

Ethnic Differences in the Context and Experience of Psychiatric Illness: A Qualitative Study

Edited by William O'Connor and James Nazroo

A study carried out on behalf of the Department of Health by:

National Centre for Social Research

Department of Epidemiology and Public Health at the Royal Free and
University College Medical School



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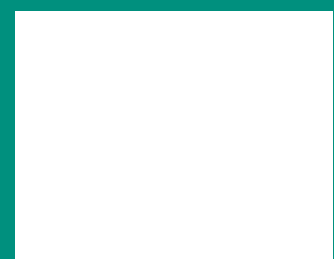
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1 Introduction

James Nazroo and William O'Connor

1.1 Community-based studies of psychiatric morbidity

Over the past decade a series of surveys on the mental health of the population of Great Britain has been commissioned by the Department of Health, Scottish Executive and the National Assembly for Wales (or their predecessors). The series began in 1993, with a survey of the adult population aged between 16 and 64 living in private households in Great Britain.¹ Since then, additional surveys have covered children aged 5 to 15 living in private households,² and prisoners in England and Wales.³ The study reported here was conducted alongside a second survey of the adult population covering those aged between 16 and 74 and living in private households throughout Great Britain,⁴ but this study has as its focus five of the main ethnic minority groups in England (Bangladeshi, Caribbean, Indian, Irish and Pakistani people), together with a general population White group to provide a point of comparison.

The need for such studies is clear. The recent survey of psychiatric morbidity among adults indicated that almost one in six people have a neurotic disorder (depression, anxiety, mixed anxiety and depression disorder, phobia, obsessive-compulsive disorder and panic disorder),⁴ while the 1993 survey and the recent survey of adult psychiatric morbidity suggested that one in 250 people suffer from a psychotic illness.^{1,4} It is also apparent that the prevalence of mental illness varies across population groups. For example, women have higher overall rates of neurotic disorders than men, similar rates of psychotic disorders and lower rates of alcohol and drug dependence,^{1,4} and the prevalence of mental illness also appears to be related to socioeconomic position and ethnicity.^{5,6,7} Understanding how the prevalence of mental illness might be changing over time and how it varies across populations is of importance both for policy development and an understanding of aetiology.

The relative prevalence of mental illness among different ethnic groups in Britain, however, is both a controversial and complex field of inquiry.⁸ Existing research evidence suggests that, as with physical health, there are important and possibly large differences in mental health across ethnic groups. Two key findings in the literature are the apparently high rates of schizophrenia and other forms of psychosis among African Caribbean people, and apparently low rates of mental illness generally among South Asian people.⁹ However, findings are not entirely consistent across different studies,¹⁰ and there have been few community-based studies of ethnic differences in the prevalence of mental illness, with most work focusing on rates of contact with services for those with psychotic disorders.^{11,12,13,14}

An additional and important difficulty with conducting population surveys on ethnic differences in mental health is the possibility that there are important cultural differences in the way in which people experience and express mental illness.^{15,16,17} This means that the research tools used in surveys, which are based on western psychiatric practice, may be more appropriate (and, consequently, more effective at case finding) for some ethnic groups than others.

This study was commissioned by the Department of Health to begin to address these issues. It consisted of both a quantitative survey (reported on elsewhere)¹⁸ and a qualitative study, which is reported on here. This involved follow-up in-depth interviews with a sub-sample of those included in the quantitative survey.

The quantitative epidemiological method has been successful in measuring broad patterns of health and illness, and in isolating specific problems or specific groups where patterns of ill health are concentrated. Such an approach forms the basis of most investigations of inequalities in health, including ethnic inequalities in mental health. However, some have taken a critical view of the epidemiological method, particularly within the mental health field, suggesting that this approach ignores social context and the experiences of people as *lived* rather than as *constructed* by diagnostic categories.^{19,20} Central to this critical view has been the claim that the idioms used to express mental distress, the ways in which people describe their feelings and their understanding of the category 'mental health', vary across different cultural groupings, and that this needs to be addressed by both research and practice.^{21,22} Kleinman describes how the use of inappropriate disease categories to assess illness experience can lead to 'category fallacies'. This is where the application of a particular disease category that was developed in one cultural group is applied to another group and fails to identify many people to whom it can apply, because it lacks coherence in the second culture.²¹ So, a central concern of studies of ethnic differences in mental illness should be whether the idioms used to express mental distress are culturally informed; and culturally informed to a sufficient extent to make western psychiatric models of illness and survey methods culturally specific or culturally bound. The implication is that standardised research instruments will perform inconsistently across different ethnic groups, greatly restricting the validity of conclusions based on their use in surveys such as the quantitative part of this study.¹⁸ Indeed, detailed analysis of the quantitative *Fourth National Survey of Ethnic Minorities*, which included survey measures of mental health together with a more detailed assessment, lent some support for this possibility.^{7,23}

Used in addition to quantitative methods, qualitative methodologies can be particularly useful for addressing such a concern, by further developing our understanding of the factors and experiences underlying the quantitative patterning of mental health. In addition, they are able to explore more subtle variations, where the particular language used to describe emotions and experiences, or where the context of the situation, can provide further insights that may be missed by the 'itemised' approach of quantitative material. In this report we will contextualise the findings from the quantitative study,¹⁸ using information imparted by respondents during follow-up in-depth qualitative interviews, as well as posing some questions about the measurement and diagnosis of mental illness across different ethnic groups.

1.2 The study of ethnic minority psychiatric illness in the community (EMPIRIC)

As described above, this study was conducted alongside a survey of the adult population of Great Britain, and had a focus on some of the main ethnic minority groups in England. It consisted of two elements, a quantitative survey of rates of mental illness among different ethnic groups in England (reported elsewhere)¹⁸ and a qualitative study investigating ethnic and cultural differences. This report is based on the qualitative interviews, which involved a sub-sample of respondents to the quantitative survey. It is concerned both with understanding the context of respondents' lives and how this shapes their experiences of mental distress; and with exploring how far the quantitative western assessments of mental illness used elsewhere in this study,¹⁸ in particular the CIS-R, adequately capture the experience of mental distress across different ethnic groups.

In order to overcome the difficulty of obtaining a large representative sample of ethnic minority groups, for the quantitative survey, EMPIRIC used the existing 1999 Health Survey for England (HSE) to draw its ethnic minority sample.²⁴ The HSE comprises a series of annual surveys commissioned by the Department of Health and designed to provide information on aspects of the population's health that cannot be obtained from other sources. The 1999 survey was the ninth in the series of surveys and the first to increase the representation of ethnic minority groups, boosting the sample of adults and children from Black Caribbean, Indian, Pakistani, Bangladeshi, Chinese and Irish communities. The

boosted sample of Chinese people in the 1999 HSE was obtained by following up informants identified for inclusion in a 1998 study on the health of Chinese people.²⁵ As that sample had already been through two waves of attrition (the 1998 and the 1999 surveys), it was not included in EMPIRIC.

1.3 Methods for the qualitative study

Qualitative research is of particular value for an exploratory study such as this. The interactive probing and questioning methods used allow flexibility in the structure and content of interviews, which facilitates exploration of individual circumstances and experiences in a way that is responsive to the accounts of individual respondents. This is essential for the detailed investigative approach that the study required. However, it is important to note that qualitative research samples are not designed to be statistically representative of the researched population, and this means that statements about incidence or prevalence cannot be sustained. Similarly it is not possible to determine statistically discriminatory variables from qualitative data. Where relationships are described between, for example, circumstances and needs, the purpose in doing so is to present explanations identified explicitly or implicitly by respondents and hypotheses for further research.

1.3.1 Sample design and selection

The sample for the qualitative follow-up study was purposively selected from those who participated in the quantitative survey and who gave their consent to be re-contacted about future research. The sample was not designed to be statistically representative. Unlike quantitative samples, those used for qualitative studies are chosen to cover the full range of sub-groups within the given population, in order to identify and explain variations in the nature of experiences and views between them. The sample was, therefore, purposively selected on the basis of a range of key characteristics identified as relevant to the given population. Given the intention to explore cultural differences in the experience of mental illness, the key variables included in the sample design were:

- **Ethnic group:** The study focussed on all of the six ethnic groups included in the quantitative survey – Bangladeshi, Caribbean, Indian, Irish, Pakistani and White people.
- **Main language spoken:** The study aimed to include a variety of community languages across the three South Asian ethnic groups, because of the potential relationships between languages used, culture and idioms of distress.
- **Age:** The study was focused on respondents aged between 25 and 50 years old. It was decided at the outset to limit the age range of the study in order that the focus would be on mental distress among adults. We also decided to limit the age group studied to prevent a great disparity in ages between migrants and non-migrants.
- **Migration history:** Clearly, in any study exploring ethnic difference, it is important to have diversity in migratory experiences, particularly where a hypothesis about cultural difference is being explored. This study included respondents who were either born in Great Britain or moved here prior to beginning secondary education – that is before 11 years of age – or had moved to this country at age 11 or later (which would mean that none of their primary school education would have taken place in the UK).
- **Gender:** Both male and female respondents were interviewed.

In addition, respondents were purposively selected on the basis of their experience of mental distress, as determined by the CIS-R score, a measure of common mental health disorders that was collected as part of the quantitative survey.²⁶ The study focused on two types of respondents: those with a CIS-R score of 12 or over and those with a CIS-R score of lower than 12, but who had indicated through the answers given to other modules in the survey that they had possibly experienced some form of mental distress. The inclusion of the second group was intended to ensure that the sample did not only reflect those whose

distress had been identified by the CIS-R to allow a more complete exploration of the applicability of psychiatry's model of mental distress.

Letters of invitation were sent to all potential respondents, using the language in which the person had been interviewed in at the survey. This gave those who did not wish to participate further the opportunity to withdraw. Following this, a screening interview was administered in the appropriate language to establish eligibility for the qualitative study according to the quotas for purposive selection. Selected individuals were then invited to take part and arrangements were made for an interview. Respondents were asked to indicate any preferences concerning the ethnic origin or gender of the interviewer and the language in which the interview would be conducted. Copies of the recruitment documents (in English) are included in Appendix B.

One hundred and sixteen people participated in the qualitative study across each of the six ethnic groups covered in the survey. Table 1.1 shows the composition of the sample in terms of the key sampling variables. The sample is evenly distributed across the six ethnic groups covered in the survey. Slightly more women than men were interviewed, particularly among Black Caribbean and South Asian groups. Achieving a diversity of migration experiences was difficult in some groups since the range of migration characteristics was limited within ethnic groups. For instance, Bangladeshi respondents were more likely to have moved to the UK after the age of 11, while Indian respondents were more likely to have been born in England or to have moved here prior to commencing secondary education.

1.3.2 **Conduct of the interviews**

All interviews were in-depth, exploratory and interactive in form, based on a topic guide that was developed by the research team in conjunction with the Department of Health. This listed the key themes to be covered during the interview, and the subtopics within each to be explored, and is a standard instrument in qualitative research studies. A copy of the guide is included in Appendix A. Interviews were carried out in respondents' own homes and they were paid £15 in appreciation of their time and help in taking part, as is usual with this type of research. Thirty-four of the interviews were conducted in languages other than English, all with people from one of the South Asian groups (see Table 1.1), but most commonly Bangladeshi people, for whom interviews were predominantly conducted in Bengali or Sylheti. All interviews were tape-recorded and transcribed verbatim. Those interviews carried out in languages other than English were translated and transcribed by the interviewer to minimise the loss of context.

The interviews began by exploring with respondents current events in their life – such as housing, health, employment, family, relationship and household circumstances – and attempted to assess whether the respondent was currently experiencing any form of mental distress. Where respondents identified episodes of distress, the interview went on to explore the respondent's views about the origin of that distress, the meanings attached to the situation (by themselves and other people); the practical, emotional and physical ramifications; and the ways in which respondents tried to cope with their experience. Interviewers knew in advance whether respondents had a high or low CIS-R score in the quantitative survey. However, they were instructed not to introduce this information into the interview at any point. Furthermore, interviewers made no mention of distress or other associated terms (such as stress, depression or anxiety) unless the respondent introduced such topics into the discussion. All interviews were responsive to and inclusive of the mode of expression used by the respondent.

Differences in the occurrence and nature of distress meant that the length of the interviews varied quite widely, ranging from as little as thirty minutes to over two hours. Pilot fieldwork took place in August 2000, to test the topic guide and recruitment strategy. The main fieldwork took place between October 2000 and March 2001. Fieldwork was relatively unclustered and took place in a variety of areas in England including London and the Southeast, East Anglia, East and West Midlands, Yorkshire and Lancashire.

Table 1.1

Sample profile							
	Ethnic group						Total
	Bangladeshi	Black Caribbean	Indian	Irish	Pakistani	White British	
Gender							
Male	9	9	7	8	8	8	49
Female	9	11	12	13	11	11	67
Age							
25-30	5	3	3	2	5	4	22
31-35	4	4	3	3	3	4	21
36-40	4	4	7	2	3	6	26
41-45	2	7	5	5	5	2	26
46-50	3	2	1	9	3	3	21
Migration							
Was born in UK or moved prior to age 11	6	14	10	16	9	19	74
Moved to UK at age 11 or later	12	6	9	5	10	0	42
CIS-R score							
Survey identified mental distress	7	10	11	9	11	9	57
Survey did not identify mental distress	11	10	8	12	8	10	59
Language of interview							
Bengali	11	0	0	0	0	0	11
Bengali/English	2	0	0	0	0	0	2
Sylheti	1	0	0	0	0	0	1
Punjabi	0	0	4	0	1	0	5
Urdu	0	0	2	0	5	0	7
Urdu/English	0	0	0	0	1	0	1
Pothari	0	0	0	0	5	0	5
Pothari/English	0	0	0	0	1	0	1
Hindi/English	0	0	1	0	0	0	1
English	4	20	12	21	6	19	82
Religion							
Christian	0	11	0	7	0	7	25
Muslim	18	0	3	0	19	0	40
Sikh	0	0	5	0	0	0	5
Hindu	0	0	6	0	0	0	6
Buddhist	0	0	0	1	0	0	1
Rastafarian	0	2	0	0	0	0	2
None	0	7	5	13	0	12	37
Social class							
Manual	8	9	7	5	9	6	44
Non-Manual	3	10	12	16	4	13	58
Not applicable*	7	1	0	0	6	0	14
Marital status							
Married	15	6	15	13	15	11	75
Divorced/Separated	2	4	2	5	2	1	16
Widowed	0	0	0	0	1	0	1
Single	1	10	2	3	1	7	24

*This includes those who had never had paid employment, and therefore could not be coded into an occupational class.

Inevitably, given the nature of the discussions, some respondents became upset during the course of the interview. In several cases, respondents remarked that they had revealed traumatic experiences about which they had never spoken to anyone before. Interviewers used specific strategies during such interviews. They were aware of the potential sensitivity of the interviews and in all cases aimed to be non-judgmental and empathetic. Also, in the event of a respondent becoming upset, they were given the opportunity by the interviewer not to continue with either the discussion of the traumatic event or with the remainder of the interview. Furthermore, the topic guide was structured so that the focus of the discussion shifted towards the end of the interview from personal to more general issues.

With the aim of bringing the interview to a close, respondents were asked more forward-looking questions, particularly about what advice or suggestions they had for other people who had had similar experiences to them, or for agencies and organisations who provide services to people in difficult situations. Finally, where appropriate, interviewers left with respondents a leaflet containing contact details for support organisations such as Mind, Sane, The Samaritans and the Citizen's Advice Bureau. In addition, for each of the fieldwork areas, interviewers were equipped to provide details of local culturally specific support organisations or agencies that offered advice or support in a variety of community languages.

1.3.3 Data analysis

Data from the qualitative study were comprehensively and systematically analysed using 'Framework', a content analysis method developed at the National Centre for Social Research for use with qualitative research data.^{27,28} Framework uses a thematic approach to classify and interpret qualitative research data. The approach treats every transcript in a systematic way within a common analytical framework. This means that Framework is a consistent and transparent method of analysis that enhances validity and reliability in interpretative findings.

The first stage of analysis involves familiarisation with the transcribed data and identification of emerging issues to inform the development of a thematic framework. This comprises a series of thematic matrices or charts, containing a variety of emergent topic headings, in which data from each case is summarised. The context of the information is retained and the page of the transcript from which it comes is noted, so that it is possible to return to a transcript to explore a point in more detail, or extract text for verbatim quotation. The charts are stored in spreadsheet format, usually in Microsoft Excel.

Organising the data in this way enables the views, circumstances and experiences of all respondents to be explored within a common analytical framework that is both grounded in and driven by their own accounts. The thematic charts allow for the full range of views and experiences to be compared and contrasted both across and within cases; and for patterns and themes to be identified and explored. By storing the data in a spreadsheet, cases can be grouped and regrouped according to emergent themes and key analytical variables. This approach ensures that the analysis is comprehensive, consistent and that links with the verbatim data are retained.

The final stage involves classificatory and interpretative analysis of the charted data in order to identify patterns, explanations and hypotheses.

1.4 Ethical clearance

Ethical approval for EMPIRIC was obtained from the North Thames Multi-centre Research Ethics Committee (MREC) and ratified by all Local Research Ethics Committees (LRECs) in England.

1.5 The content of the report

Throughout the report, verbatim passages from transcripts and case illustrations are presented. To preserve the anonymity of respondents, specific details – such as names or places – that might identify respondents, have been omitted or changed.

The remainder of this report contains four individual papers, each of which is concerned with a different aspect of the qualitative data. The first of these (Chapter 2) focuses upon the causes of illness – as perceived by respondents – the meanings attached to particular life experiences and their perceived role in producing mental distress. This is then followed by a paper that examines the symptoms, idioms, or metaphors used by respondents to describe mental distress (Chapter 3). Here particular emphasis is placed on illuminating the

different modes of expression – both emotional/psychological and physical – and the metaphorical language used by respondents to describe mental distress. Chapter 4 provides an overview of the variety of strategies employed by respondents to cope with or manage mental distress, particularly the use of personal resources and religion. The final paper explores respondents' use of and satisfaction with formal sources of support such as general practitioners and psychiatric care, counselling and therapeutic services, and other forms of help including alternative medicine.

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2 Explaining mental distress: narratives of cause

Steve Fenton and Saffron Karlsen

2.1 Introduction

The question of the disjuncture between medical, scientific and popular conceptions of health and illness has been a principal focus of research and theory in the sociology and anthropology of medicine. The literature constitutes a double challenge to medicine especially in the field of mental health, exploring the problem of non-appreciation of ‘folk’ ideas by practitioners and recognising the challenge such conceptions pose to the very categories of bio-medicine.^{1,2} In Britain specifically, it was the 1980s that saw the emergence of a literature on health and ethnic groups in Britain. Curren and Stacey’s *Concepts of health and disease: a comparative perspective*³ contained a classic research analysis exploring concepts of mental well- and ill-being among Pathan mothers in Britain. This was an early contribution to the exploration, by qualitative methods, of meanings of health and illness among patients and communities in Britain, with particular reference to migrants and their descendants. But there had been some earlier work exploring the extent to which popular views of health and illness causation coincided with medical scientific views: for example, Mildred Blaxter’s work with women in Aberdeen.⁴ Also, Krause⁵ explored the ways in which Punjabis in Britain might describe and explain their illness.

Fenton and Sadiq-Sangster⁶ explored the way women from different ethnic groups in Bristol described their mental and emotional states and how they placed this within a narrative of causation. While the authors found that these descriptions correlated strongly with the expression of most of the standard western symptoms of depression, they were also able to show that some of these standard symptoms were not present, suggesting that at least the form that the disease took was different. They also pointed out that such descriptions often included some discussion of what, on the surface, could be assumed to be symptoms of mental health problems, but in reality constituted part of the core experience of the illness, raising the possibility that there were more fundamental differences between this illness and depression. Ahmad’s⁷ work exploring inter-ethnic difference in patients’ concepts of cause of illness found for the most part, however, that such ethnic differences were slight or non-existent.

This literature has not only established the importance of people’s views of their health and illness states, but has also argued for a nuanced understanding of ‘culture and mental health’. This implies avoiding stereotypical generalisations, for example that certain groups have no real understanding of ‘mental illness’. At the same time it has become necessary to guard against unsubstantiated ‘cultural’ explanations of differences in health or health behaviour.⁸ Fenton and Charsley⁹ explore how epidemiological models of illness may be set beside sociological models which incorporate qualitative accounts of subjects describing their illness, its causes and context. This chapter is a novel contribution to our knowledge of how people in particular ethnic communities describe and account for their illness and its causes.

2.2 Discourses of causality

In this chapter we will discuss the concept of cause of illness. We will look at the principal headings under which the ‘discourses of causality’, as used by respondents, can be conceptually organised.

Respondents generally understood the idea of ‘cause’ or ‘precipitating circumstances’, in that they made recurrent mention of ‘how it all began’, and in doing so detailed a range of circumstances, situations, or difficulties that they felt underpinned their experience of mental distress. Some of the most commonly mentioned ‘causes’, both shorter and longer term, were:

- Difficulties within families and personal relationships;
- Experience of racism;
- Employment;
- Financial difficulties; and
- Poor physical health

Each of these is traced below with a referencing of illustrative cases. Two other broad features of the qualitative reports also became evident during the analysis. One is the *interconnections* of reported causes and contexts; the second is possible sources of *group differences* – acknowledging that there is also difference within as well as across ethnic groups.

2.2.1 **Family relationships**

Family relationships were described as a source of distress by all of the ethnic groups included in the study, particularly where they involved loss, separation and divorce, and interpersonal violence and abuse, and were given equal emphasis by men and women. This encompassed different types of relationships: between spouses or partners, within an immediate family (such as between parents and children, or between siblings), or with wider family.

Marital problems, divorce and separation

Marital problems and breakdowns, together with their consequences, were discussed as an important cause of emotional distress. The circumstances of the relationship breakdown, particularly those involving violence, betrayal, financial difficulty, or situations that resulted in lone parenthood, or difficult arrangements to get access to children, were particularly influential in terms of the trauma produced. For example, an Irish woman, aged 29, who had been in an “*extremely abusive*” relationship – her partner had attacked both her and her young daughter – described how this had led to a loss of confidence and self-esteem and left her feeling that she was “*damaged as far as another relationship goes*”. She spoke of the subsequent difficulties she experienced with trust and commitment and how she worried that she may not be able to form another relationship and would “*end up alone*”. Similarly, a 47-year-old Irish man described “*a sense of failure*” about his divorce: “*I’ve been brought up that one only gets married once, married for life and that’s it*”. Some respondents talked about divorce in terms of getting married “*too young*” and not being careful enough in their choice of partner.

In contrast to these experiences of relationship breakdown, the tension arising from ongoing unsuitable marriages and difficult relationships with in-laws was a recurrent theme among respondents in South Asian groups. Such relationships clearly produced enormous difficulties with no obvious escape. However, these problems were not experienced in a uniform way. While ‘family’ was seen by some to exert unwanted constraints and to make unreasonable demands on them, others appeared to think the demands were reasonable, but feared that they could not meet them. A 45-year-old Indian woman describes how her family, and the wider Indian community, made her feel inadequate and that she was not fulfilling of her familial obligations. A 46-year-old Pakistani widow described how she had been “*told off*” by her father-in-law, saying “*people don’t let you live, do they?*”. Family problems were not confined to South Asian groups, of course, either in their severity or in the way they were seen as the ‘cause’ of distress.

Difficulties surrounding the arrangement of marriage were a recurrent theme in the accounts of both women and men in the Pakistani, Bangladeshi and, to a lesser extent,

Indian groups. Some of the younger women who had migrated from Pakistan, Bangladesh and India had particular problems related to becoming a bride *and* coming to a new country at the same time. One 49-year-old Indian woman who moved to the UK aged 27 after an arranged marriage described the pressure she felt at getting married to someone and moving to a country she did not know and, in doing so, having to come to terms with a very different culture and his very traditional family. So, while women migrating from South Asian countries as brides did not necessarily object to the principle of the arranged marriage, in some cases they did object to both having no contact with the husband-to-be prior to the marriage and finding that the husband – in Britain – has no concept of changing gender roles. In expectations of greater freedom for women such brides were often ahead of their British husbands. This perhaps reflects social change in the Indian sub-continent and the fact that ‘traditionalist’ communities in the UK may not be keeping pace with this change.¹⁰ The 49-year-old Indian woman described earlier discussed her frustration at being kept in a “*traditional Asian position*” and, allied to this, that she felt her husband did not consult her about anything, even about selling his business, speaking only to his “*own*” family – she had “*no voice*”. In contrast, a 28-year-old Pakistani woman described how, because she was born in the UK, her husband felt that she was “*too modernised*”.

Many women in the South Asian groups complained about how their husbands treated them. The various problems included not being allowed to go out, to work, or to have friends, feeling a lack of support or feeling frustration about not being included in key decision-making. This treatment was seen to be typical of South Asian men, with one Pakistani man discussing how he acted in a way that “*a lot of Pakistani men wouldn’t*”, treating his wife like the head of the household and apologising when he upset her. But not all the men interviewed felt that their behaviour had only negative consequences for women. For example, in one interview, where the wife was present and commented on the responses given by her husband, she described her frustration that he would “*rather tell outside people*” about his problems. He replied that he wished to avoid giving her his “*pressure*”.

As well as more general issues, problems associated with arranged marriages partly arose from how decisions were made in relation to the marriage in the event of marital difficulties. One 32-year-old Pakistani woman, who was born in the UK, described how she felt unable to act about her husband’s suspected affair because “*it’s just really for my parents, I can’t take a step*”. In addition, the pressures on some men to get married and to make a good match was seen by some to lead to bad choices and, ultimately, unstable relationships. One 37-year-old Pakistani man, who moved to the UK when he was 11, commented that his plans to go to university and to pursue a career in the RAF had been “*ruined*” because he had to get married and provide for his wife and family. He now works part-time in a take-away. One man blamed his divorce on having to make a quick decision about marrying someone he did not know:

“it’s like going into somewhere blindly and you can’t see things clearly. I’ve been looking for a bride, I couldn’t find the right bride, at the last moment I had to get married”.

(Male, 30, Bangladeshi, migrated to GB aged 9, high CIS-R score, interviewed in English and Bengali)

Another problematic issue that seemed to be particular to those in the South Asian groups, and that exacerbated problems with in-laws and other wider family members, involved living arrangements after marriage. South Asian people often lived with one set of parents and siblings, which, in some circumstances, caused considerable stress.

Despite these accounts, it should not be assumed either that arranged marriages are necessarily difficult or that, where they are difficult, the configuration is the same in all cases. For example, one 28-year-old Pakistani woman, who was born in the UK, described how after their arranged marriage she and her husband had initially had some problems, because they did not know or understand each other, but how they now have a very close and supportive marriage. It is important to appreciate that so-called arranged marriages are frequently successful, and the difficulties of cultural change are often successfully managed.

Other family difficulties

The legacy of past family difficulties, or longstanding problematic relationships with family members was seen by some to be the cause of current distress. Such experiences were often located in childhood. For example, an Indian man in his thirties, who had been born in the UK, spoke of a *“traumatised childhood”* that *“wasn’t a relaxed family situation”* and involved *“no real affection”*, partly because his mother was *“clinically depressed all her life”*. He said that his childhood experiences, combined with other problems in his life made him feel *“cursed”*. Another respondent, a 47-year-old Irish man who had been out of work for some time as a result of his mental ill health, described how his father had had a troubled upbringing, which had affected the whole family, and particularly him. While he felt that he now understood his father better, his major concern was that his illness would affect his family in the same way his father’s did him when he was a child. And a Black Caribbean woman described how her lack of confidence stemmed from her father’s physical and psychological abuse towards herself, her siblings and her mother.

More recent family problems were also a source of difficulty. Caring for family members was seen by some respondents to be a source of considerable strain and worry. For instance, one woman, who cared for her sick husband and six children in a three-bedroom house, spoke of the distress brought about by her home situation:

“My husband is sick, my daughters are sick, no job, so many children, small house to live – so I only know how much day to day worry I have”.

(Female, 44, Bangladeshi, migrated to GB aged 2, low CIS-R score, interviewed in Bengali)

Respondents were also concerned about and alert to the impact their own problems could have on other family members. In this respect, respondents talked about not wanting to be a *“burden”* on their families, especially where this might lead to difficulty for others. For example, the 32-year-old Pakistani woman described earlier was concerned that her father’s health might deteriorate if she told him about her marital problems. And one young Black Caribbean man described how him being attacked by his ex-girlfriend’s new partner led to his mother having a stroke. And, in turn, problems experienced by family members were a source of distress for some respondents. So, for the man just described, his mother’s stroke was far worse for him, *“it was like the biggest heartbreak”*, and more instrumental in the development of the distress he reported, than anything associated with his girlfriend or the attack. Feeling unable to give sufficient or effective support to family members in difficulty made people feel impotent or isolated. However, some respondents also found that being a source of emotional support for friends and family caused problems. One Irish 29-year-old woman described how her family are constantly ringing for advice, which makes her feel that she has no-one to turn to herself in times of crisis: *“who do I ring sometimes, you know?”*.

Bereavement

Bereavement also had serious consequences for mental health across all of the groups included in the study. A 35-year-old Bangladeshi man, who had severe mental health problems, described feeling like his *“world collapsed”* when his mother died. In general, when it happened, respondents described bereavement as an important precursor to depression. Again, however, the circumstances of the bereavement acted as an important mediator. For example, while these issues affected individuals in all populations, they appeared to be associated with particular difficulties for those where there were family tensions and difficulties over funerals, especially where they involved international travel, problems that particularly affect people from ethnic minority groups.

2.2.2 Employment issues

Another set of causes of mental distress mentioned in the interviews were a variety of problems related to employment. For some the type of work that they did was related to a sense of underachievement. One Bangladeshi man in his late thirties, who had been living in the UK for ten years, described his work as a restaurant chef as boring and *“below me”*.

Similarly, an Indian man of similar age and migration history, who worked as an assistant accountant, described how he feels overlooked at work, that his job is not progressing, and how this produces feelings of “*stagnation and boredom*”. In migrant communities, it is common for people to work ‘below their qualifications’.¹¹

Another recurrent work-related difficulty was that of being overworked. This was sometimes the only source of distress for some people. However, where it was reported along with other difficulties, it was difficult to decipher whether work was the cause of distress, or whether the combination of many different sources of stress culminated in a feeling of ‘being over-worked’. For instance, a White British 46-year-old woman talked about how she felt she had to reduce the number of jobs she was doing for the sake of her “*future health*”, although then went on to describe how her work problems were exacerbated by other family, marital and health problems. People described the tensions of trying to hold a job – when they knew that working conditions or job security were at risk. For example a White British man in his early thirties commented on how the restructuring of the company for which he was an account manager had made him feel stressed and “*vulnerable*”. Most of his longstanding colleagues had been made redundant and he felt that the new regime was “*making my life difficult*”.

Bankruptcies also lead to serious health problems for some people. One 37-year-old Pakistani man, who moved to the UK at 11 years of age, had owned a shop for five years. He had great difficulties while running the shop, which led to long hours and a lot of stress and, ultimately, to the shop being repossessed. This made him feel shocked and embarrassed: “*you lose your self-confidence, afraid to meet people, lose your self-respect*”. Such feelings were often exacerbated by having to take on menial work to make ends meet. For instance, the man described above was forced to take on a part-time job in a local takeaway, a job that he described as “*rubbish*”. Business bankruptcies were concentrated among the South Asian groups and, as others have illustrated,¹² may reflect less experience in business enterprise and/or that such businesses are less well funded, compared with others, particularly for Pakistani and Bangladeshi people. This may be because they have been ‘pushed’ towards self-employment as a response to unemployment. Bankruptcies are then a real risk, and very distressing.

There were also cases where problems at work, or health problems, made people unable to work. Losing (or ‘downgrading’) employment or being on long-term sickness leave had significant effects on self-esteem and personal identity. One 45-year-old Pakistani man, who had worked as a machinist for 15 years before becoming unemployed, described how he had enjoyed his work and how he now feels bored and that he is no longer “*achieving in life*”. Another man, aged 30 and from Bangladesh, who had had to stop work after being involved in a car accident, described how this made him feel “*hopeless*”. A 42-year-old White British man expressed concerns that colleagues at work thought that he was “*trying to work his ticket*”, because the doctors are having problems diagnosing the condition that is keeping him off work.

2.2.3 Financial difficulties

Financial worries were a common theme in respondents’ accounts, and these problems seemed to be very stressful, both on their own, and in the way that they often accompanied other negative life events. In some cases, financial problems were related to a lack of employment and trying to live on benefits. For example, a White British 34-year-old single mother talked about how she worries that she is not looking after her son properly, because she does not have enough qualifications to allow her to get employment and improve their income enough to counterbalance the associated reduction in benefits. One man who cares for his disabled wife was particularly frustrated at what he felt was a lack of recognition from the Government:

“I could do with more state benefit ... you’re a fulltime carer, you’re on call 24 hours, 24/7, you don’t get appreciated for it”.

(Male, 40, Irish, born in GB, low CIS-R score, interviewed in English)

Failing businesses also led to financial difficulties, as was described in an earlier section. And people sometimes struggled to find the money to pay for education. For example, a 26-year-old Black Caribbean man who was trying to put himself through university commented that he had *“never been in so much debt in all my life”*.

In addition to other problems, relationship breakdowns produced significant financial strain as people tried to set up a household on their own, or with their children, perhaps having been left in some financial debt. A Black Caribbean single mother in her mid-thirties described how she felt a *“smack in the face every time”*, as she discovered how much debt her ex-partner had left her in. Similarly, a 39-year-old White British single mother spoke of her financial problems occurring as a result of her ex-partner being *“dead irresponsible with money”*.

Financial difficulties also affected other aspects of life. This was particularly evident in the problems people had with their housing, especially in South Asian households where large, often multigenerational, households can potentially lead to overcrowding. One Bangladeshi woman in her mid-forties talked about how her youngest daughters have to sleep with her and her husband due to lack of space, but she did not feel that their situation was unusual: *“everyone over here having more or less same problem like me”*. Such problems were not exclusive to those in South Asian groups. White British respondents also described problems with housing, such as their home being in a bad state of repair or just general overcrowding. For example, a single mother who shared her bedroom with her two sons commented on how *“it would be quite nice just to have my space that I could relax in”*.

2.2.4 Racism

Experiences of racism were central to the accounts of ‘non-White’ respondents and were also present for some Irish respondents. Such experiences were clearly painful and important in the deep impact they had on people’s lives. People referred to racism in a range of contexts. One such context was bullying (of their children or themselves) at school, in which the person or child may become fearful of going to school. One Indian man, who was born in the UK, said:

“White kids and Indian kids just didn't mix, it was just kind of like they just spent all playtime beating each other up ... I found that quite a shock ... I genuinely hated it”.

(Male, 36, Indian, born in GB, high CIS-R score, interviewed in English)

People experiencing such racism sometimes developed physical symptoms that prevented them from going to school and become part of a pattern of severe personal stress either for the child, the parent, or both. The Indian man mentioned above described how he *“would have asthma attacks, not want to go to school, it's one way of hiding, it got me lots of attention at home”*.

Reports of racism in the workplace were also common. An Indian woman, who had been born in the UK, described how she was forced to give up her job as a teacher as a result of the racially-motivated discrimination and bullying she experienced:

“How can I forget I used to be crying, crying ... all the time ... worst day in such a state I couldn't even walk home ... my body was shaking, I couldn't even walk from the school office to my classroom”.

(Female, 29, Indian, born in GB, low CIS-R score, interviewed in English)

Racism experienced in the workplace was not always overt or explicit and respondents sometimes spoke of what one person called *“hidden racism”*. Here respondents referred to situations where they felt that their work life or career was impeded by racial prejudice, but could not identify a particular incident to substantiate their fears. For example, a lack of promotion, or the loss of the job altogether was sometimes felt to be the result of racism: *“sometimes when you phone up for jobs ... they say they're going to phone you back and you know they're not going to”*. On this point an Indian man, who felt he was struggling to succeed in his career in the face of prejudice, reflected that:

“You can kind of explain it on individual terms...you can rationalise it...the thing about institutional racism [is] statistically after a while you can’t explain these things just on individual explanations”

(Male, 36, Indian, born in GB, high CIS-R score, interviewed in English)

Respondents also described experiencing racism in public places, either through shouted abuse or physical violence, generally from people unknown to respondents. A Pakistani man talked about the racism he experienced while running his shop:

“[It was] very downhearting, because you’re there and you’re working, minding your own business, and you’re providing a service ... you’re not appreciated and that’s very sickening”.

(Male, 37, Pakistani, migrated to GB aged 11, high CIS-R score, interviewed in English)

Another respondent felt that he had been labelled as a *“troublemaker”* because of the combination of his ethnicity and his occupation:

“The kind of attitude people have as well is that you’re young and you’re Asian and that you’re a taxi driver so you have got to be a troublemaker... you’re pulled up and blamed for something as soon as because of your colour ... there are people who do not even consider you to be a human being if you’re not White”.

(Male, 26, Pakistani, born in GB, low CIS-R score, interviewed in Punjabi)

Physical attacks, where they occurred, severely undermined confidence and led to an unwillingness to venture out into public places. More generally respondents spoke of how vulnerable they felt in public as a member of a non-White ethnic group. A Black Caribbean man in his mid-forties remarked that: *“it’s quite messy going out there ... you end up getting killed, end up getting stabbed”.*

The effects of racism on respondents’ mental and physical health were clearly profound, a finding which gives qualitative support to a relationship has been found quantitatively.¹³ There was recurrent mention of how *“tiring”* it was to cope with racism. Dealing with racism was said to require an enormous amount of energy, both in handling the situation itself and in coping with its ‘internal’ (or personal) consequences, in sustaining and encouraging themselves to move on and get over it.

2.2.5 Health concerns

Another key area thought by respondents to lead to mental distress was concern about physical health, although the two were rarely neatly separated in the accounts provided by respondents (for more discussion of this, see Chapter 3: Idioms of Mental Distress). For example, a 37-year-old Indian man described how his back was painful when he was under stress and how he had problems with his digestion, which led him to worry that he had bowel cancer, although he also said that he believes this to be unlikely.

This connection between physical and mental ill health was especially evident where the respondent appeared to have been given an unsatisfactory (from his or her point of view) understanding of the condition by a doctor, including its causes and consequences. This, and where the respondent was not convinced by a medical diagnosis, may also explain the concern about their treatment expressed by some respondents, particularly, though not exclusively, those in South Asian groups. One 40-year-old Bangladeshi woman, who had moved to the UK when she was 17, said that she only takes the medication her doctor gave her for her gastric pain when the pain is very bad, because *“I don’t trust doctors’ medicine too much”*. The connection between mental and physical health was also particularly apparent where medical personnel had difficulty diagnosing the problem, a situation that was not specific to particular ethnic, gender, or language groups. For example, one White British man in his early forties experienced a condition that had kept him away from work for a year, but he had yet to receive any diagnosis. He talked about how he desperately wants a diagnosis and a sense of closure, even if it means he has to accept he is *“mad”*, *“it’s confusing, it’s very, very, very frustrating ... basically it leads to a lot of stress”*.

Health problems also made the impact of other negative life circumstances greater for some respondents. For example, a 40-year-old Bangladeshi man described how his work stress had been worse since his health had been bad. He reported having diabetes and high blood pressure.

2.2.6 General causes

Although respondents did make direct connections between events occurring in their lives (and often complex chains of events) and their experiences of mental distress and illness, they also located the cause and nature of mental illness in individual personalities and the environment more generally.

In terms of individual vulnerability to mental illness, a Bangladeshi woman, who had a high CIS-R score herself, described how mental illness *“can get hold of people in different ways, some people have it in the brain, others have it in their soul [“jaan”], some people have their, go bad inside”*. Similarly another woman with a high CIS-R score, said:

“I feel sorry for people ... they go ... mentally disturbed ... because they can’t cope with society in general and they can’t handle the system ... If they don’t take their medication they’re like animals ... crazy ... mad ... so mentally disturbed and gone”.

(Female, 39, Black Caribbean, migrated to GB aged 14, high CIS-R score, interviewed in English)

Indeed, some respondents talked about depressive personalities. For example, a Black Caribbean man commented that *“a lot of people are just miserable people full stop ... they just like being miserable ... you ain’t got nothing to be depressed about you just want to be depressed”*. Related to this, some people felt that mental health problems are not curable. The Bangladeshi woman described above also said that there is no cure for *“illness in the head there is no medicine ... nothing will work for this. You cannot alter someone’s mind”*. And a Black Caribbean man, who had a low CIS-R score, said: *“Once it’s in your head, you can’t get rid of it”*. These findings support those of Fenton and Sadiq-Sangster⁶ who identified an expression of distress used by Pakistani origin women in Bristol that they described, using their respondents’ words, as *“thinking too much in my heart”*.

Another set of explanations for mental illness related it to the build up of worries and stress. A 26-year-old Black Caribbean man, with a high CIS-R score, commented: *“The brain can only take so much before it starts to overload”*. An Irish man described how external stress becomes internalised:

“Depression comes from ... down the line ... you become inactive through the anxiety and ... you withdraw from ... social things ... and then you become demoralised ... the next thing you know you do become depressed and you’re always fighting ... to avoid sinking into [it]”.

(Male, 47, Irish, born in GB, high CIS-R score, interviewed in English)

More specifically, some respondents from non-White ethnic minority groups described how their ill health had been at least partially caused by specific external factors, a curse or the British climate and culture, for example. One Pakistani woman, interviewed in Pothari, suspects that someone may have made a *“Taweess”* (amulet) or that someone has looked at her in the wrong way (*“nazaar”*) which has caused her health problems. The cold British climate not only caused ill health itself, but also made people feel lonely and trapped inside their homes, unable to meet people. One Black Caribbean woman in her late thirties, who had moved to the UK from Jamaica when she was 14, said:

“This country is so damn lonely ... when you’re in Jamaica you can go outside and sit down, it’s hot, it’s beautiful, you know, it’s not cold ... [in Britain] you have to wait for summer to come before you can go outside and relax”.

(Female, 39, Black Caribbean, migrated to GB aged 14, high CIS-R score, interviewed in English)

And some people felt that their problems were specifically related to the ‘British’ way of doing things, with a Pakistani man commenting: *“in this culture there are a lot of bills”*.

In contrast, some ethnic minority respondents felt that there were specific ways in which their own community affected their experiences of mental ill health. People in South Asian groups talked about how there is little understanding or experience of mental health problems in their *“community”*, while other health problems are very common and so produce less worry. One 30-year-old Bangladeshi man, with a high CIS-R score, described feeling *“very lonely”*, because he felt that he was the only one in the Bengali community who had problems of this nature. Some respondents also discussed such influences on people from different cultures and how this might lead them to deal with mental ill health in different ways. For example, a Pakistani man, who had moved to the UK aged 11 and who had a high CIS-R score, discussed how other people in a similar situation to himself might: *“[go] off the rail, probably English will start drinking and drugs, but I didn’t do that”*.

2.2.7 Interconnections

The broad areas mentioned above occur across all the cases, regardless of ethnic or gender group or likelihood of mental illhealth (as defined by their CIS-R score). For some respondents the problems affecting their lives are concentrated in one of these areas. Others experienced a range of problems occurring in a number of different areas. While some respondents perceive an interconnection between these different problems, others discuss an overriding ‘cause’ of their distress, and other problems which are identified as being secondary, or unrelated, to their mental distress. Often, though, problems were discussed in a manner which suggested that they occurred in clusters or chains, with further problems arising as a consequence of earlier negative experiences, or operating to intensify the impact of the already difficult situation. As described earlier, there were particular problems which seemed more likely to be perceived as being interconnected, financial difficulties and both employment and family or marital problems, for example. On the whole, causal patterns were more likely to be recognised among more recent experiences. More severe problems, however, were seen to have long-lasting effects: childhood abuse, for example, still able to exert an influence on mental health long into adulthood.

For example, one 31-year-old Indian woman discussed a lifetime history of problems: including being physically, mentally and sexually abused as a child; being forced to live with her husband’s family after her marriage at 17, whom she did not know and who took over her life; and the physical abuse she experienced from her husband. At interview she lived alone with her son and had been burgled four times since moving into her current house, as well as experiencing a lot of racism in the area. She also has problems related to her dyslexia, as well as financial and health problems. When asked about what she saw as the cause of her mental distress, however, she focussed on two specific areas, both concerning problems with her family. She talked about her problems living with her husband’s family, and the physical abuse she experienced from him. She also mentioned the sexual and physical abuse she experienced as a child. More recently, she feels her family are hassling her, rather than letting her *“get on with things”* which is causing her distress. She did not report the other problems she has experienced as being related to her current distress. In this way, some respondents felt one or two particular experiences were paramount in terms of the development of their mental distress. Similarly, a 50-year-old woman talks about her recent loss of contact with her family after her mother’s death, the difficulties associated with her marital problems and subsequent divorce and her problems at work. She is divorced and lives alone with her 25-year-old daughter, with whom she has some conflict, problems which she says are a consequence of a *“personality clash”*, her daughter being badly behaved and disrespectful, as well as unambitious in terms of her career. She also discusses concerns about her current partner. She feels she does not really have any mental health problems, but any problems she has are produced only by her problematic relationship with her daughter, although she also feels she has some anxiety stemming from her desire to retire to Jamaica and her concern that she will have insufficient funds to do so.

Though some respondents discussed their experiences in an itemised way, others saw (at least some of) these experiences as being closely related, and even interconnected. For example, one 48-year-old Pakistani man had a high CIS-R score, and was unemployed and in financial debt after being made bankrupt. At interview, there were some ongoing financial disputes. His father died and he spent some time in prison, where he started using illicit drugs. He mentions experiencing racism throughout his life, from both the White and Pakistani community (for not marrying a Pakistani woman). He also says his family cause him problems. He felt his mental illhealth, drug dependency, financial difficulties and his wife's health problems were all a consequence of the bankruptcy.

There was, in some narratives, a clear inter-relationship between various negative life experiences that could in some senses be seen as a chain of events. One 39-year-old single mother had been in debt since her relationship with her partner broke down, because of his financial irresponsibility. Due to the young age of her children she feels she has no option to return to work for some time. Both her parents have died: her father's death 10 years ago she found "very upsetting". She also experiences recurrent pain in her hip. She feels her low self-esteem has been caused by her experience with her ex-partner, but she also experiences stress as a result of bringing up her children alone, the lack of space in their accommodation (she currently sleeps in the same room as her sons) and her financial difficulties. She also feels that she has let her children down, again as a consequence of circumstances related to the relationship breakdown. She feels she needs more support, and this is the reason behind things "getting to her". The breakdown of the relationship is therefore seen to have lead to a number of problems, including financial difficulties, which in turn prevent her from seeking alternative accommodation; feelings of guilt and stress; and insufficient support; each of which have an impact on mental health.

2.2.8 Group differences

It is important to emphasise that almost all the broadly defined causes described above occur across all groups. But one or two broad distinctions could be suggested. As mentioned earlier there are frequent references to racist abuse and its consequences in all 'non-White' 'minority' groups. And distinctive to people from the Black Caribbean group is a longing for home, although some South Asians refer to the difficult adaptation to Britain. Also, whilst family difficulties occur in all the different groups, in South Asian communities it appears to be linked also to a sense of community reputation or community pressure. The references made in these groups to 'community' are virtually absent in Black Caribbean and White groups who in this and other respects are like each other. While any generalisation about this situation is obviously tentative, it would seem that the accounts of people from South Asian groups show a concern for community reputation and, for some, an anxiety about the reputation of the family within the community, which among the different South Asian groups is almost certainly stronger than among non-South Asian groups. This situation could be seen to produce some of the particular problems related to marital difficulties when they occur within an arranged union, or other family problems, for example. For the other ethnic groups included in the study, there are also reports of 'family breakdown' which are closely linked to accounts of personal mental distress. But these accounts are rarely linked to an idea of 'community'. Rather, unlike for South Asian groups, in a number of cases they are associated with serious family disruption, violence and the breakdown of relationships, and problems linked to the law (eg prison sentences) and external (eg child care) agencies. Again, this should not be read as a final statement, or generalisation, but as a tendency indicating a pattern of difference.

2.3 Summary and conclusions

In this chapter we have explored what people see as the causes of their mental distress, and the ways in which these experiences have affected their health and lives. We have identified several key areas which were recurrently discussed by respondents. These areas were raised across the ethnic and language groups, however there were also important

differences between the different ethnic groups in some areas. Family and marital problems, for example, were experienced by people across the different ethnic groups, but there were also some particular problems associated with divorce and separation that are concentrated among White and Black Caribbean groups and problems with being in arranged marriages that are concentrated among people in South Asian groups. Experience of racism was also concentrated among those in non-White ethnic groups. There was no ethnic or language specificity in the discussion of other problems, including those related to employment, financial difficulties and health.

Our exploration of respondents' discussions of the experiences affecting their lives also suggested that different life experiences vary in the way they affected mental health. Racism, for example, was described as producing feelings of fear and tiredness, while financial difficulties (particularly bankruptcy or unemployment) were associated with a loss of self-respect, and bereavement left people feeling distraught. It is also important to recognise that the circumstances of an experience will be crucial. Both marital and employment problems, for example, may lead to, or be associated with financial difficulties, and employment problems were related to health difficulties and experiences of racism. So, while the broad experiences discussed in the preceding sections will all produce mental distress, there will also be subtle differences in the way these different experiences will affect mental health, which means that people will talk about themselves, and their mental health, differently. This evidence suggests that while health practitioners may find that these broad issues underlie severe anxieties and depressions across the different ethnic groups, they will also vary in nature from case to case. The chapter has also shown that although 'explanations' and 'causes' can be cited under single headings, in practice the sources of stress in someone's life are two- and three-fold with the co-occurrence of causes exacerbating the sense of severe distress, and affecting the ability of the individual to recover.

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3 Idioms of mental distress

James Nazroo and William O'Connor

3.1 Introduction

A central concern of studies of ethnic differences in mental illness is whether the idioms used to express mental distress are culturally informed; and culturally informed to a sufficient extent to make western psychiatric models of illness culturally specific or 'culturally bound'. In this chapter, the symptoms, idioms, or metaphors, used by respondents to describe mental distress are outlined. We begin by reflecting upon the significance of symptomatic expression in the detection, understanding and measurement of mental distress among minority ethnic groups. Following this, the different modes of expression – both emotional/psychological and physical are described – and the metaphorical language used by respondents to describe mental distress is examined. Here, it is worth remembering that the purposive selection of the sample for the qualitative study means that comparisons can be drawn between those who had high and low scores on the CIS-R (those with low scores were sampled on the basis of having reported difficulties in their lives), across different ethnic groups and, for ethnic minority respondents, age on migration and whether, or not, the interview was conducted in English. Finally, the chapter considers the implications of these idioms for models of mental distress rooted in western psychiatric practice.

3.2 Culture-bound syndromes

Evidence from studies of treatment rates suggest that the prevalence of mental illness among populations that have been broadly described as South Asian appears, on balance, to be lower than that for the general population.^{1,2,3} It has been suggested that these lower detected rates could reflect language and communication difficulties, or a general reluctance among some South Asian groups to consult with doctors over mental health problems, rather than a genuinely lower prevalence of mental illness. More fundamentally, it is possible that they may reflect a difference in the symptomatic experience of South Asian people with a mental illness compared with white people. It has been suggested, for example, that some groups may experience particular "culture-bound" syndromes – that is a cluster of symptoms that is restricted to a particular culture – such as "sinking heart" described by Punjabi people.⁴ Or some may be more likely to somatise mental illness – that is experience and describe psychological distress more in terms of physical symptoms,⁵ which are less likely to be identified as mental illness in both epidemiological research and clinical practice. For example, it has been demonstrated that a standardised western assessment of psychological distress under-estimates problems among South Asian people living in Glasgow relative to their white peers when compared with self-reports of distress, or a measure that more directly assessed somatic symptoms.⁶ And that this under-estimation may be specific to distress resulting from situations that were more commonly experienced by South Asian people, such as a low standard of living.⁷ Of course, culture-bound syndromes need not be specific to, nor indeed uniform across, South Asian groups. The very category "South Asian" has been viewed as inappropriate, too wide and misleading in health research.^{8,9}

Kleinman, in what comes close to a relativist perspective on mental illness, has suggested that the problems with cross-cultural psychiatric research may be even more fundamental

than this. Depression and somatisation, for example, are typically seen as different, culturally informed, ways of expressing biologically similar disorders. However, Kleinman suggests that the reliance on a *biological* definition of disease crucially undermines an understanding of how different the culturally shaped illness may be, including symptoms, help-seeking behaviour and course of illness.³

Given the reliance of psychiatric research on the identification of clusters of symptoms that reflect an underlying disease and the potentially different idioms for mental distress used in different cultures, as described above, Kleinman argues that cross-cultural psychiatric research can easily lead to a 'category fallacy', because the idioms of mental distress in the researched group are simply different from those used in the research tool.³ So he points out the obvious fallacy in attempting to identify the prevalence of "semen loss" or "soul loss" in white western groups.³ This may, of course, equally be the case for instruments designed to detect western expressions of mental illness when applied to other cultures. Indeed, Jadhav has been able to describe the historical and regional development of "western depression", leading him to suggest that this apparently universal disorder is culturally and historically specific.²

There has been little empirical work in this area, so there is only limited evidence to support this position. In one example, Fenton and Sadiq-Sangster identified an expression of distress used by Pakistani origin women in Bristol that they described, using their respondents' words, as "thinking too much in my heart".¹⁰ While they found that this correlated strongly with the expression of most of the standard western symptoms of depression, they were also able to show that some of these standard symptoms were not present (those relating to a loss of meaning in life and self-worth), suggesting that at least the form that the disease took was different. They also pointed out that "thinking too much in my heart" was not only a symptom as such, but a core experience of the illness, raising the possibility that there were more fundamental differences between this illness and depression. Another study has suggested that cultural differences in the expression of mental distress meant that South Asian people who consulted with their GPs about mental health problems often went undiagnosed.¹¹

The *Fourth National Survey*, despite its quantitative nature, lends some support for such a perspective. Although South Asian people in that study were overall found to have low rates of mental disorder, this in fact only applied to those who had migrated to the UK in late childhood or adulthood (ie aged 11 or more on migration), "second generation" South Asian people did not have lower rates of mental disorder.¹² Two possible explanations were considered for this finding in the study. First, that this was a consequence of language differences, with those less fluent in English being less likely to have symptoms adequately identified, despite the use of translations and ethnically matched interviewers. Age on migration is, of course, strongly related to English language ability for South Asian people, and similar findings to those just described were found if fluency in English was used instead of age on migration in the analysis.¹² The second possible explanation is that the difference between "migrant" and "non-migrant" South Asian people was a consequence of variation in cultural distance from western idioms of mental distress, that is those who were migrants were more culturally distant and therefore less likely to describe their mental distress in a way that would be detected by the research instruments used in the study. To explore the relative contribution of these two possibilities, both fluency in English and age on migration were considered together in a regression analysis. In the resulting model the crucial factor appeared to be that related to cultural distance (ie age on migration), rather than familiarity with language or quality of translation (ie fluency in English), lending support to Kleinman's hypothesis.¹²

3.3 Symptomatic expression

There was general discussion within the qualitative interviews of difficulties that were mental, or psychological, or “*psychiatric*”, in origin. There was common usage, across all ethnic groups included in the study, of English language terms such as “*depression*”, “*stress*”, “*anxiety*”, being “*mentally ill*”, or “*mentally disturbed*”, to describe mental health problems. Furthermore, there did not appear to be any variation in the use of these terms by migration status. Those who were interviewed in languages other than English used equivalent terms, such as the Bengali terms “*dorchita*” (meaning feeling anxious) “*oshanti*” (having no peace) and “*shorill shanti*” (something being stressful). Other, more colloquial, phrases, like people going “*mad*”, or “*off their heads*”, were also used cross-culturally.

Respondents also described their feelings in *both* mental and physical ways; respondents discussed their physical and mental health as related. As one Indian woman put it: “*if you stay happy then your health will stay happy too*”. So, as with discussions of the causes of mental distress, the descriptions of symptoms of mental distress showed that they were closely inter-related and difficult to untangle. However, for ease of comparison with psychiatric models, in the following symptomatic expression is split into two broad (but as just suggested not exclusive) categories: emotional, or psychological, and physical. Then some description is provided of the metaphors used by respondents to describe their mental distress.

3.3.1 Emotional or psychological symptoms

The following section deals with emotional or psychological symptoms expressed by respondents throughout the qualitative interviews. Again for ease of comparison with psychiatric models they have been grouped according to five categories, though clearly no such classification was expressed by respondents themselves.

Stress, anxiety, worry, nervousness

The general terms “*stress*”, “*anxiety*” and “*worry*” were used by respondents across the different ethnic groups, regardless of age on migration to the UK and whether or not the respondent had a high CIS-R score. The term stress was used recurrently to describe mental distress, with respondents from all ethnic groups describing how they “*suffered from stress*”, got or were “*stressed out*”, or that they were, or knew of people who were, “*stressed*”. Likewise, common to all groups were descriptions of being “*worried*”, or “*having worries*”, as well as being “*tensed up*”, “*wound up*”, or “*anxious*” in relation to, or in response to, circumstances, or events.

Descriptions of distress were sometimes articulated in a way that implied that events or circumstances (known, or unknown) were playing on one’s mind. This was evident across the six ethnic groups. For example, Indian respondents spoke of having “*stress on my mind*” or “*something on my mind*”, while a Bangladeshi respondent spoke of how “*things affect in my mind*”. This somewhat corresponds with responses among some Black Caribbean respondents who spoke of “*living with something hanging over you*” or of “*underlying worry*”.

Such emotions were commonly expressed in terms of “*pressure*” by the South Asian respondents. This was usually described in physical terms (such as “*pressure in the head*”) and somatic responses such as these are discussed in further detail below. However, pressure was also articulated by South Asian respondents in a way that implied that it was psychological, for example, “*the pressure of ill-health*”, or “*pressure from work*”. One Bangladeshi respondent described how difficulties in his family life “*pressurise me mentally*”, while an Indian respondent spoke of her “*pressure on my mind*”. These descriptions are similar to the way in which the term “*pressure*” is used by White and Black Caribbean respondents who typically spoke of events that “*put pressure on you that can break you*”, or more generally being “*under pressure*”, or “*feeling pressurised*”.

Bangladeshi responses sometimes described how the “*mind feels small*”, or of fighting and pulling inside the body (“*shorill taan mareh*”). One woman told of how “*illness in the head*”

can get hold of people in different ways, “some people have it in the brain others have it in their jaan (soul), some people ... go bad inside”. The importance placed on “shanti” (peace) and the avoidance of “oshanti” (having no peace, being stressful) by some respondents underlines the importance of this term as a way of describing distress among Bangladeshi respondents. One respondent described how her “body and soul is not feeling peace ... my inside is just anxious”. Others spoke of being “unstable”, “unsteady”, or “restless” in response to events; the latter being terms which were also recurrently used by White British and Irish respondents.

There were some expressions that were almost exclusive to White British, Irish and Black Caribbean respondents. They typically spoke of stress or anxiety “levels” in a way that was absent from the narratives of most South Asian respondents – particularly the migrant respondents. Here there were accounts of “increased stress levels”, for example, one Black Caribbean woman recounted how her “stress levels went kling!” in response to a difficult situation. In addition, phrases such as being “wrecked in the head”, “cracking up”, “fraught”, “traumatised” and “mad”, or accounts of being “driven mad”, were mainly found in the White groups and among Black Caribbean respondents. Also recurrent here were reports of events or circumstances “getting on top of me” or “getting the better of me”.

Being “nervous”, “on edge”, “uneasy”, fearful, or panicked (either generally, or in terms of attacks) was a theme in the descriptions of respondents with a high CIS-R score, but mainly by those in the White (Irish and British) groups. However, these experiences were not entirely absent from the discussions of symptoms by respondents in other groups. Related feelings of being “trapped”, restricted, desperate, without control and the “world closing in on you”, were fairly universal experiences across groups.

Depression, Sadness and Hopelessness

Terms like “depression”, “being depressed”, going through “a depressive episode” were used across the six ethnic groups. Related phrases such as sadness, unhappiness, downhearted, heartbreak, or “heartache” also featured in respondents’ descriptions of their feelings, regardless of ethnic group. Other descriptions included being “tearful”, “upset” “fed up” and “in despair”. Expressions like “nervous breakdown” were almost exclusively located within the White and Black Caribbean groups, as were phrases like having “chronic depression”, or being in a “semi-depressed state”.

There were some ethnic differences in the way that sadness was articulated. Indian respondents spoke of one’s “heart going”, of “unhappiness spread out” and one man described his wife’s mental distress as her “loosing all her health”. Among Pakistani respondents, the emphasis was again on somatic expressions of “pressure”, particularly among those interviewed in Punjabi, Urdu, or Pothari; however, there were also accounts which told of how the “mind goes all strange”. Bangladeshi respondents spoke of “real sadness” or “sorrow” that they experienced in response to events such as bereavement or divorce. Black Caribbean responses were similar to those of the White groups, particularly in the way that all three ethnic groups spoke of “getting emotional”, or “emotions being haywire”, or of being “dead emotional”, or “emotionally needy”.

Hopelessness or despondency was an experience described by respondents in all of the different ethnic groups, but on the whole only by those who had high CIS-R scores. One Indian man described “feeling cursed”, a Pakistani man spoke of how his financial problems were there for him “morning and night”, while an Irish woman, also with a high CIS-R score, spoke of having “no hope for the future, no glimmer of light”. In all groups, hopelessness was expressed in terms of an uncertainty about the future and was generally accompanied with pessimism that anything would change in the future, or if it did, with the fear that it would change for the worse. Here there was a clear sense of “loss of control” and a common presumption that no one or no thing could change the course of events or circumstances. However, among some Muslim respondents feelings of hopelessness were eased, or perhaps avoided, by a belief in fate and in an acknowledgement that control of individual circumstances ultimately rests with Allah. One Pakistani Muslim woman with a high CIS-R score told of how she does not think much about the future: “what’s the point in

pretending and thinking and wanting when really what's going to happen and you as an individual are not going to have much control over it". Similarly, a Bangladeshi Muslim woman also questioned *"the point of worrying – it can just get hold of your body, affect your health, make you worse – only Allah can give you peace"*. Respondents with other religious beliefs – particularly Christian – placed less emphasis on a fatalistic divine power, or God, and more on the role of religious belief as a source of guidance or support at times of difficulty. Consequently, hopelessness was more apparent among those individuals or indeed by those who had few or no religious beliefs. The role of religion as a source of support or comfort is discussed elsewhere in this report.

Anger

Feelings of anger and frustration at oneself or other people were features of respondents' discussions. Typical phrases used by respondents were being *"short-tempered"*, or *"aggressive"*, having *"tantrums"*, or *"snappiness"*. Alternatively, respondents described being *"agitated"*, *"resentful"*, *"grumpy"*, *"ratty"*, *"cross"*, *"bitter"*, and *"irritated"*. There was also recurrent discussion of *"moodiness"*, or experiences of *"mood swings"*, though such expressions were used almost exclusively located among White and Black Caribbean respondents.

At times respondents expressed anger at their own experiences of mental distress – as if it were an entity or object in itself - though this was exclusively among respondents who had a high CIS-R score.

There were many accounts of how respondents demonstrated their anger. An Indian respondent spoke of how he *"shouts too much, [is] insulting ... and upsets kids"*. A Pakistani man with a high CIS-R score spoke of how he took his *"temper"* out on his wife, *"blaming her"* for the debt he had accrued. Similarly, a Pakistani woman with a high CIS-R score spoke of her anger with her children during her *"depression"*, how she sometimes hit them, and how she asked her GP for medication to prevent her from becoming so angry. Similar outbursts were reported by Bangladeshi respondents, one of whom told how if he is *"tensed"*, his *"mood turns down"* which he felt can affect his family life – *"At that time if my children try to cuddle me, I get angry. I simply shout at them saying 'you please leave me alone'"*. One Black Caribbean man talked about how depressed people tend to *"growl"* at others while another spoke of an occasion where a person's actions caused him to *"spit out ... in aggression"*. White Irish and British groups, who were very similar in their responses, typically spoke of events that made them *"go completely mad"*. One White British woman recounted how she was *"living like a ball of fire because everything was too much"* while another told of how when distressed she was prone to *"flying off the handle, with shrieks and shouts and is really nasty"*. Irish respondents with high CIS-R scores described being *"manic"*, *"psychotic"* and *"self-destructive"*.

Anger, however, sometimes remained unexpressed. This was sometimes because of an individual's attempts to control emotional responses. A Bangladeshi man told of how he gets angry but tries *"not to use temper"*, instead attempting *"to keep my tolerance"*. Such restraint was related directly to what he felt was expected of him as a follower of Islam. In other accounts, non-expression of anger was because the object of anger was absent, or somewhat ethereal. This Black Caribbean woman's retelling of her anger illustrates this:

"The anger was the fact that she [her mother] had died, how dare she ... we hadn't talked about this, usually we'd talk about everything ... she hadn't told me she was going to die, so I was very, very angry with her for that. Angry that she hadn't given me a sister so I had no-one to support me and angry because it meant that I would have to either do it on my own, or get support from a stranger ... sometimes I can't believe that she left without saying goodbye ... I was angry with God, you know, because it was like - I know everybody has to die but why my mum, and this sounds really wicked, why my mum and not my dad"

(Female, 42, Black Caribbean, Born in GB, low CIS-R score, interviewed in English)

Self esteem, confidence and self worth

A loss of confidence, lack of self esteem, self respect, or courage, or feeling “*useless*” were also experiences described across many of the different ethnic groups, particularly among those with high CIS-R scores.

Respondents typically discussed how a loss of confidence stopped them from doing things or interacting with other people. Such emotions were sometimes articulated in a way that implied a loss of, or lack of, intelligence. An Indian woman, who had a difficult relationship with her husband’s family, spoke of how they made her feel like she was “*an idiot*”, while another female Indian respondent in a similar set of circumstances spoke of how she was made to feel like a “*dumb person*”. Likewise another Indian woman, who had experienced racially-motivated bullying at work described how it: “*made me feel I was nothing ... I didn’t deserve to live in this world ... had no brain, I shouldn’t have been born*”.

Other descriptions expressed a lack of self worth, or more commonly of feeling “*worthless*”. For example, an Irish 29-year-old woman who survived an abusive relationship described feeling “*like a piece of dog-doo*” while the abuse was happening. Likewise, a Black Caribbean woman talked of how the abuse she suffered at the hands of her partner left her with no confidence and feeling like a “*non-entity*”.

Where such emotions were expressed among Pakistani respondents they tended to be articulated in terms of being “*weak*” or inferior in relation to peers, family members, or relatives. Respondents spoke of being “*ashamed*” or “*embarrassed*” to be in other people’s company, or of perceptions that others would not want to associate with them because of their inferiority. For example, a Pakistani man who had lost his business due to bankruptcy told of “*feeling small ... [when] ... sitting among friends*”, while a Pakistani woman, who experienced domestic violence, recounted how she thought “*nothing of my own life*” in comparison to others. This mode of expression was also common among Black Caribbean and White respondents. For example, a White British woman spoke of how she felt she was “*not fit to be stood in other people’s company*”.

Allied to these emotions were perceptions that one was “*unattractive*” or “*pathetic*”, but these descriptions were more typically offered by the Black Caribbean and White respondents. A Black Caribbean woman, for example, told of how she turned all the mirrors around in her house so that she could avoid having to look at herself. However, such descriptions were exceptional among Indian and Pakistani respondents who were not interviewed in English and almost entirely absent among Bangladeshi respondents.

A desire to hide, or be alone, was also a prominent theme in respondents’ discussions of their feelings. Across the ethnic groups respondents spoke of wanting to “*hide*” or run away; to “*lock yourself in a room, in the dark and don’t talk to anybody*”; to go “*into a hole ... I lock myself away ... I won’t talk to people*”. While it was common for respondents to describe taking practical steps to shut themselves off from other people, there were also instances where respondents felt psychologically cut off and isolated from other people by the emotions they experienced, with the implication that this was against their will. This experience was more common among respondents with high CIS-R scores.

Connected to this discourse were descriptions of feelings of guilt and shame, with some related discussions of being “*punished*”, “*victimised*”, loss of trust, “*everyone hunting me*”. Again these were described across most of the different ethnic groups, the exception being Bangladeshi people.

Another set of related experiences, expressed exclusively by White respondents with high CIS-R scores, were feeling lost and sorry for oneself. Suicidal thoughts were much less prominent in the discussions by respondents in South Asian groups compared with other groups, and this absence appeared to be related to religiosity. Among Irish, White British and Black Caribbean respondents accounts of instances of suicidal acts by means of slitting the wrists, or throat, taking overdoses, jumping from cliffs, or driving cars off bridges, were recurrent. Suicidal thoughts, where they were recounted, were generally expressed as a wish “*to sleep*”, or “*to stop everything*”.

Indeed, the role of suicide in the description and explanation of mental distress is remarkably different among the White and Black Caribbean groups compared with the South Asian groups. Here suicide is in many ways regarded almost as the conceptual yardstick for judging the extent of one's distress, in a way that is markedly absent from the accounts of South Asian respondents. For example, a Black Caribbean woman who suffered abuse from her partner underscored that *"it never got to a point where I thought, oh, I'm going to end this, I want to get out of this, I never ever got to that stage"*. Conversely, a White British woman remembered that at one point her family problems were so bad that *"it got to the point where if I had tablets what could cause damage I would have done I think"*, while another White British woman experiencing marital problems remarked that *"it gets to the point where you feel like you don't want to go on yourself"*.

Ability to function

Along with these descriptions of distressing emotional experiences, respondents also talked about the impact of their distress on their functioning. So across ethnic groups respondents described classical symptoms of:

- Problems with getting to sleep, disturbed sleep and waking (early) and being unable to get back to sleep.
- Fatigue, or feeling *"weary"*.
- Loss of interest, concentration and poor memory. Recurrent here was a loss of interest in *"worldly things"* and not being able to concentrate on television, radio, or newspapers, described by one Irish respondent as *"watching stuff on the telly but not watching it"*. There were also some accounts that emphasised loss of memory such as forgetting appointments made, or forgetting where one was going. Respondents sometimes spoke of *"floating off"*, of how the *"mind wanders off somewhere"*, or more simply of *"mind not there"*. One Pakistani man described it as: *"you're not in the world, you're in your own little world somewhere else"*. This was sometimes described by White British and Irish respondents as like *"walking around like a zombie"*. There were also accounts of not being able to *"think"* properly.
- Loss of motivation. This was more typically discussed by non-migrant ethnic minority respondents, or white respondents. It encompassed a lack of enthusiasm for work, education, social activities, family and parenting responsibilities, because *"just don't feel like doing it"*, or because *"can't be bothered"*. One White British woman told of how during her "depression" she could not gather the motivation to cook, or to bathe, while a Black Caribbean man told of how his distress made it *"difficult to get out of bed"*. Some accounts emphasised not being able to do anything other than sit at home and cry, described by one respondent as having *"no life"*.
- A change of (usually loss of) appetite.
- Weight change.

3.3.2 **Physical symptoms**

A range of physical, or somatic, symptoms were described by respondents across all of the ethnic groups. Particularly recurrent were discussions of pain. These included pain in the chest, feeling tightness in the chest and having palpitations, which were fairly universal across groups. Headaches and backaches were also a common experience across ethnic groups. For example, a Bangladeshi man who had migrated to the UK described how he avoided situations that would cause him *"too much headache"*. *"Too much headache"* was also produced by the children of a Black Caribbean mother, adding to the other problems she had *"round my head"*, suggesting that some of this discussion was metaphorical.

However, less specific experiences of general aches and pains, or more specific experiences of heat, or burning in the body, or head, or feeling like their head is coming off, or splitting (*"maatar fatail-lar"* in Bengali), were more typically described by non-English speaking respondents in South Asian groups. Related to this were descriptions of intense

pressure focussed in the head, or brain (the head “steaming”, or “boiling”, or “pressure” in the head), perhaps because of dwelling on problems too much, which were present in the discussions of people with high CIS-R scores who had migrated from South Asian countries. For example, an Indian woman, who moved to the UK aged 21, and who had a high CIS-R score, when talking about the way her grief manifested itself said: *“the pressure stays in my head all the time ... sometimes after thinking and thinking I get this tugging at the back of my neck”*. A 48-year-old Pakistani man who moved to the UK aged 14 and had a high CIS-R score, described how he feels *“like my head’s going to burst”*.

A sense of blood pressure rising was another experience described by migrants from South Asia, but by those with both high and low CIS-R scores. This experience was not in response to any formal diagnosis, at least for most of these respondents, so it is unclear whether it was indicative of an actual physical symptom, or associated with something more emotional in origin, such as the feelings of “pressure” in the head or brain described above.

A range of digestive problems were described by respondents in all ethnic groups, but typically by those with low CIS-R scores. These included stomach problems, stomach ulcers, irritable bowel syndrome, colitis and constipation.

Although not exclusive to the descriptions of Bangladeshi and Pakistani respondents who had migrated to the UK, a wide range of other physical symptoms were more common to their accounts. These included feeling weak, body being gripped by shaking, or pulling (*“shorill kaafel”* and *“shorill taan mareh”* in Bengali), restlessness, dizziness (*“maatar fatail koreh”*) and breathlessness. For instance, a Bangladeshi woman, who attributed her difficulties to the belief that an evil spirit (*“Jhudoor”*) had taken her over, described her physical symptoms in the following way:

“My whole body gets hot. Then I’m semi conscious but my whole body gets hot, inside my head its hot that’s when I feel a crazy force inside me (“bebush olaakan abor”) that’s when I just feel anxious (“osteer”). I feel inside my body is just pounding. After that my whole body will shake ... inside my chest I feel its fighting and my head feels so hot you have pour water on me, especially my forehead”

(Female, 28, Bangladeshi, migrated to GB age 18, low CIS-R score, interviewed in Bengali)

These symptoms were particularly common among those with high CIS-R scores. More fundamental physical changes were described by a few respondents with high CIS-R scores who had migrated from South Asian countries: looking ill, or changing colour (an experience of Indian respondents in this category); paralysis (an experience of Pakistani respondents in this category); and a sense that they might die (though not related to any suicidal tendencies) (also an experience of Pakistani respondents in this category).

3.3.3 Metaphors

Although above we have identified quite specific experiences of symptoms within the accounts provided by respondents, their accounts were obviously not as itemised as this. Indeed, many of the respondents used quite metaphorical language during the interviews to describe their experiences. Some of these descriptions appeared to fit quite closely with models of mental illness rooted in western psychiatry. For example, in recounting her experience, a White British woman said:

“The worst thing about depression ... it puts you into this spiral and once you get so far down it’s hard to get ... out ... you go down this little whirlpool ... it’s like pulling yourself up the rungs of a ladder and your arms aren’t strong enough to pull you right the way up”.

(Female, 46, White British, high CIS-R score)

And an Irish man, who also had a high CIS-R score, described how he is *“treading water”*, trying not to *“sink”* into his depression, but that he cannot see the *“light at the end of the tunnel at the moment”*. An Irish woman, also with a high CIS-R score, also spoke of how her marital break-up:

“... stressed me out to the point where I thought there was nothing ahead of me ... everything was grinding to a halt ... it’s just like being in a dark tunnel ... seeing the light so far away, it felt like you were fighting to get to the light”.

(Female, 31, Irish, migrated to GB age 1, high CIS-R score)

Other descriptions, however, were further removed from the idioms of western psychiatry. One migrant Bangladeshi man, for example, with a low CIS-R score, spoke of how: *“my body gets really weak when I stress and fall into a spell ... I go into another world”* (“*Diyan*”). And a Bangladeshi woman, who had moved to the UK as a young child and also had a low CIS-R score, described how: *“sometimes I have a funny feeling in my head ... one kind of silver dust like elements float in front of my eyes”*. A UK-born Black Caribbean woman, also with a low score on the CIS-R, said *“I would just be sitting here sometimes and a sunset would come down and my mind would go ‘I wish I was doing that’”*. And a 38-year-old Indian woman who moved to Britain aged 18 and had a low CIS-R score described her insides as being *“made of stone”* because they had become hardened by the distress she had experienced.

As suggested by the descriptions above, a range of metaphors were used to describe the emotional and physical symptoms experienced by respondents. For example, respondents from all ethnic groups talked about experiences such as: the *“world is closing in on you”*; feeling that their world had collapsed; feeling that everything had gone *“dark”*; a sensation of drowning; being in limbo; feeling empty; and feeling devastated.

Respondents, from all groups, also talked about their head, or mind, being *“too high”* (one White British woman describing her head as *“touching the ceiling”*), although others recounted how their mind can *“feel small”*. Also recurrent across groups, but mainly among respondents with high CIS-R scores, was experiencing problems associated with the heart, heartache, the heart feeling *“heavy”*, or claustrophobic. For example, one Bangladeshi man, with a high CIS-R score, said *“my heart was almost a black heart”*.

All ethnic groups, however, articulated some sense of depression, anxiety, or stress being an impermanent, rather than an enduring phenomenon (the only exception being where respondents were very obviously in distress at the time of interview where sometimes there was a sense of hopelessness – described above), giving a sense that it was periodic and that some difficulty in coping, or functioning was associated with this episode. The transient nature of such emotions was clearly signposted in the metaphors used to describe a respondent’s relationship to distress. There were accounts of *“starting to get down”*, being *“a bit down”*, getting *“very low”*, *“reaching rock bottom”*, *“getting to my lowest depths”*. There were also stories that spoke of *“getting back on top again”*, which typically had a quality of regaining, or renewing strength, or resilience. Respondents also spoke of having *“good and bad periods”*, *“high and low points”*, or of *“waves of depression which can rise in reaction to stress”*. Some White respondents spoke of *“depression”* being *“worse in the mornings”*, or, conversely, of being *“fine in the mornings but low later”*, which further adds to the sense of distress being a transitory phenomenon. There was little evidence to suggest that such perceptions of impermanence were linked to any change in medical or psychiatric diagnoses.

There was an attempt to differentiate between what were, ordinary “run of the mill” worries, sadness, or anxiety and what constituted more serious emotional responses in the accounts of some respondents. This was either achieved by delineating some events as normal, or usual, or inconsequential, and by comparison labelling other circumstances as serious, unusual, or weighty. These quotations illustrate how different respondents explained this:

“That’s why I said when I have money my worries will go away, but some people when they have money their worries do not go away. Worry is such a thing that in people worry comes automatically, even if someone has a million pounds he will have to think carefully what he does with it, to put it in the bank, all night he will calculate what to do with it, it will be in his mind. So there is happy worry and sad worry – (“koorshi chinta, dhookor

chinta) – it is the happy worry that does not harm people but the sad worry harms people ... people have to worry but there is a difference between happy and sad worry, in life there is not just one thing to worry about there are lots of different types of stress”.

(Male, 44, Bangladeshi, migrated to GB age 24, low CIS-R score, interviewed in Bengali)

“It’s the stress of the life isn’t it. A lot to do ... just doing one thing after another ... I can’t say it affects [her health] but its just stressful”

(Female, 41, Indian, migrated to GB age 13, low CIS-R score, interviewed in Hindi)

“I think stress, if stopped quickly enough, can be stopped quickly, I think if it’s then left to manifest over a period of time it can turn into something a lot more than that ... Because I think the more and more deeper you get into stress and things and various sort - and the longer it continues, I think it’s more and more difficult. It then starts affecting, I won’t say it started affecting my state of mind but I think it could have done in becoming depressed, finding it difficult to get out of bed in the morning, sleeping, finding it difficult to sleep, the way that you act with people. People then taking a different view of, well, that person used to be like this and he’s no longer, or she’s no longer like that so do I either take a wide berth from them, or do I help them, so I think it could go further and further”.

(Male, 32, White British, low CIS-R Score)

3.4 Summary and conclusions

In summary, and in terms of the applicability of a western psychiatric model of mental distress, emotional experiences of distress appeared to be broadly universal, rather than culturally specific. The idioms used to represent mental distress seemed to be fairly common across ethnic groups, while the more striking expressions were most commonly used by those with high CIS-R scores. However, some diagnostically important experiences (loss of confidence or self esteem, guilt and shame) seemed less prominent, or even absent, from the accounts provided by Bangladeshi respondents and, in some cases, other respondents in South Asian groups who were not interviewed in English. So, while overall accounts were similar, the fit of particular symptoms, or items of experience, was less good for some cultural groupings than others. The apparent absence of suicidal ideation among those with strong religious beliefs is also worth noting.

Physical symptoms and idioms were common across all groups, although experiences appeared to be more fully and richly described by respondents in South Asian groups, particularly those who were migrants and interviewed in languages other than English.

This study, therefore, gives no support to claims that there is widespread “misunderstanding” of the category “mental health” among ethnic minority groups,^{9, 13} and that “Asian patients”, rather than others, somatise. The fact that the broad narratives are remarkably similar across ethnic groups would suggest that, once contact has been established with appropriate medical services, there should be no reason for differentials in the diagnosis of mental health problems. However, respondents also clearly have an elaborate language for describing mental and emotional symptoms and some specific symptoms do not appear to be universal across ethnic groups. This suggests that an itemised approach to measurement (as adopted by structured survey instruments, such as the CIS-R) might not be culturally neutral and may have a poorer fit for the experiences of some ethnic minority groups, particularly non-English speaking people in South Asian group. The additional implication is that an itemised approach to diagnosis will also fail to adequately capture experiences of mental distress.

The qualitative interviews have been very instructive because they have illustrated the language in which people describe illness, emotion and physical states and the way in which respondents see the physical and emotional/mental as intimately linked, such that they are often described together. Furthermore, it has shown how, in terms of narrative

accounts, idioms of distress bore great similarity across ethnic groups, but at the level of particular symptoms, those who have migrated from South Asian countries, particularly those in the Bangladeshi group and those not interviewed in English, appear to have experiences that are in some ways quite different from those of other respondents

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4 Coping mechanisms

Kerry Sproston and Kamaldeep Bhui

4.1 Introduction

Findings from the EMPIRIC quantitative data suggested that psychiatric morbidity was related, in part, to an individual's coping mechanisms and their levels of social support.¹ Two pathways have been postulated linking social support and mental well-being: 'direct' effects and 'buffering' effects. The direct pathway implies that high levels of social support and social contact act to improve levels of well-being, or to enhance self appraisal and self esteem, thereby positively influencing mental health.² The buffering hypothesis implies that social support only influences health in the context of exposure to acute or chronic stressors.³ In this situation, people exposed to stressors are helped to either reappraise the threat implicated in the stressor, or cope with the consequences of the stressor through emotional, informational, or material support.

This chapter describes the various types of coping mechanisms discussed by respondents. The study focused on the 'buffering hypothesis' to the extent that respondents were asked about their responses to stressors and difficulties. The strategies used fall into two main themes: personal resources and religious issues. The analysis investigated differences, and similarities, between the different ethnic groups and also the significance of other factors, such as whether the respondent was classified with psychiatric morbidity according to the CIS-R. However, the majority of differences were on an individual, rather than a group level; although some interesting associations with ethnic group were found, particularly in the description of the mediating role of religious beliefs.

There is now a greater recognition of the close link between religious practice, religious coping and mental distress.⁴ Religious coping is said to be a common response of ethnic minority people to mental distress. For example, South Asian women are said to use prayer as a major coping strategy in the face of depression.⁵ Ethnic minority people in the UK are more likely than the white majority to be practising their religious faith, indeed for some groups, religion appears to be a particularly culturally enmeshed and traditional approach to managing distress. Religious practice usually involves a social network within which people meet and pray together regularly⁶ and social networks, in turn, are known to protect against the development of mental distress, and aid in recovery.

Within religions, however, specific practices vary across the world, being influenced by local cultures and contexts. Indeed, even within one religious group there may be cultural variations in patterns of religious coping, where the demographic, migration, national and cultural experiences of a specific group is unique. Consequently, one would expect differences in religious coping strategies to be evident both across and within ethnic groups. Also relevant is the apparent secularisation of societies. This gives the impression that more people are not religious and do not benefit from religious coping strategies. However, religious ideas maintain some influence on our everyday lives and can shape appraisals of difficulties and help seeking processes among people who are not particularly religious.⁷ Indeed Lowenthal demonstrates how religion and culture influence the expression of distress, perhaps in a way that may be unfamiliar to professionals.^{8,9}

4.2 Personal resources

There were a number of strategies apparent in respondents' discussion of coping mechanisms. These related to the ways in which their individual personality characteristics allowed them to deal with external pressures. There were few apparent differences between men and women, between ethnic groups, or indeed between those classified with psychiatric morbidity and those without, although there were considerable differences between individuals. The strategies and personal approaches are outlined below. The various resources used fell into two broad categories, relating to people's general outlook on life and the difficulties it contains, and the techniques people used to deal with life events. It should be noted that, while the different resources are described separately here, most respondents reported using a variety of strategies.

4.2.1 Outlook on life

Stoicism/Positive outlook

Fundamentally this approach involved being strong in the face of adversity, and sometimes involved references to "self-respect", "pride" and "dignity". It was common across ethnic groups, ages and both genders, and reported by those with high and low CIS-R scores. Indian and Black Caribbean respondents tended to talk in terms of "getting on with things", while some Pakistani respondents talked in terms of "willpower". White British and Irish respondents used terms related to "resilience", "inner strength", "positive thinking", "pulling yourself together" and "soldiering on". As one female Pakistani respondent put it: "I suppose you just got to gather yourself and keep going. There isn't any point of wishing things were different because they aren't going to be are they?" Similarly, a Black Caribbean man, with problems at work, talked of the need to: "be a strong person with a positive mind and a strong attitude to life. If you are not a positive person you will sink deeper, you will fail".

Difficulty and distress were even sometimes seen as a positive stimulus. For instance, a Bangladeshi woman described how "pressure actually keeps me fitter as I don't like sitting down and being a housewife". However, such a perspective was, in the main, exceptional across all of the ethnic groups.

Linked with the idea of stoicism was the concept of hope and "looking at the brighter side". For example a Pakistani man, whose business had gone bankrupt, described how:

"There's always a light at the tunnel, day follows night, it goes round in circles sometimes. You get your hard times but always followed by good times."

(Male, 37, Pakistani, Migrated to GB aged 11, high CIS-R score, interviewed in English.)

And an Irish man, who suffered from panic attacks said that he "always looks on the bright side ... of a bad day ... tomorrow might be sunnier".

Survival

Survival as a way of coping was characterised by accepting difficulties, however serious, and dealing with them. Of course, it is related to a positive outlook, but this strategy did not always involve viewing problems in a positive light, rather it was characterised by accepting difficulties, however serious, and simply dealing with them (rather than attempting to be optimistic). Respondents talked of "life going on" and having to be "thick-skinned" and "accepting" pressures. One Black Caribbean male saw this survival mechanism to be common to people of his cultural group:

"Black people just get on with it, when they are mentally or physically sick, just cope with it. No matter what stress you have, you just get on with it."

(Male, 41, Black Caribbean, Migrated to GB aged 10, high CIS-R score.)

Another Black Caribbean man, who felt he had suffered bad treatment since he recently moved to the UK, said that he had felt suicidal, but that, nevertheless, he retained "the will

to live, the will to survive". However, those who championed this way of coping also expressed fears about what would happen should it fail. For example, an Indian man told of how:

"I don't give in to depression because I don't know how to give up.. I think it's a deep fear that if I did ... collapse altogether ... I really just would go to pot."

(Male, 36, Indian, Born in GB, high CIS-R score, interviewed in English.)

Hopefulness

Hope for the future was described as a positive coping mechanism in the way it permitted respondents to believe that things would improve, and that their current problems would be short-lived. This appreciation of the impermanence of events was related to the idea put forward by one Indian woman that *"having a goal makes you work for it, makes a path for you to follow ... [makes you] keep moving forward, thinking about the future"*. However, as mentioned in the chapter on idioms of distress, the ability or willingness to hope was strongly associated with the nature, and strength, of respondents' religious views, in particular the role of faith in their beliefs. For example, some respondents believed that there was no point in thinking about the future, for *"whatever God wants will happen"*.

Furthermore, some respondents made deliberate efforts to avoid considering their future, preferring to *"take each day as it comes"*, since the prospect was too worrying and/or depressing:

"I don't really think of the future, never have. I'm happy to take things one step at a time. I don't like thinking too far ahead. Don't know what will happen ... what will be."

(Female, 31, Pakistani, Born in GB, high CIS-R score, interviewed in Urdu.)

4.2.2 Techniques used to deal with events

Drawing upon lived experience

A recurrent source of strength for respondents involved their past experiences. People talked both in terms of having learned about themselves, and about life, through things that had happened to them in the past. *"You live and learn"* was a phrase that was commonly used. In this respect, there was a clear sense that past difficulties had made respondents *"emotionally stronger"*. It was typical for such respondents to declare that, having previously survived difficulties, they knew they would cope again. This strategy was also common to all ethnic groups. For example, an Indian woman, who told how she had suffered psychologically from a relationship breakdown, and also from the effects of an anti-malarial drug she had taken in Africa, reflected on how her past experience helped her cope with these issues:

"when I wonder how I will cope I reflect back and know that I coped with a thousand worse things before so you know you can do it."

(Female, 27, Indian, Born in GB, low CIS-R score, interviewed in English.)

Normalising

There was a clear tendency for respondents, when faced with difficulties, to normalise their situation by generalising to others, and reminding themselves that others were at least as badly off as themselves. This strategy was summed up by a Pakistani man, who believed that *"other people are worse off, it's not only me or them, it's plenty people"*. Likewise, a Pakistani woman, aged 37, whose problems stemmed from missing her family in Pakistan, said that to make herself feel better she reminds herself that *"there are so many people who have nothing, so I am happy in that sense"*.

Related to this was the comfort respondents derived from the belief that what they were going through was so much worse than it is for others. For example, a Pakistani man in his forties with a high CIS-R score, who had suffered a litany of problems since migrating to the UK in his teens, including bankruptcy, prison, his wife's illness, bereavement and

depression remarked that “some people have excuses, they haven’t been through hell, they haven’t been like me”.

Rationalisation

Rationalising the difficult situation was a common strategy in respondents’ accounts. It involved an attempt to impose a rational order on psychological problems in order to deal with them. Respondents used terms such as “problem solving”, “self-analysis”, “explaining the situation”, “mind over matter”, “organising”, “sorting things out in their own mind” and “mental judgement” to describe ways of dealing with difficulties in their lives. A Pakistani woman, whose stressors included her husband’s poor health and the death of her parents, elaborated on how:

“every problem have a solution ... I don’t believe in that nothing can be solved ... in this country ... every corner you can find help ... by sleeping you can’t solve any problem. By moving and sorting things out you can solve the problem.”

(Female, 45, Pakistani, Migrated to GB age 21, interviewed in English.)

Similarly, an Irish respondent, with physical health problems and anxiety, talked about the importance of “trying to tie down where the anxiety is coming from because once you can tie it down there might be a way of finding a cure for it”, while an Indian woman told of how coming to terms with the pain of her relationship breakdown was “just a case of my own head working what was going on”. This rationalisation process was sometimes acted out by writing about issues. It appeared from respondents’ accounts that ordering one’s thoughts through writing had a cathartic quality. For example, an Indian woman, who was suffering from racial abuse at work, said that she coped through:

“writing a lot of letters, writing down everything helped me to put everything in my mind into context, what’s going on, where it’s going. It was fighting all along.”

(Female, 29, Indian, born in GB, low CIS-R score, interviewed in English.)

Similarly, a White British woman, whose stressors included bereavement, overworking, health problems and a relationship breakdown, said that:

“When I’m really low I write things down, it helps me to release things and allows me to go back and remember what happened, whether there were any triggers.”

(Female, 46, White British, High CIS-R score.)

Avoidance

In contrast to the accounts above, some respondents associated analysis of their problems with “worry” and tried to avoid analysing, or “brooding on”, their problems or situations. Instead, they placed greater emphasis on putting things “to the back of my mind”, or “trying to ignore it, pretend it’s not happening”. In this vein, a Pakistani man, with heart problems and “depression” explained:

“just cheer up, be happy, do something with your life, don’t be sad, don’t think why it happens to you ... If I start thinking why all the time I can go worse I think ... don’t think too much about it ... that build up more, in your mind, more pressure. I just cool down.”

(Male, 45, Pakistani, Migration to GB aged 11, interviewed in English.)

Such avoidance strategies were also advocated by other respondents across all of the ethnic groups included in the study. For example, an Irish woman, who had suffered abuse as a child, described how she “put a mental block on it and just get on with life. I don’t dwell on it”; a Bangladeshi woman, whose concerns revolved around the physical health of her husband, suggested that “people can get worse if they worry. You have to keep away from worrying too much”; while a White British man, with problems at work, talked of putting his “head in a bucket of sand” and “locking his problems in a cupboard”. Similarly, a 45 year old Pakistani male, who had depression as a result of having heart problems and a serious heart operation, said that “I don’t like to brood, if I sit too quiet ... the depression will build up ... When I feel not well and sick I try to take my mind off it, I want to be happy”.

An approach related to avoidance was one of delay in addressing issues that caused difficulty or distress. For example, an Irish woman with relationship problems, talked about *“leaving problems and hoping they go away”*, believing that she copes better by leaving things for a while and returning to them at a later time. Other respondents, attempted not to think about issues, but said that they were unable to do so successfully.

Distraction/escapism

A recurrent way of coping, stressed by respondents from all ethnic groups, involved keeping busy or being distracted from problems. This coping mechanism included both activities concerned with the normal *“daily routine”*, as well as pursuits designed to provide a certain amount of escapism from normal life. The range of activities highlighted encompassed a wide diversity of outlets, from peeling potatoes to hill walking. But the underlying function, as articulated by respondents, was to take one’s mind off negative issues, and to get on with life. A recurrent term, used by, though not exclusive to, the Pakistani group, involved *“keeping oneself busy”*:

“I like to be busy ... it keeps your mind away from all sorts of different sort of things ... your thinking keep you straight ... it’s less stressful.”

(Female, 45, Pakistani, Migrated to GB aged 21, low CIS-R score, interviewed in English.)

Similarly, a Black Caribbean man, with health problems, described how:

“I would read a lot just to take my mind off it ... I think that’s what got me through ... friends come round in the evening, reading through the days ... it takes your mind off your problems.”

(Male, 32, Black Caribbean, Born in GB, low CIS-R score.)

As well as recreational distractions, some respondents also found that focusing on their work helped them to cope with other problems. For example, an Indian woman kept herself busy while going through a grievance procedure at work by doing voluntary work with a charity organisation, which *“calmed me down, using my time, doing something productive”*. Employing a range of strategies to distract oneself from difficulty was also common among Bangladeshi respondents, in the words of one man: *“you just try to distract yourself and watch telly ... or go to bed”*.

Crying

Tearfulness was recurrently mentioned as an emotional response to difficulties, as discussed in the chapter dealing with symptomatic expression. However, crying was also viewed by some as a way of coping with difficulty. For instance, a female Pakistani respondent with a high CIS-R score told of how she *‘feels lighter when she cries sometimes’*. However, there was no consensus on whether crying represented a positive release, or whether it should be avoided. The latter contrasting view was articulated by an Indian woman who believed that *“there’s no point in crying all the time because what can you do anyway.”*

There was more agreement on the inappropriateness of crying in public. For example, a Pakistani woman who had suffered a miscarriage along with marital problems explained how *“If I feel upset I try not to cry in front of people, I try and avoid that situation and not talk about it”*. In a similar vein, a Pakistani man, aged 43, recounted how he cries *“when he’s down”*; *“I go quietly somewhere, do my business and come back ... you don’t tell anybody else”*, and a Black Caribbean woman told of how *“I don’t sit and cry with anybody. I mostly cry on my own, in the bathroom”*.

Responsibility for others

A strong sense of responsibility to family and friends was a recurrent theme in the interviews. This sense of duty was used by some respondents as a motivation to *“keep going”* during difficult times, for the sake of others, if not for themselves. Instead of focusing on one’s own problems, much more emphasis was placed on the need to be there

for loved ones. For example, a Pakistani man, who had suffered from stress and financial difficulties as a result of bankruptcy, said that *“If you’ve got kids depending on you, you can’t afford to take that road, can’t let them down”*.

A similar need to exercise some degree of control over emotions, for the sake of others, emerged in terms of other family members, not just children. A Black Caribbean man, who suffered a violent attack appeared to subjugate his own emotions when his mother suffered a stroke so that he could concentrate on her care:

“I just suppressed it and didn’t have any feelings at all, I just wanted mum to get better – I didn’t think about me because this wasn’t about me at the time and I just had to be strong for my mum.”

(Male, 26, Black Caribbean, Born in GB, high CIS-R score.)

Relaxation

Where emphasis was given to relaxation as a way of coping with difficulty, it was often framed in terms of letting go of difficulty, in order to develop the strength necessary to cope. For instance, an Indian female said that, despite not wanting to *“run away”* from her problems at work, when she eventually did get through an official grievance process, and spent time at home, this *“helped me to cope, because work stress coming down slowly and gradually the crying went”*. Here it seemed to be distancing herself from the cause of her problems, as well as taking time to relax that helped her to cope with the situation.

In other circumstances, relaxation was viewed as a way of avoiding further difficulties (physical or emotional) that could potentially arise as a consequence of worrying about the original source of distress. For instance, an Indian woman, aged 38, described her need to relax in the following strong and somatic terms: *“I have to relax, otherwise my blood clots”*.

Finally, relaxation was a strategy that was seen by some to have more support in some cultures rather than others. For instance, a Black Caribbean man, described how the need to relax as fundamental to people of his culture:

“I’m not going to sit down and start worrying about it ... worry about it you’re going to start greying quick and get old before your time. Just take things easy basically ... we Jamaicans like to rest ... like to have a day you can just chill out.”

(Male, 32, Black Caribbean, Born in GB, low CIS-R score.)

4.2.3 Other personal resources

Respondents also displayed a range of other personal strategies for coping with distress.

The possibility of visiting or returning to *“home”* was a particular source of comfort for some respondents, especially those who were born outside of the UK. In some cases, respondents held this thought as a reassuring possibility for the future. In others, respondents claimed that they would not be happy until they were able to return. For others, a trip back *“home”* was seen to potentially help their mental state. For example, one previously mentioned Pakistani woman said that she would be happier if she moved back to Pakistan for good, but that *“I suppose we are here in this country and there is a reason for that”*.

Drugs, alcohol and cigarettes were also seen a source of considerable source of *“help”* to some respondents. A Pakistani man, who had suffered a number of problems including bankruptcy and depression, told of how he used drugs to *“allow me to forget”*. He had started using drugs in prison, which he said was *“a bad thing”*, although he said that drugs had helped him *“to avoid going mental”* and that drugs *“ease the pain when my head feels like its going to burst”*. Similarly, a Black Caribbean man, who had had problems since migrating to the UK, viewed marijuana as the only thing that would help him with his physical and emotional distress, but was unable to buy it. Finally, the comfort derived from stimulants, such as cigarettes, is described by this Black Caribbean man:

"I'm supposed to pack up smoking. I ain't got nothing. My fags, my fags and my drink is when I'm up. When I'm really down, I sit down and smoke a fag."

(Male, 41, Black Caribbean, Migrated to GB aged 10, high CIS-R Score.)

4.3 Religious coping

Although religion clearly helped some respondents to cope with difficulty, this was by no means a universal experience. On the whole, Muslim respondents had more to say about the role of religion, and offered a greater level of detail in their accounts of this than those in other religious groups did. Among the South Asian groups, there were some similarities between Hindus, Sikhs and Muslims. However, there were clear differences between Black Caribbean respondents' relationship with religion compared with that of South Asian people. Black Caribbean people, unlike most South Asian people, often described their beliefs in a more flexible way when they talked about religion. They tended to voice their views on religion in less certain, or fixed terms. Religious ways of coping featured least in the accounts of White British and Irish respondents. The following section describes some of the main ways in which religion was described and also the ways in which religion was used as a coping mechanism for personal difficulties.

4.3.1 Religion as a way of life

All of the ethnic groups used religion as a coping mechanism in one way or another, but Muslim respondents appeared to be most absorbed in their religious views. Often these were indistinguishable from their way of life in general. Here, there was great emphasis placed on surrender to God as a way of working through difficulty and a recurrent belief that God determined all, and was integral to all aspects of life.

There was a contrast between the Muslim respondents and the Black Caribbean respondents. The latter generally drew on religion and a relationship with God at the time of a problem and when things were going wrong. Difficult times were seen as trial periods to test faith and through which they became stronger. So, some Black Caribbean respondents saw their relationship with God as being discrete and limited to particular times of difficulty, to help them overcome particular problems. Even among Black Caribbean people who appeared to have a more active faith, religious beliefs and expressions seemed more compartmentalised and distinct from other areas of their lives compared with many of those in the South Asian groups. In contrast, the omnipotence and omnipresence of God was much more evident among Muslim respondents. Bangladeshi Muslim respondents emphasised moral obligation and a duty to God that involved living "*in the right way*" and a responsibility that included not "*making a problem*". This was related to the concept of stoicism, discussed earlier, in that it was expressed that difficulties were acceptable to God and therefore must be acceptable to individuals. This, in turn, encouraged stoicism in terms of accepting life events and circumstances, rather than problematising them.

Religious views seemed to affect the way in which respondents conducted their lives in other ways too. A common theme among the Bangladeshi, and to a lesser extent among other Muslim respondents, was distancing the self from negative feelings such as "*greed*". And in terms of positive feelings religion encouraged them to offer "*service*" to people and to offer "*hospitality and respect*". This, in turn, would lead to rewards, and to "*feeling good inside*". For example, a 49-year-old Muslim Pakistani man who came to the UK at the age of 15 talked of having anger and going to his mother for advice. He learnt to serve others and felt that he shouldn't be jealous or envious. These feeling and sentiments reflected, for him, the origin of his discontent and anger. If able to do these things [relinquish jealousy and envy and serve others], "*God will reward you*", he said. He also talked of stress as something that needed to be shared and when one realised how hard the stress was for another person, "*God will be pleased*". His purpose for sharing stress was not based on notions of catharsis but more on an experience of another's stress and suffering, and an awareness of its overwhelming nature. This, he said, would please God.

While religious beliefs influenced positive behaviour, and a moral code of conduct, for example in terms of relinquishing greed, there was also a sense, especially among the Muslim group, that God would help them throughout their lives. For example, one repeated theme was the view that if God had given them trouble he would, in time, heal them; God would save them. One Pakistani man talked of how God controlled everything and gave knowledge. He considered that medicine was subordinate to religion and that God gave the doctors their knowledge. And so for Muslims it seemed that all actions, events and experiences were subordinate to those of religious doctrine, but also a component part of it.

4.3.2 Religion as a source of inner strength/peace

Respondents across different religions talked of religion in terms of the positive impact that it had on their mental state. The Indian group, in particular Hindu and Sikh people, talked of religion bringing them inner strength, peace, calmness and meditation. Religion was described by some Black Caribbean people as helping them find strength, knowledge, understanding, wisdom and guidance, as well as an “*inner glow*” and “*peace*”. Some of the white respondents, too talked of their religion bringing ‘calmness’, though religion was not, on the whole, such an integral a part of their lives.

Similarly, religion was seen to offer “*spiritual relaxation*”; opening people up to “*feel calmer*”. One respondent (Church of England) talked of their life path being set out for them and that they had to “*ride it out*”. This concept is similar, in many ways, to the expression of the notion of “*karma*” commonly found in South Asian respondents. English and Irish respondents talked of finding, through their beliefs, tremendous peace at a time of difficulty.

4.3.3 Relationship with God

There appeared in the Black Caribbean, White British and Irish Christian groups more of a sense of individual responsibility in the relationship with God (compared with the Muslim groups), and more agency for the individual to make use of God’s gifts, rather than feeling completely at his mercy. For example, one Black Caribbean respondent spoke of how he talked to God, in a direct and informal way, saying “*Lord, this is hard, I messed up, it is not as if you are not providing for me*”. In contrast, among Indian, Pakistani and Bangladeshi respondents, the relationship was much more deferential. Muslim respondents in particular expressed their God in terms of omnipotence and power. Their communication with God seemed to be more formalised. Nonetheless some Caribbean respondents did talk of God as the only reason that they existed and said that they needed something greater than themselves to believe in.

4.3.4 The role of prayer/religious ceremony

The extent to which formalised rituals of prayer and worship were integral to religious beliefs varied between different ethnic groups, and different religions. Some people expressed having religious beliefs, but that they prayed irregularly, for example, at times of bereavement. For others, prayer played an important role in religion and in coping with problems. It was seen as a means through which to relieve worry. Prayer helped to “*clear the mind*” and it also appeared to be a way of getting perspective on a problem, to see “*what little problem*” there was. For example, a Pakistani woman said she prayed if she was sad, or depressed, or felt pressure. She felt that God controlled everything and was testing her. She was very isolated, had no friends, spoke little English and rarely went out. She perceived that everything was in God’s hands, so prayer fulfilled an important role for her.

As well as prayer, reciting religious verses and also using prayer beads, and other symbolic items, were other ways of reducing worry. For instance, a 46 year old Pakistani woman who’d been in the UK since the age of 23 talked of having a Taveez, which is an amulet in which religious prayers are contained. She said it stopped her from getting frightened, that she felt pious and that God would not hurt her. She also talked of the way in which her difficulties served to sustain and underline her faith, in the face of acculturative pressures.

For example, her husband was not as religious as her, and this led to some difficulties in her marriage. Several other respondents also talked of uncertainty about the impact of living in this country on their religious beliefs and how their religious beliefs are challenged either through their children, or because of their own changing attitudes.

4.3.5 **Religious attribution for difficulties**

As well as religion providing a source of reward, for example for moral conduct and good acts, it was also seen as a source of punishment. For example, some respondents believed their problems and distresses to be the product of irreligious actions. For example, a 47 year old Bangladeshi woman, who had been in the UK since the age of 29, said that if she missed prayers she did not feel good, she developed “*a temper*” and she found that prayer kept this and other “*illness away from the mind*”. Anger, aggression and loss of control – common accompaniments to mental disorders – were seen as a response to not praying enough by a number of respondents.

4.3.6 **Religion and secular lives**

The White British and Irish groups appeared remarkably similar in that, on the whole, their accounts of their lives and their coping tended not to include religious beliefs, in marked contrast to many of those in the South Asian and Black Caribbean groups.

It was perhaps surprising that the Irish group appeared not to be particularly religious or to use religious beliefs particularly strongly in comparison with other groups. They appeared very similar to the British group of people. They sought “*guidance*”, “*wisdom*” and “*knowledge*” through their religion.

However, non-attendance at Church did not necessarily hinder people’s beliefs or use of religion as a way of coping. One particular respondent, a 32 year old British woman, talked of praying as the equivalent of mini-counselling. Although she did not pray every night, she prayed whether things were going well or badly. She felt God was looking after her and felt “*a warm glow*” with it. Her belief was that religion and God helped her to take on responsibility for herself. This contrasts with the earlier accounts of Bangladeshi and Pakistani Muslim respondents, where responsibility was given up to God and one individual even talked of “*surrender to God*”.

The sense in which religious beliefs could be fitted into a largely secular lifestyle is summed up in the case below:

A 44 year old Caribbean woman, who had lived in the UK since the age of 15, said she did not believe in God but in Jesus Christ. She was a single mother and felt that God had helped her in a difficult situation, when her daughter was unwell. She could not see the contradiction. She prayed regularly, did not consider herself to be a practising Christian, but “*used her religion*” to make sense of what was going on. This demonstrates use of religious beliefs and rules among people who do not consider that they are especially religious, and shows how religious instruction can become part of lay belief systems for coping, without necessarily involving a formal commitment, or a total commitment, to religious worship. She found an experience of “*peace*”. At the time of her daughter’s illness, she felt God helped her overcome her fear. She listened to Christian radio, and that also made her feel “*holy*”. Her account suggests a changed experience of the self in response to relating to God and hearing religious radio, yet again she did not feel that she was compelled to be a part of the formal religious world or that she had strong religious beliefs.

4.4 **Summary and conclusions**

Firstly, in terms of personal resources, a wide variety of different coping mechanisms was described, ranging from distraction/escapism through to active self-analysis. The variety of techniques seemed to vary between individuals rather than between ethnic groups. A

number of metaphors and colloquialisms were used by respondents in explaining their personal resilience and their coping mechanisms, but again there seemed to be little systematic differences between ethnic groups in their terminology.

Religious belief was an extremely important coping mechanism for certain ethnic groups. Religious ways of coping appeared to play the greatest role in the lives of Black Caribbean and South Asian respondents who relied most on their beliefs in times of difficulty. The Black Caribbean group's relationship with religion was not as certain or as immediate as the religious experience of the Indian, Pakistani and Bangladeshi groups. The role of religion appeared most salient to Muslims in the South Asian groups. Religion was least obvious as a method of coping among British and Irish respondents.

Professionals and policy makers have little understanding of how religious coping expresses itself within and across ethnic and religious groups, yet, in contrast, professionals are now increasingly recognising the need to be familiar with religious and spiritual aspects of distress.¹⁰ Although most personal distress is dealt with in the informal sectors of care, where religious influences are most significant, in mental health and primary care services it appears that religious and spiritual coping is an invaluable resource that should be supported in endeavours to understand and deal with mental distress. However, despite evidence of a close link between religious ideas and coping with mental distress, formal health and social care systems have developed without due attention to the spiritual dimension of mental distress. For example, a recent study showed that South Asian men in contact with mental health services complained that their religious ideas were not always considered in their treatment and felt if they had been their care would have been better.¹¹ The objective should be to ensure that religious and spiritual issues are considered in the development of any statutory and voluntary service that encounters people with mental distress.¹²

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5 Use of services

Ini Grewal and Keith Lloyd

5.1 Introduction

The aims of the present study were to examine respondents' accounts of their pathways to services. Goldberg and Huxley's pathways to psychiatric care is a helpful frame of reference with which to compare themes emerging from the present narratives.¹ Of most relevance to the data collected here is the decision to consult (filter 1), and the detection of common mental disorder in the primary care setting (filter 2).

Use of services is affected by the incidence and prevalence of a condition in the population. At this level studies have highlighted the importance of socio-economic factors as important determinants of the prevalence of mental disorders across ethnic groups.^{2,3} Once the decision to consult has been made, the doctor must first detect that the patient is emotionally distressed and then respond appropriately. There are a number of treatments of proven efficacy and some evidence to show that diagnosis improves outcome, though this has been questioned.^{4,5} However, for common mental disorders there remains considerable debate about the level of psychiatric symptomatology that might benefit from detection and intervention.^{6,7} Indeed there are numerous paradigms in circulation about the nature and most effective treatment of these conditions in primary care settings. Among service users there appears to be a similar diversity of views about the nature and appropriate action to take concerning common mental disorders. Not all those satisfying research criteria for a mental disorder will either wish to have, gain from, or welcome, a medical treatment, but many will benefit from social support.⁸

These interacting social, patient, and service factors combine to impact upon patterns of services use.⁹ Thus, although in the Fourth National Survey of Ethnic Minorities,² Caribbeans were confirmed to have higher rates of depression than Whites, Caribbeans with depression were far less likely than their White counterparts to report receiving medication from their GP. This may suggest differences in the identification and treatment of depression in primary care among this group. Rates of mental illness among Asians were low particularly for Bangladeshi and Chinese respondents. Among Asians born in Britain, or who had received their secondary school education in Britain, rates of mental illness were similar to their White counterparts. Although young women who have migrated from India are more likely to die from suicide than other groups the Fourth National Survey found that they were no more likely to report suicidal ideation.² Ethnic differences were at least partly accounted for by socio-economic factors. After adjusting for social status those in lower social classes had higher rates of mental illness across all ethnic groups. Differences in material standard of living made at least some contribution to higher rates of depression and psychosis among Caribbean compared with White respondents. White and South Asian single parent mothers had particularly high rates of mental illness with a 10% prevalence for depression. Those who were married or cohabiting had the lowest rates. However, Caribbean single mothers did not have elevated rates and the lowest rates were found among single women without young children. Other studies have reported no differences between African Caribbean and white groups,¹⁰ but marked differences in service use and detection among Punjabi and white GP attenders.¹¹

The quantitative survey of psychiatric morbidity, which formed the first part of this study, has reported ethnic differences in morbidity, help seeking and detection.¹² The findings raised important questions about understanding of stress, access to services and the

perceived value of consulting for emotional problems. However, other questions about access to and use of services by different groups were left unanswered by the survey research, for example why Bangladeshi women are so reliant on primary care, and whether there are cultural differences in illness-related perception and behaviour. The data collected in this qualitative study can help to explain these and other issues, because it seeks to understand individual behaviour, beliefs and culture and the implications these have for service use.

This chapter explores issues regarding the use of and satisfaction with external services. By external services we mean formal sources of support such as general practitioners and psychiatric care, counselling and therapeutic services, and other forms of help including alternative medicine and religion. The chapter begins by examining motivations for seeking help from external services and types of services sought, and then moves on to consider experiences of using services broken down by type of service. To conclude, the qualitative data are used to provide explanations for some of the key questions on service use raised by the survey data.

Respondents in the qualitative study can be grouped into two categories - those who used services and those who did not. It should be made clear here that by non-users we mean those who did not use secondary services such as psychiatric services or counselling. The reason for this is that, as will become evident later, there was near universal take up of GP services, although, there were some who did not access any external services at all, including GPs, and this is also discussed below.

The user and non-user division will allow us to explore the variety of routes that respondents took to accessing services. Also it will allow an assessment of whether need alone drives the decision to access external services, and how this criterion is overshadowed by issues of preference and appropriateness of services available.

5.2 Non-users of services

It is evident from the interview data that non-users of services are not a homogenous group. Rather, they differ in the extent to which they feel that their lack of service use is guided by choice or by a host of other factors. There is a clear distinction between those who *chose* not to use services and those who believed that their options or choices to use services were limited or denied them.

5.2.1 Non-users by choice

A variety of explanations was offered to support the decision not to access services. These are described below.

Reliance on informal support networks

At one extreme were those who did not seek help from any source – family or external services – and believed in just “*having to manage it*”. Others sought support from family and friends but refused assistance from external sources, or, as some described it, from “*strangers*”.

“... I’m such a private person, I just couldn’t go and tell a stranger my problems, you know. I’d have to know them to tell them ... no matter how bad I was ... I think it’s a lot to do with our culture as well, you know”

(Female, 31, Pakistani, born in GB, high CIS-R score, interviewed in Urdu)

It is worth noting that although the above respondent referred to her cultural background as a possible explanation for the reluctance to use, in this case, counselling services, it was a view shared by those from the other ethnic groups.

Perceptions of mental health

Respondents from all the ethnic groups recounted having suffered from physical complaints. Further, they reported having sought help for the ailment and receiving treatment, which had remedied the problem. However, some did not seem to apply the 'problem + treatment = cure' theory to mental health disorders. Instead believing that unlike physical conditions mental or emotional symptoms could not be cured because "you cannot alter someone's mind" and this appeared to dissuade some from considering services.

Self-perception of illness was also a factor that influenced the choice to access services. There were some who did not perceive their circumstances or experience as necessitating external help or support. While some within this group were those with low CIS-R scores and perhaps did not genuinely require the assistance of services, others who proclaimed that they had no use for services had high CIS-R scores. Despite expressing distress in some way, these respondents regarded their state of health as "natural" and their situation as made up of "frustrations [that] prevail in everyone's life". Consequently, they did not "give any importance" to services or seek help from formal or informal sources. In many ways, it could be said that they 'normalised' their distress and did not medicalise it or conceptualise medical help seeking.^{4,11}

Experiences of others

There was evidence to suggest that other people's negative experiences of external services discouraged some from taking a similar route. The incidences did not necessarily have to have involved mental health related services. One example concerned a White British woman who lost confidence in her GP following what she judged to have been poor treatment of her daughter after a miscarriage. However, usually it was others' accounts of mental health services, whether based on actual experience or attitude, which coloured people's expectations and subsequent decision not to access services. The following quote demonstrates the significance of someone else's opinion, in this case a respondent who had declined the offer of counselling after her family warned about the danger of losing her children if she sought external help.

"The first session I did open a bit with this counselling person in the hospital, then following I've been told by family and friends, don't open it, they'll take your baby away when you have your baby and I thought I can't have that, I can't afford to do that. So I shut myself back and cancelled the counselling appointment and everything. But I wish I did go through it ... yes, it would have helped me a lot"

(Female, 31, Indian, migrated to GB aged 12, high CIS-R score, interviewed in English)

Influence was not limited to the opinions of people known to the individual, such as family and friends. More generally, perceptions based on literature suggesting negative outcomes of mental health services had a similar affect. The view expressed below by a Black Caribbean woman may have been shaped by, for example, studies into mental health reporting higher levels of diagnosis of mental disorders among the Black Caribbean population.

"I don't trust anything outside the family or friends ... too many Black people are diagnosed schizo, mad ... may be they don't understand what you're saying ... so you're mad, and then they're writing it down and then it stays with you for the rest of your life ... I could never ever go to the doctor or social worker"

(Female, 42, Black Caribbean, born in GB, low CIS-R score)

Image of secondary services

As demonstrated above there was some resistance to accessing external services, however, services such as counselling, therapy, and psychiatric care met particularly strong opposition.

A common perception was that these services offered little more than “*just talking*”, and that they had “*enough friends*” who were already fulfilling such a role. Some went further pointing out that not only did such services not suit them but that they did not suit the service – “*I’m not much of a talker really*”.

There was also resistance to using these services because of the stigma that was believed to be attached to them. For example, one Irish woman spoke of the fear of someone finding out and thinking “*there was something wrong with her*”.

5.2.2 Non-users for other reasons

The discussion so far has concerned individuals who had *made a choice* not to access services. The second type of non-user identified by the qualitative data involved those who felt that they had had no choice in their decision. There were a number of apparent explanations for this.

Awareness of secondary services

Awareness of the existence of services had a definite impact on the use of secondary services across all ethnic groups. There was little discussion, even when prompted, among the South Asian (Bangladeshi, Indian and Pakistani) respondents about services apart from those provided by GPs. This may suggest a general lack of awareness of their existence or how to obtain services such as psychiatric help and counselling. The lack of awareness was more pronounced among the South Asian groups compared with the Black Caribbean, White British and Irish groups. Further than this awareness, does not seem to increase or decrease among the South Asian groups by CIS-R score, gender, language, or migration status.

Referral to secondary services

The role of the GP as a gatekeeper to secondary services was a target of some criticism across ethnic groups. In this respect, some believed that their GP denied them access to appropriate secondary services by refusing to refer them. Such denial of access was not always seen as fair and there was some belief that, at times, the decision making around referral was based on misjudgements about a respondent’s situation. Examples cited included when it was felt a GP wrongly believed that a respondent was coping and did not need further help, or that their condition was not serious enough.

Such decision making was challenged by some respondents. For example, a 40 year old pregnant Irish woman who feared that she was not going to be a good enough mother, demanded that her GP refer her to therapeutic services to help her cope better with the situation. However, lack of confidence prevented others from challenging the GP’s assessment. Reluctance to contest such decisionmaking was associated with lack of knowledge about service availability, that is not knowing *what* to ask for, and the lack of ability to express their needs effectively, that is not knowing *how* to ask. The latter point was generally made by South Asian respondents whose first language was not English. This perhaps reflects a greater level of accessibility for patients to consultations that are conducted in community languages. In addition, the language in which consultations are conducted clearly has implications for the degree of control a patient feels in a diagnostic or treatment situation.

Appropriateness of service personnel

While some did not question the benefits of the services available, they did feel that the personnel delivering the services prevented them from gaining those benefits, and effectively meant that they had no choice but to not use the services. Service provision was viewed as incompatible for a number of reasons. First, the language in which services were provided was not always appropriate and was seen by some (mainly non-English speaking respondents) as a key barrier to service use. For example, a Pakistani woman who was interviewed in Pothari described how not being able to communicate with a counsellor in one’s first language meant that she “*couldn’t explain her feelings*”.

Lack of cultural awareness and understanding among service providers was another reason that services were perceived to be inaccessible. The Black Caribbean woman quoted below based her reluctance to seek help from external sources on her fear that service providers would misinterpret her behaviour due to their lack of understanding of her cultural background.

"I could never go to the doctor or to the social worker and say, you know, this is my problem because they don't take into account your culture ... there are things I do naturally as a Black person ... it's just ignorance, people not willing to ... take a look at other people's background and cultures ... may be I acted the way I acted because it was a cultural thing ... and I guess that's where people think ... they're racist ... because we're not doing it the white way"

(Female, 42, Black Caribbean, born in GB, low CIS-R score)

Not having a shared social class was another factor that could make the service provider unsuitable. The differing attitudes of an Irish woman towards her psychiatrist and her social worker indicate the significance of social class. She described her psychiatrist as *"middle class ... who hasn't got an idea"* and her social worker as someone who *"helps her because she trusts him completely – he is more from my background, more working class"*.

5.3 Users of services

5.3.1 Overview of services used

A wide range of services were used by those interviewed in the qualitative study. These can be grouped broadly into three categories: medical and psychiatric services; counselling and therapeutic services (with services provided by statutory agencies, such as social services drug rehabilitation teams, or by voluntary groups/self-help groups such as Samaritans and Relate), and other formal sources of help (for example, 'alternative medicine', religious healers, and courses, such as stress management).

While contact with a GP was near universal, there were some variations in the types of people who used the other services noted above. Users of psychiatric, counselling and therapeutic services were located among those with a high CIS-R score. Regarding ethnicity there was a recurrence of Irish respondents among the users of psychiatric services. In terms of 'alternative medicine' the South Asian migrants made reference to religion-based sources of help such holy water. While respondents from all of the ethnic groups reported using homeopathy and herbal medicine, the White British and Irish groups' list extended to acupuncture, hypnotism, stress management courses, self-help literature, and spiritual relaxation classes. Users of services provided by large, established voluntary organisations, such as Relate and Samaritans, were to be found among the White British and Irish respondents, rather than the other ethnic groups represented in this study.

As noted above contact with a GP appeared to be almost universal. Moreover, GPs were a primary route to other services such as psychiatric care, counselling, and therapy. However, there were some exceptions where the route to secondary services had not originated from a GP. These were rare but included for example accessing university-based counselling through one's own initiative; being referred to a women's refuge-based counselling service by the police after an incident; and undergoing counselling as part of an academic course. For women one route into services was pregnancy. This was an entry point into the 'system' for women for a wide range of services generally. In addition, problems related to pregnancy, such as miscarriage and postnatal depression, also triggered referral to certain mental-health related services.

In the South Asian groups, referral to counselling or therapeutic services appeared to result from 'special' circumstances rather than through the more common route taken via GP services. For example, one Indian man had a white girlfriend who had been in contact with services for her mental health problems; an Indian woman underwent counselling as part of

her HND course; while a Pakistani man was referred to social services drug rehabilitation counselling services after he acquired a drug problem while he was in prison. However, as noted earlier the users of psychiatric, counselling and therapeutic services were located among those with a high CIS-R score and this was also true for the South Asian groups. In other words, the 'special' circumstances may not necessarily have been the trigger for their referral. Nevertheless, there is evidence to suggest that language may have had a bearing on access to, or referral to, services since Bangladeshi, Pakistani and Indian respondents who had used some form of counselling or therapeutic services were all able to speak English.

5.3.2 Experience of services

A number of factors influenced how respondents gauged their experiences of services. In general, the level of control over treatment, perception of its appropriateness, and its outcome underlay expressed satisfaction. Experiences by type of service, namely the three categories defined above: medical and psychiatric; counselling and therapeutic; and other sources of formal help are discussed in this section.

General Practitioners

The General Practitioners service was often the first and sometimes the only (especially for the South Asian groups) point of contact. This situation was not unusual or peculiar to the South Asian groups, 95% of all mental health problems are dealt with exclusively in primary care and only 1 in 20 receive a referral to other agencies.¹ One possible explanation for the reliance by the South Asian groups on the GP may be the high esteem in which doctors (GPs) continue to be held, especially among the older generations as the quote below suggests.

"And our people still, especially people who come from villages, they think doctor know better, ... just like some people from villages, some people believe more on GP, they think what a GP is saying, she or he is saying right, that's the way they are ... People are brought up in a different way. Back home, most of the old people, Asian old people came from back home, the tradition back home is different than here and they believe that OK, doctor know it all, that's why they ask doctor"

(Female, 45, Indian, low CIS-R score, migrated to GB aged 24, interviewed in English)

Another reason suggested by the South Asian groups for reliance upon GP services was the fact that they might share ethnicity or language with their physician – *Our doctor is good, he is Pakistani*. The notion of the benefits of 'shared experiences' also extended to gender, and was present among other ethnic groups, as this Irish woman illustrates:

"Luckily we've got a female doctor, when I say luckily because I just do not think men, even male doctors, appreciate just how much turmoil and emotional change you go through when you have children and how much you actually give up"

(Female, 33, Irish, born in GB, low CIS-R score)

Among all ethnic groups there were mixed views about GPs' ability to treat mental disorders and the extent to which they were open to other types of services. There was a popular belief, a view shared by many GPs⁶, that GPs had limited experience of dealing with mental health issues, and that their expertise lay more with attending to physical ailments.

"Because I don't think that they were actually the right people to give advice, basically maybe through their lack of training or experience in dealing with it If I actually went in with an illness of stress but also with a physical illness in the sense of having the ulcers or starting to get those and I think he was more interested in, and she, were more interested in actually dealing with that because that's what they knew that they could deal with and the stress was maybe a little bit more out of their league or out of their remit"

(Male, 32, White British, low CIS-R score)

Another common perception, and it may be linked to the idea above, was that GPs are overly reliant on medication as a form of treatment. A number of reasons were offered to explain why this was an unpopular intervention. The perception that medication was for physical ailments and not for mental health complaints was recurrent. Others questioned their diagnosis of mental ill health and therefore any treatment prescribed. For example, a 44 year old Indian woman with a high CIS-R score disapproved of her GP prescribing her sleeping tablets because she knew that *“there was nothing wrong inside”* her.

The fear of becoming dependent on drugs was another rationale for resisting medication as a form of treatment. For instance, a 45 year old White British woman with a high CIS-R score decided against seeking help from her GP because she did not want to become *“hooked”* on hormone replacement therapy. Reticence to take medication for mental distress was, for some, linked to a feeling that they were already taking sufficient amounts of medication for other conditions. For example, a 45 year old Pakistani man, who was already on a high level of medication for a heart condition, said he did not wish to increase his intake. There was some belief that medication affected one’s ability to continue with daily life and meet responsibilities, such as looking after children or driving.

However, not everybody was averse to taking medication to treat mental distress. Below is a quote from such a respondent, though, the physical nature of his symptoms may have influenced his willingness to take medication.

“Well, missus was at work and ... I dropped missus, come home, park up car, I went for a run about 3 mile, come home, had a shower and lay in bed and I felt all this side numb ... All right side went and I told doctor ... and doctor said, oh, he said, got to be depression ... took them [tranquillisers] for a bit but then I was all right ... they did work. And then I was all right”

(Male, 48, Pakistani, migrated to GB aged 14, high CIS-R score, interviewed in English)

Concerns about inappropriate treatment were sometimes shared with GPs. For example, a 39 year old White British woman described how she had asked for medication to be stopped because she was not happy being on drugs. The GP did as she asked and initiated a discussion with her about treatment alternatives. However, in other contexts, treatment that was perceived by the respondent to be inappropriate went unchallenged. This sometimes led to non-compliance with treatment regimes, in particular to respondents *“never finish[ing] the course”*.

Alongside the concerns expressed above there was evidence to suggest that GPs are shifting emphasis from only examining physical issues to exploring the possibility of psychological explanations. A 36 year old Indian man with a high CIS-R score talked about how his GP, while still prescribing sleeping tablets, was *“always saying ‘we generally think really it's more to do with levels of stress in life, it's not really a physical problem’”*. And others noted a move to non-medication based courses of treatment with *“the doctor nowadays asking you ‘what is the problem, what do you think?’”*.

Other concerns – evident across all groups – tended to contradict this perception of a more holistic approach and instead voiced general dissatisfaction about delays in booking appointments, or the limited duration of GP consultations, the latter meaning that GPs did not spend *“enough time to understand you, [or] your problems”*.

Finally, in some cases those referred on to a hospital found it difficult to deal with the boundaries of responsibilities between GPs and hospital-based doctors. For instance, a 47 year old Irish man with a high CIS-R score was prescribed medication while in hospital but on discharge, he was led to believe that he could not discuss that treatment with his GP. He reported feeling unhappy with this condition, as he felt unable to discuss his situation with the medical professional he was in regular contact with, that is, his GP.

Psychiatric services

As noted above there was limited evidence to suggest that use of psychiatric services was common among Bangladeshi, Pakistani and Indian respondents. Therefore, the experiences below are largely drawn from the other ethnic groups.

A distinction was made between services provided by GPs, therapist, self-help organisations and those by psychiatrists. A common view was that the latter were for “real” problems. However, those who received psychiatric care reported that the specialised focus of the treatment meant that it was possible to recognise issues that may not be picked up by a service with a more generic approach, for example during a GP consultation. But, on a negative note, there was some evidence to suggest that individuals were sometimes left unsupported in dealing with the consequences of having identified such issues.

“... he opened all this book of worms and then just left me to deal with it, I had 6 weeks with that and my life was hell after seeing him. It was hell”.

(Female, 39, White British, high CIS-R score)

Counselling and therapeutic services

As with services provided by psychiatrists, there was little evidence of the South Asian respondents using counselling and therapeutic services. Therefore, the views expressed below are again largely drawn from the experiences of the other groups.

Common perceptions included that counselling was for “mad” people or that it was “self-indulgent”. There was a recurrent view that its sole purpose was for talking, with little evidence that this led to any practical solutions (it is worth noting here that cognitive therapy was cited as an approach that did help in a practical way). Furthermore, it was felt that talking could, in fact, stir things up and make the situation worse. Also, as noted earlier, “talking things through” was a function seen by some to be already performed by friends and family or indeed by themselves, through self-analysis, described by one respondent as “talking to my mirror”. Perceptions such as these meant that dropping out of counselling or therapy was a common experience.

However, the emphasis on “talking” in counselling and therapeutic services was what made them attractive to others. In this respect, it was suggested that it was precisely the ‘talking’ that helped to develop understanding of one’s condition beyond the confines of physical ailments, and enabled one to look at the whole picture. For instance, a 35 year old Black Caribbean woman was able, through counselling, to recognise that the consequences of her miscarriage were wider than physical, and consequently was able to consider it with reference to her marital relationship. The opportunity that counselling and therapeutic services offered for recognition and acceptance of mental distress was viewed as the constructive aspect of such services. For example, a 33 year old Irish woman gained much solace from her counsellor’s belief that she had had a lot to cope with. This may be linked to the perception that physical ailments, rather than mental disorders, are more readily acknowledged by more generic services, such as GPs.

The safety perceived within a counselling environment coupled with the lack of judgement that was viewed as inherent in such services, were identified as further positive features. These attributes were said to enable one to go further and deeper into analysis than one might previously have felt capable. However, for others the safe environment was the very thing that limited the benefit of counselling and therapeutic services. For them a safe environment equalled an ‘unrealistic’ environment. For example, a 34 year old White British man questioned the benefits of talking through problems about work within the safe environment of a therapeutic setting, building up confidence and techniques for coping, saying “it goes out the window once you get back to work and you get that phone call and someone is screaming at you”.

Finally, there were those who spoke very positively of their experience of counselling and therapy due to the specific approach that had been adopted. In other words they were not advocating such services generally, but believed that certain practices had made their experience of counselling and therapy beneficial. Such commended practices included cognitive therapy, being counselled by someone with shared experiences like Women’s Aid, or receiving counselling at a recognised and established organisation as opposed to “in somebody’s front room”, which may indicate a greater suspicion of private or individual counselling practices based within a person’s home.

Other sources of help

Use of 'alternative medicines' such as homeopathy, acupuncture, religion-based sources of help (eg mullahs, holy water) tended to occur alongside 'mainstream' services, such as GPs, psychiatric and counselling services, or were employed after mainstream services were felt to have been ineffective. For example a 31 year old Bangladeshi man resorted to "holy water" after "normal" medicine had failed for two years. The success of religion-based sources of help such as holy water and amulets was considered to be based on faith – "if you believe in it, it helps".

Homeopathy and herbal medicines received mixed reviews. Some reported success – "it calms you, it relaxes you", while others suffered as a result of deviating from their 'mainstream' prescription. One such case involved a 47 year old Bangladeshi woman who had to return to her prescribed medicine for arthritis after using a homeopathic alternative for one week and, as a result, suffered from swelling.

In addition to the experiences of 'alternative' medicines discussed thus far, some White British and Irish respondents also referred to 'taught courses' to help reduce stress. For example, a 32 year old White British man described how a work-based stress-management course had helped him to "understand what was happening and why it was happening".

5.4 Summary and conclusions

In this chapter we have made a distinction between users and non-users of secondary services and within the latter group between those who considered themselves to have made an informed choice about their non-user status ("non-users by choice") and those who believed it to have been influenced by other factors ("non-users not by choice").

A key finding applicable to users and non-users of services was the centrality of language in determining accessibility of services and patterns of service use. Among the non-users of secondary services there was evidence to suggest that GP consultations not conducted in the patient's first language reduced the level of participation by the patient. For example, it appeared to influence their ability to fully explain their situation, or request a referral to a secondary service. And among those who did get referred to secondary services, such as counselling, the negative impact of communicating in a second language appeared to continue. Further evidence to support the significance of language was that the South Asian respondents who reported accessing counselling or therapeutic services were all able to speak English. Therefore, the inaccessibility of services based on language may be one explanation for the quantitative survey finding that access to counsellors or psychologists was highest among the White, Irish and Black Caribbean groups.

The qualitative data also revealed that for all ethnic groups the GP was a key player in the experience of seeking services. Referrals to services such as psychiatric care, counselling and therapy usually originated from a GP. However, ethnic variations occurred in the take up of services beyond those provided by a GP. In other words where GPs were the *first* point of contact with services for the White British, Irish and Black Caribbean groups, for the South Asian groups the GP was often the *first and only* contact with external services. This offers some explanation for the quantitative survey finding that Bangladeshi men and women were the most likely to report having consulted a GP in the last six months and the least likely to have made use of health services other than a GP. The qualitative data suggested a number of reasons for the South Asian groups' reliance on GPs. First was the unsuitability of service providers in terms of cultural awareness and second the continuing esteem in which GPs are held by South Asian communities. This combined with the local accessibility of GP practices and perceived chances of sharing a language – again indicating the importance of language matching – or culture meant that they remained the most accessible source of external help.¹²

Another conclusion of the quantitative survey was that White informants were significantly more likely than other groups to report having attended the GP for a stress-related or emotional problem in the last six months.¹² The qualitative findings indicated that the reluctance to consult GPs for mental disorders was present across groups. The reasons included the view that mental disorders are not curable in the same way as physical ailments; the prospect of a drug-based treatment; and a common perception that the treatment of mental disorders was beyond the expertise of GPs. This provides some explanation for the quantitative result that less than a quarter of those with a high CIS-R score reported having seen a doctor for a stress-related or emotional problem in the last six months.¹²

The present qualitative study has revealed a number of factors which influence service use: the role of potential service user's own perceptions of their distress; the accessibility of services (and within this the centrality of having a shared language); and service users' expectations of the role and availability of health professionals. These are factors that should be taken into account in any service planning and they highlight the valuable insights to be gained from consumer involvement in the research process.

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OBJECTIVES:

- to explore respondent's own personal ideas, beliefs and accounts of the stresses and strains of everyday life and the impact of these upon their own wellbeing;
- to understand how good or bad they perceive their everyday lives to have been recently and more long term;
- to hear their stories or accounts about why and how some times have been better or worse than others.

EXPLAIN:

About the National Centre, confidentiality, tape recording & timing

1. INTRODUCTION

start off by saying a little bit about yourself...

- who lives with
- age

2. CURRENT CIRCUMSTANCES

To get a picture of your life in the recent months...

Interviewer note:

- probe all areas listed below
- use your discretion to explore periods/issues of difficulty and distress as they arise or at the end of the current circumstances section. All difficult and distressing times should be explored fully using section 4 of this guide

Housing & household relationships

- how long lived here/where moved from
- current tenure
- likes and dislikes about
- explore the nature of household relationships

Wider family

- where they live
- level of contact

Ethnicity

- ask respondent to explain the ethnic identity they cited in the previous survey (as stated on recruitment questionnaire)

Friendships

- whether have friendships outside their family/household
- establish how important friendships are
- where lacking in friends establish why

How spends daily life
probe for the following:

- caring for children/relatives
- working in the home
- working for family
- paid employment
- education

Employment

- any work outside the home
- if so occupation nature of work level of time commitment likes and dislikes about work
- if not when last worked previous occupation

Education/training

- any education at present
- what studying/learning objectives when finished

Other activities outside the home

- voluntary/community activity
- hobbies/interests outside of work

Health

- general perception of health
- any difficulties – probe only for major ones

Finances

- views about current financial status
- whether adequate
- difficulties/debt

Discrimination/Racism

- experience of in daily life
- probe especially for neighbourhood, work environment

Religion/Spirituality

- whether have a religious affiliation/belief
- explore the role religious/spiritual beliefs play everyday life

3. PERCEPTION OF DIFFICULTY & DISTRESS

- Expectations of Happiness/individual satisfaction
 - whether expects for other people/what sorts of people
 - whether expects happiness/individual satisfaction for themselves in life
- Perception of life now
 - establish whether see their life now as mainly happy or not/as difficult or relatively carefree
- if not so happy/more difficult now*
 - identify the main causes of unhappiness/difficulty at present (if not already obvious)
 - memories of happy times in past – what has changed?
 - explore each period of difficulty fully using Section 4 below
 - difficulties should only be explored if they are current or recent (within past 5 years). Note however that an individual can experience current difficulty/distress because of something that happened sometime in the past. If this is the case it should be explored.
- if happy/not difficult now*
 - explore briefly what features make it a happy time for them
 - establish what helps sustain happiness in their lives
 - explore how current circumstances compare with previous life circumstances

if past circumstances difficult

- identify time(s) in past that recall as most difficult/distressing
- explore each difficult period using Section 4 below

if past circumstances equally happy

- move to the end of the interview

4. EXPERIENCE OF DIFFICULT OR DISTRESSING PERIODS (whether current or previous) *KEY SECTION*****

Use the following section to explore periods of difficulty or distress in life identified by the respondent

- Nature of difficulty or distress
 - ask them to describe in their own words why they identify the circumstances as difficult
 - determine how and in what ways do these worries, stresses, strains or difficulties trouble them

Possible causes

- how see or understand what is happening to them
- how they feel the difficulty came about
- explore fully— who or what they believe made it arise

How describe what is happening to them

- explore what terms the respondent uses to describe both the difficulty and the effect/impact it has on their life
- probe fully the meaning of all terms
- do not introduce terms like illness/illhealth/disease unless they do

Effects and impacts
Investigate which areas of their life are affected by difficulty/distress

- Practical
 - explore whether difficulty/distress has affected ability to do things
 - which activities/duties have been affected

Bodily/Physical

- establish in the course of probing about period of difficulty whether it has ever brought about:
 - tearfulness
 - tiredness
 - bodily aches and pains
 - loss of appetite

Emotional

- how the feel about themselves/make sense of what is happening to them
- whether now they think is affected
 - probe, as appropriate, whether the time of difficulty or distress affected:
 - their sense of self worth
 - feeling of purpose
 - sense of control over their lives
 - feelings of hope about the future
 - ability to concentrate
 - interest in other things

Other effects/impacts

Establish shorter and longer lasting effects

Solutions

- whether perceive difficulty as changeable/subject to improvement
- investigate what factors could bring about improvement/change in circumstances

Role of other people in life

- how family/friends view what is happening to them
- how relate to other family/friends during period of difficulty
- explore whether & how family/friends are a support during difficult times

Strengths & support

- explore what factors determine whether they seek help or not
 - what helps them through this period
 - personal resources
 - others around in similar circumstances
 - others who understood what going through
 - any involvement with GP
 - use of health services or statutory / voluntary organisations
 - which services/organisations & for what purpose
 - identify most positive or helpful source of support or help was

Overcoming distress & difficulty

if in the past

- whether / how event or period ended
- anything they tried to do / managed to do
- what precipitated change
- what prevented change
- what made things worse

if current

- move to section 5

5. POTENTIAL SUPPORT AND HELP

What would have made a difference to them at times when they have experienced difficulty/distress

- knowledge of different places/services available
- who runs them
- what do they do
- how did/can they help

Explore what could / should be done

- to help people in same situation
- to help people avoid being in that situation
- what needs to change
- what difference would it make

What needs to be learnt from their experiences

To finish....

- Thank the respondent, give them the incentive & get them to sign a receipt
- If appropriate, acknowledge any difficulties or distress experienced during the interview
- If necessary, suggest the respondent contact their GP to discuss their difficulties/distresses further
- Also, leave a copy of the leaflet containing useful contact telephone numbers
- If other organisations may be useful, suggest getting back in touch with details

Appendix B:

Recruitment documents

Dear

Thank you for taking part in our recent survey of health and wellbeing, which has been commissioned by the Department of Health. The information you provided has been very helpful. At that time, you kindly agreed to take part in any follow-up studies that were carried out. I am writing to let you know that we have now started such a study and are planning to carry out interviews over the next month.

The aim of the follow-up study is to find out more about people's health and wellbeing. One of our interviewers may be in touch with you over the next week or so to check that you are still happy to take part and arrange a suitable time for the interview. Unfortunately, we will not be able to interview everyone – if we do not contact you, thank you very much again for your earlier help.

Everyone who takes part in our follow-up study will be given £15 as a small token of thanks for their help. The interview will last about an hour and a half, and will take place in your home (or somewhere else if you prefer). The *National Centre for Social Research* is an independent research institute and, as with the previous survey, everything that you say is treated confidentially.

If you have any questions, please call me or my colleague Ini Grewal at the *National Centre for Social Research* on 020 7250 1866. Also, please let us know if there is anything that we can do to make it easier for you to take part.

Yours sincerely



William O'Connor
Qualitative Research Unit

A STUDY OF HEALTH AND WELLBEING

Thank you for agreeing with this research about health and wellbeing. I can confirm that the interview will take place as follows:

Date:.....

Time:.....

Place:.....

Name of interviewer(s):.....

The interview will last between about 1½ hours, and you will be given £15 as a thank you for your time and help.

The *National Centre for Social Research* has been asked to carry out this research on behalf of the Department of Health. The *National Centre* is a fully independent social research organisation and all work we carry out is undertaken in the strictest confidence. No information that could identify you will be passed to anyone else.

We hope that you will enjoy taking part in the interview. If you require any further information, please contact myself or Ini Grewal on 020 7250 1866 or write to us at the above address.

Yours sincerely



William O'Connor
Qualitative Research Unit

P6000

A study of health and wellbeing
Qualitative Follow-up
Screening Questionnaire

October 2000

ENTER SERIAL NO

Date

RECRUITER NAME _____

1) INTERVIEWER CODE SEX OF RESPONDENT

Male 1
Female 2

2) What was your age last birthday?

ENTER AGE IN YEARS [] []

3) To which of the following groups listed do you consider you belong...READ OUT...

CODE ONE ONLY

- ...White British 1
- ...Black - Caribbean 2
- ...Black - African 3
- ...Black - Other 4
- ...Indian 5
- ...Pakistani 6
- ...Bangladeshi 7
- ...Chinese 8
- ...Irish 9
- or None of these 10

4) INTERVIEWER CODE WHICH LANGUAGE IN WHICH THE RESPONDENT WOULD MOST PREFER TO BE INTERVIEWED

Note: explain the difference between a survey interview and a depth interview

- Bengali 1
- English 2
- Punjabi 3
- Urdu 4
- Sylheti 5

PLEASE TURN OVER

5) INTERVIEWER CODE FROM SAMPLE SHEET (Col G)

CODE ONE ONLY

Respondent... was born in GB or moved here before the age of 11
...moved to GB at age 11 or later 1 2

6) INTERVIEWER CODE FROM SAMPLE SHEET (Col H)

CODE ONE ONLY

Respondent is...
Type A (CIS-R Score of 12 or higher) 1
Type B (CIS-R Score below 12) 2

7) INTERVIEWER CODE FROM SAMPLE SHEET (Col I)

CODE ONE ONLY

Respondent is...
...Muslim 1
...Christian 2
...Other religion 3
...No specific religion 4

NOW CHECK THE QUOTA SHEET and RECORD OUTCOME

8) OUTCOME OF SCREENING INTERVIEW

Refusal (ENTER REASON)	1	END
Not in quota	2	
Recruited for interview	3	GO TO Q9

9) FILL IN INTERVIEW DETAILS ARRANGED (note do not insert address here)

DATE _____
TIME _____
PLACE _____