinking Categorically about Others. [Article]. *Annual Review of Psychology 2000;51:93-120*, **51**, 93-120.

- Madden, T. J. (1992). A comparison of the theory of planned behavior and the theory of reasoned action. *Personality & Social Psychology Bulletin*, **18**, 3-9.
- Manson, S. M. (1996). The wounded spirit: a cultural formulation of post-traumatic stress disorder. *Culture, Medicine & Psychiatry*, **20**, 489-498.
- Masalha, S. (1999). Psychodynamic psychotherapy as applied in an Arab village clinic. *Clin.Psychol.Rev.*, **19**, 987-997.
- Massoth, D. L. (1993). Explanatory models for illness: Applicability of the construct to the qualitative and quantitative description of temporomandibular disorders.
- Mauksch, L. B. & Roesler, T. (1990). *Expanding the context of the patient's explanatory model using circular questioning*. US: Families Systems and Health Inc.
- McCabe, R. & Priebe, S. (2004). Assessing the stability of schizophrenia patients' explanatory models of illness over time. *Journal of Mental Health (UK)*, **13**, 163-169.
- Mead, G. H. (1934). *Mind, Self and Society*. Chicago: University of Chicago Press
- Mena, F. J., Padilla, A. M., & Maldonado, M. (1987). Acculturative Stress and Specific Coping Strategies among Immigrant and Later Generation College Students. *Hispanic Journal of Behavioural Sciences*, **9**, 207-225.
- Messick, S. (1995). Validity of psychological assessment: Validation of inferences from persons' responses and performances as scientific inquiry into score meaning. *American Psychologist*, **50**, p-741749.

- Migliore, S. (1994). Gender, emotion, and physical distress: The Sicilian-Canadian "nerves" complex. *Culture, Medicine & Psychiatry*, **18**, 271-297.
- Morgan, M. (1988). Managing hypertension: Beliefs and responses to medication among cultural groups. *Sociology of Health & Illness*, **10**, 561-578.
- Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. 2001. The Revised Illness Perception Questionnaire (IPQ-R). *Psychology & Health* .
- Moss-Morris, R., Petrie, K. J., & Weinman, J. (1996). Functioning in chronic fatigue syndrome: Do illness perceptions play a regulatory role? *British Journal of Health Psychology*, **1**, England, [http](http://).
- Mumford, D. B., Tareen, I. A., Bajwa, M. A., Bhatti, M. R., Pervaiz, T., & Ayub, M. (1991). An investigation of 'functional' somatic symptoms among patients attending hospital medical clinics in Pakistan--I. Characteristics of 'non-organic' patients. *Journal of Psychosomatic Research*, **35**, 245-255.
- Mumford, D. B., Tareen, I. A., Bhatti, M. R., Bajwa, M. A., Ayub, M., & Pervaiz, T. (1991). An investigation of 'functional' somatic symptoms among patients attending hospital medical clinics in Pakistan--II. Using somatic symptoms to identify patients with psychiatric disorders. *Journal of Psychosomatic Research*, **35**, 257-264.
- Murdock, G. P., Wilson, S. F., & Frederick, V. 1978b. Cultural illness and health. *Anthropological studies* **9**. Washington DC, American Anthropological Association
- Murdock, G. P., Wilson, S. F., & Frederick, V. (1978a). World distribution of theories of illness. *Ethnology*, **17**, 449-470.

- Murphy, H. (1982). *Comparative Psychiatry: The International and Intercultural Distribution of Mental Illness*. Berlin: Springer Verlag
- Nunnally, J. C. (1978). *Psychometric theory*. (2nd ed.) New York: McGraw-Hill
- Office for National Statistics. 2001. Census. <http://neighbourhood.statistics.gov.uk/> .
- Oquendo, M., Horwath, E., & Martinez, A. (1992). Ataques de nervios: proposed diagnostic criteria for a culture specific syndrome. *Culture, Medicine & Psychiatry*, **16**, 367-376.
- Oquendo, M. A. & Graver, R. (1997). Treatment of an Indian woman with major depression by Latina therapist: Cultural formulation. *Culture, Medicine & Psychiatry*, **21**, 115-126.
- Ots, T. (1990). The angry liver, the anxious heart and the melancholy spleen: The phenomenology of perceptions in Chinese culture. *Culture, Medicine & Psychiatry*, **14**, 21-58.
- Pandolfi, M. (1990). Boundaries inside the body: women's sufferings in southern peasant Italy. *Culture, Medicine & Psychiatry*, **14**, 255-273.
- Pang, K. Y. (1990). Hwabyung: the construction of a Korean popular illness among Korean elderly immigrant women in the United States. *Culture, Medicine & Psychiatry*, **14**, 495-512.
- Pang, K. Y. C. (1998). Symptoms of depression in elderly Korean immigrants: Narration and the healing process. *Culture, Medicine & Psychiatry*, **22**, 93-122.

- Park, R. E. 1927. *Human Nature and Collective Behavior*. Hughes, E. C., Johnson, C. A., Masuoka, J., Redfield, R., and Wirth, L. *The Collected Papers of Robert Ezra Park Vol III Society*. 13-21. Glencoe: Illinois, Free Press
- Parsons, C. D. (1984). Idioms of distress: Kinship and sickness among the people of the Kingdom of Tonga. *Culture, Medicine & Psychiatry*, **8**, 71-93.
- Patel, V. (2001). Cultural factors and international epidemiology. *British Medical Bulletin*, **57**, 33-45.
- Patel, V. (1995). Explanatory Models of Mental Illness in Sub-Saharan Africa. *Soc.Sci.Med.*, **40**, 1291-1298.
- Petrie, K. J., Weinman, J., Sharpe, N., & Buckley, J. (1996). Role of patients' view of their illness in predicting return to work and functioning after myocardial infarction: longitudinal study. *BMJ*, **312**, 1191-1194.
- Piaget, J. (1967). *The child's conception of the world*. Totowa, NJ: Littlefield, Adams
- Pike, K. L. (1967). *Language in relation to a unified theory of the structure of human behaviour*. The Hague: Mouton
- Pimm, T. J. & Weinman, J. (1998). Applying Leventhal's Regulation Model to Adaptation and Intervention in Rheumatic Disease. *Clin.Psychol.Psychother.*, **5**, 62-75.
- Popper, K. (1963). *Conjectures and Refutations*. London: Routledge
- Preville, M., Potvin, L., Boyer, R., & Boulerice, B. (2000). *Relationship between physical health status and responses to a psychological distress measure*. Canada: Canadian Journal on Aging.

- Prohaska, T. R., Leventhal, E. A., Leventhal, H., & Keller, M. L. (1985). Health practices and illness cognition in young, middle aged, and elderly adults. *J. Gerontol.*, **40**, 569-578.
- Raguram, R., Weiss, M. G., Keval, H., & Channabasavanna, S. M. (2001). Cultural dimensions of clinical depression in Bangalore, India. *Anthropology & Medicine*, **8**, 31-46.
- Rasmussen, S. J. (1992). Reflections on tamazai, a Tuareg idiom of suffering. *Culture, Medicine & Psychiatry*, **16**, 337-365.
- Rechtman, R. (2000). Stories of trauma and idioms of distress: From cultural narratives to clinical assessment. *Transcultural Psychiatry*, **37**, 403-415.
- Rethman, P. (1999). Deadly dis-ease: Medical knowledge and healing in northern Kamchatka, Russia. *Culture, Medicine & Psychiatry*, **23**, 197-217.
- Rodrigues, M., Patel, V., Jaswal, S., & de Souza, N. (2003). Listening to mothers: qualitative studies on motherhood and depression from Goa, India. *Social Science & Medicine*, **57**, 1797-1806.
- Roesch, S. C. & Weiner, B. (2001). A meta-analytic review of coping with illness: Do causal attributions matter? *Journal of Psychosomatic Research*, **50**, 205-219.
- Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1988). Social learning theory and the Health Belief Model. *Health Educ. Q.*, **15**, 175-183.
- Rutter, C. L. & Rutter, D. R. (2002). Illness representation, coping and outcome in irritable bowel syndrome (IBS). *Br J Health Psychol.*, **7**, 377-391.

- Saraceno, B. & Saxena, S. (2002). *Prevention and Promotion in Mental Health*
Geneva: WHO.
- Scharloo, M., Kaptein, A. A., Weinman, J., Hazes, J. M., Willems, L. N., Bergman, W.,
& Rooijmans, H. G. (1998). Illness perceptions, coping and functioning in
patients with rheumatoid arthritis, chronic obstructive pulmonary disease and
psoriasis. *J.Psychosom.Res.*, **44**, 573-585.
- Schieffelin, E. L. (1996). Evil spirit sickness, the Christian disease: The innovation of a
new syndrome of mental derangement and redemption in Papua New Guinea.
Culture, Medicine & Psychiatry, **20**, 1-39.
- Schreiber, S. (2001). Migration, traumatic bereavement and transcultural aspects of
psychological healing: Loss and grief of a refugee woman from Begameder
County in Ethiopia. *Br.J.Med.Psychol.*, **68**, 135-142.
- Seltzer, A. (1983). Psychodynamics of spirit possession among the Inuit. *Can.J*
Psychiatry, **28**, 52-56.
- Sembhi, S. & Dein, S. (1998). The use of traditional healers by Asian psychiatric
patients in the UK: A pilot study. *Mental Health*, **1**, 127-133.
- Skultans, V. (1991). Women and affliction in Maharashtra: A hydraulic model of health
and illness. *Culture, Medicine & Psychiatry*, **15**, 321-359.
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing Interpretative Phenomenological
Analysis. In M.Murray & K. Chamberlain (Eds.), *Qualitative Health Psychology -
Theories and Methods* (pp. 218-240). London: Sage.
- Snyder, M. (1984). When belief creates reality. *Advances in Experimental Social*
Psychology, **18**, 247-305.

- Sobo, E. J. (1996). The Jamaican body's role in emotional experience and sense perception: Feelings, hearts, minds, and nerves. *Culture, Medicine & Psychiatry*, **20**, 313-342.
- Storck, M., Csordas, T. J., & Strauss, M. (2000). Depressive Illness and Navajo Healing. *Medical Anthropology Quarterly*, **14**, 571-597.
- Streit, U., LeBlanc, J., & Mekki-Berrada, A. (1998). A Moroccan woman suffering from depression: Migration as an attempt to escape sorcellerie. *Culture, Medicine & Psychiatry*, **22**, 445-463.
- Torsch, V. L. & Xueqin-Ma, G. (2000). *Cross-cultural comparison of health perceptions, concerns, and coping strategies among Asian and Pacific Islander American elders*. US: Sage Publications, Inc.
- Tung, M. P. M. (1994). Symbolic meanings of the body in Chinese culture and "somatization.". *Culture, Medicine & Psychiatry*, **18**, 483-492.
- Van Moffaert, M. M. M. P. (1998). Somatization patterns in Mediterranean migrants. In Ed (Ed.), *Okpaku, Samuel O* (pp. 301-320). DC,US: American Psychiatric Press, Inc. xxiii,458 pp.SEE BOOK: Washington.
- Wallston, K. A., Wallston, B. S., & DeVellis, R. (1978). Development of the Multidimensional Health Locus of Control (MHLC) Scales. *Health Educ.Monogr*, **6**, 160-170.
- Watson, D. (1982). The actor and the observer: How are their perceptions of causality divergent? *Psychological Bulletin*, **92**, 682-700.

- Watson, D., Clark, L. A., & Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: the PANAS scales. *J Pers.Soc.Psychol.*, **54**, 1063-1070.
- Watt, S. & Norton, D. (2004). Culture, ethnicity, race: what's the difference. *Paediatric Nursing*, **16**, 37-42.
- Weinman, J., Petrie, K., Moss-Morris, R., & Horne, R. (1996). The Illness Perception Questionnaire A New Method for Assessing the Cognitive Representation of Illness. *Psychology & Health*, **11**, 431-445.
- Weiss, M. G., Desai, A., Jadhav, S., Gupta, L., Channabasavanna, S. M., Doongaji, D. R., & Behere, P. B. (1988). Humoral concepts of mental illness in India. *Soc.Sci.Med.*, **27**, 471-477.
- Weiss, M. G., Doongaji, D. R., Siddhartha, S., Wypij, D., Pathare, S., Bhatawdekar, M., Bhawe, A., Sheth, A., & Fernandes, R. (1992). The Explanatory Model Interview Catalogue (EMIC). Contribution to cross-cultural research methods from a study of leprosy and mental health. *Br.J.Psychiatry*, **160**, 819-830.
- Weiss, M. G., Sharma, S. D., Gaur, R. K., Sharma, J. S., Desai, A., & Doongaji, D. R. (1986). Traditional concepts of mental disorder among Indian psychiatric patients: preliminary report of work in progress. *Soc.Sci.Med.*, **23**, 379-386.
- Weiss, M. (1997). Explanatory Model Interview Catalogue (EMIC): Framework for comparative study of illness. *Transcultural Psychiatry*, **24**, 235-263.
- Wikan, U. (1989). Illness from fright or soul loss: a North Balinese culture-bound syndrome? *Culture, Medicine & Psychiatry*, **13**, 25-50.

- Williams, B. & Healy, D. (2001). Perceptions of illness causation among new referrals to a community mental health team: "explanatory model" or "exploratory map"? *Soc.Sci.Med.*, **53**, 465-476.
- Williams, S., Weinman, J., Dale, J., & Newman, S. (1995). Patient expectations: what do primary care patients want from the GP and how far does meeting expectations affect patient satisfaction? *Fam.Pract.*, **12**, 193-201.
- Witztum, E. & Goodman, Y. (1999). Narrative construction of distress and therapy: A model based on work with Ultra-Orthodox Jews. *Transcultural Psychiatry*, **36**, 403-436.
- Witztum, E., Grisar, N., & Budowski, D. (1996). The "Zar" possession syndrome among Ethiopian immigrants to Israel: Cultural and clinical aspects. *Br.J.Med.Psychol.*, **69**, 207-225.
- World Health Organization (2001). *The World Health Report 2001, Mental Health: New Understanding, New Hope*.
- Yeung, A. S. & Chang, D. F. (2002). Adjustment disorder: intergenerational conflict in a Chinese immigrant family. *Culture, Medicine & Psychiatry*, **26**, 509-525.
- Yi, K. Y. (2000). Shin-byung (divine illness) in a Korean woman. *Culture, Medicine & Psychiatry*, **24**, 471-486.
- Yilmaz, A. T. & Weiss, M. G. (2000). Cultural formulation: Depression and back pain in a young male Turkish immigrant in Basel, Switzerland. *Culture, Medicine & Psychiatry*, **24**, 259-272.
- Young, A. (1976b). Some implications of medical beliefs and practices for social anthropology. *American Anthropology*, **78**, 5-24.

Young, A. (1976a). Internalizing and externalizing medical belief systems: An
Ethiopian example. *Soc.Sci.Med.*, **19**, 147-156.

Young, A. (1982). *Rational men and the explanatory model approach*. Netherlands:
Kluwer Academic Publishers.

**Protocol for
Bart's Explanatory Model Interview**

***ALL INTERVIEWER INSTRUCTIONS ARE HIGHLIGHTED IN BOLD ITALIC
CAPITALS***

Record Time & Date of Interview Start :

Subject ID :

[Say]

This is a survey about how people perceive and understand illness and distress. It is totally anonymous and confidential. We will keep no reference to your name and your answers will be combined with others before they are analysed. We are very interested in **your personal beliefs**, which means there are no right or wrong answers to the questions we are going to ask you.

Please answer the questions carefully, but do not spend too much time on any one of the questions. As much as you can try to answer the question independently from your previous answers. Please be honest and try **not** to report what you think we or other people might want to hear, but what **you** actually believe in.

I would like to start interviewing you about your understanding of illness and distress.

A) Have you experienced something that distressed you in the past month?

[IF YES – NEXT QUESTION

***IF NO – PROBE WITH WORRIED YOU, MADE YOU UPSET, DEPRESSED,
EMOTIONAL PROBLEMS, DIFFICULT TO FUNCTION IN YOUR LIFE?]***

1) Could you tell me what you call this problem?

***[WRITE DOWN ALL THE ANSWER – IF PERSON SAYS DON'T KNOW OR NOT
SURE PROBE UNTIL NAME IS FOUND]***

2) Could you please describe to me what***[FILL WITH NAME ESTABLISHED IN
1]*** is?

***[WRITE DOWN OR RECORD INITIAL RESPONSE, THEN PROBE FOR
DIFFERENT SUB-DOMAINS – FOR INTERVIEWERS' REFERENCE FULL LIST
OF SYMPTOMS REPORTED IN THE LITERATURE IS ATTACHED IN APPENDIX
1 OF THIS PROTOCOL. MAIN DOMAINS ARE SOMATIC – PHENOMENAL;
PERCEPTUAL, MENTAL – COGNITIVE, EMOTIONAL; AND BEHAVIOURAL –
INTERPERSONAL, PERSONAL UNTIL YOU HAVE ASSESSED BELIEFS OF ALL
SUB-DOMAINS]***

Spontaneous

[PROBE EXAMPLES - MENTAL - DO YOU EXPERIENCE ANY MENTAL PROBLEMS LIKE LACK OF CONCENTRATION OR FEELING LOW AND OUT OF SINK? SOMATIC – DO YOU EXPERIENCE ANY PHYSICAL OR BODILY PROBLEMS LIKE PALPITATIONS OR FATIGUE? BEHAVIOURAL - DO YOU EXPERIENCE ANY BEHAVIOURAL PROBLEMS LIKE CRYING, SMOKING OR DRINKING MORE THAN YOU USED TO?]

3) I would also like to know from you what do you think has caused**[FILL IN NAME ESTABLISHED IN 1]?**

[RECORD INITIAL RESPONSE – THEN PROBE AGAIN FOR ANSWERS ON DIFFERENT SUB-DOMAINS – FULL LIST OF SUBDOMAINS & CATEGORIES IS AGAIN ATTACHED IN APPENDIX 2 OF THIS PROTOCOL: PSYCHOSOCIAL – PERCEPTUAL, EMOTIONAL. INTERPERSONAL, SUPERNATURAL – SPIRITUAL IMBALANCE AND SPIRITUAL ILL-WILL, BEHAVIOURAL, AND SITUATIONAL – NATURAL, PHYSICAL, IMMUNOLOGICAL, GENETIC, ECONOMICAL AND SITUATIONAL]

Spontaneous

[PROBE EXAMPLES: PSYCHOSOCIAL - DO YOU THINK YOUR PROBLEMS WERE CAUSED BY STRESS OR PROBLEMS WITH PEOPLE? SUPERNATURAL – DO YOU THINK YOUR PROBLEMS WERE CAUSED BY HIGHER FORCES OR BLACK MAGIC? BEHAVIOURAL – DO YOU THINK YOUR PROBLEM WAS CAUSED BY DRINKING TOO MUCH OR EATING THE WRONG THINGS? – SITUATIONAL – DO YOU THINK YOUR PROBLEMS WERE CAUSED BY THE WEATHER, ILLNESS OR FINANCIAL PROBLEMS?]

4) How long has lasted so far?

- | | | | |
|-----------------|--------------------------|-------------|--------------------------|
| Less than a day | <input type="checkbox"/> | 1-2 months | <input type="checkbox"/> |
| 1 day | <input type="checkbox"/> | 3-6 months | <input type="checkbox"/> |
| 2-3 days | <input type="checkbox"/> | 7-12 months | <input type="checkbox"/> |
| 4-6 days | <input type="checkbox"/> | 2-5 years | <input type="checkbox"/> |
| 1-2 weeks | <input type="checkbox"/> | 5-10 years | <input type="checkbox"/> |
| 3-4 weeks | <input type="checkbox"/> | | |

5) How long do you expect it to last?

- | | | | |
|-----------------|--------------------------|-------------|--------------------------|
| Less than a day | <input type="checkbox"/> | 1-2 months | <input type="checkbox"/> |
| 1 day | <input type="checkbox"/> | 3-6 months | <input type="checkbox"/> |
| 2-3 days | <input type="checkbox"/> | 7-12 months | <input type="checkbox"/> |
| 4-6 days | <input type="checkbox"/> | 2-5 years | <input type="checkbox"/> |
| 1-2 weeks | <input type="checkbox"/> | 5-10 years | <input type="checkbox"/> |
| 3-4 weeks | <input type="checkbox"/> | Forever | <input type="checkbox"/> |

6) Do you go through cycles when gets better or worse?

- | | |
|--------------------------|--------------------------|
| Yes | No |
| <input type="checkbox"/> | <input type="checkbox"/> |

7) How has having affected your life? What are the main difficulties and advantages you experience since having.....?

[RECORD INITIAL RESPONSE. THEN PROBE FOR OTHER SUBDOMAINS. FULL LIST OF REPORTED CONSEQUENCES IS AGAIN ATTACHED IN APPENDIX 3. SUB-DOMAINS ARE SELF, SOCIAL, FINANCIAL, PHYSICAL AND BEHAVIOURAL]

Spontaneous

[PROBE EXAMPLES SELF – WHAT HAS HAPPENED TO YOURSELF AS A RESULT OF THE PROBLEM? SOCIAL – WHAT HAS HAPPENED TO YOUR FAMILY OR RELATIONSHIP AS A RESULT OF THE PROBLEM? PHYSICAL – WHAT HAS HAPPENED TO YOUR HEALTH AS A RESULT OF THE PROBLEM? FINANCIAL – WHAT HAS HAPPENED TO YOU FINANCIALLY AS A RESULT OF YOUR PROBLEM? BEHAVIOURAL – HAVE YOU CHANGED YOUR BEHAVIOUR AS A RESULT OF YOUR PROBLEM?]

8) Generally, would you say that having has had a big or small impact on your life?

[TICK]

Big

Small

APPENDIX 1

9) Has having **[FILL IN NAME ESTABLISHED IN 1]** affected your

[TICK]

- | | | | |
|--------------------|--------------------------|-------------|--------------------------|
| Physical Ability | <input type="checkbox"/> | Personality | <input type="checkbox"/> |
| Social life | <input type="checkbox"/> | Behaviour | <input type="checkbox"/> |
| Financial security | <input type="checkbox"/> | Status | <input type="checkbox"/> |

[IF THIS QUESTION ELICITS ANYTHING MORE THAN MENTIONED IN 7. RECORD ANSWER BELOW]

10) How do you think should **[FILL IN NAME ESTABLISHED IN 1]** be best dealt with? How can **[FILL IN NAME ESTABLISHED IN 1]** be best resolved?

[RECORD ANSWER – NO PROBING]

11) I would like to ask you to tell me whether you have tried or considered any of the following methods to resolve your problem? **[RECORD UNDER CONSIDERED]**

	Considered	Tried
Dieting/Fasting	<input type="checkbox"/>	<input type="checkbox"/>
Exercising	<input type="checkbox"/>	<input type="checkbox"/>
Using alcohol, tobacco or illicit drugs	<input type="checkbox"/>	<input type="checkbox"/>
Keeping busy	<input type="checkbox"/>	<input type="checkbox"/>
Talking to somebody	<input type="checkbox"/>	<input type="checkbox"/>
Socialising	<input type="checkbox"/>	<input type="checkbox"/>
Taking medication	<input type="checkbox"/>	<input type="checkbox"/>
Using herbal remedies	<input type="checkbox"/>	<input type="checkbox"/>
Relaxation/massage	<input type="checkbox"/>	<input type="checkbox"/>
Seeing (APPROPRIATE TRADITIONAL HEALER e.g. HAKEEM)	<input type="checkbox"/>	<input type="checkbox"/>
Praying	<input type="checkbox"/>	<input type="checkbox"/>
Chanting	<input type="checkbox"/>	<input type="checkbox"/>
Dancing	<input type="checkbox"/>	<input type="checkbox"/>
Thinking	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX 1

12 a) Who did you talk to about this problem? **[RECORD ANSWER UNDER A]**
b) Was talking to**[FILL IN NAME OF PEOPLE CONSULTED]** helpful?

A)	B)		
1) _____	YES	NO	
2) _____	YES	NO	
3) _____	YES	NO	
4) _____	YES	NO	
5) _____	YES	NO	

13) Why-why not? OPEN -ENDED

[RECORD ANSWER – NO PROBING]

[SAY]

This means we have finished with this interview. However I would also like you to fill in the following three checklists and am happy to assist you if you need any help. We have included the checklists as we want to be sure that we can truly understand what the problem is and what it means to you.

APPENDIX 1

Please tick any of the following boxes if you believe that the symptoms are part of your problem.

- CRYING.....
- DISTURBED SLEEP.....
- CHANGE OF EATING PATTERNS.....
- PALPITATIONS.....
- INDIGESTION.....
- UNUSUAL SKIN SENSATIONS.....
- VISUAL DEFICIENCY.....
- LOSS OF BODILY FLUID.....
- PAIN.....
- ACHES.....
- FATIGUE.....
- NERVES- AGITATION.....
- HEAT OR HEAVINESS IN ANY PART OF THE BODY.....
- BODILY WEAKNESS.....
- NAUSEA.....
- DYSPHORIA (FEEL DOWN).....

- IRRITABILITY.....
- FEEL NERVOUS- ANXIOUS.....
- FEEL FRIGHTENED.....
- LACK OF CONCENTRATION.....
- LOSS OF INTEREST.....
- WORRYING THOUGHTS/TORMENT.....
- SUICIDAL THOUGHTS/PLANS.....
- FEEL GUILTY.....
- FEEL ASHAMED.....
- WITHDRAWAL FROM OTHERS.....
- CANNOT COMPLETE TASKS.....
- BE VIOLENT TOWARDS PEOPLE.....
- BECOME MUTE.....
- SCREAM.....
- SWEAR.....
- SUBSTANCE USE.....
- TOBACCO, ALCOHOL, MEDICINES, DRUGS.....
- BE VIOLENT TOWARDS THINGS.....
- OBSESSIVE BEHAVIOUR.....
- NEGLECT OF HYGIENE.....
- HALLUCINATIONS.....
- RAMBLING.....
- SUICIDE PLANS.....

OTHER

APPENDIX 1

Have any of the following causes contributed to your illness? Tick the boxes if you believe that this might have contributed to developing your illness.

- STRESS.....
- YOUR AGE
- YOUR GENDER
- YOUR CULTURE.....
- YOUR RELIGION.....
- YOUR ETHNICITY.....
- WORRY
- GUILT/SHAME.....
- EMOTIONS (EXCESSIVE)
- WORK PROBLEMS
- FAMILY PROBLEM.....
- MARITAL PROBLEM
- LONELINESS/ISOLATION
- LOSS/BEREAVEMENT
- RACISM – PREJUDICE/ STEREOTYPE.....
- FATE/ DESTINY' (DELIBERATE).....
- BAD LUCK (RANDOM).....
- ANCESTORS' SPIRITS
- WEAKENED SPIRIT/ SOUL LOSS.....
- TEST OF FAITH.....
- BLACK MAGIC/EVIL EYE/SORCERY
- PUNISHMENT (GOD) – TABOO BREACH
- DIET/INGESTION
- SUBSTANCE (AB-) USE (ALCOHOL, TOBACCO, DRUGS).....
- LACK OF OR NO SEX.....
- WIND/ WEATHER.....
- CLIMATE.....
- ASTROLOGY.....
- ILLNESS AND/OR DISABILITY
- IMBALANCE OF BODILY FLUIDS
- BLOOD, (BAD BLOOD, HOT BLOOD ETC).....
- POISON
- VIRUS/GERM
- HEREDITY (GENES)
- FINANCIAL PROBLEMS
- ANY KIND OF TRAUMA/SHOCK (E.G. CAR CRASH, WAR)

OTHER

APPENDIX 1

Finally we would also like to know whether you experienced any of the following consequences?

- INCREASINGLY FOCUS ON YOUR BODY/ THE ILLNESS.....
- BEING TORMENTED BY INTERFERING THOUGHTS
- FEELING BAD
- FEELING SAD
- FEELING IRRITABLE
- FEELING AGGRESSIVE
- LOWERED SELF-ESTEEM
- FEAR.....
- YOUR ROLE (IN YOUR FAMILY, COMMUNITY ETC HAS CHANGED
- BEING EXCLUDED FROM SOCIAL ACTIVITIES
- BEING REJECTED OR ISOLATED.....
- BEING STIGMATISED OR LOSS OF STATUS
- BEING PHYSICALLY ABUSED.....
- BEING LOCKED UP
- LOSING YOUR JOB
- BECOMING DISABLED.....
- LOSING YOUR FINANCIAL SECURITY
- PAIN.....
- LOSING WEIGHT
- GAINING WEIGHT.....
- ABUSING ALCOHOL, TOBACCO, MEDICATION OR ILLEGAL DRUGS
- STOP PARTAKING IN ACTIVITIES THAT YOU ENJOY

OTHER

I would like to take the time to thank you very much for spending the time talking to me and filling in these checklists, your answers are very important to us.

Thank you very much !!!

Screening questionnaire

For telephone survey

NOTE: Interviewer instructions are all in UPPER CASE ITALIC

RECORD]

Date of Interview: _____ Time Interview Start: _____ ID No: _____

AY]

Good Morning/ Evening. My name is and I am calling from Bart's Hospital, University of London. I would like to speak to _____. **[IF NOT AVAILABLE , VERIFY THAT THE PERSON WILL STILL BE CONTACTED UNDER THIS TELEPHONE NUMBER – WHEN PERSON GETS ON THE PHONE REPEAT NAME AND LOCATION].** We are conducting at the moment a survey that explores perceptions of distress. The survey has been approved by the City and East London health authority and we have also written to inform you about the project. **[IF DOES NOT REMEMBER READ OUT INVITATION TO PARTICIPATE – MAKE SURE INDIVIDUAL IS AWARE OF REQUIREMENTS AND DECIDES TO PARTICIPATE OUT OF FREE CHOICE].** The survey is completely confidential and should take no longer than 15 minutes. Would it be convenient to talk with you now or should we call back another time?

RCLE]

OK to continue

This is not a convenient time

ARRANGE CALLBACK ___/___ @ ___ o'clock

Refusal

THANK AND TERMINATE THE INTERVIEW

Named person not known under this number

ASK WHETHER PERSON HAS NEW CONTACT DETAILS.

RECORD NEW DETAILS IF AVAILABLE

IF NOT THANK

AND TERMINATE THE INTERVIEW

How would you describe your ethnicity?

White

Asian or Asian British

White British

Indian

White Irish

Pakistani

White Other

Bangladeshi

Asian Other

Mixed

White and Black Caribbean

Black or Black British

White and Black African

Black African

White and Asian

Black Caribbean

Mixed Other

Black Other

Chinese

Other: _____

If person says any of the grey shaded ethnic identities, the survey is complete. Say] Thank you for your time! [If eligible, proceed]

Firstly, we would like to know if you have had any medical complaints and how your health has been in general, over the last few weeks. Please answer all the questions by saying which answer applied mostly to you. Remember that we want to know about complaints that you experienced in the past few weeks up to one month and **not** those that you had in the past.

Have you recently been able to concentrate on whatever you're doing? [CIRCLE]

More than usual Same as usual Less than usual Much less than usual

Have you recently lost much sleep over worry?

Not at all No more than usual Rather more than usual Much more than usual

Have you recently felt that you are playing a useful part in things?

More so than usual Same as usual Less useful than usual Much less useful

Have you recently felt capable of making decisions about things?

More so than usual Same as usual Less so than usual Much less than usual

Have you recently felt constantly under strain?

Not at all No more than usual Rather more than usual Much more than usual

Have you recently felt you couldn't overcome your difficulties?

Not at all No more than usual Rather more than usual Much more than usual

Have you recently been able to enjoy your normal day-to-day activities?

More so than usual Same as usual Less so than usual Much less than usual

Have you recently been able to face up to your problems?

More so than usual Same as usual Less so than usual Much less able

Have you been feeling unhappy and depressed?

Not at all No more than usual Rather more than usual Much more than usual

Have you recently been losing confidence in yourself?

Not at all No more than usual Rather more than usual Much more than usual

Have you been thinking of yourself as a worthless person?

Not at all No more than usual Rather more than usual Much more than usual

Have you recently been feeling reasonable happy, all things considered?

More so than usual About same as usual Less so than usual Much less than usual

Now, I would like you to tell me whether you experienced any of the following symptoms during the past month. If you have not experienced them please say absent, if you have experienced them please indicate whether you experienced them more or less than 15 days of the last month.

	Absent	Present < 15 d	Present >15 days
Severe headache.....	1	2	3
Fluttering or a feeling on something moving in your stomach.....	1	2	3
Constriction of your head as if it was tightly gripped from the outside	1	2	3
Pain in the chest or the heart.....	1	2	3
Dry mouth or throat.....	1	2	3
Lack of energy (weakness) much of the time.....	1	2	3
Sweating a lot.....	1	2	3
Pressure of tightness on your chest or heart	1	2	3
Choking sensation in your throat	1	2	3
Aches and Pain all over your body	1	2	3
Palpitations (Heart Pounding)	1	2	3
Trembling or shaking	1	2	3
Passing urine more frequently	1	2	3
Feel that your head is heavy.....	1	2	3
Unexplainable tiredness [tired even when you are not working].....	1	2	3
A feeling of pressure inside your head as if your head is going to burst	1	2	3
Constipation.....	1	2	3
Sweating palms	1	2	3
Weak or sinking heart.....	1	2	3
Excessive wind or belching.....	1	2	3
Hands and feet feel cold	1	2	3

I would like to finish this interview by asking you some general questions about you and your personal background.

When was your date of birth: ___ / ___ / 19___ Gender: M F

Where was your place of birth: _____

How many years have you lived in the UK: _____ [**RECORD ALL, IF BORN IN ENGLAND**]

What was your first language: _____

How many children do you have? _____

Who else do you live with? _____

- Which best describes how you spend most of your time
- In paid employment
 - A full-time student
 - Homemaker / full-time parent
 - Retired
 - Permanently sick or disabled
 - Unemployed
 - Other _____

Describe what you do (or have done) for a living in as much detail as possible?

How old were you when you left school? Years

Did you go to primary school in Britain? YES NO

Which type of residency do you live?

- House/ Flat (Owner)
- House/ Flat (Housing association)
- House/ Flat (Private Rent)
- Boarding out (incl B&B)
- Hostel, supported/group home
- Sheltered Housing
- Residential Home
- Hospital Ward
- Other: _____

Which of the following benefits do you receive

- Free NHS Prescriptions
- Income Support
- Housing Benefit
- Family Credit
- Disability Benefit
- Other _____
- None of these

Have you suffered from any illnesses and/or chronic conditions? YES NO

If yes please describe to me what they are?

We would like to thank you very much for taking part in this survey! Your answers will be very important to us. At a later stage in this project, we might contact you again as we will select randomly some individuals to ask some more detailed questions about their perceptions. THANK YOU FOR HELPING US SO FAR!

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

ID No

Date.....

YOUR VIEWS ABOUT YOUR ILLNESS

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

	I have experienced this symptom <i>since my illness</i>		This symptom is <i>related to my illness</i>		
	Yes	No	Yes	No	
Pain	Yes	No	_____	Yes	No
Sore Throat	Yes	No	_____	Yes	No
Nausea	Yes	No	_____	Yes	No
Shortness of Breath	Yes	No	_____	Yes	No
Weight Loss	Yes	No	_____	Yes	No
Fatigue	Yes	No	_____	Yes	No
Stiff Joints	Yes	No	_____	Yes	No
Sore Eyes	Yes	No	_____	Yes	No
Wheeziness	Yes	No	_____	Yes	No
Headaches	Yes	No	_____	Yes	No
Upset Stomach	Yes	No	_____	Yes	No
Sleep Difficulties	Yes	No	_____	Yes	No
Dizziness	Yes	No	_____	Yes	No
Loss of Strength	Yes	No	_____	Yes	No

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by checking the appropriate box.

VIEWES ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1 My illness will last a short time					
2 My illness is likely to be permanent rather than temporary					
3 My illness will last for a long time					
4 This illness will pass quickly					
5 I expect to have this illness for the rest of my life					
6 My illness is a serious condition					

APPENDIX 3

P7	My illness has major consequences on my life				
P8*	My illness does not have much effect on my life				
P9	My illness strongly affects the way others see me				
P10	My illness has serious financial consequences				
P11	My illness causes difficulties for those who are close to me				
P12	There is a lot which I can do to control my symptoms				
P13	What I do can determine whether my illness gets better or worse				
P14	The course of my illness depends on me				
P15*	Nothing I do will affect my illness				
P16	I have the power to influence my illness				
P17*	My actions will have no affect on the outcome of my illness				
P18*	My illness will improve in time				
P19*	There is very little that can be done to improve my illness				
P20	My treatment will be effective in curing my illness				
P21	The negative effects of my illness can be prevented (avoided) by my treatment				
P22	My treatment can control my illness				
P23*	There is nothing which can help my condition				
P24	The symptoms of my condition are puzzling to me				
P25	My illness is a mystery to me				
P26	I don't understand my illness				
P27	My illness doesn't make any sense to me				
P28*	I have a clear picture or understanding of my condition				
P29	The symptoms of my illness change a great deal from day to day				
P30	My symptoms come and go in cycles				
P31	My illness is very unpredictable				
P32	I go through cycles in which my illness gets better and worse.				
P33	I get depressed when I think about my illness				
P34	When I think about my illness I get upset				
P35	My illness makes me feel angry				
P36*	My illness does not worry me				
P37	Having this illness makes me feel anxious				
P38	My illness makes me feel afraid				

CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my illness					
C11	Overwork					
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR illness. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

Items for IPQ-R Subscales

1. **Identity (sum of yes-rated symptoms in column 2 on p. 1)**

2. **Timeline (acute/chronic) items IP1 - IP5 + IP18**

3. **Consequences items IP6 - IP11**

4. **Personal control items IP12 - IP17**

5. **Treatment control items IP19 - IP23**

6. **Illness coherence items IP24 - IP28**

7. **Timeline cyclical IP29 - IP32**

8. **Emotional representations IP33 - IP38**

9. **Causes C1 - C18 - do not use these as a scale. Start analysis with separate items**

- used as grouping variables (ie those who do/do not believe in a specific causal factor). With a sufficient sample size (n=90 or more), factor analysis can be used to identify groups of causal beliefs (eg lifestyle ; stress etc) which can then be used as sub-scales (e.g. *see Weinman et al, 2000*).

SCORING - score each item for the above sub-scales (except Identity and Causes –*see above*) as follows – Strongly disagree=1; disagree=2; neither etc=3; agree=4; strongly agree=5, EXCEPT for the starred items (*) which are reverse scored (ie strongly disagree =5; disagree=4 etc etc). Get total score for each sub-scale.

Reasons for revising the IPQ

Work with the original IPQ had occasionally shown that one of the sub-scales (cure/control) had low internal reliability. Closer investigation of this showed that there were 2 separate components to this scale personal control and perceived efficacy of treatment (ie outcome efficacy beliefs) - so we have created 2 sub-scales to assess these separately.

Additional scales have been incorporated to assess 3 new, related concepts - cyclical timeline beliefs, emotional impact of illness, and perceived coherence of illness. The latter is essentially an indicator of how helpful the individual's model of illness is to the individual- thus it assesses the extent to which they find the illness/symptoms puzzling etc. Thus it is a sort of meta-cognition measure and arose from a big, recently completed outcome study with RA patients . This evaluated the efficacy of a cognitive intervention which seemed to work by making the illness more understandable to the individual, and hence enabled them to cope more effectively.

The new scale was devised to incorporate all these changes and a version of it was administered to a large sample of patients with chronic illness. Their data was factor-analysed and the separate components came out very cleanly, and the resulting sub-scales had very good internal reliability co-efficients Cronbach alphas of .8 and .9).

A paper describing the new scale and its development will be submitted for journal publication during this year.

Reference

Weinman, J, Petrie, KJ, Sharpe, N & Walker, S . (2000) Causal attributions in patients and spouses following first-time myocardial infarction and subsequent lifestyle changes. *Br. J. Health Psychology*, 5, 263-273.

culturation scale

PLEASE tick **ONE** box for each question.

	All of the time	Quite often	Some of the time	Not very often	Never
Are your preferences of clothes, food, friends and language the same as the choice that your parents would make for themselves?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you prefer or feel more comfortable speaking another language?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is your choice in clothes similar to people from your own culture?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you like eating food from other people's culture?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you choose your good friends from your own cultural group?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Is your choice in clothes similar to people from other cultures?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you prefer or feel more comfortable speaking English compared to any other language?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you like eating food from your own culture?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are your preferences of clothes, food, friends and language the same as the choice that your children would make for themselves?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you choose your good friends from other cultural groups?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Clinical Interview Schedule - Revised
Stage II interview

A Somatic Symptoms

1 Have you had any sort of ache or pain in the past month?
Yes 1 A3
No.....2

2 During the past month have you been troubled by any sort of discomfort, for example, headache or indigestion?
Yes 1
No.....2 B

3 Was this ache or pain/discomfort brought on or made worse by feeling low, anxious or stressed?
Yes 1
No.....2 B
informant has more than one pain/discomfort
refer to any of them

4 In the past seven days, including the last [DAY OF WEEK]. On how many days have you noticed the ache or pain/discomfort?
More than 4 days 1
1-3 days2
None.....3 B

5 In total, did the ache or pain/discomfort last for more than 3 hours on any day in the past week/ on that day?
Yes 1
No.....2

6 In the past week, has the pain/discomfort been
Very unpleasant..... 1
A little unpleasant2
Not unpleasant3
Rating Prompt

7 Has the pain/discomfort bothered you when you were doing something interesting in the past week?
Yes 1
No/Has not done anything interesting.....2

8 How long have you been feeling this ache or pain/discomfort as you have just described?
Less than 2 weeks 1
2 weeks but less than 6 months2
6 months but less than a year3
1 year but less than 2 years4
2 years or more5

SUM OF BOLD CIRCLED

B Fatigue

B1 Have you noticed that you've been getting tired in the past month?

Yes 1 B3
No.....2

B2 During the past month, have you felt that you've been lacking in energy?

Yes 1
No.....2 C

B3 Do you know why you have been feeling tired/lacking in energy?

Yes 1(a)
No.....2

a) What is the main reason? **[RING ONE ONLY]**

Problems with sleep..... 1
Medication2
Physical Illness3
Working too hard (including housework, looking after baby)4
Stress, worry or other psychological reason5
Physical Exercise6 C
Other7

B4 In the past seven days, including last [DAY OF WEEK] on how many days have you felt tired/ lacking in energy?

4 days or more 1
1- 3 days2
None.....3 C

B5 Have you felt tired/ lacking in energy for more than three hours in total on any day in the past week?

Exclude time spent sleeping

Yes..... 1
No.....2

B6 Have you felt so tired/ lacking in energy that you've had to push yourself to get things done during the past week?

Yes, on at least one occasion..... 1
No.....2

B7 Have you felt tired/ lacking in energy when doing things that you enjoy during the past week?

Yes, at least once..... 1 B9
No.....2

[Spontaneous] Does not enjoy anything3

B8 Have you in the past week felt tired/ lacking in energy when doing things that you used to enjoy?

Yes..... 1
No.....2

B9 How long have you been feeling tired/lacking in energy in the way you've just described?

- Less than 2 weeks 1
- 2 weeks but less than 6 months 2
- 6 months but less than a year 3
- 1 year but less than 2 years 4
- 2 years or more 5

SUM OF BOLD CIRCLED

C Concentration and Forgetfulness

C1 In the past month, have you had any problems in concentrating what you are doing?

Yes, problems concentrating..... 1
No.....2

C2 Have you noticed any problems with forgetting things in the past month?

Yes..... 1
No.....2

C3 [Interviewer check C1 or C2 = yes, circle 1 and continue, if both no circle 2 and go to D]

Has Problems with Concentr./ Forget 1
Others2 D

C4 Since last [DAY OF WEEK] on how many days have you noticed problems with your concentration/memory?

4 days or more 1
1 to 3 days 2
None 3 C9

Concentration problems

Interviewer check If C1 = Yes continue, if No, circle 1 and ask C7

DNA..... 1C7

C5 In the past week could you concentrate on a TV programme, read a newspaper article or talk to someone without your mind wandering?

Yes 2
No/not always 1

C6 In the past week, have these problems with your concentration actually **stopped** you from getting on with things you used to do or would like to do?

Yes 1
No.....2

Forgetfulness problems

Interviewer check If C2 = Yes continue, if No circle 1 and ask C8

DNA..... 1C8

C7 (Earlier you said you have been forgetting things.) Have you forgotten anything important in the past seven days?

Yes 1
No.....2

APPENDIX 5

C8 How long have you been having the problems with your concentration/ memory as you have described?

- Less than 2 weeks 1
- 2 weeks but less than 6 months 2
- 6 months but less than a year 3
- 1 year but less than 2 years 4
- 2 years or more 5

SUM OF BOLD CIRCLED

D Sleep Problems

D1 In the past month, have you been having problems with trying to get to sleep or with getting back to sleep if you woke up or were woken up?

Yes 1 D3
No.....2

D2 Has sleeping more than you usually do been a problem for you in the past month?

Yes 1
No.....2 E

D3 On how many of the past seven nights did you have a problem with your sleep?

4 nights or more 1
1-3 nights 2
None..... 3 E

D4 Do you know why you are having problems with your sleep?

Yes 1 (a)
No.....2

a) Can you look at this and tell me the **main** reason for these problems?

- code one only
- Noise 1
 - Shift work/ too busy to sleep 2
 - Illness/discomfort..... 3
 - Worry/ thinking 4
 - Needing to go to the toilet 5
 - Having something to do e.g. looking after baby..... 6
 - Tired 7
 - Medication..... 8
 - Other 9

Interviewer check If D1 = Yes continue, if not circle 1 and ask D8

DNA..... 1D8

D5 Thinking about the night you had the least sleep in the past week, how long did you spend trying to get to sleep? (If you woke up or were woken up I want you to allow a quarter of an hour to get back to sleep)

Less than ¼ hour 3 E
At least ¼ hour <1 hour 1 D7
At least 1 hour <3 hours 2 D7
3 hours or more 2

Only include time spent
Trying to get to sleep

APPENDIX 5

D6 In the past week, on how many nights did you spend 3 or more hours trying to get back to sleep?

- 4 nights or more**1
- 1 – 3 nights2
- None3

D7 Do you wake more than half an hour earlier than you need to and find you can't get back to sleep?

- Yes1 D10
- No.....2 D10

D8 Informants who slept more than usual

Thinking about the night you slept the longest in the past week, how much longer did you sleep compared with how long you normally sleep for?

- Less than ¼ hour3 E
- At least ¼ hour <1 hour**1 D10
- At least 1 hour <3 hours**2 D10
- 3 hours or more**2

D9 In the past week, on how many nights did you sleep for more than 3 hours longer than you usually do?

- 4 nights or more**1
- 1 – 3 nights2
- None3

D10 How long have you had these problems with your sleep as you have described?

- Less than 2 weeks1
- 2 weeks but less than 6 months2
- 6 months but less than a year3
- 1 year but less than 2 years4
- 2 years or more5

SUM OF BOLD CIRCLED

APPENDIX 5

E Irritability

E1 Many people become irritable or short tempered at times, though they may not show it. Have you felt irritable or short tempered with those around you in the past month?

Yes/no more than usual.... 1 E3
No.....2

E2 During the past month did you get short tempered or angry over things which now seem trivial when you look back on them?

Yes 1
No.....2 F

E3 Since last [DAY OF WEEK], on how many days have you felt irritable or short tempered/angry?

4 days or more 1
1-3 days . 2
None..... 3 F

E4 What sort of things made you irritable or short tempered/angry in the past week?

E5 In total, have you felt irritable or short tempered/angry for more than one hour (on any day in the past week)?

Yes 1
No.....2

E6 During the past week, have you felt so irritable or short tempered/angry that you have wanted to shout at someone even when you haven't actually shouted?

Yes 1
No.....2

E7 In the past seven days, have you had arguments, rows or quarrels or lost your temper with anyone?

Yes 1 (a)
No.....2 E10

a) Did this happen once or more than once in the past week?

Once 1
More than once 2 E9

E8 Do you think this was justified?

Yes justified 2 E10
No, not justified 1 E10

APPENDIX 5

E9 Do you think this was justified on every occasion?

Yes2

No, at least one was unjustified1

E10 How long have you been feeling irritable or short tempered/angry as you have described?

Less than 2 weeks 1

2 weeks but less than 6 months2

6 months but less than a year3

1 year but less than 2 years4

2 years or more5

SUM OF BOLD CIRCLED

APPENDIX 5

F Worry about Physical Health

F1 Many people get concerned about their physical health. In the past month, have you been at all worried about your physical health?

Include women who are worried about
Their pregnancy

Yes, worried 1 F3
No /concerned 2

Check Screening to double check ask
* Do you have a physical health problem

Yes 1 G
No 2

F2 During the past month, do you find yourself worrying that you might have a serious physical illness?

Yes 1
No 2 G

F3 Thinking about the past seven days, including last [DAY OF WEEK], on how many days have you found yourself worrying about your physical health/ that you might have a physical illness?

4 days or more 1
1 - 3 days 2
None 3 G

F4 In your opinion, have you been worrying too much in view of your actual health?

Yes 1
No 2

F5 In the past week has this worrying been

Running Prompt

Very unpleasant 1
A little unpleasant 2
Not unpleasant 3

F6 In the past week, have you been able to take your mind off your health worries at least once, by doing something?

Yes 2
No, could not be distracted once ... 1

F7 How long have you been worrying about your physical health in the way you have described?

Less than 2 weeks 1
2 weeks but less than 6 months 2
6 months but less than a year 3
1 year but less than 2 years 4
2 years or more 5

SUM OF BOLD CIRCLED

G Depression

G1 Almost everyone become sad, miserable or depressed at times.
Have you had a spell of feeling sad, miserable or depressed in the past month?

- Yes 1
- No 2

G2 During the past month, have you been able to enjoy or take an interest in things as much as you usually do?

- Yes 1
- No/no enjoyment or interest 2

G3 Interviewer check if G1=Yes, circle 1 and continue, if G2=No, circle 2 and ask G5, any other responses to the above questions circle 3 and go to I

- Code first that applies
- G1=1 1
- G2=2 2 G5
- DNA 3 I

G4 In the past **week** have you had a spell of feeling sad, miserable or depressed?

Use the informant's own words if possible

- Yes 1
- No 2

Interviewer check, if G2=No/ no enjoyment or interest ask G5, if G2=Yes, circle 1, go G6.

- DNA 1 G6

G5 In the past **week**, have you been able to enjoy or take an interest in things as much as usual?

Use the informant's own words if possible

- Yes 2
- No/no enjoyment or interest 1

Interviewer check, If G4 or G5=1 continue, if not circle 1, go to H

- DNA 1H

G6 Since last [DAY OF WEEK] on how many days have you felt sad, miserable or depressed/ unable to enjoy or take an interest in things?

- 4 days or more 1
- 2 or 3 days 2
- 1 day 3

APPENDIX 5

G7 Have you felt sad, miserable or depressed/ unable to enjoy things for more than 3 hours in total (on any day in the past week)?

Yes1
 No.....2

G8 a) What sorts of things made you feel sad, miserable or depressed/unable to enjoy or take an interest in life? Can you choose from this list?

Ring code all that apply in column a	a	b
Members of the family.....	01	01
Relationship with spouse/ partner	02	02
Relationship with friends	03	03
Housing.....	04	04
Money/bills	05	05
Own physical health (incl. Pregnancy)	06	06
Own mental health	07	07
Work or lack of work (incl. Students).....	08	08
Legal difficulties	09	09
Political Issues/ the news	10	10
Other.....	11	11
Don't know/ no main thing.....	99	99

Interviewer check, if a) = several items checked continue with b), if only one item circled circle 1 and ask G9

DNA..... 1G9

b) What was the main thing?

Ring one item column b.

G9 In the past week, when you felt sad, miserable or depressed/ unable to take an interest in things, did you ever become happier when something nice happened or when you were in company?

Yes/at least once2
No1

G10 How long have you been feeling sad, miserable or depressed/ unable to enjoy or take an interest in things as you have described?

Less than 2 weeks 1
 2 weeks but less than 6 months2
 6 months but less than a year3
 1 year but less than 2 years4
 2 years or more5

SUM OF BOLD CIRCLED

H Depressive Ideas

Interviewer check if Sum of G > 1, ask H1, if Sum of G = 0/ blank circle 1 below and go to I.

DNA..... 1I

H1 I would now like to ask you about when you have been feeling sad, miserable or depressed/ unable to enjoy or take an interest in things? In the past week, was this worse in the morning or in the evening, or did this make no difference?

Prompt as necessary

- In the morning 1
- In the evening 2
- No difference/ other 3

H2 Many people find that feeling sad, miserable or depressed/ unable to enjoy or take an interest in things can affect their interest in sex. Over the past month, do you think your interest in sex has

Running prompt

Spontaneous

- Increased 1
- Decreased 2
- Or stayed the same 3
- Not applicable 4

H3 When you have felt sad, miserable or depressed/ unable to enjoy or take an interest in things in the past seven days,

Individual prompt	Yes	No
Have you been so restless that you couldn't sit still?..	1	2
Have you been doing things more slowly, For example walking more slowly?	1	2
Have you been less talkative than normal	1	2

H4 Now thinking about the past seven days have you on at least one occasion felt guilty or blamed yourself when things went wrong when it hasn't been your fault?

- Yes, at least once..... 1
- No..... 2

H5 During the past week, have you been feeling you are not as good as other people?

- Yes..... 1
- No..... 2

H6 Have you felt hopeless at all during the past seven days, for instance about your future?

- Yes..... 1
- No..... 2

APPENDIX 5

H7 Interviewer check, if H4, or H5 or H6 =1, circle 1 and continue, if all no circle 2 and read H10

Guilt, Hopeless etc..... 1
DNA..... 2 H10

H8 In the past week, have you felt that life isn't worth living?

Spontaneous Yes, but not in the past week **Yes..... 1**
..... 2 H10
No..... 3 H10

H9 In the past week, have you thought of killing yourself?

Spontaneous Yes, but not in the past week **Yes..... 1 a)**
..... 2 H10
No..... 3 H10

a) Have you talked to your doctors about these thoughts (of killing yourself)?

Spontaneous Yes..... 1 H10
No, but talked to other people 2 read b
No..... 3 read b

b) You have said that you are thinking about committing suicide. Since this is a very serious matter it is important that you talk to your doctor about these thoughts

H10 Thank you for answering those questions on how you have been feeling. I would now like to ask you a few questions about worrying.

Max Score = 5

SUM OF BOLD CIRCLED

I Worry

11 (The next few questions are about worrying.) In the past month, did you find yourself worrying more than you needed to about things?

Yes, worrying 1 I3
No.....2

12 Have you had any worries at all in the past month?

Yes 1
No.....2 J

13 a) Can you look at this list and tell me what sorts of things you worried about in the past month?

Ring code all that apply in column a	a	b
Members of the family	01	01
Relationship with spouse/ partner	02	02
Relationship with friends	03	03
Housing	04	04
Money/bills	05	05
Own physical health (incl. Pregnancy)	06	06
Own mental health	07	07
Work or lack of work (incl. Students).....	08	08
Legal difficulties	09	09
Political Issues/ the news	10	10
Other.....	11	11
Don't know/ no main thing.....	99	99

Interviewer check, if a) = several items checked proceed to b), if only one item circled only circle 1 below and continue

DNA..... 114

b) What was the main thing you worried about?

Ring one item column b.

4 Interviewer check if I3a) = 06, circle 1 and continue, if a) not 06, circle 2 and ask I6

Physical health worries 1
DNA.....2 I6

Check section F to record this worry about physical health if not already recorded.

15 Interviewer check if I3a) only 06 circled, circle 1 go to J, if I3a) other worries too read a)

Only Physical Health Worries 1J
Other worries too2 a)

APPENDIX 5

a) For the next few questions, I want you to think about the worries you have had **other** than those about your physical health.

16 On how many of the past seven days have you been worrying about things (other than your physical health)?

- 4 days or more** 1
- 1 - 3 days 2
- None..... 3 J

17 In your opinion, have you been worrying too much in view of your circumstances?

Refer to worries other than physical health

- Yes** 1
- No** 2

18, In the past week, has this worrying been

Running Prompt

Refer to worries other than physical health

- Very unpleasant** 1
- A little unpleasant 2
- Not unpleasant 3

9 Have you worried for more than 3 hours in total on any one of the past seven days?

Refer to worries other than physical health

- Yes** 1
- No** 2

10 How long have you been worrying about things in the way you have described?

- Less than 2 weeks 1
- 2 weeks but less than 6 months 2
- 6 months but less than a year 3
- 1 year but less than 2 years 4
- 2 years or more 5

SUM OF BOLD CIRCLED

J Anxiety

J1 Have you been feeling anxious or nervous in the past month?

Yes, anxious or nervous ... 1 J3
No.....2

J2 In the past month, did you ever find your muscles get tense or that you couldn't relax?

Yes 1
No.....2

J3 Some people have phobias, they get nervous or uncomfortable about specific things or situations when there is no real danger. For instance, they may get nervous when speaking or eating in front of strangers, when they are far from home or in crowded rooms, or they may have a fear of heights. Others become nervous at the sight of things like blood or spiders.

In the past month, have you felt anxious, nervous or tense about any specific things or situations when there was no real danger?

Yes 1
No.....2

J4 Interviewer check

If J1 or J2 = 1 AND J3 = 1, circle 1 and continue 1
If J1 or J2 = 1 AND J3 = 2, circle 2 AND ask J7 2 J7
Others, circle 3 and go to K 3 K

J5 In the past month, when you felt anxious/nervous/tense, was this always brought on by the phobia about some **specific** situation or thing or did you sometimes feel **generally** anxious/nervous/tense?

Always brought on by phobia..... 1 K
Sometimes feel generally anxious 2

J6 The next questions are concerned with **general** anxiety/ nervousness/ tension only. I will ask you about the anxiety, which is brought on by the phobia about specific things later.

On how many of the past seven days have you felt **generally** anxious/nervous/tense?

4 days or more 1
1 to 3 days 2
None 3 K

J7 In the past week, has your anxiety/nervousness/tension been

Very unpleasant..... 1
A little unpleasant 2
Not unpleasant 3

Running Prompt

APPENDIX 5

J8 In the past week, when you've been anxious/nervous/tense have you had any symptoms on this list?

Heart racing or pounding, Hand sweating or shaking, Feeling dizzy, Difficulty getting your breath, Butterflies in stomach, Dry mouth, Nausea or feeling as though you wanted to vomit

Yes.....1 a)
No.....2 J10

a) Which of these symptoms did you have when you felt anxious/nervous/tense?

- Circle all that apply
- Heart racing or pounding 1
 - Hand sweating or shaking 2
 - Feeling dizzy 3
 - Difficulty getting your breath 4
 - Butterflies in stomach 5
 - Dry mouth 6
 - Nausea or feeling as though you wanted to vomit 7

J9 Have you felt anxious, nervous, tense for more than 3 hours in total on any day of the past seven days?

Yes.....1
No.....2

J10 How long have you had these feelings of general anxiety/ nervousness/ tensions as you described?

- Less than 2 weeks 1
- 2 weeks but less than 6 months 2
- 6 months but less than a year 3
- 1 year but less than 2 years 4
- 2 years or more 5

SUM OF BOLD CIRCLED

APPENDIX 5

K Phobias

K1 Interviewer check, If J3 =1, circle 1 go K3 a, if others circle 2 and continue

J3=1 1 K3a)
J3=2 2

K2 Sometimes people avoid a specific situation or thing because they have a phobia about it. For instance, some people avoid eating in public or avoid going to busy places, because it would make them really nervous or anxious. In the past month, have you avoided any situation or thing because it would have made you feel nervous or anxious, even if there was no real danger?

Yes 1 K3b)
No..... 2 L

K3 a) Can you look at this list and tell me which of the situations or things listed made you the most anxious/nervous/tense in the past month?

	A.....	B
Crowds or public places, incl. travelling alone or being far from home	1	1
Enclosed Spaces	2	2
Social situations, incl. eating or speaking in public, being watched or stared at	3	3
The sight of blood or injury	4	4
Any specific single cause, incl. Insects, spiders and heights	5	5
Other Specify	6	6

Interviewer check If K1 =2, circle 1 and go to K7, if 1, continue

No Phobia 1 K7

K4 In the past seven days, how many times have you felt nervous or anxious about (Situation/Thing)?

4 times or more 1
1 to 3 times 2
None 3 K6

K5 In the past week, on those occasions when you felt anxious/nervous/tense? Did you have any of the following symptoms?

Heart racing or pounding, Hand sweating or shaking, Feeling dizzy, Difficulty getting your breath, Butterflies in stomach, Dry mouth, Nausea or feeling as though you wanted to vomit

If has any of the above circle
Yes..... 1 a)
No..... 2 K6

APPENDIX 5

a) Which of these symptoms did you have when you felt anxious/ nervous/ tense?

- | | | |
|---------------------|---|---|
| | Heart racing or pounding | 1 |
| | Hand sweating or shaking | 2 |
| | Feeling dizzy | 3 |
| Code all that apply | Difficulty getting your breath | 4 |
| | Butterflies in stomach | 5 |
| | Dry mouth | 6 |
| | Nausea or feeling as though you wanted to vomit | 7 |

K6 In the past week, have you **avoided** any situation or thing, because it would have made you feel anxious/ nervous/ tense even though there was no real danger?

- Yes 1
 No.....2 K8

K7 How many times have you avoided such situations or things in the past seven days?

- 1-3 times** 1
4 times or more 2
 None 3

K8 Interviewer check K4, K7 if 1 or 2 ask question, if no circle 1 and sum

..... 1 L

How long have you been having these feelings about these situations/ things as you have just described?

- Less than 2 weeks 1
 2 weeks but less than 6 months 2
 6 months but less than a year 3
 1 year but less than 2 years 4
 2 years or more 5

SUM OF BOLD CIRCLED

L PANIC

L1 Interviewer check if J4 =Others, circle 1 and go to section M, if J4=1 or 2 ask question

J4=3 1M

Thinking about the past month, did your anxiety or tension ever get so bad that you got in a panic, for instance make you feel that you might collapse or lose control unless you did something about it?

Yes 1
No..... 2 M

L2 How often has this happened in the past week?

Once 1
More than once 2
Not at all 3 L8

L3 In the past week, have these feelings of panic been

Running prompt A little uncomfortable or unpleasant 2
Or have they been very unpleasant or unbearable..... 1

L4 Did this panic/ the worst of the panics last for longer than 10 minutes?

Yes 1
No..... 2

L5 Are you relatively free of anxiety between these panics?

Yes 1
No..... 2

L6 Interviewer check If K1 =1, continue, if K1=2, circle 1 and ask L7

K1=2..... 1 L7

Interviewer check K3, for (situation/ thing) that brings on phobia

Is the panic always brought on by (situation/thing)?

Yes 1
No..... 2

L7 How long have you been having these feelings of panic as you have just described?

Less than 2 weeks 1
2 weeks but less than 6 months 2
6 months but less than a year 3
1 year but less than 2 years 4
2 years or more 5

SUM OF BOLD CIRCLED

M COMPULSIONS

M1 In the past month, did you find that you kept on doing things over and over again when you knew that you have already done them, for instance checking things like tabs or washing yourself when you had already done so?

Yes 1
No..... 2 N

M2 On how many days in the past week did you find yourself doing things over again that you had already done?

4 days or more 1
1 to 3 days 2
None 3 N

M3 Since last [DAY OF WEEK] what sorts of things have you done over and over again?

M4 During the past week, have you tried to stop yourself repeating (Behaviour)/ doing any of these things over again?

Yes 1
No..... 2

M5 Has repeating (behaviour)/ doing any of these things made you upset or annoyed with yourself in the past week?

Yes, upset or annoyed ... 1
No, not at all 2

M6 Interviewer check M3, if M3 > 1, ask question, if M3 = 1, circle 1 and ask M7

One compulsion 1M7

Thinking of the past week, which of the things you mentioned did you repeat the **most** times?

M7 Since last [DAY OF WEEK], how many times did you repeat (behaviour see M6) when you had already done it?

3 or more repeats..... 1
2 repeats 2
1 repeat 3

M8 How long have you been repeating (behaviour)/ any of the things you mentioned in the way which you have described?

- Less than 2 weeks 1
- 2 weeks but less than 6 months 2
- 6 months but less than a year 3
- 1 year but less than 2 years 4
- 2 years or more 5

SUM OF BOLD CIRCLED

NOBSESSIONS

N1 In the past month did you have any thoughts or ideas over and over again that you found unpleasant and would prefer not to think about, that still kept on coming into your mind?

Yes 1
 No.....2 O

N2 Is this the **same** thought or idea over and over again or are you worrying about something in general?

Same thought 1
 Worrying in general.....2 *O

***Check Section I that you recorded this worry**

N3 What are these unpleasant thoughts or ideas that keep coming into your mind?

Interviewer: Do not probe, do not press for answer

N4 Since last [DAY OF WEEK], on how many days have you had these unpleasant thoughts?

4 days or more 1
 1 to 3 days 2
 None 3 O

N5 During the past week, have you tried to stop yourself thinking about these thoughts?

Yes 1
 No.....2

N6 Have you become upset or annoyed with yourself, when you have had these thoughts in the past week?

Yes, upset or annoyed ... 1
 No, not at all 2

N7 In the past week, was the longest episode of having such thoughts:

Running prompt

A quarter of an hour or longer?..... 1
 Or was it less than this? 2

N8 How long have you been having these thoughts in the way which you have just described?

Less than 2 weeks 1
 2 weeks but less than 6 months 2
 6 months but less than a year 3
 1 year but less than 2 years 4
 2 years or more 5

SUM OF BOLD CIRCLED

0 Overall Effects

Interviewer check if Informants scored 2 or more an any section A-N, continue, if no thank and close

Now I would like to ask you how all of these things that you have told me about have affected you overall. In the past week, have the way you have been feeling ever actually **stopped** you from getting on with things you used to do or would like to do?

Yes 1a)
No.....2b)

a) In the past week, has the way you have been feeling stopped you doing things once or more than once?

Once 1 Close
More than once2 Close

b) Has the way you have been feeling made things more difficult even though you have got everything done?

Yes 1 Close
No.....2 Close

**Protocol for
Bart's Explanatory Model Interview (BEMI)**

Record Time & Date of Interview Start :

Subject ID :

Thank you very much for coming to this interview. This is an interview about how people perceive and understand illness, stress and distress. It is totally anonymous and confidential. We will keep no reference to your name and your answers will be combined with others before they are analysed. We are very interested in **your personal beliefs**, which means there are no right or wrong answers to the questions we are going to ask you.

As much as you can try to answer the question independently from your previous answers. Please be honest and try **not** to report what you think we or other people might want to hear, but what **you** actually believe in.

A) Have you experienced something that stressed you in the past month?

YES NO

[IF YES – NEXT QUESTION

**IF NO – PROBE WITH WORRIED YOU, MADE YOU UPSET, DEPRESSED,
EMOTIONAL PROBLEMS, DIFFICULT TO FUNCTION IN YOUR LIFE?]**

1) Could you tell me what you call this problem? Prompt How would you call it, what names do you give it?

2) Could you please describe to me what[**FILL WITH NAME ESTABLISHED IN 1**] is?

3) What do you think has caused[*FILL IN WITH NAME ESTABLISHED IN 1*]?

4) How long has lasted so far?

- | | | | |
|-----------------|--------------------------|------------------|--------------------------|
| Less than a day | <input type="checkbox"/> | 3-6 months | <input type="checkbox"/> |
| 1 day | <input type="checkbox"/> | 7-12 months | <input type="checkbox"/> |
| 2-3 days | <input type="checkbox"/> | 13 –23 months | <input type="checkbox"/> |
| 4-6 days | <input type="checkbox"/> | 2-5 years | <input type="checkbox"/> |
| 1-2 weeks | <input type="checkbox"/> | 6-10 years | <input type="checkbox"/> |
| 3-4 weeks | <input type="checkbox"/> | 11 – 20 years | <input type="checkbox"/> |
| 1-2 months | <input type="checkbox"/> | 21 years or more | <input type="checkbox"/> |
| | | Don't Know | <input type="checkbox"/> |

5) How long do you expect it to last?

- | | | | |
|-----------------|--------------------------|---------------|--------------------------|
| Less than a day | <input type="checkbox"/> | 1-2 months | <input type="checkbox"/> |
| 1 day | <input type="checkbox"/> | 3-6 months | <input type="checkbox"/> |
| 2-3 days | <input type="checkbox"/> | 7-12 months | <input type="checkbox"/> |
| 4-6 days | <input type="checkbox"/> | 13 –23 months | <input type="checkbox"/> |
| 1-2 weeks | <input type="checkbox"/> | 2-5 years | <input type="checkbox"/> |
| 3-4 weeks | <input type="checkbox"/> | 6-10 years | <input type="checkbox"/> |
| Don't Know | <input type="checkbox"/> | Forever | <input type="checkbox"/> |

6) Do you go through cycles whengets better or worse?

Yes(1) No (0)

Don't Know

7a) How has having affected your life?

b) What are the main difficulties and advantages you experience since having.....?

8) Generally, would you say that having has had a big or small impact on your life?

Big (0) Small (1)

9) Has having **[FILL IN WITH NAME ESTABLISHED IN 1]** affected your

- | | | |
|--|--|--------------------------------------|
| <input type="checkbox"/> Physical Ability | <input type="checkbox"/> Personality | <input type="checkbox"/> Social life |
| <input type="checkbox"/> Behaviour | <input type="checkbox"/> Financial Security | |
| <input type="checkbox"/> Decision Making or Thinking | <input type="checkbox"/> Status/ role in the community/ family | |

10a) How do **you** think should**[FILL IN WITH NAME ESTABLISHED IN 1]** be best dealt with?

10 b) How can **[FILL IN WITH NAME ESTABLISHED IN 1]** be best resolved?

11) a) Who did you talk to about this problem? **[RECORD ANSWER UNDER A]**

b) Was talking to**[FILL IN NAME OF PEOPLE CONSULTED RECORD ANSWER UNDER B]** helpful?

A)	B)		
1) _____	YES	NO	Don't Know
2) _____	YES	NO	Don't Know
3) _____	YES	NO	Don't Know
4) _____	YES	NO	Don't Know
5) _____	YES	NO	Don't Know

12) Why-why not? OPEN -ENDED

This means we have finished with this interview. However I would also like you to fill in the following four checklists and am happy to assist you if you need any help. We have included the checklists as we want to be sure that we can truly understand what the problem is and what it means to you.

BEMI CHECKLISTS

Please tick any of the following boxes if you believe that the symptoms are part of your problem.

- HAVING DISTURBED SLEEP
- EATING MORE
- EATING LESS
- EATING DIFFERENT TYPES OF FOOD
- PALPITATIONS (HEART POUNDING)
- INDIGESTION
- UNUSUAL SKIN SENSATIONS (crawling under the skin)
- VISUAL DEFICIENCY
- LOSING BODILY FLUID (Blood, Semen, Sweat)
- PAIN/ ACHES
- FATIGUE/ TIREDNESS
- NERVES or BEING AGITATED or RESTLESS
- HEAT OR HEAVINESS IN ANY PART OF THE BODY
- BODILY WEAKNESS
- NAUSEA or FEELING SICK
- DYSPHORIA (FEEL DOWN)
- FEELING IRRITABLE or FED UP BORED
- FEELING NERVOUS, ANXIOUS or PARANOID
- FEELING FRIGHTENED OR FEARFUL
- LACK OF CONCENTRATION or FORGETFULNESS
- LOSS OF INTEREST or NOT BEING ABLE TO ENJOY THINGS
- WORRYING THOUGHTS or OBSESSIVE THOUGHTS
- SUICIDAL THOUGHTS (for example 'Life is not worth it')
- FEELING GUILTY
- FEELING ASHAMED
- FEELING LONELY
- PREFER TO BE ALONE or NO SOCIAL LIFE
- NOT BEING ABLE TO COMPLETE TASKS
- BEING VIOLENT TOWARDS PEOPLE
- BECOMING MUTE OR STOP TALKING
- CRYING
- SCREAMING
- SWEARING
- BEING RESTLESS OF CONTINUOUSLY MOVING ABOUT
- NOT DOING A LOT OF THINGS OR AVOIDING TO DO THINGS
- USING TOBACCO, ALCOHOL, MEDICINES OR DRUGS
- BEING VIOLENT TOWARDS THINGS (throwing, smashing things)
- OBSESSIVE BEHAVIOUR (checking things, washing yourself, counting things)
- NEGLECTING YOUR HYGIENE (stop washing yourself, wearing fresh clothes)
- HALLUCINATIONS
- RAMBLING or TALKING NONSENSE
- MAKING PLANS FOR SUICIDE

If any of your symptoms are not listed above please describe them to us in the lines beneath:

Have any of the following causes contributed to your problem? Tick the boxes if you believe that this might have contributed to developing your problem.

- STRESS
- YOUR AGE
- YOUR GENDER
- YOUR CULTURE/ WAY OF LIFE
- YOUR RELIGION
- YOUR ETHNICITY OR RACE
- WORRY
- GUILT OR SHAME
- EMOTIONS (EXCESSIVE)
- WORK PROBLEMS (INCLUDING LACK OF WORK)
- FAMILY PROBLEM
- MARITAL OR PARTNER PROBLEM
- LONELINESS/ISOLATION FROM OTHER PEOPLE
- BEREAVEMENT OR LOSS
- PREJUDICE/ STEREOTYPE
- RACISM (PREJUDICE & INAPPROPRIATE BEHAVIOUR TOWARD PEOPLE OF YOUR ETHNIC ORIGIN)
- FATE/ DESTINY' (DELIBERATE)
- BAD LUCK (RANDOM)
- ANCESTORS' SPIRITS
- WEAKENED SPIRIT OR SOUL LOSS
- TEST OF FAITH
- BLACK MAGIC/EVIL EYE/SORCERY
- PUNISHMENT (GOD) – TABOO BREACH
- DIET OR FOOD INTAKE
- SUBSTANCE (AB-) USE (ALCOHOL, TOBACCO, DRUGS, MEDICATION)
- LACK OF OR NO SEX
- THE WIND
- CLIMATE OR WEATHER
- ASTROLOGY OR STARS
- ILLNESS OR DISABILITY OR HANDICAP
- IMBALANCE OF BODILY FLUIDS (TOO MUCH OR TOO LITTLE BLOOD SEMEN, BILE ETC)
- BLOOD, (BAD BLOOD, HOT BLOOD ETC)
- PROBLEM WITH THE BONES
- POISON
- VIRUS/GERM
- HEREDITY (GENES)
- FINANCIAL PROBLEMS
- ANY KIND OF TRAUMA/SHOCK (E.G. CAR CRASH, WAR)
- BEING ABUSED

If any of your causes or explanations are not listed above, please describe them to us:

We would also like to know whether you experienced any of the following consequences? Please tick the box if you have experienced them as a **result** of having your problem!

- INCREASINGLY FOCUS ON YOUR BODY/ ILLNESS
- BEING TORMENTED BY INTERFERING THOUGHTS
- FEELING BAD, BITTER OR UNPLEASANT
- FEELING SAD
- FEEL LIKE CRYING
- FEELING IRRITABLE
- FEELING AGGRESSIVE
- HAVING LITTLE CONCENTRATION OR MEMORY
- LOSING CONFIDENCE AND/OR SELF-ESTEEM
- NO MOTIVATION AND LESS OUTGOING
- FEAR
- CHANGE OF YOUR ROLE (IN YOUR FAMILY, COMMUNITY ETC)
- BEING EXCLUDED FROM SOCIAL ACTIVITIES
- BEING REJECTED OR ISOLATED
- BEING STIGMATISED OR LOSS OF STATUS
- BEING PHYSICALLY ABUSED
- BEING LOCKED UP
- LOSING YOUR JOB
- LOSING YOUR PARTNER/ CHILDREN
- LOSING YOUR FIREDS
- BECOMING DISABLED
- LOSING YOUR FINANCIAL SECURITY
- PAIN
- LOSING WEIGHT
- GAINING WEIGHT
- USING ALCOHOL, TOBACCO, MEDICATION OR ILLEGAL DRUGS TO COPE
- STOP PARTAKING IN ACTIVITIES THAT YOU ENJOY

If you experienced any further consequences that are not listed please describe them to us.

Finally we would like to know whether you have considered or tried any of the following methods to resolve your problem and whether you found them helpful. Please tick the boxes for considered if you have thought about the method, **and/ or** tick the box in the tried column if you have tried the method and tick the box for helpful if you found it helpful.

	Considered	Tried	Helpful
Dieting/Fasting/ Eating different foods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Exercising	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using alcohol, tobacco or illicit drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Keeping busy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talking to your family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talking to your friends.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Talking to your GP/ nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Socialising.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking medication.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using herbal remedies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relaxation/massage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Seeing a traditional healer (Hakeem, witch doctor)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Praying.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chanting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dancing.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Yoga	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spending time on a hobby	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I would like to take the time to thank you very much for spending the time talking to me and filling in these checklists, your answers are very important for us.

Thank you very much !!!

Cultural identity scale

Please tick which option applies mostly to you:

What is the ethnic background of your closest friend?	Same	Other	
What ethnic group member would you prefer to date?	Same	Other	
How would you identify yourself?	British	Other	Both
If someone were to insult the British, would you feel offended?	Yes	No	
Do you prefer to be with those that share your cultural heritage?	Yes	No	
In what language do you speak to the majority of your friends?	English	Other	
What language(s) is/are spoken where you live?	English	Other	Both

Please tick on this scale from 1-5 which statement applies mostly to you. Tick DOES NOT APPLY (DNA) on the Right hand when you feel that items do not apply to you. For example - item 5 does not apply to you if English was your first language.

1) I feel uncomfortable when others make jokes about or put down people of my ethnic background.

Strongly agree Agree Undecided Disagree Strongly Disagree

2) I have more barriers to overcome than most people.

Strongly agree Agree Undecided Disagree Strongly Disagree

3) Many people have stereotypes about my culture and ethnic group and treat me as if they are true.

Strongly agree Agree Undecided Disagree Strongly Disagree

4) I don't feel at home.

Strongly agree Agree Undecided Disagree Strongly Disagree

5) People think I am unsociable when in fact I have trouble communicating in English. DNA

Strongly agree Agree Undecided Disagree Strongly Disagree

6) I often feel that people actively try to stop me from advancing.

Strongly agree Agree Undecided Disagree Strongly Disagree

7) It bothers me that I have an accent.

Strongly agree Agree Undecided Disagree Strongly Disagree DNA

8) It bothers me when people pressure me to assimilate.

Strongly agree Agree Undecided Disagree Strongly Disagree

9) Because I am different I do not get enough credit for the work/ things I do.

Strongly agree Agree Undecided Disagree Strongly Disagree

10) I often think about my cultural background.

Strongly agree Agree Undecided Disagree Strongly Disagree

APPENDIX 8

Data Management tool

SYMPTOM CHECKLIST	Subdomains	Interview (2)	Checklist (1)	Not part of problem
HAVING DISTURBED SLEEP	Somatic			1
EATING MORE				2
EATING LESS				2
EATING DIFFERENT TYPES OF FOOD				2
PALPITATIONS (HEART POUNDING)				3
INDIGESTION				4
UNUSUAL SKIN SENSATIONS (CRAWLING UNDER THE SKIN ETC)				5
VISUAL DEFICIENCY				6
LOSING BODILY FLUIDS				7
PAIN/ ACHES				8
FATIGUE OR TIREDNESS				9
NERVES OR BEING AGITATED OR RESTLESS				10
HEAT OR HEAVINESS IN ANY PART OF THE BODY				11
BODILY WEAKNESS			12	
NAUSEA OR FEELING SICK			13	
DYSPHORIA OR FEELING DOWN)	Mental			14
FEELING IRRITABLE OR FED UP BORED				15
FEELING NERVOUS, ANXIOUS OR PARANOID				16
FEELING FRIGHTENED OR FEARFUL				17
LACK OF CONCENTRATION OR FORGETFULNESS				18
LOSS OF INTEREST OR NOT BEING ABLE TO ENJOY THINGS				19
WORRYING OR OBSESSIVE THOUGHTS				20
SUICIDAL THOUGHTS (E.G. LIFE'S NOT WORTH IT)				21
FEELING GUILTY				22
FEELING ASHAMED				23
HALLUCINATIONS				24
FEELING LONELY				25
PREFER TO BE ALONE OR NO SOCIAL LIFE		Behavioural		
NOT BEING ABLE TO COMPLETE TASKS				27
BEING VIOLENT TOWARDS PEOPLE				28
BECOMING MUTE OR STOP TALKING				29
CRYING				30
SCREAMING				31
SWEARING				32
BEING RESTLESS OR CONTINUALLY MOVING ABOUT				33
NOT DOING A LOT OF THINGS OR AVOIDING TO DO THINGS				34
USING SUBSTANCES - TOBACCO, ALCOHOL, MEDICINES, DRUGS				35
VIOLENT TOWARDS THINGS (THROWING OR SMASHING THINGS)				36
OBSESSIVE BEHAVIOUR (CHECKING, WASHING, COUNTING THINGS)				37
NEGLECT OF HYGIENE (STOP WASHING YOURSELF, WEARING FRESH CLOTHES)				38
RAMBLING OR TALKING NONSENSE				39
MAKING PLANS FOR SUICIDE				40

APPENDIX 8

CAUSES	Subdomains	Interview (2)	Checklist (1)	Not part of problem (0)
STRESS	PSYCHOSOCIAL			1
YOUR AGE				2
YOUR GENDER				3
YOUR CULTURE				4
YOUR RELIGION				5
YOUR ETHNICITY OR RACE				6
WORRY				7
GUILT OR SHAME				8
EMOTIONS (EXCESSIVE)				9
WORK PROBLEMS (INCLUDING LACK OF WORK)				10
FAMILY PROBLEMS				11
MARITAL OR PARTNER PROBLEMS				12
LONELINESS OR ISOLATION FROM OTHER PEOPLE				13
BEREAVEMENT OR LOSS				14
RACISM/ PREJUDICE / STEREOTYPE				15
ANY KIND OF TRAUMA / SHOCK				16
ABUSE				17
FATE/ DESINTY (DELIBERATE)	SPIRITUAL			18
BAD LUCK (BY CHANCE)				19
ANCESTORS' SPIRITS				20
WEAKENED SPIRIT SOUL LOSS				21
TEST OF FAITH				22
BLACK MAGIC OR EVIL EYE SORCERY				23
PUNISHMENT (GOD) – TABOO BREACH				24
ASTROLOGY OR STARS			25	
DIET OR FOOD INTAKE	BEHAVIORAL			26
SUBSTANCE ABUSE (ALCOHOL, TOBACCO & DRUGS)				27
LACK OF OR NO SEX				28
THE WIND	WEATHER			29
CLIMATE OR WEATHER				30
ILLNESS OR DISABILITY OR HANDICAP	PHYSICAL			31
IMBALANCE OF BODILY FLUIDS (TOO MUCH OR TOO LITTLE BLOOD SEMEN, BILE)				32
BLOOD (BAD BLOOD OR HOT BLOOD ETC)				33
PROBLEM WITH THE BONES				34
POISON				35
VIRUS OR GERMS				36
HEREDITY (GENES)				37
FINANCIAL PROBLEMS	ECONOMICAL			38

APPENDIX 8

CONSEQUENCES	SUBDOMAINS	Interview (2)	Checklist (1)	Not part of problem (0)	
INCREASINGLY FOCUS ON YOUR BODY THE ILLNESS	SELF/PSYCHOLOGICAL			1	
BEING TORMENTED BY THOUGHTS THAT INTERFERE WITH YOUR THINKING				2	
FEELING BAD, BITTER OR UNPLEASANT				3	
FEELING SAD				3	
FEEL LIKE CRYING				3	
FEELING IRRITABLE				3	
FEELING AGGRESSIVE				3	
HAVING LITTLE CONCENTRATION OR MEMORY				4	
LOSING CONFIDENCE AND SELF ESTEEM				5	
NO MOTIVATION AND LESS OUTGOING				6	
FEAR				7	
ROLE/ STATUS (IN YOUR FAMILY, COMMUNITY)		SOCIAL			8
BEING EXCLUDED FROM SOCIAL ACTIVITIES					9
BEING REJECTED OR ISOLATED				10	
BEING STIGMATISED OR LOSS OF STATUS				11	
BEING PHYSICALLY ABUSED				12	
BEING LOCKED UP				13	
JOB/ WORK				14	
RELATIONSHIP WITH PARTNER/KIDS				15	
RELATIONSHIP WITH FRIENDS			16		
BECOMING DISABLED	FINANCIAL			17	
FINANCIAL SECURITY				18	
PAIN	PHYSICAL			19	
LOSING WEIGHT				20	
GAINING WEIGHT				21	
USING ALCOHOL TOBACCO MEDICATION OR ILLEGAL DRUGS TO COPE	BEHAVIORAL			22	
STOP DOING ACTIVITIES THAT YOU ENJOY				23	

APPENDIX 8

TREATMENT	Interview (2)	Chceklist (1)			Not part of problem (0)
		Con	Tried	Help	
DIETING/ FASTING/ EATING DIFFERENT FOODS					1
EXERCISING					2
USING ALCOHOL, TOBACCO OR ILLICIT DRUGS					3
KEEPING BUSY					4
TALKING TO YOUR FAMILY					5
TALKING TO YOUR FRIENDS					6
TALKING TO YOUR GP/ NURSE					7
SOCIALISING					8
TAKING MEDICATION					9
USING HERBAL REMEDIES					10
RELAXATION / MASSAGE					11
SEEING A TRADITIONAL HEALER (HAKEEM ETC)					12
PRAYING					13
CHANTING					14
DANCING					15
THINKING					16
YOGA					17
SPENDING TIME ON A HOBBY					18

HEALER	Spontaneous Tried (2)	Spontaneous Helpful	Spontaneous Non helpful
SELF			1
FAMILY			2
FRIENDS/ COMMUNITY			3
GP			4
PHARMACIST			5
PSYCHIATRIST/NEUROLOGIST			6
HOMEOPATH/ ACUPUNCTURIST			7
TRADITIONAL HEALER			8
PSYCHOTHERAPIST			9
FAITH HEALER			10
PRIEST OR EQUIVALENT			11

APPENDIX 9

Community Organisation	Remit
Idea Store	Local Library, Internet café, Café, Events, Provides access to knowledge, organises adult education courses
Groundwork Hackney	Equips long-term unemployed with skills in e.g. gardening, landscape, teaching and classroom assistant
Jagonari	An Asian women's community centre aims to provide educational opportunities, information, advice, social gatherings, cultural events, sport and leisure activities - in a safe, welcoming environment which is geared towards accommodating women only.
Bangladeshi Welfare Association	The relief of poverty among people of Bangladeshi ethnic origin living in Tower Hamlets by providing advice and counselling upon such matters as welfare rights, housing and homelessness & immigration.
Tower Hamlets and Hackney College	Community Colleges, Providing all forms of Vocational courses, A-levels, Adult education etc
Haggerston, Piermont and Lofthill Community centre	Community centres with computer facilities, fruit and veg markets, toddler groups,
Brixton Sheltered Project, Hibiscus, Hackney Caribbean Elderly Organisation, UJIMA	Organisations that provide day services for the elderly
Brixton Carer	Provides Information and advice, Advocacy, Support, Consultation and representation, Improving services, Outreach and Register of carers, for carers and former Carers
Tower Hamlets Family Welfare Organisation	Organisation that provide help and support for families

Partial Correlation

Control Variables	How long in UK	How long in UK	Has somatic complaints checklist	Has mental complaints checklist	Has behavioural complaints checklist	Has internal cause	Has external cause	Has internal consequence	Has external consequence	Found informal helpful	Found external helpful
AGE	1.000	1.000	.040	-.050	.129	.050	-.202	-.155	.001	.268	.137
			.631	.547	.120	.549	.014	.061	.994	.001	.099
	0	0	144	144	144	144	144	144	144	144	144
	.040	.040	1.000	.353	.367	.367	.244	.370	.133	.160	.195
	.631	.631	.000	1.000	.000	.000	.003	.000	.109	.053	.019
	144	144	0	144	144	144	144	144	144	144	144
	-.050	-.050	.353	1.000	.335	.136	.415	.422	.345	.048	.135
	.547	.547	.000	.000	.000	.102	.000	.000	.000	.568	.104
	144	144	144	0	144	144	144	144	144	144	144
	.129	.129	.367	.335	1.000	.173	.139	.300	.100	.173	.226
	.120	.120	.000	.000	.000	.037	.094	.000	.229	.037	.006
	144	144	144	144	0	144	144	144	144	144	144
	.050	.050	.367	.136	.173	1.000	.107	.345	.086	.138	.113
	.549	.549	.000	.102	.037	.000	.197	.000	.301	.096	.174
	144	144	144	144	144	0	144	144	144	144	144
	-.202	-.202	.244	.415	.139	.107	1.000	.332	.274	.138	.220
	.014	.014	.003	.000	.094	.197	.000	.000	.001	.098	.008
	144	144	144	144	144	144	0	144	144	144	144
	-.155	-.155	.370	.422	.300	.345	.332	1.000	.115	.116	.166
	.061	.061	.000	.000	.000	.000	.000	.000	.167	.163	.045
	144	144	144	144	144	144	144	0	144	144	144
	.001	.001	.100	.100	.100	.086	.274	.115	1.000	.035	.021
	.994	.994	.229	.229	.229	.301	.001	.167	.000	.675	.798
	144	144	144	144	144	144	144	144	0	144	144
	.133	.133	.100	.048	.173	.138	.138	.116	.035	1.000	.358
	.053	.053	.037	.568	.037	.096	.098	.163	.675	.000	.000
	144	144	144	144	144	144	144	144	144	0	144
	.137	.137	.226	.135	.226	.113	.220	.166	.021	.358	1.000
	.099	.099	.006	.104	.006	.174	.008	.045	.798	.000	.000
	144	144	144	144	144	144	144	144	144	144	0

Correlation matrix for Complete sample

	Psychiatric Case >12	Ethnic background	Has somatic complaints checklist	Has mental complaints checklist	Has behavioural complaints checklist	Has internal cause	Has external cause	Has internal consequence	Has external consequence	Found internal helpful	Found external helpful
Psychiatric Case >12	1	-.121*	.348**	.331**	.362**	.182**	.479**	.306**	.304**	.136*	.148*
		.048	.000	.000	.000	.003	.000	.000	.000	.029	.017
	268	268	259	259	259	259	259	259	259	259	259
Ethnic background	-.121*	1	-.241**	-.049	-.169**	-.120	-.006	-.079	.053	-.276**	-.056
	.048		.000	.430	.006	.053	.920	.203	.393	.000	.368
	268	270	260	260	260	260	260	260	260	260	260
Has somatic complaints checklist	.348**	-.241**	1	.323**	.386**	.330**	.206**	.299**	.139*	.205**	.184**
	.000	.000		.000	.000	.000	.001	.000	.025	.001	.003
	259	260	260	260	260	260	260	260	260	260	260
Has mental complaints checklist	.331**	-.049	.323**	1	.339**	.166**	.361**	.391**	.291**	.039	.116
	.000	.430	.000		.000	.007	.000	.000	.000	.526	.062
	259	260	260	260	260	260	260	260	260	260	260
Has behavioural complaints checklist	.362**	-.169**	.386**	.339**	1	.188**	.207**	.264**	.185**	.195**	.172**
	.000	.006	.000	.000		.002	.001	.000	.003	.002	.005
	259	260	260	260	260	260	260	260	260	260	260
Has internal cause	.182**	-.120	.166**	.167**	.188**	1	.167**	.350**	.078	.116	.141*
	.003	.053	.007	.007	.002		.007	.000	.211	.063	.023
	259	260	260	260	260	260	260	260	260	260	260
Has external cause	.479**	-.006	.206**	.361**	.207**	.167**	1	.227**	.306**	.136*	.183**
	.000	.920	.001	.000	.001	.007		.000	.000	.029	.003
	259	260	260	260	260	260	260	260	260	260	260
Has internal consequence	.306**	-.079	.299**	.391**	.264**	.350**	.227**	1	.088	.087	.152*
	.000	.203	.000	.000	.000	.000	.000		.158	.164	.014
	259	260	260	260	260	260	260	260	260	260	260
Has external consequence	.304**	.053	.139*	.291**	.185**	.078	.116	.088	1	.033	.025
	.000	.393	.025	.000	.003	.158	.164	.158		.601	.683
	259	260	260	260	260	260	260	260	260	260	260
Found internal helpful	.136*	-.276**	.205**	.039	.195**	.087	.136*	.087	.033	1	.274**
	.029	.000	.001	.526	.002	.164	.029	.164	.601		.000
	259	260	260	260	260	260	260	260	260	260	260
Found external helpful	.148*	-.056	.184**	.116	.172**	.141*	.183**	.152*	.025	.274**	1
	.017	.368	.003	.062	.005	.023	.003	.014	.683	.000	
	259	260	260	260	260	260	260	260	260	260	260

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

Correlations

ethnic: White British

	Psychiatric Case >12	Has somatic complaints checklist	Has mental complaints checklist	Has behavioural complaints checklist	Has internal cause	Has external cause	Has internal consequence	Has external consequence	Found informal helpful	Found external helpful
Psychiatric Case >12	1	.230*	.270**	.392**	.214*	.398**	.275**	.414**	.073	.037
		.023	.008	.000	.035	.000	.006	.000	.478	.722
	104	97	97	97	97	97	97	97	97	97
Has somatic complaints checklist	.230*	1	.494**	.496**	.496**	.204*	.366**	.123	.129	.053
	.023	.000	.000	.000	.000	.045	.000	.231	.207	.604
	97	97	97	97	97	97	97	97	97	97
Has mental complaints checklist	.270**	.494**	1	.346**	.211*	.284**	.387**	.218*	.027	.047
	.008	.000	.000	.001	.038	.005	.000	.032	.794	.646
	97	97	97	97	97	97	97	97	97	97
Has behavioural complaints checklist	.392**	.346**	.346**	1	.252*	.321**	.220*	.260*	.059	.039
	.000	.000	.001	.000	.013	.001	.031	.010	.567	.705
	97	97	97	97	97	97	97	97	97	97
Has internal cause	.214*	.496**	.211*	.252*	1	.180	.277**	.014	.026	.252*
	.035	.000	.038	.013	.000	.078	.006	.892	.801	.013
	97	97	97	97	97	97	97	97	97	97
Has external cause	.398**	.204*	.284**	.321**	.180	1	.137	.315**	.137	.191
	.000	.045	.005	.001	.078	.000	.180	.002	.180	.060
	97	97	97	97	97	97	97	97	97	97
Has internal consequence	.275**	.366**	.387**	.220*	.277**	.137	1	.130	.077	.097
	.006	.000	.000	.031	.006	.137	.000	.205	.452	.346
	97	97	97	97	97	97	97	97	97	97
Has external consequence	.414**	.123	.218*	.260*	.014	.315**	.130	1	.065	.090
	.000	.231	.032	.010	.892	.002	.205	.065	.529	.380
	97	97	97	97	97	97	97	97	97	97
Found informal helpful	.073	.129	.027	.059	.026	.137	.077	.065	1	.031
	.478	.207	.794	.567	.801	.180	.452	.529	.766	.766
	97	97	97	97	97	97	97	97	97	97
Found external helpful	.037	.053	.047	.039	.252*	.191	.097	.090	.031	1
	.722	.604	.646	.705	.013	.060	.346	.380	.766	.766
	97	97	97	97	97	97	97	97	97	97

*. Correlation is significant at the 0.05 level (2-tailed).

** . Correlation is significant at the 0.01 level (2-tailed).

Correlations

ethnic: Bangladeshi

		Psychiatric Case >12	Has somatic complaints checklist	Has mental complaints checklist	Has behavioural complaints checklist	Has internal cause	Has external consequence	Found informal helpful	Found external helpful
Psychiatric Case >12	Pearson Correlation Sig. (2-tailed) N	1 79	.372** .001 79	.461** .000 79	.326** .003 79	-.046 .690 79	.347** .002 79	.293** .009 79	.253* .025 79
Has somatic complaints checklist	Pearson Correlation Sig. (2-tailed) N	.372** .001 79	1 79	.152 .182 79	.224* .047 79	.177 .118 79	.330** .003 79	.162 .153 79	.287* .010 79
Has mental complaints checklist	Pearson Correlation Sig. (2-tailed) N	.461** .000 79	.152 .182 79	1 79	.226* .045 79	-.075 .514 79	.349** .002 79	.347** .002 79	.161 .156 79
Has behavioural complaints checklist	Pearson Correlation Sig. (2-tailed) N	.326** .003 79	.224* .047 79	.226* .045 79	1 79	.054 .634 79	.171 .131 79	.128 .262 79	.315** .005 79
Has internal cause	Pearson Correlation Sig. (2-tailed) N	-.046 .690 79	.177 .118 79	-.075 .514 79	.054 .634 79	1 79	.007 .953 79	-.003 .981 79	.004 .972 79
Has external consequence	Pearson Correlation Sig. (2-tailed) N	.347** .002 79	.330** .003 79	.349** .002 79	.347** .007 79	.242* .953 79	1 79	.192 .090 79	.206 .069 79
Found informal helpful	Pearson Correlation Sig. (2-tailed) N	.253* .025 79	.287* .010 79	.161 .156 79	.315** .005 79	.004 .972 79	.247* .028 79	.058 .613 79	-.188 .097 79
Found external helpful	Pearson Correlation Sig. (2-tailed) N	.253* .025 79	.287* .010 79	.161 .156 79	.315** .005 79	.004 .972 79	.247* .028 79	.350** .002 79	1 .002 79

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Correlations

ethnic: Black Caribbean

	Psychiatric Case >12	Has somatic complaints checklist	Has mental complaints checklist	Has behavioural complaints checklist	Has internal cause	Has external consequence	Found informal helpful	Found external helpful
Psychiatric Case >12	1	.349**	.265*	.446**	.243*	.486**	.310**	.149
		.001	.016	.000	.027	.000	.004	.180
	85	83	83	83	83	83	83	83
Has somatic complaints checklist	.349**	1	.246*	.381**	.254*	.104	.185	.216*
	.001		.024	.000	.020	.345	.092	.048
	83	84	84	84	84	84	84	84
Has mental complaints checklist	.265*	.246*	1	.417**	.212	.402**	-.041	.145
	.016	.024	.024	.000	.053	.000	.711	.190
	83	84	84	84	84	84	84	84
Has behavioural complaints checklist	.446**	.381**	.417**	1	.195	.181	.161	.160
	.000	.000	.000	.000	.076	.099	.144	.145
	83	84	84	84	84	84	84	84
Has internal cause	.243*	.254*	.212	.195	1	.210	.172	.119
	.027	.020	.053	.076	.020	.055	.117	.280
	83	84	84	84	84	84	84	84
Has external consequence	.486**	.104	.402**	.181	.210	1	.177	.145
	.000	.345	.000	.099	.055	.000	.107	.187
	83	84	84	84	84	84	84	84
Has internal consequence	.254*	.227*	.353**	.294**	.515**	.235*	.021	.149
	.021	.038	.001	.007	.000	.032	.847	.175
	83	84	84	84	84	84	84	84
Has external consequence	.149	.163	.327**	.209	.185	.336**	1	.141
	.180	.139	.002	.056	.092	.002	.064	.201
	83	84	84	84	84	84	84	84
Found informal helpful	.310**	.185	-.041	.161	.172	.177	1	.403**
	.004	.092	.711	.144	.117	.107	.000	.000
	83	84	84	84	84	84	84	84
Found external helpful	.149	.216*	.145	.160	.119	.145	.403**	1
	.180	.048	.190	.145	.280	.187	.000	.000
	83	84	84	84	84	84	84	84

*. Correlation is significant at the 0.05 level (2-tailed).

** . Correlation is significant at the 0.01 level (2-tailed).