Beliefs about mental illness and pathways to care in African Caribbeans and whites with a first episode of psychosis

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BELIEFS ABOUT MENTAL ILLNESS AND PATHWAYS TO CARE IN AFRICAN-CARIBBEANS AND WHITES WITH A FIRST EPISODE OF PSYCHOSIS

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Thesis submitted to the University of London for the degree of Doctor of Philosophy

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2003
FOR ALEX AND HELEN
ABSTRACT

Research over the past twenty years has shown that African-Caribbeans are more likely to access psychiatric care via negative and adversarial routes, such as those involving the police and compulsory admission to hospital. The reasons for these patterns are still poorly understood. Research in the fields of medical sociology and social anthropology has shown that cultural beliefs about illness exert a significant influence on responses to illness, in the form of what help is sought and when. This thesis investigates the impact of beliefs about mental illness on pathways to care in African-Caribbean and White patients with a first episode of psychosis. The study comprises a two-stage design. In the first stage, data relating to pathways to care was collected from all patients presenting to psychiatric services over an 18-month period, and quantitative analysis of pathways and associated variables was conducted, addressing the hypothesis: African-Caribbean ethnicity will be associated, independently of potential confounders, with higher rates of compulsory admissions and police referrals, and lower rates of GP referrals. In the second stage, data relating to beliefs about mental illness was collected using a semi-structured interview from a sub-sample of those patients included in the first stage, and from relatives and community respondents. Qualitative data analysis of the thematic content of interviews was conducted to address three related research questions: Do African-Caribbeans’ beliefs about mental illness differ from those of Whites? Do beliefs about mental illness differ within the African-Caribbean group according to place of birth and/or age? Do the beliefs evident among African-Caribbeans and Whites bear any relationship to the patterns of pathways to, and modes of contact with, mental health services observed in the first stage of the study? The analysis of data from the first stage shows African-Caribbeans are less likely to be referred to mental health services via a GP and more likely to enter care via the police and under compulsion than Whites. The analysis of data from the second stage suggests African-Caribbeans are less likely to believe severe mental illness is a form of illness caused even partly by biological factors. They are also more likely to believe severe mental illness should be dealt with outside of the professional medical sector. These beliefs are such as to suggests that for many African-Caribbeans, severe mental illness is beyond their “clinical horizon”. This inhibits early and voluntary help-seeking and may, at least partly, explain differences in patterns of service use observed in the first stage.
ACKNOWLEDGEMENTS

My two supervisors, Professor Julian Leff and Dr Rosemarie Mallett, have been supportive and encouraging throughout, giving their time generously and offering detailed critical feedback at all points. It has been a privilege to work with them.

The data for this thesis was collected as part of a wider epidemiological study of first presentation psychosis, the ÆSOP (Aetiology and Ethnicity in Schizophrenia and Other Psychoses) project, and I owe a debt of thanks to all those who have worked on this project. At key points during the conduct of this study a number of colleagues have been particularly helpful in facilitating access to data and in providing critical and insightful comments on work in progress. These are: Dr Gerard Hutchinson, Dr Kevin Morgan, Dr Paola Dazzan, Dr Chiara Samele, Stefan Auer, and Professor Robin Murray. Dr Kwame McKenzie also provided detailed feedback on preliminary work at a key stage in the study.

The opportunity to study for a PhD was made possible by those who I have been taught and encouraged by in the past. I am greatly indebted to Richard Jerome, History Tutor at Barnsley Sixth Form College, for invaluable support at a crucial time. I am equally grateful to Barbara Hudson, Emeritus Fellow of Green College, University of Oxford, who over a number of years now has been supportive and encouraging in all I’ve done.

Throughout my family have been patient and supportive and it is to them that I owe the greatest debt of thanks – Mum, Dad, Lee, Helen and Alex.
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CHAPTER 1

INTRODUCTION
1 INTRODUCTION

“What remains to be demonstrated is the nature of the social transaction whereby psychiatrists perceive their black patients as more dangerous”
(Littlewood & Lipsedge, 1989, pp. 275-276)

Two issues have dominated research focusing on ethnicity and mental health in the UK: 1) high rates of diagnosed schizophrenia among African-Caribbeans; and 2) high rates of compulsory admission to hospital among African-Caribbeans. Reports that migrants from the Caribbean to the UK were more likely than the indigenous White population to be diagnosed with schizophrenia began to appear in the 1960’s (Hemsi, 1967), a finding invariably replicated in subsequent research (Sharpley et al, 2001; Jarvis, 1998). This research has further shown that not only are rates higher among first generation migrants, but also among those born in the UK to Caribbean parents (ÆSOP Study Team, 2002; Bhugra et al, 1997; Harrison et al, 1988; McGovern & Cope, 1987a). Alongside this it also emerged that patients of African-Caribbean origin or heritage were more likely to be admitted to hospital via the police and compulsorily when compared to White patients (Littlewood & Lipsedge, 1981b; Sims & Symonds, 1975). When Littlewood and Lipsedge (1989) published the first full exploration of these twin issues it was clear that no consensus had emerged to explain either of the two repeated findings. Quite the opposite, in fact. These issues have proved deeply controversial and at times have produced extremely vitriolic exchanges in the academic literature (see for example, the exchange of letters between Suman Fernando and Glynn Harrison in the Psychiatric Bulletin, 1988, p. 250-251). The debate quickly became polarised, the central question being whether the problem was with psychiatry (mis- and over-diagnosis, racism) or with African-Caribbeans (higher rates of illness, more disturbed presentation). In summarising both sides of this debate, Littlewood and Lipsedge (1982) concluded that “both types of explanation appear inadequate in themselves” (p. 275) and suggested that a more satisfactory approach was one that saw both high rates of schizophrenia and of compulsory admission as the product of interactions between how African-Caribbeans presented to services and how psychiatry responded to them. The nature of these interactions, however, remained to be explained. Over twenty years on, and despite a substantial body of further research, this remains true. That is, it is still not clear why African-Caribbeans are diagnosed with schizophrenia more often nor why African-Caribbeans access mental health services via negative routes, such as the police, and under compulsion more often. In relation to this latter issue, research has been so limited in explaining the observed differences that a recent British Journal of Psychiatry editorial concluded, on the back of yet another report of higher rates of compulsory admissions among African-Caribbeans (Audini & Lelliott, 2002), that “we
continue to wade through a sea of ignorance" (Harrison, 2002, p. 199), the result being that patients of African-Caribbean origin or heritage “...continue to be exposed to the potential adverse consequences of compulsion: alienation from services, poor concordance with both physical and psychological treatments, and lengthy durations of untreated psychosis” (p. 199).

It is with this latter issue that this thesis is concerned. A key reason for ongoing ignorance in relation to this issue, as will be argued in detail in Chapter 2, is that the methodology invariably adopted in previous research has been both narrow and limited, relying almost exclusively on quantified data collected within an epidemiological framework. This has successfully mapped pathways to statutory mental health care and rates of compulsory admission, but it has failed to explain observed differences between ethnic groups. This is the starting point for this thesis. While much of the resulting debate, as already noted, has polarised around the issues of racism v. clinical presentation, some authors have speculated about the potential role of wider social and cultural factors in determining ethnic variations in pathways to care (Owens et al, 1991). In particular, the question has been posed of whether beliefs about the nature, causes and appropriate treatment of mental illness prevalent in the African-Caribbean community are such as to inhibit help-seeking from professional mental health services (Harrison et al, 1989). This suggestion arises from research in medical sociology and anthropology that has shown, in a wide range of cultural contexts and social groups, that beliefs about illness both differ widely between groups and societies and have a significant bearing on how individuals interpret and respond to symptoms (see Chapter 4 for review). This possibility, however, has not been researched in relation to help-seeking among African-Caribbeans and Whites in the UK.

The overall objective of this thesis is to investigate this neglected question of the impact of beliefs about mental illness on pathways to mental health care among African-Caribbeans and Whites. The perspective and methodology adopted to achieve this objective are informed by the substantial body of research in the social sciences focusing on the social and cultural processes that shape help-seeking, or more generally illness behaviour (see Chapter 3 for review). The first section of the remainder of this introduction will briefly elaborate on the rationale and aims of the study and outline the structure of the thesis. Following this, working definitions of key terms and concepts utilised throughout this thesis are set out.

1.1 THESIS RATIONALE AND OUTLINE
1.1.1 Why the Study of Pathways to Care is Important
The notion that individuals follow a “pathway to care” from the point of becoming ill to the point of service contact has gained wide currency in health services research. There is a vast body of research conducted by sociologists, anthropologists, social psychologists and others
considering the broad question of what determines how individuals respond to experiences of ill-health and what sources of help, if any, are consulted. This research is fuelled by the well established finding that help-seeking is not simply determined by the nature and severity of symptoms: other processes are at work and it is with understanding these that research across all disciplines is generally concerned. From a public health perspective, such research is essential. The psychological, social and cultural processes that shape responses to symptoms can be such as to delay contact with health services and work against engagement and compliance with treatment, both of which potentially lead to avoidable deteriorations in both physical and mental health. Understanding what promotes or hinders early help-seeking and voluntary engagement is therefore crucial to the development of public health initiatives and services that minimise delays and promote engagement.

This is particularly relevant in relation to psychotic mental illness and ethnic minorities. There is emerging evidence that long periods of untreated psychosis and compulsory admission to hospital are associated with poor outcomes (Birchwood et al, 2000; Birchwood et al, 1997; McKenzie et al, 1995), both of which have been shown to be more common among patients of African-Caribbean origin or heritage (Harrison et al, 1989). When set alongside findings that African-Caribbeans are diagnosed with schizophrenia and other psychotic mental illnesses more often than Whites, and the relative poverty and discrimination faced by this community, the more negative pathways to, and contacts with, mental health services represent a further source of disadvantage in an already deprived community. As Harrison (2002) recently commented: “This is a tragedy for the community and one of the most pressing challenges to the practice of psychiatry in inner-city areas” (p. 198).

1.1.2 Objective, Hypothesis and Research Questions

The primary objective of this thesis is to investigate the relationship between beliefs about mental illness and pathways to, and mode of contact with, mental health services at first presentation among a sample of African-Caribbeans and Whites (British, Irish, and European) meeting ICD-10 criteria for a psychotic illness (ICD-10 F20-29 and F30-39 (psychotic codings) (see Box 1.1)). To achieve this objective, research was conducted using a two-stage design. The first stage, using quantitative methods, focused on mapping pathways to care in a full cohort of African-Caribbean and White patients with a first episode of psychosis who were recruited as part of a larger epidemiological study of psychosis. The second stage, using qualitative methods, investigated the potential role of beliefs about mental illness, and by extension the cultural context, in shaping the patterns observed at the first stage. The first stage set out to test the hypothesis that:
1. African-Caribbean ethnicity will be associated, independently of potential confounders, with higher rates of compulsory admissions and police referrals, and lower rates of GP referrals

The second stage set out to address three related research questions:

1. Do African-Caribbeans' beliefs about mental illness differ from those of Whites?
2. Do beliefs about mental illness differ within the African-Caribbean group according to place of birth and/or age?
3. Do the beliefs evident among African-Caribbeans and Whites bear any relationship to the patterns of pathways to, and modes of contact with, mental health services observed in the first stage of the study?

Two brief comments are necessary at this point about the focus of the thesis. Two broad ethnic groups, African-Caribbeans and Whites, are taken as the starting point primarily because the issue this thesis aims to address is derived from research focusing on these two groups. The uncritical use of such broad ethnic categories is problematic, and many authors have pointed out the need for researchers to be clear about what such categories mean and how individuals have been ascribed to one or other of them (Singh, 1997; McKenzie & Crowcroft, 1994). This is dealt with in the final section of this introduction. The focus on first contact with mental health services among patients with a psychotic mental illness is intended to overcome some of the limitations of previous research. One of the key problems with much of this has been that patient samples have frequently included all diagnostic groups and those at different stages of their "illness careers", a strategy that makes it difficult to control for diagnosis and the effects of previous contacts with services on subsequent engagement. By focusing on first presentation patients with a psychotic illness, the diagnostic group most likely to be compulsorily admitted, this study both overcomes these problems and creates the basis for follow-up studies that can investigate service use over time.

1.1.3 Structure of the Thesis
The thesis falls into three parts. The first part reviews the literature that underpins the hypothesis and research questions set out above, and prepares the ground and rationale for the perspective and study design adopted. In this first part, Chapter 2 provides a comprehensive review of research focusing on pathways to, and mode of contact with, mental health services among African-Caribbeans and Whites. Chapter 3 makes the case for a broadening out of the methods and perspectives brought to bear on this issue. The vast body of research in the fields of sociology and anthropology concerned with the issue of health service utilisation
has, to date, been largely ignored in studies of pathways to mental health services and ethnicity. Very few papers make even passing references to this literature. This is regrettable, as the insights and methodological approaches of these disciplines, particularly the emphasis on help-seeking as a social process that is shaped by specific cultural contexts, have the potential to move research forward. Specifically, this body of work shows that culturally shaped beliefs about illness influence the process of interpreting and responding to symptoms. Chapter 4 considers more fully research that has directly considered beliefs about illness and mental illness. This wide ranging and diffuse body of work has been consistent in demonstrating that the cultural context of help-seeking, as operationalised in accounts of culturally shared beliefs, shapes pathways to, and interactions with, professional health services. The first part is, thus, necessarily wide-ranging in order that the diverse literatures that inform this thesis can be fully discussed. The second part of the thesis provides a rationale for the methodological approach adopted (Chapter 5) and describes the study design (Chapter 6). The third part of the thesis presents the findings from the two stages of the study. Chapter 7 presents and discusses results from the first stage, and Chapters 8 and 9, the most extensive, present and discuss findings from the second stage. In Chapters 7, 8 and 9 the findings from each stage are presented with limited reference to the other stage. It is in Chapter 10 that the two stages are brought together and the full implications of the findings, in relation to each other, are discussed, addressing the most important question - Do the beliefs evident among African-Caribbeans and Whites bear any relationship to the patterns of pathways to, and modes of contact with, services observed in the first stage of the study? The conclusion to the study addresses both the limitations of the study and the implications of the research for service development and future research.

Before moving on to the background literature, it is necessary to briefly discuss some of the key terms and concepts used throughout the thesis.

1.2 IMPORTANT TERMS AND CONCEPTS

1.2.1 Culture, Ethnicity and Race

The terms culture and ethnicity are often used interchangeably, along with race, thus obscuring the meaning of each. As Fernando (1991) has commented: "Race, culture and ethnicity are difficult to disentangle in practical situations; confusion between them is rife in many areas of thought" (p. 12). There is a vast literature addressing these concepts, and recently ethnicity has been the subject of much debate (for example, Cohen, 1999; Hall, 1996). These debates are not rehearsed here. This section draws on this literature, but only in so far as it allows for clarification of each concept for the purpose of this thesis. This section aims to: 1) set out briefly definitions for each of these terms; and 2) describe how ethnicity has been determined and assigned in each stage of the study.
A useful starting point in disentangling what is meant by culture, race and ethnicity is Fernando's (1991) summary table defining race, culture and ethnicity according to how each is characterised, determined and perceived (see Table 1.1).

Table 1.1. Race, culture and ethnicity (from Fernando, 1991, p. 11).

<table>
<thead>
<tr>
<th>Characterised by</th>
<th>Determined by</th>
<th>Perceived as</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td>Physical Appearance</td>
<td>Genetic Ancestry</td>
</tr>
<tr>
<td>Culture</td>
<td>Behaviour</td>
<td>Upbringing Choice</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Sense of Belonging</td>
<td>Social Pressures</td>
</tr>
<tr>
<td>Group Identity</td>
<td></td>
<td>Psychological Need</td>
</tr>
</tbody>
</table>

The idea that people can be separated into racial categories on the basis of physical appearance has a long history in the West. While Benedict (1942) identified six physical characteristics that are commonly used to distinguish racial groups, including eye colour, hair colour and form, shape of nose, and stature, it is skin colour that has most often been used as the characteristic dividing peoples into racial groups. While science has an unfortunate history of conducting research as if these distinguishing physical features marked and signified crucial differences between groups in terms of intellect, level of civilisation and so on, recent advances in genetics have established the spuriousness of the underpinning assumption that “races” are genetically and biologically homogenous. Population geneticists have demonstrated that: “The genetic differences between the classically described races of man are on the average only slightly greater than those which exist between nations within a racial group, and the genetic differences between individual human beings within a population are far larger than either of these” (Jones, 1981, quoted in Fernando, 1991, p. 16).

In short, skin colour and other physical characteristics do not determine biologically distinct racial groups. Nonetheless, the popular belief that people are separable into distinct groups on the basis of these characteristics persists and underpins ongoing racism. As Fernando (1991) puts it, “… though a biological myth, race continues to be a social reality” (p. 19).

Racial groups are, therefore, social constructs that sustain unfounded assumptions of the inherent inferiority of certain groups. The use of racial categories has now largely disappeared from scientific research and been replaced by the use of ethnicity, a more acceptable and benign term. However, researchers often categorise people into “ethnic” categories in such a way that these are indistinguishable from racial categories – the crude dichotomy between Black and White, for example (Cole et al, 1995). People from diverse cultural and ethnic backgrounds are consequently often grouped together on the basis
primarily of skin colour, with the underlying assumption that this marks an important and meaningful distinction that might explain an outcome of interest, for example, rates of compulsory admission.

Culture has been variously defined as: shared patterns of belief, feeling and adaptation that people carry in their minds (Leighton & Hughes, 1961); an organised group of ideas, habits and conditioned responses shared by members of a society (Linton, 1956); a pattern of shared behaviour characteristics of a society (Brody, 1964); and a blue print for living (Kluckholm, 1944). Fernando’s (1991) summary of culture as characterised by behaviour and attitudes and as determined by upbringing and choice shares much with these definitions. What is common to all is the basic idea that culture provides a set of socially shared guidelines or rules that shape and constrain beliefs, attitudes and behaviour. This should not imply culture is static or homogenous. Beliefs, attitudes and the like inevitably undergo modifications as individuals are exposed to and experience other cultural systems and ideas. As Helman (1994) has argued, while ethnic, religious and other groups in modern societies will “each have their own inherited cultural perspective” (p. 3), it is inevitable that in the process of migration and assimilation, or simply through exposure to other cultures within multi-cultural contexts, “many of these groups will undergo some process of acculturation whereby they incorporate some of the cultural attributes of the larger society [and of other groups]” (p. 3). This is an important point, particularly in terms of distinguishing between culture and ethnicity. While cultural heritage may form a significant component of ethnic identity (see below), it does not define it and those who perceive themselves as belonging to an ethnic group may well differ markedly in terms of the cultural reference points that inform their beliefs and actions. This warns against conflating culture and ethnicity and stresses the importance of investigating cultural differences within ethnic groups, a point particularly relevant to this thesis and the attempt to understand how beliefs about illness, and more generally the cultural context, shape responses to illness among the two broad ethnic groups. For the purposes of this thesis, then, culture is defined in terms of a collection of socially shared, though changeable, rules and constraints on belief and action that influence how individuals act on, interpret and give meaning to the environment. Beliefs about misfortune and illness, being central features of all cultures, provide a window into the types of rules and ideas that shape and constrain action. Indeed, Ware and Kleinman (1992) have suggested that illness beliefs can be one way of operationalising culture in research. A final point on culture. Given what has been said about the fluidity of culture and the potential for ethnic groups to embody diverse cultural traditions and beliefs, it cannot be assumed that all members of each of the ethnic groups will share the same beliefs about illness and misfortune: heterogeneity is to be expected, hence the second research question posed in the second stage of the study (see above).
Ethnicity comprises elements of race and culture. Yinger (1981) has argued that members of an ethnic group "are thought of by themselves and/or others to share a common origin and to share important segments of a common culture" (p. 10). Fernando (1991) has identified some of the inherent difficulties in defining ethnicity and ethnic groups:

"The bonds that bind together people of an ethnic group are often not clear cut; they are not definable in terms of physical appearance (race) or social similarity (culture) alone, although both may be involved. The overriding feature of an ethnic group is the sense of belonging together that the individuals feel; it is basically a psychological matter. This feeling may be promoted or even initiated by the way society at large perceives people." (p. 3-4)

Aspects of race and culture may, therefore, engender a sense of common identity that determines ethnicity. For example, as Fernando (1991) suggests, a sense of belonging may emerge from the shared experiences of discrimination in a racist society - emergent ethnicity. This is arguably a key factor that has driven the emergence of a Caribbean identity among migrants from the culturally diverse Caribbean islands to the UK. Therefore, while race and culture form part of ethnicity, it is the common identity forged from these that determines ethnic identity. Further, ethnicity is potentially fluid and changeable over time and space, as exposure to other contexts and cultures allows for the reformulation of individual identity. It is evident then that the use of fixed ethnic categories in cross-sectional research is problematic in that key components of ethnicity - sense of belonging and changability - are absent.

For the purposes of this thesis, this brief discussion of race, culture and ethnicity is important as background to how culture is understood throughout and how ethnicity has been ascertained and ascribed at each stage of the study. If the key component of ethnicity is a sense of belonging then this suggests that ethnicity can only accurately be determined by self ascription. Where this is not possible, it is essential that the basis on which ethnicity has been assigned to research subjects is both justified and made explicit and the limitations noted so that what the categories represent can be clearly understood (McKenzie & Crowcroft, 1996; Hutchinson & McKenzie, 1995). So, for the first stage of this study, in which data on self-ascribed ethnicity was not available for all patients, ethnicity was determined using place of birth and/or place of heritage. The African-Caribbean group, therefore, includes people born in the Caribbean and people whose parents or grandparents were born in the Caribbean. Patients of mixed African-Caribbean and other parentage were excluded. The White group includes people born in the UK, Ireland or Europe to White parents. The method of categorising ethnicity chosen for the first stage is pragmatic and thus limited in that it will
inevitably obscure within group differences and possibly wrongly classify people who would define their ethnicity differently. Still, this method of categorising respondents is justifiable on two grounds: 1) it is useful, for comparative purposes, to start with the ethnic categories used by previous researchers; and, 2) as data relating to self ascribed ethnicity was available for all respondents included in the second stage of the study, this has allowed a comparison between researcher ascribed and self-ascribed ethnicity for a sub-sample of the full cohort, thus enabling consideration of areas of discrepancy between the two. It is in the second stage, moreover, that within group differences are explored. In short, the limitations of the ethnic categorisations used in the first stage are acknowledged and, in the second stage, probed.

1.2.2 Psychosis

Psychiatry has traditionally distinguished between psychotic and neurotic mental illnesses, and while this distinction has become increasingly less central to classificatory systems, ICD-10 (WHO, 1992) and DSM-IV (APA, 1994), it remains very much in use in clinical practice and research. Wing (1978) provided the following definitions:

"A ‘psychotic’ state is one characterised by delusions or hallucinations, in which the individual is unable to differentiate his grossly abnormal thought processes from external reality and remains unaware of his deficiency. A ‘neurotic’ state is one in which the psychological abnormalities are much less severe, in the sense that they do not interfere with the discrimination between internal and external worlds and the individual is well aware that he [or she] has obsessions or phobias, though the knowledge may not help him [or her] to understand them.” (p. 44-45)

This is one of many attempts to define psychosis. The primary focus on delusions and hallucinations, with lack of awareness, makes it a relatively narrow definition. Less restrictive definitions include hallucinatory experiences that the sufferer realises are abnormal and, more broadly still, others include disorganised speech and grossly disorganised behaviour (APA, 1994). For the purposes of this thesis, psychotic mental illness is defined pragmatically and relatively broadly according to whether a person screens positive using the Screening Schedule for Psychosis (see Appendix 2)\(^1\). That is, a psychotic episode is diagnosed if a person experiences at least one of the following:

- Hallucinations or pseudo-hallucinations in any modality

\(^1\) The screen used was developed for this study and is purposefully over inclusive to ensure all possible cases of psychosis were included.
• Delusions
• Marked thought and speech disorder (e.g. incoherence, irrelevance, thought blocking, neologisms, incomprehensibility of speech) other than simple retardation or acceleration
• Marked psychomotor disorder (e.g. negativism, mutism or stupor, catatonic excitement, constrained attitudes or unnatural postures maintained for long periods) other than simple retardation or acceleration
• Emergence or marked exacerbation of bizarre and grossly inappropriate behaviour (e.g. talking or giggling to self, acts incomprehensible to others, loss of social constraints, etc.)

Or two of the following:

• Marked reduction or loss of interests, initiative and drive, leading to serious deterioration of the performance of usual activities and tasks
• Emergence of marked exacerbation of social withdrawal (active avoidance of communication with other people)
• Severe excitement, purposeless destructiveness or aggression
• Episodic or persistent states of overwhelming fear or severe anxiety
• Gross and persistent self-neglect

Psychotic symptoms most commonly occur in the schizophrenia spectrum disorders (F20-F29 in ICD-10 (see Box 1.1)), but they also occur in affective disorders (F30-F39 (psychotic codings) in ICD-10 (see Box 1.1)). All are rare. The lifetime prevalence of schizophrenia, for example, is between 0.5 and 1%, depending on whether it is defined broadly (F20-29, ICD-10) or narrowly (F20, ICD-10) (Murray, 1997), and the one year incidence is between 7 and 14 per 100,000 for narrowly defined schizophrenia (Jablensky et al, 1992). As already noted, reported rates of schizophrenia have been consistently higher for African-Caribbeans in the UK, with figures ranging from two times (Bhugra et al, 1997) to eighteen times (Harrison et al, 1988) those for Whites – differences that persist across generations. Further, when all psychotic illnesses are considered, the rates are similarly high (ÆSOP Study Team, 2002). The aetiology of psychosis, and specifically schizophrenia, remains unknown, though research does offer important clues. What seems clear is that the causal pathway to psychosis is multi-factorial, potentially involving genes, brain structure, bio-chemistry and a range of environmental risk factors, including birth complications and psycho-social stress (Dazzan & Murray, 1999). The emphasis given to each of these factors
varies from researcher to researcher and in recent years, with advances in genetics and brain imaging, biological explanations have become increasingly dominant in professional accounts of the aetiology of severe mental illness, with psychological and social factors relegated to a subsidiary role of triggering underpinning biological dysfunction (Warner, 2000). In broad and somewhat crude terms, most professional accounts fall within biopsychosocial or stress-diathesis models (Warner, 2000; Engel, 1977), in which some form of interaction between factors in these three domains (biological, psychological or social) or between environmental stress and biological vulnerability are posited to explain the onset of psychotic mental illness, differences coming in the emphasis placed on particular factors in relation to specific disorders (i.e. schizophrenia, manic-depressive psychosis, etc). Indeed, increasingly the possibility is being advocated that different factors may be operating in different individuals leading to a common end outcome of psychotic mental illness, in some biological dysfunction or neurodevelopmental impairment being key and in others psycho-social factors being more important. In relation to excess rates of psychosis among African-Caribbeans, for example, the view that this is accounted for by the more adverse social conditions within which many live is gaining increasing ground (Mallett et al, 2002; Hutchinson et al, 2002). Treatment for psychosis invariably involves anti-psychotic medication and, less often, psychologically and socially orientated therapy (Warner, 2000; Birchwood & Tarrier, 1994).

The foregoing provides a brief and somewhat crude overview of the professional concept of psychosis, with some general comments about causal theories. This serves two purposes. Firstly, it provides a working definition of psychosis. Secondly, it provides a brief outline of professional theories of aetiology and treatment approaches, bearing in mind the important caveat that within these broad parameters there are substantial differences in emphasis among psychiatrists. This thesis is primarily concerned with how those who have been diagnosed as suffering from a psychotic illness conceptualise the unusual experiences and behaviours that lead psychiatrists to make such diagnoses. As such, the thesis contrasts, to borrow a dichotomy from anthropology, etic (outsider or, in this case, psychiatric) understandings with emic (insider or, in this case, patient) understandings (Skultans & Cox, 2000b) in order to assess whether discrepancies between the two hinder early and voluntary help-seeking among the two broad ethnic groups, African-Caribbeans and Whites. This brief outline of the professional concept is useful, therefore, as a basis from which to compare such a perspective with lay beliefs.
### Box 1.1. ICD-10 classifications of psychotic disorders.

<table>
<thead>
<tr>
<th>F20- F29</th>
<th>Schizophrenia, schizotypal and delusional disorders</th>
<th>F30- F39</th>
<th>Mood (affective) disorders (psychotic codings)</th>
</tr>
</thead>
<tbody>
<tr>
<td>F20</td>
<td>Schizophrenia</td>
<td>F30</td>
<td>Manic Episode</td>
</tr>
<tr>
<td>F20.0</td>
<td>Paranoid Schizophrenia</td>
<td>F30.2</td>
<td>Mania with psychotic symptoms</td>
</tr>
<tr>
<td>F20.1</td>
<td>Hebephrenic Schizophrenia</td>
<td>F31</td>
<td>Bipolar affective disorder</td>
</tr>
<tr>
<td>F20.2</td>
<td>Catatonic Schizophrenia</td>
<td>F31.2</td>
<td>Bipolar affective disorder, current episode manic with psychotic symptoms</td>
</tr>
<tr>
<td>F20.3</td>
<td>Undifferentiated Schizophrenia</td>
<td>F31.5</td>
<td>Bipolar affective disorder, current episode severe depression with psychotic symptoms</td>
</tr>
<tr>
<td>F20.4</td>
<td>Post-schizophrenic depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F20.5</td>
<td>Residual Schizophrenia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F20.6</td>
<td>Simple Schizophrenia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F20.8</td>
<td>Other Schizophrenia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F20.9</td>
<td>Schizophrenia, unspecified</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F21</td>
<td>Schizotypal Disorder</td>
<td>F32</td>
<td>Depressive episode</td>
</tr>
<tr>
<td>F22</td>
<td>Persistent Delusional Disorders</td>
<td>F32.3</td>
<td>Severe depressive episode with psychotic symptoms</td>
</tr>
<tr>
<td>F23</td>
<td>Acute and Transient Psychotic Disorders</td>
<td>F33</td>
<td>Recurrent depressive disorder</td>
</tr>
<tr>
<td>F24</td>
<td>Induced Delusional Disorder</td>
<td>F33.3</td>
<td>Recurrent depressive disorder, current episode severe with psychotic symptoms</td>
</tr>
<tr>
<td>F25</td>
<td>Schizoaffective Disorders</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F25.0</td>
<td>Schizoaffective Disorder, manic type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F25.1</td>
<td>Schizoaffective Disorder, depressive type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F25.2</td>
<td>Schizoaffective Disorder, mixed type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F25.8</td>
<td>Other Schizoaffective Disorders</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F25.9</td>
<td>Schizoaffective Disorder, unspecified</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F28</td>
<td>Other Non-organic Psychotic Disorders</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F29</td>
<td>Unspecified Non-organic psychosis</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
PART I

ORIENTATIONS
ORIENTATIONS (I)
NEGATIVE PATHWAYS TO PSYCHIATRIC CARE AND ETHNICITY
In the UK, people with a mental illness can access specialist mental health services via a number of routes or points of referral, including GPs, accident and emergency departments, social and housing agencies, the police, prisons, and the courts. Mental health care is provided both in community settings, usually via community mental health teams, and in hospitals. Most contacts with mental health services are voluntary, but various sections of the Mental Health Act 1983 (MHA) also provide for the compulsory detention in hospital of people suffering from a mental disorder, who do not accept voluntary admission, and who pose a threat to themselves or others, or for whom detention is necessary to prevent a deterioration in mental health. This basic outline of referral routes and types of contacts with mental health services is illustrated in Figure 2.1 and the main MHA 1983 sections are set out in Table 2.1.

Figure 2.1. *Common routes to psychiatric care.*

<table>
<thead>
<tr>
<th>GP</th>
<th>Social Services, etc.</th>
<th>A &amp; E</th>
<th>Police</th>
<th>Courts / Prisons</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Community Patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Voluntary Patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Compulsory Patient</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 2.1. *Main sections of the MHA 1983 allowing for the compulsory detention of patients.*

<table>
<thead>
<tr>
<th>Part</th>
<th>Section</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>II (Civil)</td>
<td>2</td>
<td>Admission for assessment</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Admission for treatment</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Emergency admission for assessment</td>
</tr>
<tr>
<td></td>
<td>5(2)</td>
<td>Doctor's holding power (for in-patients)</td>
</tr>
<tr>
<td></td>
<td>5(4)</td>
<td>Nurse’s holding power (for in-patients)</td>
</tr>
<tr>
<td>III (Forensic)</td>
<td>35</td>
<td>Remand to hospital by courts for a report</td>
</tr>
<tr>
<td></td>
<td>36</td>
<td>Remand to hospital by courts for treatment</td>
</tr>
<tr>
<td></td>
<td>37</td>
<td>Hospital order by court for treatment</td>
</tr>
<tr>
<td></td>
<td>47</td>
<td>Transfer to hospital for sentenced prisoners</td>
</tr>
<tr>
<td></td>
<td>48</td>
<td>Transfer to hospital for remand prisoners</td>
</tr>
<tr>
<td></td>
<td>136</td>
<td>Removal of people from public places by police to a place of safety</td>
</tr>
</tbody>
</table>
By far the most common route to mental health services is via a GP (Goldberg & Huxley, 1980). The structure of professional health care services in the UK is such that GPs assume a key role as gatekeepers to secondary services. Ideally, GPs should be the initial point of contact for all illnesses not requiring emergency treatment. GPs, in this model, act as a filter to secondary services, identifying those who need specialist care and making referrals as necessary. Early detection of illness and treatment may be associated with positive outcomes (Birchwood et al 2000), and from this perspective early contact with a GP and referral represents the most favourable route to specialist health care services. Other routes to secondary health care operate in times of crisis and emergency, in situations where immediate intervention is necessary. In relation to psychiatry, these points of access to secondary services are wider than for other illnesses, including as they do criminal justice agencies and social and housing services. Patients who access mental health services via these routes are likely to have experienced symptoms for longer periods prior to contact and are more often admitted to hospital compulsorily (Harrison et al, 1989). Not surprisingly these less favourable pathways to mental health services are associated with poor outcomes (McKenzie et al, 1995), as noted in the introduction, making the promotion of early help-seeking via primary care services a legitimate component of mental health care delivery.

There is a considerable literature mapping variations in pathways to, and mode of contact with, mental health services between ethnic groups in the UK, much of it focused on differences between African-Caribbeans and Whites. This chapter provides a detailed review of research in this area, addressing specifically the questions: a) what are the reported differences in pathways to, and modes of contact with, mental health services between African-Caribbeans and Whites; and b) what explanations have been suggested for the observed variations. There is a much greater consensus in relation to the first question than the latter, and the final section of this chapter goes on to consider why it is that, despite over twenty years of research, the reasons for the apparent differences in routes to care between ethnic groups are still poorly understood. The literature included in this review is restricted to that reporting original data comparing African-Caribbeans (or more generally, Black patients) and Whites according to pathways into, and mode of contact with, mental health services. Relevant literature was identified using three main sources. Firstly, the bibliographic databases Medline, PsycINFO and ISI Web of Science were searched using the keywords: “pathways”, “ethnicity”, “African-Caribbeans”, “compulsory admission” and “Mental Health Act”. Secondly, key review papers, collections of papers and published bibliographies in this field were used to identify further research papers (Bhui & Bhugra, 2002a; Bhugra & Cochrane, 2001; Spector, 2001; Bhugra, 2000; Bhugra & Bahl, 1999; Wall, Churchill et al, 1999; Jarvis, 1998). Thirdly, the references of papers identified using the first two methods
were scrutinised for further potential papers. Fifty papers were identified and the key findings from each of these are summarised in Appendix 1.

2.1 AFRICAN-CARIBBEANS, PATHWAYS TO CARE AND THE MENTAL HEALTH ACT 1983 (1): What is the evidence?

Variations in routes taken to, and mode of contact with, psychiatric services have been the focus of research since at least the Second World War. Hollingshead and Redlich (1958), in their classic study of social class and mental illness in the USA, found psychotic patients from social class V were significantly more likely than those from social classes I & II to enter care via non-medical agencies, particularly via the police, and to be compulsorily admitted to hospital. Research mapping differences between ethnic groups in terms of pathways to care has similarly focused on source of referral to mental health services, i.e. whether via a GP or the police, and mode of contact with services, i.e. whether compulsory or not. The early studies comparing pathways to care between African-Caribbeans and Whites found similar variations to those of Hollingshead and Redlich (1958), namely an excess of compulsory admissions and police involvement among African-Caribbeans (Harrison et al, 1984; Littlewood & Lipsedge, 1981a, 1981b; Rwegellera, 1980). Since then there has been a steady growth of evidence confirming and expanding these general findings (Appendix 1). At each stage, the balance of evidence points towards more negative outcomes for African-Caribbeans and other Black minority groups compared to Whites, the overall impression being that African-Caribbeans have a much more coercive relationship with psychiatric services.

2.1.1 Source of Referral to Services

The early research considering patterns of service use in ethnic minorities, particularly African-Caribbeans, emerged in the context of growing evidence showing excess rates of schizophrenia and other psychotic illnesses amongst African-Caribbeans. Rwegellera (1980), for example, as part of research primarily geared towards identifying rates of mental illness among different ethnic groups, found that African-Caribbeans were less likely to be referred by a GP and more likely to be brought to mental health services by the police or a Mental Welfare Officer. This corresponded with early research focusing on use of Section 136 of the MHA 1959, which, as in the MHA 1983, provided for the removal of any person in a public place to a place of safety if the person was suspected by the police to be suffering from a mental illness. This work showed higher than expected police referrals of patients from ethnic minority groups, most notably African-Caribbeans (Sims & Symonds, 1975). Interestingly, the emerging evidence of high rates of police involvement and low rates of GP referral among African-Caribbeans was consistent across different areas (Fahy, 1989; 1987), and subsequent studies have confirmed these general findings in London (Fahy et al, 1987),
Nottingham (Owens et al., 1991), Bristol (Harrison et al., 1984), Manchester (Thomas et al., 1993) and Birmingham (Birchwood et al., 1992). Of the 14 studies identified in the literature search that reported rates of police involvement, in only two were there no significant differences between White and African-Caribbean or Black patients (Moodley & Perkins, 1991; Macmillan & Johnson, 1987). Likewise, in only one of the nine studies reporting rates of GP involvement were there no significant differences (Commander et al., 1999). Not surprisingly, GP referral and police referral are negatively correlated (Cole et al., 1995): they are the flip side of the same coin, namely willingness or otherwise to seek help. This is further reflected in the consistently reported association between GP referral and voluntary admission (for example, Burnett et al., 1999; Owens et al., 1991) and police referral and compulsory admission (for example, Cole et al., 1995; Gunn et al., 1991; Sims & Symonds, 1975).

2.1.2 Mode of Contact with Services

A more substantial body of research has compared rates of compulsory admission among African-Caribbeans, other Black ethnic groups and Whites. The early finding by Littlewood and Lipsedge (1981a) that African-Caribbeans and West Africans were twice as likely to have been admitted to hospital under a section of the MHA 1959 has been replicated in a number of studies that have used varying methodologies and been conducted in different contexts. McGovern and Cope (1987b), for example, used data on all patients admitted to hospital in an area of Birmingham over a four year period to calculate the rates of compulsory admission under a civil section of the MHA 1983 per 10,000 of the population at risk. They found that rates for African-Caribbeans (69.7 per 10,000 for Caribbean born and 73.6 per 10,000 for UK born) were significantly higher than for Whites (11.5 per 10,000). Owens et al. (1991), in their study of consecutive hospital admissions over a two-year period in Nottingham, found that 46% of African-Caribbeans were admitted formally compared to 10% of Whites. Moodley & Perkins (1991) observed similar patterns in a much smaller study in London, as did Thomas et al. (1993) in Manchester. Harrison et al. (1989), in a carefully designed study of patients with a first episode of psychosis, found that 45% of African-Caribbean were admitted compulsorily compared to 21% of patients from a non-African-Caribbean sample. These figures are remarkably similar to those in a study of consecutive hospital admissions over a six month period by Singh et al. (1997) (43.2% African-Caribbean v. 18.8% White). More recently, similarly excessive rates of compulsory admission have been found among African-Caribbeans in audits of bed use and analyses of official statistics (Audini & Lelliott, 2002; Koffman et al., 1997; Bebbington et al., 1994). The most recent of these (Audini & Lelliott, 2002) used existing data sets from 26 regions, covering a combined population of 9.2 million, to examine detentions under Part II of the MHA 1983. This showed significant
differences in rates of episodes of detention between Black (450 per 100,000) and Asian (324 per 100,000) groups and Whites (68 per 100,000). While these studies relate to all African-Caribbeans, many have further shown that rates of compulsory admission are higher still among young African-Caribbean men (for example, Audini & Lelliott, 2002; Thomas et al, 1993; McGovern & Cope, 1987b), as are rates of police involvement (for example, Pipe et al, 1991). Of the 29 studies identified in the literature search that reported rates of compulsory admission for Whites and African-Caribbeans or other Black ethnic groups, 22 have found significantly higher rates of compulsory detention among African-Caribbeans.

A small number of studies have specifically considered admissions under Part III of the MHA 1983. Admissions under this part of the Act shed light on the relative numbers from each ethnic group who are admitted to hospital whilst involved in the criminal justice system. These studies in general conform to the overall impression gained from research in this area that African-Caribbeans have a more coercive relationship with psychiatric services. Indeed, differences between African-Caribbeans and Whites are even greater in studies that have considered admissions under Part III of the Act. McGovern & Cope’s (1987b) study found rates for admissions under Part III to be 41.1 per 10,000 population at risk for Caribbean-born patients, 15.2 per 10,000 for UK-born patients of Caribbean parents, and 3.7 per 10,000 for Whites. A follow-up study of patients with a diagnosis of schizophrenia by McGovern et al (1994) did not show a significant difference in rates of admission under Part II of the MHA 1983, but it did show higher rates of admission under Part III of the Act for Black patients (13% Black v. 2% White). Black patients were also more likely to have been convicted and/or imprisoned during the follow-up period, a finding that is indicative of higher levels of contact in general between Black ethnic minorities and the criminal justice system.

This is again apparent in studies of transfers, or of patients requiring transfer, from prison to psychiatric hospitals under both Sections 47 and 48 of the MHA 1983 (Bhui et al, 1998; Banerjee et al, 1995; Anderson & Parrott, 1995) and in those studies of the prevalence of mental illness among prison populations (Bermingham et al, 1996; Brooke et al, 1996; Mitchison et al, 1994; Gunn et al, 1991).

2.1.3 Admissions to Secure Psychiatric Facilities

Research has further shown that African-Caribbeans and other Black minorities are more often admitted to secure psychiatric facilities than are Whites (Commander et al, 1997a; Koffman et al, 1997). This holds at each stage of increasing security, and as with compulsory admissions and police involvement, is more pronounced for young Black men. Moodley & Thornicroft (1988), for instance, found that all African-Caribbean men (n = 13) included in their sample of 100 consecutive compulsory admissions were detained in locked wards compared to 56% of White men. A study of in-patient violence by Noble and Rodger (1989)
revealed an excess of African-Caribbeans in locked wards in both a violent group (37.1% African-Caribbean v. 15.7% White) and a non-violent control group (52.2% v. 14%). Strikingly, the differences are more prominent in the non-violent group, suggesting the excess of African-Caribbeans in locked wards was not a function of acts of in-patient violence. Murray (1996) conducted a census of all patients in medium secure facilities on a single day in 1991 and found that African-Caribbeans were in general over represented, comprising 17.5% of all in-patients. This overall figure, however, masked even higher proportions of African-Caribbeans in medium secure facilities in inner-London, where 40% of all medium secure in-patients were African-Caribbean, the figure rising to 75% in one unit. Similarly, Coid et al (2000), in a study of prevalence rates of treated mental disorder in different ethnic groups compulsorily admitted to secure forensic psychiatric services, found that standardised admission rates were almost six times higher for Black male patients (473 Black men v. 85 White men) and three times higher for Black female patients (282 Black women v. 85 White women). This pattern persists through to the high security hospitals, with a number of studies showing higher than expected numbers of African-Caribbeans and other Black minorities among in-patients (Shubsachs et al, 1995; Naismith & Coldwell, 1990).

2.1.4 Summary
Research considering pathways to, and mode of contact with, mental health services in different ethnic groups has been predominantly concerned with three stages and outcomes:

- Source of referral to psychiatric services, including use of Section 136 by the police
- Mode of contact with psychiatric services
- Admissions to secure psychiatric facilities

Across all three areas the findings are remarkably consistent. Of the 50 papers identified in the literature search, in 45 there are differences between African-Caribbeans, other Black minorities and Whites at one or more of these three points of engagement with services: in other words, 90% of the research in this area indicates that African-Caribbeans and other Black minorities have, at some point, more negative and coercive interactions with psychiatric services than the White majority.

2.2 AFRICAN-CARIBBEANS, PATHWAYS TO CARE AND THE MENTAL HEALTH ACT 1983 (2): Why are there differences?
Proposed explanations of the consistent findings that African-Caribbeans have a more coercive relationship with mental health services can be grouped into three categories: 1)
those focusing on clinical characteristics, mainly diagnosis and clinical presentation; 2) those focusing on racism in the delivery of services; and 3) those implicating wider social and cultural processes.

2.2.1 Interpreting the Evidence: patient characteristics v. racism

The earliest theories of why African-Caribbeans followed more negative routes to care focused on diagnosis and clinical presentation (Rwegellera, 1980). A diagnosis of psychosis is associated with police involvement and compulsory admission (Gray et al., 1997; Szumukler et al., 1981) and, as most of the early research was of all hospital admissions, irrespective of diagnosis, this raised the possibility that the reported excess of African-Caribbeans in these areas was a function of higher rates of schizophrenia and other psychoses in this group (Bhugra et al., 1997; Harrison et al., 1988). Studies that have controlled for diagnosis have produced conflicting results, some showing ethnicity to be a predictor of compulsory admission independent of diagnosis (Koffman et al., 1997; Davies et al., 1996; Thomas et al., 1993; Perkins & Moodley, 1993; Littlewood & Lipsedge, 1981a; Moodley & Perkins, 1991) and others finding that the effect of ethnicity was reduced or no longer significant after controlling for diagnosis (Johnson et al., 1998; Bebbington et al., 1994). Studies suggesting diagnosis is the primary predictor of compulsory admission are certainly fewer than those implicating ethnicity, and on balance it appears that while taking account of diagnosis may serve to lessen the observed differences, an excess of psychosis among African-Caribbeans cannot alone explain the repeated findings. This conclusion is supported by those studies that have considered only patients with a psychotic illness, and, with the exception of two recent studies of patients with a first episode of psychosis that will be discussed below (Burnett et al., 1999; Cole et al., 1995), these have invariably repeated the findings of higher rates of police involvement and compulsory admission among African-Caribbeans and other Black minorities (Commander et al., 1999; Takei et al., 1998; McKenzie et al., 1995; McGovern et al., 1994; Chen et al., 1991; McGovern & Cope, 1991; Harrison et al., 1989). More attention has consequently focused on differences in clinical presentation.

Early research found evidence to suggest African-Caribbeans presented as more disturbed than Whites (Rwegellera, 1980), and subsequent studies have produced similar results. Dunn and Fahy (1990), for instance, found that a violent presentation was more common among African-Caribbean men subject to Section 136 in their study of consecutive police referrals in London. Similarly, Pipe et al. (1991) reported that young Black patients were more likely to be perceived as threatening and disturbed and more often denied illness. In an audit of hospital in-patients in two London boroughs over a six-month period, Bebbington et al. (1994) found, using log-linear modelling, that the most parsimonious model of predictors of compulsory admission included only two factors: diagnosis and challenging
behaviour, though a second model did show a mild effect for ethnicity. Evidence that the over-representation of African-Caribbeans in restrictive sectors of the mental health system is due to greater disturbance at presentation is more substantial than that for diagnosis alone, but it is still equivocal. At least as many studies have failed to find that disturbed presentation significantly affects the observed relationship between ethnicity and outcomes in any of the areas noted above: source of referral, mode of admission, and location of in-patient care. Owens et al (1991), for instance, found no difference between Whites and African-Caribbeans in violent, disturbed or bizarre behaviour prior to admission, and Davies et al (1996) reported that only three factors independently predicted compulsory admission in their sample of consecutive admissions: Black Caribbean ethnicity, Black African ethnicity and living alone.

Another feature of clinical presentation that has attracted attention in relation to ethnic variations in pathways to care is that of patient insight into illness. There is a body of work showing a relationship between ethnicity, compulsory admission and poor insight, with poor insight being viewed primarily as an indicator of a worse clinical presentation. Moodley and Perkins (1991), in a small study of pathways to care in inner-London, found that 32% of African-Caribbeans did not believe they had a problem compared to none of the Whites. Pipe et al (1991) also reported that Black patients more often denied illness, and Commander et al (1999) found African-Caribbeans had lower rates of self-perceived illness. Similar results have been reported by Perkins and Moodley (1993) and Johnson and Orrell (1996), and a follow-up study by van Os et al (1996) suggested a more general connection between poor insight and compulsory admission.

Interpreting the findings relating to disturbed presentation and insight has not, however, been straightforward. In relation to insight, for example, studies have invariably used crude, all or nothing, measures of insight that mean it is not possible to determine whether denial of illness is a function of the underlying illness or a reflection of different explanatory models of distress employed by patients from minority ethnic groups. Certainly, it is not possible to conclude from this research that denial of illness, as measured in these studies, is evidence of a more severe illness. The specific problem of interpreting research regarding insight is paralleled in relation to findings concerning clinical presentation in general. In short greater levels of actual or perceived disturbance among African-Caribbeans could be indicative of one or more of the following: a) a more severe illness at presentation; b) more externalised idioms of distress among African-Caribbeans creating the impression of a more severe illness at presentation; and c) racial stereotyping, leading professionals to wrongly construe African-Caribbeans as threatening and disturbed. Each of these possibilities has been advocated (Griffith, 1983; Littlewood and Lipsedge, 1981b; Rwegellera, 1980) but the available evidence says very little about whether one or all of these
reflect what happens at the point of contact between African-Caribbeans and predominantly White psychiatrists and other professionals.

The latter of the three possible interpretations raises the question of racism in mental health service delivery and its role, if any, in explaining the greater use of coercion among African-Caribbeans and other Black minorities. There is some evidence that White psychiatrists and other professionals do stereotype Black patients. Lloyd and Moodley (1990), for example, found that mainly White staff frequently perceived Black schizophrenic patients as "big, dangerous and chronically psychotic" (p.907). Lewis et al (1990) found that psychiatrists did stereotype Black people presenting with a psychosis as more likely to become violent and more likely to need neuroleptic medication. More in-depth qualitative research conducted by Browne (1996) has added to this. In this study, Browne explored professional and ex-user perceptions of race in relation to the process of compulsory admission to hospital, using semi-structured interviews. This qualitative data was supplemented with an examination of case records and administrative data. The statistics confirmed previous research suggesting the relationship between Black patients and psychiatric services is more coercive. The qualitative data revealed common stereotypes among professionals, including police officers, approved social workers, GP's and psychiatrists, of Black people as inherently dangerous, and it further suggested that these stereotypes were influencing decisions. A number of commentators, Fernando (1991) prominent among them, have taken this a step further and argued that the greater use of coercion in interventions with Black patients is one aspect and consequence of the deep-seated racism inherent in psychiatry and Western society. From this perspective both the over-diagnosis of schizophrenia and the excessive use of coercive interventions to manage Black distress are products of a racist psychiatry, based on White Western ethnocentric notions of normality and abnormality. This analysis is to a large extent historical and does not easily suggest research projects that can investigate these assertions. For Fernando the concentration of research on these questions is in fact part of the process of constructing Black people as deviant and problematic and so should be resisted.

The nature of Fernando's analysis brings it in to conflict with the methods and perspectives of psychiatric research, ensuring an impasse in the debate about racism, clinical presentation and compulsory admission. That body of work investigating the assumptions and attitudes of White professionals towards ethnic minority patients offers only indirect evidence for stereotyping as a factor in explaining the more coercive relationship African-Caribbeans have with mental health services. It is the ambiguity of research evidence on this question and the widely differing perspectives of those involved in analysing this issue, that has underpinned the polarisation of explanations. That said, there have been limited attempts to speculate about the role of wider social and cultural factors influencing pathways to care in
different ethnic groups, and these suggest ways of moving forward the polarised debate sketched above.

2.2.2 Alternative Hypotheses: the potential role of social and cultural factors

There have been three interrelated explanations proposed in the literature that merit further discussion as they move beyond questions of clinical presentation and racism and begin to acknowledge the potential role of social and cultural factors in shaping patterns of help-seeking. These are explanations in terms of: a) social isolation; b) the role of the family; and c) beliefs about mental illness.

A role for social isolation in predicting negative pathways to care and compulsory admission was first suggested in an early study by Szmukler and colleagues (Szmukler et al, 1981; Szmukler, 1981). They found that a number of factors indicative of social isolation and dislocation, such as being unemployed, living alone, and having few social contacts, were significantly more common among compulsory patients than among voluntary patients. The hypothesis arising from this, that lack of social contacts reduces the visibility of disturbance, delays help-seeking and consequently increases the risk that referral and contact will be compulsory, is certainly plausible. While Szmukler et al (1981) did not report ethnic differences in rates of compulsory admission, the fact that African-Caribbeans are more likely to be socially isolated and disadvantaged compared to the White majority means this is one possible determinant of differences between the two groups (Modood et al, 1997).

Of particular interest in relation to this are two recent studies that have considered pathways to care in patients with a first episode of psychosis, both of which have found no association between ethnicity and compulsory admission (Cole et al, 1995; Burnett et al, 1999). The factors significantly associated with compulsory admission in Cole et al's (1995) sample were: living alone, living in public housing, absence of GP or family/friends involvement in the pathway and living away from family. Only absence of GP or family/friends involvement remained significant after other factors were controlled for using logistic regression analysis. Burnett et al (1999) similarly found that sociodemographic and service related factors were the most important in pathways to care at first contact. More interestingly still, this study also included an analysis of data from the Camberwell Register, which recorded all contacts with in-patient and outpatient psychiatric services of people living in the Camberwell Health District between 1965 and 1984. This confirmed the finding that there were no ethnic differences in rates of compulsory admission at first contact, but further analysis showed that there was an excess of compulsory re-admissions among African-Caribbeans. Together these studies suggest two conclusions. Firstly, they indicate that social isolation is a significant factor predicting compulsory admission, particularly at first contact. It is pertinent to recall that of the three factors found to be independently associated with compulsory admission in
the study by Davies et al (1996) one was living alone. Secondly, these studies suggest that ethnic differences in pathways to care and rates of compulsory admission develop over time in the course of repeated contacts with psychiatric services, which raises the possibility that African-Caribbeans have more negative experiences of services at first contact. This finding needs replication as other first onset studies have reported significant differences (Harrison et al, 1989). Nonetheless, these studies have emphasised the need for research to separate out first and subsequent admissions and for a greater focus on broader social determinants of pathways to care in different ethnic groups. What is particularly interesting about the hypotheses that have emerged from this research is that they allow room for stereotyping, racism and clinical presentation as factors shaping initial interactions between African-Caribbeans and mental health services, which in turn may lead to dissatisfaction and distrust that hinders voluntary engagement among this group subsequent to first contact.

Families are often involved in seeking help with, or for, a relative (Cole et al, 1995), which has led to speculation about the role families play in promoting or hindering early help-seeking among different ethnic groups (Owens et al, 1991; Harrison et al, 1989). Harrison et al (1989), in their study of patients with a first episode of psychosis, reported that African-Caribbeans experienced overall longer periods of untreated symptoms. Such delays may mean that African-Caribbeans present at a point when their illness is more severe and/or they may reflect a lack of willingness to engage with mental health services. A number of possibilities were proposed by Harrison et al (1989) to explain their findings, all related to how families and patients responded to the early signs of illness. Firstly, there are some indications that African-Caribbean communities more heavily stigmatise mental illness and this could create a reluctance to seek help until crises develop (Wolff et al, 1996a; 1996b). It may mean that African-Caribbean families interpret early symptoms and behavioural disturbance in legal rather than medical terms, leading them to call on the police more often as a first resort. This has some support from Owens et al (1991) who found that police contacts among African-Caribbeans were often initiated by family and friends, in contrast to White families who would more often seek help from a GP in the first instance. Secondly, and related to the first possibility, Harrison et al (1989) further noted a tendency among African-Caribbean families to actively avoid a relative with a developing mental illness, a response that created and exacerbated social isolation. By delaying contact with services and increasing social isolation these types of responses may be a component of the processes that underpin ethnic differences in pathways to care.

There have been frequent allusions in the literature to the possibility that many African-Caribbeans hold beliefs about mental illness and appropriate treatments that work against active help-seeking from professional services (Jarvis, 1998; Harrison et al, 1989). That is, African-Caribbeans may more often conceptualise mental illness in non-medical
terms, as stress or pressure or as the result of supernatural or spiritual forces, with the likely outcome that help is sought from alternative sources, such as traditional healers, churches, and family and friends. As with stigma, this would help explain Harrison et al’s (1989) and Owens et al’s (1991) findings regarding treatment delays and family responses, as well as the research showing fewer referrals via GPs. The only two studies that have attempted to investigate beliefs about mental illness in African-Caribbeans and pathways to care have not supported the hypothesis that beliefs shape pathways (McGovern & Hemmings, 1994; Morley et al, 1991), but these studies were extremely limited both in terms of number of subjects and methodology. This will be discussed more fully in subsequent chapters.

2.2.3 Summary
The three factors discussed above – social isolation, family responses and beliefs about mental illness – are evidently interrelated, each one potentially shaping, at the same or different stages, the patterns of service use and access observed in the research to date. However, none of these processes or factors has been the subject of detailed research. Their relevance to ethnic differences in pathways to care in the UK remains speculative. What work has been done has centred on mapping patterns of service access and use among African-Caribbeans and Whites, and the findings from this have proved notably consistent. This research has, however, been much more equivocal about what factors might explain these patterns, with ambiguity in the evidence creating a fertile context for polarised and highly political debates about the role of racism in the mental health system. The sum result has been limited progress in understanding the processes that give rise to ethnic variations in pathways to care, with the concomitant consequence that few concrete proposals have been formulated for service reforms that may reduce the number of Black patients experiencing mental health services as primarily coercive.

2.3 AFRICAN-CARIBBEANS, PATHWAYS TO CARE AND THE MENTAL HEALTH ACT 1983 (3): Why are the differences poorly understood?
The primary reason why ethnic differences in pathways to, and mode of contact with, mental health services are still poorly understood, despite 20 years of research and at least 50 published papers, is to do with the way in which this issue has been researched. This critique falls into two parts. The first relates to the general approach to research in this area, and the second relates to specific issues in study design that have limited comparability across studies.

Research in this area has been conducted almost exclusively by psychiatrists utilising epidemiological and survey methods. These approaches have generally involved two steps. The first is to enumerate rates of police involvement, GP referral, compulsory admission and
the like. This establishes patterns in different ethnic groups. The second step uses quantified
data collected from case notes (Pipe et al, 1991), ward staff (Owens et al, 1991) and, less
often, interviews with patients and relatives (Burnett et al, 1999) to explore, and test
hypotheses relating to, correlations between the outcomes of interest (source of referral, mode
of admission, and so on) and sociodemographic and clinical characteristics. The basic
assumption is that observed associations will reveal, or at least hint at, the factors determining
police referral, compulsory admission, and the like. This approach creates a static, one
dimensional model of pathways to care. Selected, fixed variables are tested for associations
with a single end outcome, be it compulsory admission or GP referral or whatever, usually at
a one off point in time. Skrabanek (details from Bhopal, 1997) has referred to this
‘contingencies’ approach (Pescosolido, 1991) as ‘black box’ epidemiology. That is,
epidemiology where the causal mechanism behind an observed association (i.e. between
African-Caribbean ethnicity and compulsory admission) remains hidden and unknown
(“black”), but the inference is that the causal mechanism is within the association (i.e.,
something about African-Caribbeans, such as clinical presentation, causes the increased rate
of compulsory admission) (Bhopal, 1997). However, as has been shown, the inferences that
can be drawn about the meaning of associations between ethnicity and pathways to care are
numerous and it is this that sustains conflicting and often polarised explanations.

Related to this, there have been few attempts to develop or utilise theoretical models
that could help bring research findings in this area together and from which further, clearer
research questions could be developed. The only exception here is the attempt by
Commander et al (1999) and lately Bhui and Bhugra (2002a) to employ and extend Goldberg
and Huxley’s (1992; 1980) levels and filters model of pathways to care. This model
conceptualises the pathway to care in terms of five levels extending from the community to
in-patient care, with entry to each level being determined by one of four filters. Through a
series of research projects Goldberg and Huxley (1992; 1980) estimated the prevalence of
mental disorder at each level. The model is illustrated in Figure 2.2.
Figure 2.2. Goldberg & Huxley’s ‘Levels and Filters Model of Pathways to Care’ (1992).

<table>
<thead>
<tr>
<th>Level 5</th>
<th>Psychiatric In-patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5.71 per 1000 per year*</td>
</tr>
</tbody>
</table>

**Filter 4**

Admission to Psychiatric Beds

<table>
<thead>
<tr>
<th>Level 4</th>
<th>Total Morbidity – Mental Illness Services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>23.5 per 1000 per year*</td>
</tr>
</tbody>
</table>

**Filter 3**

Referral to Mental Illness Services

<table>
<thead>
<tr>
<th>Level 3</th>
<th>Mental Disorders Identified by Doctors (Conspicuous Psychiatric Morbidity)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>101.5 per 1000 per year*</td>
</tr>
</tbody>
</table>

**Filter 2**

Ability to Detect Disorder

<table>
<thead>
<tr>
<th>Level 2</th>
<th>Total Mental Morbidity – Attendees in Primary Care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>230 per 1000 per year*</td>
</tr>
</tbody>
</table>

**Filter 1**

Illness Behaviour

<table>
<thead>
<tr>
<th>Level 1</th>
<th>The community</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>260-315 per 1000 per year*</td>
</tr>
</tbody>
</table>

* Annual Period Prevalence Rates

Commander et al (1999) added a sixth level, compulsory in-patient admission, to make the model more applicable to the focus of research on ethnic minorities and pathways. Recently, Bhui and Bhugra (2002a) have attempted to modify this model further to make it more applicable to what is known about pathways to care in different ethnic groups. Further stages are added at each level to, in their words, “reflect the appraisal, expression and presentation of distress in primary care, as well as the appraisal of community distress” (Bhui & Bhugra, 2002a, p. 27). These modifications are illustrated in Figure 2.3.
While this usefully broadens the points on the pathway to care that need consideration, the model remains primarily epidemiological. Not only this, given the evidence reported in this review, the overly linear representation of pathways in this model, with a central role for GPs, does not fit what is known about pathways to care among African-Caribbeans. Fewer than
50% of African-Caribbeans with a psychotic illness will present to services via a GP and upwards of 20-30% will enter care via the police or criminal justice system (Owens et al., 1991). Points of entry are numerous and may come at any level. Further, the evidence showing African-Caribbeans and other Black minorities are more often admitted to secure psychiatric facilities suggests the need for yet a further level if the pathway to and through psychiatric services is to be fully captured. It is certainly the case that by utilising the concept of filters to model why some patients progress to higher levels of contact with secondary services this framework does offer the potential for the mechanisms determining pathways through the various levels to be studied. However, the proposed filters are narrow or unclear and do not allow room for all the possible factors that may be influencing who accesses higher levels. It is interesting that while Commander et al (1999) introduced a further level, they failed to specify what the filter(s) was between this and the lower level. Bhui and Bhugra (2002a), moreover, do not specify what filters might be operating, for example, in determining referrals from criminal justice agencies. Most research utilising the framework has concentrated on counting the numbers accessing the various levels, leaving the filtering mechanisms poorly understood. This is precisely the problem with research relating to ethnic minorities and pathways to care.

The general problem of too narrow a focus is compounded by specific differences in study design that limit the comparability of studies. In four key areas studies have varied widely: a) sample; b) source used to collect data; c) instruments used to collect data; and d) definitions of ethnic groups. Firstly, patient samples have ranged between those including all consecutive hospital admissions (Moodley & Perkins, 1991), those including all current in-patients (Davies et al., 1996) and those including only first admissions with a psychotic illness (Cole et al., 1995). The recent first presentation studies (Burnett et al, 1999; Cole et al., 1995) have emphasised just how much studies of all admissions are limited in not being able to control for the impact of previous service contacts on subsequent pathways to care. The grouping of all patients in samples without taking account of prior experiences of services misses a vital factor that may have influenced the route taken into care and mode of contact with services. Secondly, as already noted above, the source used to collect data has varied widely between studies, from those using case notes to those involving interviews with patients, relatives and/or professionals. The majority have used case notes, the pitfalls of which are well known. Inevitably, data source affects both the reliability and validity of data, as does the instrument used to collect data. In this third area, instruments used to collect data, there has been extremely limited consistency in the use of standardised instruments. Most studies have developed their own schedules, while a limited number have relied on the Psychiatric and Personal History Schedule (PPHS) (WHO, 1996). The result is that apparently similar variables may not be comparable. For example, level of insight has
variously been determined from notes (Johnson & Orrell, 1996) and from structured and semi-structured interviews. The characteristics of clinical presentation have similarly been measured in different ways, such that it is difficult to know whether data relate to actual or perceived disturbance, a vitally important distinction given the possible interpretations of a finding of higher levels of disturbance in certain groups. Finally, the grouping of people into ethnic categories has been inconsistent and often the basis for grouping people has not been explicit. The ethnic minority groups have been variously categorised as New Commonwealth, Black, Black Caribbean, African-Caribbean, Black African, and West African. Most have not used self-ascribed ethnicity and many have relied on place of birth and/or best guess from available information, which often was only case notes. This further compounds the problem that any choice of ethnic categorisation will obscure important differences within groups (Singh, 1997; McKenzie & Crowcroft, 1994), and raises questions about just what ‘ethnicity’ represents in these studies (Hutchinson & McKenzie, 1995). The overall result is that while there is consistent evidence on the broad outline of differences in patterns of service access and use, there has not been any similar growth of evidence relating to factors associated with source of referral, compulsory admission and admissions to secure facilities. Lack of consistency in all of these areas may be obscuring important determinants of pathways to care.

These two key methodological limitations – a narrow methodology and inconsistencies in study design – explain why the research to date has failed to generate a coherent and convincing account of why African-Caribbeans follow negative routes to psychiatric care. This analysis of research to date has important implications. At the most general level, it points to a need for research efforts to be broadened to include a wider range of perspectives and methodologies. There is a vast literature in the social sciences exploring help-seeking, illness behaviour and patient interactions with health care systems, much of it well known and influential. Only a handful of the studies identified in this review make any reference to this wider literature (for example, Harrison et al, 1989), and in the main there has been no attempt to bring the insights from sociological and anthropological studies of help-seeking to bear on the issue of ethnic differences in pathways to care in the UK. Those speculative theories implicating social isolation, the role of families and beliefs about mental illness in pathways to care hint at ready points of contact between research in the social sciences and that concerning the relationship between ethnic minorities and mental health services; it is precisely these factors that have been extensively explored and theorised by sociologists and anthropologists in relation to different social groups and in different social and cultural contexts. The next chapter explores the relevance of this literature to the question of ethnic differences in pathways to care, specifically in relation to providing

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conceptual models, suggesting specific determinants of pathways to care, and offering alternative methodologies.
CHAPTER 3

ORIENTATIONS (2)
PERSPECTIVES FROM SOCIOLOGY AND ANTHROPOLOGY
3 ORIENTATIONS (2)  
PERSPECTIVES FROM SOCIOLOGY AND ANTHROPOLOGY

"One might wonder if the social sciences contain knowledge and pursue questions which are irrelevant to illness and care"  
(Kleinman, 1991, p. 143)

Sociologists and anthropologists have long been interested in all aspects of health and healing, not least the circumstances under which individuals enter into contact with professional health care services and become patients. The purpose of this chapter is to provide an overview of key features of this work that offer potentially useful tools and insights that can be applied to the study of ethnic variations in pathways to care. The focus will be on two areas: 1) the concept of illness behaviour and those factors identified as important in shaping illness behaviour; and 2) conceptual and theoretical frameworks for the study of help-seeking. Before considering each of these a more general discussion is necessary of the relationship between psychiatry and social science, the reasons why cross-disciplinary work has historically been limited, and how recent developments are creating a climate in which closer collaboration between the two is possible.

3.1 PSYCHIATRY AND SOCIAL SCIENCE: Points of Divergence, Points of Convergence

Any attempt to draw definitive lines of demarcation between psychiatry, sociology and anthropology inevitably masks both commonalities between, and diverse perspectives within, these disciplines. Naturally, sociology and anthropology share much in common, each being concerned with understanding the social world and man's place in it. The emphasis in each is very much on how social and cultural processes both shape, and are shaped by, individuals in what Skultans and Cox (2000b) have referred to as "an ongoing process of mutual influence" (p. 8). Distinctions between the two reside in the focus and methods of research. The primary focus of sociological analyses, for example, has been more on discrete components of the social world, such as class, gender, and ethnicity, than has that of anthropology, which has more often sought to analyse whole cultures, stressing the interconnectedness of the various aspects of the society under scrutiny. In terms of method, sociology, or at least a significant strand in sociology, has made greater use of quantitative methods to analyse the relationships between the various discrete components of interest, an emphasis no doubt heavily influenced by the positivist beginnings of the discipline (Comte, 1986; Durkheim, 1970). In contrast, the defining method and approach of anthropology is that of participant observation and the interpretative endeavour of the researcher in rendering accessible and understandable local
cultures. The emphasis on local meanings and interpretation, which eschews universal laws and objective causal processes, marks a further point of distinction from, at least, positivist sociology. That said, there has long been an interpretative tradition in sociology, stretching back to Weber (Parkin, 1982) and forward to post-modern sociology, that overlaps considerably with the focus and methods of social anthropology. Medical sociology contains both strands, as is reflected in the different methods utilised in, for example, research mapping health inequalities, which is primarily quantitative (for example, Graham, 2000), and in that concerned with beliefs about illness and doctor-patient interactions, which is dominated by qualitative approaches (Morgan, 2000). It is in this latter body of work, which importantly is of most relevance to pathways to care and ethnicity, that the distinctions between it and similarly focused anthropological studies are most blurred, as will become apparent below.

The relationship between psychiatry and the social sciences has a chequered history, with examples of both fruitful collaboration and periods of extreme animosity, the legacy of which is ongoing ambivalence of each towards the other (Skultans, 1991). Underpinning this animosity are basic differences in the philosophical assumptions that characterise dominant strands in each discipline concerning the nature of knowledge and scientific enquiry. Psychiatry's position as a sub-specialty of medicine carries with it both an adherence to the methods of the natural sciences – empirical observation, hypothesis testing, objective quantification and classification of phenomena, etc. – and a strong tendency to privilege biological explanations of mental phenomena over psychological or social ones. This has created scepticism about the usefulness and relevance of the social sciences to the subject matter of psychiatry, particularly that strand of social science concerned with interpretation and subjective meanings. More than this, social scientists were at the forefront of the anti-psychiatry movement of the 1960's and 1970's, a movement that attacked the very foundations of psychiatry, questioning the reality of mental illness and branding psychiatry as society's stooge, as an agent of social control serving the function of silencing difference (Foucault, 1965; Laing, 1960; Szasz, 1960). Psychiatry's response to the charge that it was "invalidating, medicalising and brutalising the meaning in mental disorder" (Bolton, 1997, p. 255) was both a re-assertion of the legitimacy of its approach to the understanding and treatment of mental illness and a counter-attack accusing its critics of being unscientific and engaging in unfounded theorising (Roth & Kroll, 1986; Sedgwick, 1982; Clare, 1976). The acrimonious debate made explicit the underlying philosophical and methodological differences that divide the dominant perspectives in psychiatry and the social sciences. The result is a legacy of mistrust that has not been entirely overcome by the many examples of fruitful collaboration between psychiatrists and social scientists nor by the increasing awareness that social and cultural dimensions are crucial to a full understanding of mental
illness (Leff, 2001; Kleinman, 1987). It is instructive that the closest collaborations have come where social scientists have accepted the basic legitimacy of psychiatry and its concepts and sought to identify the social influences on the cause and course of mental illness (for example, Leff & Vaughn, 1985; Brown & Harris, 1978; Brown et al, 1972; Brown & Rutter, 1966).

There have been strong arguments for the development of closer collaborations between psychiatry and the social sciences (Skultans & Cox, 2000a; Kleinman, 1991, 1987; Brown, 1980). These have focused on the relevance of social science concepts, theories and methodologies to the range of questions addressed by psychiatry, including mental illness across cultures, diagnosis, service access and provision, and outcomes. Kleinman (1991), for example, has noted how clinicians frequently use social science concepts, often without realising it, such as ethnicity, social class, social networks and culture. Each of these concepts is tied to sociological and/or anthropological literatures that have sought to clarify what each concept represents. Their use in psychiatric and epidemiological research, however, is often crude and ill thought through, as noted in the introduction. Kleinman (1987) has further argued that the anthropological emphasis on the study of social processes, diversity and subjective meanings offers a counter-balance to the overemphasis in psychiatry on outcomes, universals, and objective measures. A combination of perspectives, from this view point, promises a fuller understanding of both cross-cultural similarities and differences in mental illness and treatment responses and options. A similar, and related, argument has been made with regard to research methods. Traditionally the methods of psychiatry (i.e. quantitative) have been viewed as incompatible with those of social science (i.e. more qualitative), on the assumption that each is based on fundamentally opposed philosophies about the nature of knowledge and the world. Of course, this is but one context in which the quantitative – qualitative debate has been held, and this will be considered more fully in later chapters. For now it is sufficient to note that those who advocate a greater degree of cross-disciplinary collaboration have argued that the divisions between the two broad types of research method have been overstated, and that they should be viewed as complementary rather than contradictory (Pope & Mays, 1995). From this perspective, there are lessons to be learned on both sides about the types of methods available, the questions they can address and the implications and practicalities of combining them (Murray, 1998).

It is in the face of strong arguments for closer collaboration between psychiatry and social science and a growth of research demonstrating how this can be done successfully, that the historical tensions between psychiatry and social science are diminishing (Cooper, 1992). It is certainly too much to suggest traditional suspicions have been put aside, but the increase in papers and projects based on cross-disciplinary and multi-method research is indicative of a more fertile climate for greater convergences between psychiatry and the social sciences.
(Leff, 2001; Buston et al, 1998). This is the wider context for considering the relevance of the concepts, theories and methods of sociology and anthropology in relation to help-seeking and pathways to care among different ethnic groups in the UK.

3.2 HELP-SEEKING, PATHWAYS AND HEALTH SERVICE USE: The View from the Social Sciences

Interest in the processes shaping how, when and why individuals present to health services and enter the role of patient developed from the observation that the nature and severity of symptoms alone did not determine when and what type of help was sought (Armstrong, 1994). Studies of pathways to care and responses to illness by social scientists mushroomed in the 1950's and 1960's on the back of pioneering work by Clausen and Yarrow (1955) and Hollingshead and Redlich (1958), among others. Much of this early work was characterised by an emphasis on help-seeking as a social process (Clausen & Yarrow, 1955), an idea that is at the centre of the concept of illness behaviour (Mechanic, 1962; 1968). Illness behaviour refers to the ways in which individuals, and significant others, perceive, evaluate and act upon the symptoms of illness, “Thus, the study of illness behaviour involves the study of attentiveness to pain and symptomatology, the examination of processes affecting how pain and symptoms are defined, accorded significance and socially labelled, and the consideration of the extent to which help is sought, change in life regimen affected, and claims made on others” (Mechanic, 1968, p. 116). The distinction between illness and illness behaviour resembles the often made distinction between disease and illness in medical anthropology, in which disease is the malfunctioning of biological and/or psychological processes and illness is the psychosocial experience and meaning of such underlying processes. From this perspective, according to Kleinman, illness behaviour is simply the way sociologists have conceptualised illness (Kleinman, 1986, p. 151). What is central to each of these concepts is the idea that disease is transformed into illness or illness behaviour through a social process that shapes how an individual and significant others interpret and respond to symptoms1. Research that has been conducted within this broad frame has both confirmed and elaborated the basic premises of the concept of illness behaviour, further clarifying the types of factors and processes that are important in shaping responses to disease or illness. Indeed, the concept has formed the basis of research exploring use of health services in relation to a wide range of symptoms and illnesses, from coughs (for example, Cornford et al, 1993) to cancers (for example, Yates et al, 1993), from chest pains (for example, Richards et al, 2002) to mental illness (for example, Fosu, 1995), and so on.

1 Illness behaviour can occur without underlying disease, but this is usually discussed in terms of 'abnormal illness behaviour' (Pilowsky, 1988).
On the basis of early research, Mechanic (1968) identified ten variables known to influence illness behaviour, which are listed in Box 3.1.

Box 3.1. *Ten variables known to influence illness behaviour (from Mechanic, 1968, pp. 142-155).*

1. Visibility, recognisability, and perceptual salience of deviant signs and symptoms
2. The extent to which the symptoms are perceived as serious
3. The extent to which symptoms disrupt family, work and other activities
4. The frequency of appearance of the deviant signs or symptoms, their persistence, or their frequency of recurrence
5. The tolerance threshold of those who are exposed to and evaluate the deviant signs and symptoms
6. Available information, knowledge, and cultural assumptions and understandings of the evaluator
7. Basic needs which lead to autistic psychological processes
8. Needs competing with illness responses
9. Competing possible interpretations that can be assigned to the symptoms once they are recognised
10. Availability of treatment resources

This is not an exhaustive list, as Mechanic (1968) made clear, but there are common threads running through these ten variables that highlight a small number of key factors that have been found to exert a significant influence on illness behaviour. These are:

- The nature of symptoms (Variables 1, 2, and 4)
- The influence of cultural factors, particularly beliefs about illness which shape the interpretation of symptoms (Variables 2, 6 and 9)
- The impact of symptoms on family and social functioning (Variables 3, 7, and 8)
- The response of significant others (Variable 5)
- The range of treatment responses available (Variable 10)

There are clear overlaps between these factors. While at any one point on the pathway to care certain factors may be more important than others, what happens at each point is likely to be the product of a range of these, and possibly other, factors interacting to produce the observed illness behaviour. There is good, accumulated evidence that variables in all of these areas shape help-seeking.

Variations in patterns of illness behaviour between cultural groups have been well documented. While it is unlikely that cultural differences account for all of the variations observed between ethnic groups in patterns of help-seeking, the detailed work that has explored how culture impacts on responses to illness points to these types of factors having a
strong influence on differences in health service access and use. The response to physical discomfort and/or unusual behaviour depends on how these signs are appraised by the individual and others, and this process of appraisal is culturally shaped. Hollingshead and Redlich (1958) in their study of social class and mental illness found differences in interpretations of abnormal behaviour between persons from social classes I and II and those from social class V, with the former being more likely to appraise abnormal behaviour as indicative of psychological dysfunction and the latter less likely to appraise such behaviour as deviant. The result was greater tolerance of abnormal behaviour for longer periods among the lower social class groups and few attempts to seek help. The impact of culturally shaped appraisals of, or beliefs about, episodes of illness, termed Explanatory Models by Kleinman (1980), on illness behaviour has been the subject of a vast body of research in both medical sociology and anthropology. This will be the subject of the next chapter. For now, the example of a classic study by Helman (1978) can be used to illustrate how culturally based illness beliefs shape help-seeking and interactions with health care services.

In his study of older residents in north London, Helman (1978) sought to explore what was meant by the popular notion “feed a cold, starve a fever” and how lay beliefs related to this notion influenced interactions with health care professionals. The qualitative data collected by Helman revealed a widespread folk classificatory system of what medicine terms infectious diseases, resting on the separation of illnesses into hot, cold, wet and dry, as in Figure 3.1.

![Figure 3.1: Folk classificatory system of infectious diseases (from Helman, 1978, p. 119).](image)

<table>
<thead>
<tr>
<th></th>
<th>Hot</th>
<th>Cold</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wet</td>
<td>Fever</td>
<td>Cold</td>
</tr>
<tr>
<td></td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td>Fluid</td>
<td>Fluid</td>
</tr>
<tr>
<td>Dry</td>
<td>Fever</td>
<td>Cold</td>
</tr>
</tbody>
</table>

This system was based on perceived, and entirely subjective, notions of changes in body temperature associated with particular symptoms. Colds were caused by contact with the natural environment, for example damp or rain or wind, or by cold entering vulnerable areas of the body, such as feet or the head – i.e. getting feet wet or going out with wet hair. Catching a cold was consequently the fault of the individual, who could have done otherwise to avoid becoming ill. Treatment involved increasing a sufferer’s temperature with, for example, hot food, hot drinks and rest in a warm bed, and by generating personal body heat using tonics or food, hence ‘feed a cold’. Fevers, in contrast, were thought to be caused by germs, bugs or viruses. Importantly, while some of these terms are borrowed from medicine, their folk meaning bears little resemblance to their medical meaning. Germs and the like pass
from one person to another, as in the idea of ‘picking up a germ’, and as such are the result of social interaction, the consequent belief being that an individual is less responsible for contracting fevers than colds. Remedies involve expelling the offending agent by, for example, sweating it out or “coughing up the muck”, or by attacking the germs with modern medicine, i.e. antibiotics (see Figure 3.2).

Figure 3.2. Beliefs underpinning the aphorism, “Feed a cold, starve a fever" (from Helman, 1978, p. 122).

<table>
<thead>
<tr>
<th>Cold</th>
<th>Fever</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caused by</td>
<td>Natural environment; penetration of cold</td>
</tr>
<tr>
<td>Responsibility</td>
<td>Individual</td>
</tr>
<tr>
<td>Remedy</td>
<td>Hot drink, food (feed a cold), rest in warm bed</td>
</tr>
</tbody>
</table>

Further, the belief that both bacterial and viral infections can be treated with antibiotics, noted in younger residents, inflated the expectation that medicine would be prescribed for all these kinds of illnesses, a belief reinforced by the over-prescription of antibiotics by doctors. Related to this, Helman noted that doctors often couched their diagnoses and prescribed treatments in lay terms: “you’ve picked up a bug”, “it’s a tummy bug – I’m afraid there’s one going around”, etc. thereby further reinforcing popular beliefs. This example illustrates a number of general points about how culturally framed beliefs about illness shape the appraisal of symptoms, help-seeking and doctor-patient interactions. It shows, for example, how beliefs about causation and the nature of illness can impact on how individuals respond: for colds, a hot drink and warm bed; for fevers, getting it out of the system with the help of modern medicine. The study further suggests that where cultural idioms are shared and form the basis for communication between doctor and patient, engagement and satisfaction are likely to be increased. Conversely it is also possible to see how, given the use of unspoken cultural assumptions in the process of communication, there is scope for problems when the cultural idioms of patient and doctor are not shared or understood. This is most evident in work that has shown how the tendency of some ethnic minorities to somatise emotional distress can result in difficulties in communication between the patient and the, usually White, doctor (Kleinman & Good, 1985; Racy, 1980).

The appraisal of symptoms as indicative of illness does not always result in help-seeking. Zola (1973), in an influential paper, identified five “triggers” that he suggested are important in determining what, when and whether help is sought:
• The occurrence of an interpersonal crisis (for example, family conflict or bereavement)
• Perceived interference with social or personal relations
• "Sanctioning" (i.e. pressure from others to seek help)
• Perceived interference with vocational or physical activity
• "A kind of temporalising of symptomatology" (p. 683) (i.e. setting a time limit after which help will be sought, e.g. "if it isn’t better in 3 days, or 1 week, or 7 hours, or 6 months, then I’ll take care of it" (p. 685))

Zola (1973) demonstrated that illness behaviour and the decision to seek medical help is, at least partly, a function of the family and social context within which illness is experienced. Resolving health problems, for example, is only one of a number of competing demands on individuals and it may be that other needs, from the point of view of the sufferer, are more salient at any point. Caring for children, work, study and other such activities may take higher priority than seeking help for health problems, particularly if consultation may lead to time consuming treatment and/or hospitalisation. This maps on to two of the variables identified by Mechanic (1968) – 7) basic needs which lead to denial, and 8) needs competing with illness response – and broadly falls into those explanations of illness behaviour in terms of level of interference with family and social life. While “sanctioning” clearly implies input from others, the other “triggers” are suggestive of individuals being engaged in a form of cost-benefit analysis regarding the utility of seeking medical help (Cornford et al, 1993). The process of weighing up the pros and cons of seeking professional help will be influenced by culturally defined roles, obligations and norms governing what is considered an appropriate response to specific symptoms and illness. Intriguing early work by Zborowski (1952) in which responses to pain were investigated in different cultural and ethnic groups provides a good example of how such cultural expectations shape illness behaviour. This study found, on the one hand, that American and Irish patients showed tolerant, matter-of-fact attitudes towards pain and a tendency to withdraw from others if experiencing acute pain, no doubt to retain the impression of stoicism. Italian and Jewish patients, on the other, tended to be more demanding and expressive, making their experiences more visible and apparent. These patterns have been broadly confirmed in subsequent research, with the caveat that migrants may have modified responses to illness compared to those evident in their culture of origin because of the stresses of migration and the process of acculturation (Pilowski & Spence, 1977). More recently, a study of socio-economic variations in responses to chest pain in Scotland (Richards et al, 2002) found that respondents from deprived areas were less likely to seek help than others due to a tendency to normalise chest pains in the context of high general
levels of ill-health and due to a constellation of related beliefs about the appropriateness of seeking help and fear of being blamed for "high risk behaviours", i.e. smoking, drinking, and poor diet.

What the concept of illness behaviour and related research shows is that responses to illness do not occur in a social or cultural vacuum. Not only do culturally shaped beliefs and patterns of coping influence help-seeking, the process of interpreting and responding to illness involves others in the sufferer's social network, such that help-seeking can be said to be the product of ongoing negotiations between an individual and significant others. Scambler (1997) has noted that it is rare for someone to seek professional medical help without first discussing symptoms with others. This is confirmed by an earlier study by Scambler et al (1981) which found that upwards of 75% of respondents had consulted non-professionals, usually relatives, prior to seeking professional help. How these other lay people perceive and evaluate the treatment needs of the individual experiencing symptoms of illness is consequently a further factor that often forms part of the complex mix of influences shaping illness behaviour in particular situations. In some circumstances, pressure may be exerted on an individual to seek help (e.g. "sanctioning", see above) or others may actively seek help on behalf of a relative who is perceived as ill. Mechanic (1968) stressed the need for research to distinguish between self-defined and other-defined illness, a point emphasising that the definition of, and response to, illness is a social process which may provoke conflict, as much as agreement, between an ill person and significant others about what is wrong and what should be done. Freidson (1960) conceptualised the set of social relationships that shape individual responses to illness as the "lay referral system":

"... the whole process of seeking help involves a network of potential consultants, from the intimate and informal confines of the nuclear family through successively more select, distant, authoritative lay men, until the 'professional' is reached. This network of consultants, which is part of the structure of the local community and which imposes form on the seeking of help, might be called the 'lay referral structure'. Taken together with the cultural understandings involved in the process, we may speak of it as the 'lay referral system'" (Quoted in Mechanic, 1968, pp. 135-136).

The nature of the lay referral system will differ between cultural and sub-cultural groups, and indeed between individuals within social and cultural groups. Freidson (1970) further developed this model, highlighting two key features of lay referral networks that influence illness behaviour: a) the degree of congruence between the subculture of the potential patient and that of doctors; and b) the relative number of lay consultants interposed between the
initial perception of symptoms and the decision whether or not to go to the doctor (Scambler, 1997; Freidson, 1970). Lack of congruence between the culture of potential patient and doctor and a large lay referral network, according to this framework, work to hinder early help-seeking, a hypothesis that has gained some support in a study by McKinley (1973) suggesting large social networks among some Scottish women in social class V worked as a barrier to engagement with antenatal care.

The range of health related services and practitioners available in any society, and the ease with which these can be accessed, set important limits on help-seeking behaviour. This is the final broad factor identified by Mechanic (1968) in his early review. There are three related components to this – 1) what services are available; 2) how accessible they are; and 3) the extent of local knowledge about the range of services and how to access them – and each has been the subject of significant research from a social science perspective.

To a greater or lesser extent, all societies are characterised by health care pluralism; that is, in all societies there exists a wide range of health related services and practitioners, ranging from traditional and spiritual practices to complementary therapies, such as homeopathy, to modern Western medical services. Despite the success of Western medicine in treating a wide range of illnesses, traditional and complementary approaches have continued to flourish and form part of the range of options open to individuals in the event of ill-health (Campion & Bhugra, 1998; Patel et al, 1997, 1995; Leff, 1980). In developing countries, where traditional healers are common and often a first resort for ill individuals, the introduction of Western medical facilities has produced a remarkably consistent response across cultures. That is, usually a distinction is drawn between European and non-European illnesses, the latter believed to be less susceptible to Western medicine and more the domain of traditional medicine (Leff, 1988; Maclean, 1976; Ngubane, 1976; Ritchie, 1976; Orley & Leff, 1972). In developed countries, traditional healing and complementary therapies may be less central to health care provision, but there are still significant numbers of such practitioners who attract, seemingly, ever larger numbers of consultations. More is known about the extent of complementary therapies in developed countries than alternative healing, and their use alongside professional medicine, for example by GPs, is increasing. Thomas et al (1991) estimated that there were 1909 complementary health services, such as homeopathy, acupuncture, herbalists, etc., registered and working in the UK in 1987, and in an average week as many as 70,600 patients were seen by this group of practitioners. Much less is known about traditional, religious and spiritual healers practicing in the UK. Patients, moreover, have been shown to utilise different health care options both simultaneously and consecutively in seeking a remedy for ill-health, often favouring those practices that correspond to their own world view (Chadda et al, 2001; Kua et al, 1993; Leff, 1988; Kleinman, 1980). The extent to which individuals are aware of the range of health care
services and practitioners available, their beliefs about the appropriateness of specific practices to their perceived problems, and the accessibility of these services in terms of, for example, distance and affordability, will consequently exert a strong influence on patterns of illness behaviour.

3.3 FRAMEWORKS FOR THE STUDY OF HELP-SEEKING: Sociology and Anthropology

A number of overarching frameworks have been developed by social scientists for the study of help-seeking behaviour, drawing together the insights from the type of research outlined above (for example, Eraker et al, 1984; Andersen, 1995). Two such models are considered here, one from anthropology (Kleinman, 1980), the other from sociology (Pescosolido & Boyer, 1999), as each offers particularly useful insights that have informed the study conducted for this thesis and which may prove valuable generally in researching ethnic differences in pathways to care.

3.3.1 The Health Care System

In his seminal book, *Patients and Healers in the Context of Culture*, Kleinman (1980) developed a number of concepts that have since been widely used and debated in health related research. Based on wide ranging research in Taiwan and China, Kleinman (1980) developed the concept of the Health Care System as a basis for researching and comparing health related beliefs, behaviours and practices across cultures. The premise on which the concept of the Health Care System was built was that the health related components of all societies are more or less systematically interconnected and form a cultural system in the sense that religion or language or kinship are most usefully viewed as cultural systems. Kleinman (1980) held that “the internal structures (of health care systems) are roughly the same across cultural boundaries, while the content varies with the social, cultural and environmental circumstances of each system” (p. 49).

The structure of health care systems, according to this framework, comprises three sectors, the popular, folk and professional, each of which overlaps to some degree with the others, as illustrated in Figure 3.3.
The popular sector includes all the therapeutic options that people utilise, without any payment and without consulting folk healers or medical practitioners, i.e. self medication, advice or treatment from friends and family, self help groups, etc. Most popular health care takes place amongst people and environments known to the ill-person, and models of disorder, beliefs about illness and appropriate responses are likely to be shared by all involved. The folk (or traditional) sector comprises those 'healers' not part of the official medical system, what might be referred to as alternative and/or complementary healers and therapies. Some are closely related to the professional sector, and indeed some may at points be incorporated into the professional sector or rest on the border between the two, as with homeopathy, chiropractic, and, in China and Taiwan, Chinese Medicine. The majority, however, are related more to the popular sector. As Helman (1994) has noted, most folk healers share the cultural values and beliefs of the communities they serve, including beliefs regarding the origins, significance and treatment of distress, which produces a number of advantages over western doctors who are often separated from their patients by social class, economic position, gender, specialised education and sometimes cultural background. The explanations employed by folk healers are often culturally familiar and family involvement is frequent, such that the focus is not solely on the ill individual (Leff, 1988). The professional sector is principally the legally sanctioned medical establishment. Increasingly this means western medicine, though not always. While conceptually it makes sense to view these sectors separately, in reality the boundaries between them are fluid and firm lines of demarcation are often difficult to draw. The cultural underpinnings of each sector are not unaffected by the other sectors and the wider social context, so that there is ongoing cross-fertilisation of beliefs and practices between sectors, meaning the cultural content of each is undergoing constant modification.

Central to this framework are beliefs about illness. As noted above, the interpretation of bodily and psychological changes both by the sufferer and those around him/her are shaped by culturally shared beliefs about what such changes represent, and it is these beliefs that
inform individual Explanatory Models of illness episodes. Kleinman defined Explanatory Models as "the notions of sickness and its treatment that are employed by all those engaged in the clinical process" (p. 105), which includes patients, relatives and doctors. He further argued that: "The interaction between the Explanatory Models of patients and practitioners is a central component of health care. The study of practitioner Explanatory Models tells us something about how practitioners understand and treat sickness. The study of patient and family Explanatory Models tells us how they make sense of given episodes of illness, and how they choose and evaluate particular treatments" (Kleinman, 1980, p. 105). At the heart, then, of the Health Care System are beliefs about illness which both shape, and are shaped by, the range of treatment options available and interactions with health services. An example given by Kleinman will illustrate this further. The popular belief in Taiwan of medicine as "the magic bullet", providing speedy treatment for acute problems and symbolized through the giving of injections, created the expectation that consulting a western physician would result in the giving of an injection. At the same time, the financial structure of Taiwanese health care meant doctors were paid more for administering injections, the sum result being that almost all medicines that could be were given by injection and, of 300 cases observed by Kleinman and colleagues in clinics of western style practitioners, "fewer than one fourth failed to receive injections of one sort or another" (Kleinman, 1980, p. 287). This further illustrates how popular perceptions and the structures of the local health care system interact to produce specific types of illness behaviour.

The framework and concepts developed by Kleinman (1980) (Health Care System, Explanatory Models) have informed a considerable body of research and been the subject of much debate. Explanatory Models and related research will be considered further in the next chapter. Critiques of the framework of Health Care Systems proposed by Kleinman have centred on the limited account it takes of wider socio-economic and structural determinants of health and illness related behaviours (Young, 1982) and the validity of the model applied to other contexts. Others, for example, have suggested that the "professional sector", as Kleinman conceptualised it, is too broad and needs to be broken down to distinguish between medical and non-medical professionals who may become involved in responding to illness and mental illness (Pescosolido et al, 1998). This however, is more about modifying the framework to fit local contexts, such that this does not negate the general value of the model. Kleinman (1997) himself has expressed his unease at what he now calls his preoccupation with models in his early work. Still, any model applied too rigidly can hinder research, but if applied flexibly they can generate hypotheses and research, even if the outcome of that research is modification or even abandonment of the framework. The strengths of what Kleinman proposed rest in the emphasis on the interconnectedness of all health related components in society and on how health and illness related behaviours are socially and
culturally shaped through the complex interaction of a wide range of factors in specific local settings.

3.3.2 The Network Episode Model

The emphasis of Kleinman’s work on the interconnectedness of the health related components of local societies reflects the anthropological perspective he adopts. Within sociology, particularly in the USA, a number of models of help-seeking have been proposed, the most recent of which, The Network Episode Model (NEM), offers further useful insights into how research considering illness behaviour in different contexts can proceed (Pescosolido & Boyer, 1999; Pescosolido, 1991). This model has been developed in order to overcome what Pescosolido (1991) argues are the weaknesses of previous models in explaining how it is that individuals come to use health services, in particular of Andersen’s Socio-Behavioural Model (Andersen, 1995) and Becker’s Health Belief Model (Eraker et al, 1984), both of which have been influential in sociology and social psychology respectively. These models, according to Pescosolido (1991), share three underlying assumptions or characteristics that mean they cannot adequately describe or explain how and why people use health services, namely:

1. The assumed underlying mechanism of help-seeking is rational choice
2. Decision making is located within the individual
3. The focus is on one-off decisions or end points

Pescosolido (1991) has argued that it is the concentration of these models on one-off decisions concerning whether or not to seek help, within a rational choice frame, that creates a static, one-dimensional picture of help-seeking, and which in turn has fostered the use of predominantly quantitative methodologies – what she calls a “contingencies approach”. While the research focusing on ethnic variations in pathways to care in the UK has never utilised any of the models Pescosolido has in mind, the approach generally adopted in these studies fits what Pescosolido (1991) styles as “contingency approaches” – that is they provide a sociodemographic and clinical profile of service users at specific end points and explore the correlations between these and other variables, and from this specify the “contingencies” of service use. Certainly, Andersen’s (1995) Socio-Behavioural Model, with its focus on organisational influences on help-seeking, and Becker’s Health Belief Model (Eraker et al, 1984), with its focus on illness attributions, consider wider factors than have usually been researched in relation to ethnicity and pathways to care, but Pescosolido’s basic criticism, that these models fail to capture the dynamic, social processes that characterise help-seeking, specifically, their embeddedness within social networks, is merited. If this is true of those models that have attempted to incorporate a wider range of factors to account for help-seeking
behaviour, it is yet more pertinent a comment on the limitations of the research reviewed in Chapter 2.

Pescosolido (1991) contrasts the contingency/rational choice models with those that have conceptualised service use as part of an “illness career”, a perspective that originated with the work of Clausen and others (for example, Horwitz, 1977; Clausen & Yarrow, 1955), who mapped sequences of help-seeking involving lay persons, professionals, and agencies during the course of illness. From out of this type of work models were developed that viewed illness careers in terms of stages, though these have had to be modified in light of the fairly obvious point that such processes, with all the inevitable idiosyncrasies, cannot be captured by rigid stages models (Goldsmith et al, 1988). As this work is more dynamic, it has also been more descriptive, frequently requiring a narrative approach, allowing those engaged in the process to tell the story of help-seeking. This has favoured a qualitative methodology, thereby further distinguishing this work from that based on models such as Andersen’s (1995) Socio-Behavioural Model. The different perspectives thus lend themselves to distinct methodologies, which further cements differences, driving a wedge between the two bodies of work and making an integrated perspective difficult. It is this that Pescosolido tries to achieve with the Network Episode Model.

The Network Episode Model specifically attempts to “draw from the strengths of the dynamic and contingency models” (Pescosolido & Boyer, 1999, p. 406). The starting point for the model is the basic idea that “dealing with health problems is a social process that is managed through contacts (or social networks) that individuals have in the community, the treatment system and the social service agencies (including support groups, churches and jails)” (Pescosolido & Boyer, 1999, p. 406). It rests on an alternative formulation of decision making than that embodied in rational choice theory. Responses to illness frequently emerge from a process of negotiating the meaning of symptoms within a social network. Members of this network may offer advice, cajole, encourage, etc., particular responses which may or may not shape how someone ultimately responds. People may be weighing the costs and benefits of certain actions, but these can be offset by the influence of others. In this sense the model is interactionist; it is social rather than individual. The individual is located within a particular social context, a network of relationships, and it is within this context that health decisions are taken. This is the basis for the key component of the Network Episode Model: the social network. Figure 3.4 shows the four components of this model: social content, social support system, the treatment system and the illness career. Research utilising this model is still relatively limited (Pescosolido et al, 1998), but theoretically it does mark an important step forward both in its emphasis on decision making as a social process, which echoes Freidson (1970) and its attempt to provide a framework within which both contingency and process orientated approaches can be combined, thereby drawing on the strengths of each.
3.3.3 The Relevance of Existing Frameworks

There are clear similarities between the health care system model proposed by Kleinman (1980), the Network Episode Model and that work related to the concept of illness behaviour outlined above. All conceptualise responses to illness as socially and culturally shaped processes involving a range of actors within and external to the sufferer’s social network. The types of factors identified as being salient in driving these processes are similar: beliefs about illness, the influence of significant others, the range of health care options available, and so on. Thus, two key points emerge from this literature that are particularly relevant to this thesis:

1. Mode of contact with psychiatric services is the outcome of a social process, involving a series of decisions made in the context of the sufferer’s social network and the wider health care system
2. Culturally shaped beliefs about mental illness are central to the whole process, influencing decisions made at each stage on the pathway to care.

This work, then, provides a number of well formulated concepts and frameworks that can be applied to the design, analysis and interpretation of studies of pathways to care among different ethnic groups and it demonstrates the need to consider a range of factors at different levels in order to fully understand how people come to use health services. The research reported in this thesis attempts to draw from the work of Kleinman, Mechanic, Pescosolido and others in terms of how help-seeking is conceptualised, in the focus on beliefs about mental illness, and in the methodology adopted. That is, help-seeking is viewed as a socially and culturally shaped process involving a number of decision points, and the methodological strategy adopted attempts, following Pescosolido (1991), to utilise the strengths of both the contingency and process orientated approaches through the combined use of quantitative and qualitative methods. Methodological issues are discussed more fully in Chapter 5. Further, as will be seen, Kleinman's concept of the Health Care System provides the framework within which the relationship between beliefs about mental illness and pathways to care are explored in the final chapter.

To set this study fully in the context of previous research, it is now necessary to turn to the literature that has dealt specifically with beliefs about illness and mental illness and their influence on illness behaviour. This is the subject of the next chapter.
CHAPTER 4

ORIENTATIONS (3)
CULTURE, BELIEFS AND ILLNESS BEHAVIOUR
There is a substantial, scattered and diverse body of research that has investigated culturally shaped beliefs about health and illness in a wide range of contexts and social groups. The purpose of this chapter is to steer a course through this literature, focusing on that which is of most relevance to the study of beliefs about mental illness and pathways to care among African-Caribbeans and Whites. To achieve this, the chapter is split into three main sections. The first, and main, section reviews key literature from the fields of anthropology, sociology and social psychology. This review covers important and instructive research on illness beliefs generally, as well as that dealing specifically with beliefs about mental illness, and is organised around studies, firstly, in non-western settings and, secondly, in western countries. The inclusion of broader research on illness beliefs allows the diversity of beliefs across cultures to be more fully documented and serves to set beliefs about mental illness within a wider context. The second section considers examples of classificatory systems that have been proposed for the study of beliefs about illness cross-culturally. The third section discusses more critically the status of lay beliefs and examines just what it is that researchers can claim to elicit when they probe respondents about their views on various aspects of mental illness.

4.1 CROSS-CULTURAL VARIATIONS IN BELIEFS ABOUT ILLNESS

Local conceptualisations of illness have been studied by researchers working within a wide range of disciplines, including anthropology, sociology, social psychology and cross-cultural psychiatry. Each has approached the subject from a particular perspective, utilising a range of research methods. As noted in the previous chapter, there are overlaps between these disciplines, particularly anthropology and sociology, such that any distinctions drawn should not be considered definitive boundaries but more points of divergence between the dominant approaches within each field. With this caveat in mind, a broad schematic outline of different approaches to the study of beliefs about illness is provided in Figure 4.1.
4.1.1 Making The Strange Familiar

Anthropologists, in particular, have documented both how beliefs about illness vary widely across cultures and how these beliefs profoundly influence illness behaviour. The frequent characterisation of anthropology as the discipline that renders the strange familiar is apt in relation to beliefs and healing practices. In revealing the enormous diversity of beliefs across cultures, anthropologists have shown how beliefs that often appear bizarre and irrational form internally coherent systems of belief that guide action and behaviour. Evans-Pritchard (1937), for example, in an early study, revealed beliefs prevalent among the Azande, a small society in the Sudan, implicating witchcraft in causing illness and a range of misfortunes. He further showed that various rituals were used by the Azande to identify the source of witchcraft and illness, and once this had been achieved, the response was to either confront the perpetrator to withdraw their influence or reap vengeance by practising witchcraft in retaliation. Similar ideas have been found in other areas of Africa (Patel, 1995) and the
Beliefs linking the supernatural and spiritual to illness are further evident in those societies where the direct actions of spirits are implicated. Lewis (1971), for instance, described a number of African societies in which people believed that illness could be caused either by disease bearing spirits that struck randomly and independently of an individual's behaviour or by angry ancestral spirits who possessed individuals whose immoral or anti-social behaviour had angered them. Further, the belief that illness results from some external agent or force entering the body, be it a spirit, germ or other disease carrying object, has been recorded in a host of different contexts. Leff (1988) has reviewed a small number of studies, some of them anthropological, that establish a close relationship between these types of beliefs and healing practices and rituals that are designed to expel the offending agent. Onyango (1976), for example, interviewed a traditional healer who believed a disorder involving sudden transformations in mood and behaviour, a kind of bipolar disorder, was caused by a hairy worm in the head, the highs being when the worm was awake and the lows when it was sleeping. The remedy involved making the sufferer sneeze to expel the worm. Gelfand (1964) described the belief among the Shona of southern Africa that madness was caused by angered ancestral spirits (ngozi) possessing the madman. The healing process involved an elaborate ritual which ended with the healer commanding the spirit to leave the patient for an animal, usually a hen.

Beliefs invoking spiritual and supernatural forces are particularly evident in relation to the emotional and behavioural disturbances that in the west are conceptualised as mental illness, but which in other cultures are variously labelled madness, craziness and so on. Patel (1995), in his review of literature covering studies in 11 sub-Saharan African countries, showed that for all the diversity in beliefs about mental illness, there were important cross-cultural similarities, the most salient being the universal belief in supernatural forces as a primary cause of mental illness. These beliefs closely mirror those already discussed and included beliefs both that angered ancestral spirits and forms of witchcraft could cause mental illness. It is evident, moreover, from Patel's (1995) review that the types of experiences and behaviours believed to characterise madness were, across many African societies, centred on outward, manifestly disturbed behaviour and on disturbances in social relationships rather than on inner psychological and emotional dysfunction, as is the case in psychiatric classifications. Interestingly, a study by Good (1987) in Kenya showed that beliefs implicating spirits in causing illness were much more central to explanations of illness in rural areas, a finding that has been paralleled in studies in India (Srinivasan & Thara, 2001; Padmavathi et al, 1998), and which hints at a diminution of beliefs related to the spiritual realm in the face of industrialisation, education and external influences from the west. That said, there is considerable research showing that the encroachment of western ideas does not
simply result in the abandonment of traditional beliefs. As noted in the previous chapter, in
most cases western ideas and practices are incorporated into traditional systems pragmatically
and a distinction is often drawn between European and non-European illnesses, the key factor
being treatment efficacy. For those illnesses where western medicine has proved least
successful traditional beliefs and practices persist most forcefully – mental illness remains a
non-European illness in this sense. These divisions are evident in Kleinman's (1980) study of
Taiwan and China, for example, in the division between those illnesses susceptible to the
powerful injections of western medicine and those, including mental illness, which remain the
remit of various healers, including Chinese medical practitioners, shamans, and ch’ien
interpreters.

The folk beliefs described by anthropologists have not only comprised supernatural
and spiritual components. Folk systems of belief have been shown to be much more complex
and multi-faceted than this, with varying causal explanations and related health practices
being linked to diverse illnesses. Laguerre’s (1987) ethnography of African-Caribbean folk
medicine provides a pertinent example here. Rooted in African, Indian and European
religions and medical traditions, which were fused together in the historical, social and
environmental contexts of the Caribbean, African-Caribbean folk medicine constitutes a
syncretic system of diverse beliefs and practices. Within this diversity, broad explanatory
frames for ill-health can be identified that locate the causes of illness in either the magical,
supernatural, or natural realms. In the former, for example, individuals variously called
voodoo men, obeah men or conjurers are believed to be capable of making charms or working
magic to cause illness, including mental illness, a belief similar to those implicating
documented the belief that illness, particularly mental illness, was caused by spirits with
whom an individual had breached his/her contract. Alongside beliefs relating illness to other
worldly phenomena were widespread notions of illness as resulting from a loss of balance in
either the body’s blood or temperature. Too much blood, for example, was believed to be a
cause of strokes, a belief that has also been found in western populations (Snow, 1983). The
concept of balance has been documented as a feature of illness belief systems in a wide range
of settings (Kleinman, 1980; Helman, 1994) and is evident, for example, in the beliefs elicited
by Helman (1978) from north London residents in the study described in the previous chapter.
Each set of beliefs described by Laguerre (1987) gives rise to healing practices and shapes
responses to illness. For example, as well as causing illness, obeah men and the like were
believed to cure by removing a spell or hex. The use of herbs to regulate blood and
temperature was found to be widespread, with a complex body of knowledge built up through
a process of trial and error that linked specific herbs to illnesses based on whether the illness
was hot or cold, or resulted from too much or too little blood. The purpose was always to restore equilibrium.

The diversity and complexity within folk belief systems is equally evident in one of the very few detailed studies of beliefs about mental illness or madness in a Caribbean society, in this case Barbados (Fisher, 1985). What is particularly interesting about Fisher’s (1985) study is that the beliefs documented share important similarities with those evident in other Caribbean islands in which the majority population is of African heritage, as evident through occasional research, anecdote and literature (Littlewood, 1993, 1988; Hutchinson et al, 1999; Desai, 1998; Laguerre, 1987). This is clear, for example, in what were believed to be the core features of madness – visible behavioural disturbance, dangerousness and violence, unpredictability, and “mad” appearance. Informants invariably located the madman either in a public space or in the local mental hospital (“When I think of madmen, I think of strange people who walk the streets”, p.73) and equated “serious” madness with violence (“They are very dangerous”, p. 76), this being most evident in the distinction drawn between “fools” (“peaceful madman”, p.67) and “real madman” (p. 67). Further, it is the unpredictable nature of strange and violent behaviour that marks a madman apart from others, making his/her behaviour un-understandable. Generally, madness was viewed as being both permanent and pervasive, affecting the individual forever and entirely (“Once mad, always mad”, p. 58). The focus on appearance and outwardly visible disturbed behaviour as the core characteristics of madness, evident in this study of Barbados, does appear to be common across the Caribbean. Indeed, the images of madness documented by Fisher (1985) are notably similar to those found in Trinidad by Littlewood (1988). He comments: “[In Trinidad] the madman is loud, boisterous, erratic and potentially explosive. His most frequently mentioned characteristic is violence” (p. 78). As well as being documented in limited and scattered studies in other islands, there are numerous literary references to these aspects of madness (Fisher, 1985). Above all, as Fisher (1985) points out, this is a pejorative conceptualisation of madness, in which madness is feared and stigmatised, the response being to shut “madmen” away in the local mental institution.

Beliefs concerning the causes of madness documented in Fisher’s study are also very similar to those reported in studies of other islands (Littlewood, 1988). In short, causal explanations fall into two broad categories: “studiation” and obeah. “Studiation” refers broadly to worry, thinking too much, “working the brain too hard” and so on. The central idea is that worrying or thinking too much about problems can send people mad. More specifically, it refers to education, particularly studying books, as illustrated in this dialogue from Patterson’s (1971) *The Children of Sisyphus*: “Ah still don’ believe too much a dis studyin’ fe black people. Look ‘pon Mr. Soloman, yu see ‘ow funny-funny ‘im gwan … ‘im try fe study more dan wha’ ‘im teacher could teach ‘im. Send ‘im start mad” (1971, p.89,
Alongside this belief that studiation (worry, book study) could cause madness, the other framework within which madness was accounted for was that of obeah. As noted above, obeah is a form of sorcery, in which magic or supernatural forces are harnessed by an obeah practitioner or doctor to cause harm or to heal. Thus, Fisher (1985) found that obeah was viewed as both a possible cause and cure for madness, particularly by lower class Barbadians, beliefs again apparently common across the Caribbean among people of African heritage. To quote Littlewood (1988) again: “... in the area of what we may gloss as ‘psychopathology’, both madness (approximating to the psychiatrist’s ‘psychosis’) and malkadi (‘epilepsy’) are principally regarded as the consequence of obeah and are manifested by altered behaviour” (p. 76). While the power believed to be at work is supernatural, obeah is invoked in interpersonal disputes to cause enemies misfortune, giving rise to the idiom of “somebody must be working something against me” (Fisher, 1985, p. 107) to explain difficulties. Interestingly, Fisher (1985) views obeah as “a metaphor for bad living, misfortune, and poverty. When adversity strikes, illness occurs or deprivation lingers, people can talk in the idiom of obeah” (p. 107), an interpretation that resembles Snow’s (1983) in relation to spiritual beliefs about the origins of illness among African-Americans (see below). These explanations for madness lead on to beliefs about appropriate responses, many of which are preventive, designed to stave off madness before it strikes, i.e. not worrying or studying too much on problems, not becoming involved in interpersonal disputes. This emphasis on prevention inevitably arises from the common perception of madness as an all or nothing, incurable state. What is clear, moreover, is that, whichever of these idioms is invoked, for many Barbadians, and many in other Caribbean islands, “madness is not medical” (p. 122), as one of Fisher’s (1985) respondents put it: “Everybody in my family, including my neighbours, believe that the mental hospital can’t help. It’s not a medical problem.” (p. 122).

The depth with which anthropologists have detailed and analysed indigenous medical systems, evident in Laguerre’s (1987) and Fisher’s (1985) work, is made possible through anthropology’s distinctive perspective and methods. That is, the analysis of whole cultural systems and the interrelationships between the component parts through participant observation, which involves the researcher immersing him/herself in the society under study, allows the full complexities of belief systems, health practices, and their wider social significance to be documented. The cultural relativism that underpins much research in medical anthropology further adds to this. The perspective is not one that privileges one body of knowledge over another, but one that seeks to understand cultural systems from the perspective of their own internal logic and meaning. A consistent finding that has emerged from this type of research is that beliefs and practices relating to health and illness often have wider social functions and meaning, for example, in sustaining social stability, preventing rule
breaking, and resolving interpersonal and social conflict. Beliefs about obeah can be viewed
in these terms. A further telling example is that of that of ch'ien interpreters, common in
China and Taiwan, who perform a type of divination, diagnosing and advising on the
resolution of presented problems. Invariably the advice is culturally conservative. Further,
beliefs that socially unacceptable behaviour may anger ancestral spirits, who may respond by
causing illness, help to regulate social behaviour. There is a significant moral component to
such beliefs. The individual is responsible, resulting in blame, and the onus is on the
individual to right the social wrong in order to remedy the illness. This moral dimension to
health beliefs and practices is common across cultures, though it takes very different forms. It
can be seen, for example, in more modern beliefs linking lifestyle and ill-health, particularly
diet, but also lack of exercise, risky behaviours, such as sexual promiscuity, and so on
(Calnan, 1987; Blaxter, 1983). Linked to this, many commentators have noted that non­
western societies often conceptualise illness more in terms of disturbed social or family
relationships and that healing practices consequently often take the form of promoting
conflict resolution (Linde, 2001; Kleinman, 1980; Waxler, 1977; Murphy, 1964). Maclean
(1971) showed that the remedies prescribed following divination among the Yoruba were
primarily concerned with restoring relationships between the sufferer and his/her family.
Divination in Puerto Rican spiritism focuses on assessing a sufferer's social relationships,
through a process of questioning the sufferer while the medium is in contact with the spirit
realm: “The medium spends some time on the psychological state of the client, then moves to
an exploration of his family, job and love life. The final diagnosis names a spiritual cause
which relates to the social circumstances revealed during the dialogue” (Leff, 1988, p. 134;

Beliefs relating to health and illness evidently impact directly on how individuals and
others respond to illness. Not all involved, however, will share the same interpretations of
what is wrong. In particular, patients and relatives whose concepts of illness are rooted in
traditional beliefs may differ markedly from western physicians in their understanding of
what the illness represents and how it should be treated. This creates a potential barrier to
communication and engagement. A key concept here is that of Explanatory Models of illness
episodes, developed by Kleinman (1980) in the course of his work in Taiwan and China. The
concept of Explanatory Models was discussed in the previous chapter and so does not need to
be considered in detail here. It is important to note, however, that this concept has been used
extensively in research since, though not exclusively, or even mainly, by anthropologists (for
example, Bhui & Bhugra, 2002b; Philips et al, 2000; Callan & Littlewood, 1998; Lloyd et al.
1998; Eisenbruch, 1990; Millett et al, 1996). This is perhaps understandable given that the
primary concentration on beliefs, in relative isolation from other factors, is contrary to the
anthropological focus on interlocking aspects of social and cultural systems. The notion of
Explanatory Models has been criticised for this reason and for over formalising lay beliefs (see Section 4.3 below). Nonetheless, it remains a useful tool for investigating how illness is conceptualised, and the types of questions that have to be asked to elicit Explanatory Models can equally be applied to more general studies of illness beliefs\(^1\). Further, the concept of Explanatory Models makes no judgement about the superiority of one account over another, rather it provides a means of assessing the underlying beliefs that have guided help-seeking decisions in patients, but more than that, it provides a method for comparing the Explanatory Models of all those involved in the clinical process, and from this can be applied in clinical practice (Bhui & Bhugra, 2002; Kleinman, 1980, 1997). This is important because inconsistencies between the Explanatory Models of patients and healers, as already suggested, may have negative consequences for the outcome of the therapeutic intervention, a point which will be returned to.

4.1.2 Making the Familiar Strange (1): Beliefs about Illness

Fitzpatrick (1984) has commented that: "... by analysing beliefs that seem very strange and exotic to western readers, [anthropologists] make possible a more critical awareness of one's own more familiar and taken for granted beliefs" (p. 255). Research by both sociologists and, to a lesser extent anthropologists, has investigated beliefs about illness in western populations, drawing attention to the equally considerable diversity of beliefs and their impact on illness behaviour. This research has tended to focus on beliefs among different social groups (i.e. men or women, ethnic groups, social classes, etc.), a feature that reflects the sociological perspective of much of this work. Again, this perspective is apt if, in contrast to anthropology, sociology is the discipline that renders the familiar and taken for granted unfamiliar.

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\(^1\) Kleinman (1980, p. 106) suggested the following questions as a starting point for eliciting Explanatory Models of illness episodes:

1. What do you call your problem? What name does it have?
2. What do you think has caused your problem?
3. Why do you think it started when it did?
4. What does your sickness do to you? How does it work?
5. How severe is it? Will it have a short or long course?
6. What do you fear most about your sickness?
7. What are the chief problems your sickness has caused for you?
8. What kind of treatment do you think you should receive? What are the most important results you hope to receive from the treatment?
The likely increased complexity and variability of cultural beliefs and health related behaviours in multi-cultural and multi-ethnic populations was noted in the introduction. Specifically, the co-existence of beliefs derived from a multitude of traditions, be they common to the indigenous country or introduced by migrants, and the cross-fertilisation of ideas and practices in multi-cultural settings, ensures considerable diversity between and within social and ethnic groups. The survival of traditional beliefs about illness derived from non-indigenous cultures, frequently in modified form, has been documented among a number of ethnic minority groups. Snow (1983), for example, has described beliefs and health practices among African-Americans in the American Deep-South that share many similarities with those found in Africa and the Caribbean. Indeed, beliefs strongly reminiscent of those described by Laguerre (1987) are evident, particularly in the distinction drawn between natural and unnatural illnesses. Natural illnesses are those caused by the effects of cold, dirt or improper diet on the body, the mechanism being changes in the state of blood in the body. Diet, for example, is believed to moderate the amount of blood in the body. “High blood” (too much blood) is caused by red meat, red wine, beets, carrots and so on, essentially red foods, and is characterised by headaches, dizziness, spots before the eyes and “falling out”, a term for sudden collapse – symptoms from a bio-medical perspective indicative of hypertension. “Low blood” (too little blood) is caused by not eating the right foods, for example, eating too many pickles, olives, vinegar or garlic and not enough red meat, and is characterised by weakness, lassitude, fatigue and, again, “falling out”. In each case the appropriate remedy is to consume foods that will either raise or lower the level of blood – for high blood, those that cause low blood, and for low blood, those that cause high blood, the aim being to restore balance. The use of religious healing was also common, based on the belief that illness could result from divine punishment for improper behaviour, beliefs that again resemble those described in the anthropological literature and which again have a significant moral component to them. Unnatural sickness was classified as that caused by forms of witchcraft and magic, usually involving “poisoning” food or drink with some “evil” substance that takes root in the body. Gastrointestinal and behavioural problems were frequently attributed to witchcraft and it was widely believed that: “only a healer with ‘the power’ can take off an unnatural symptom, remove poison from the body, drive the magical snake from a vein” (Snow, 1983, p. 827). What is particularly interesting about Snow’s (1983) account of these beliefs and practices is the link he draws between them and the social, political and economic marginality of African-Americans, arguing: “In such an environment it is not surprising that many see the world as a hostile place where ‘exposure’ leaves the body vulnerable … and where God may ‘strike you down’ for sinning and where an envious neighbour may ‘put something on you’ by using evil magic” (p. 821).
It would be misleading to suggest beliefs linking illness to spiritual or supernatural forces were confined to ethnic minority groups within western societies. Indeed, supernatural and spiritual causes of ill-health have been documented among predominantly White groups, usually linked to religious belief and practice. Skultans' (1974, 1976) study of spiritualism in South Wales, for example, documented beliefs relating ill health to spirit possession and described healing practices in which spiritualist healers acted as the instrument of healing spirits. That said, studies that have explored beliefs among less specific populations have reported a diverse range of more secular folk beliefs, which still depart from those embodied in western bio-medicine in significant ways and exert strong influences on illness behaviour. The example already discussed of folk beliefs centred around the notion of “feed a cold, starve a fever” illustrates this, and while heavily influenced by anthropology this study shares much in common with those conducted by sociologists among white respondents.

What is particularly striking about much research in this area is the variety and importance of beliefs about the causes of illness expressed by respondents. Bury and Wood (1979) have commented: “The disturbing reality of disease experience gives rise to questions: Why me? and Why now?” (quoted in Blaxter, 1983, p. 59). Above all there is a search for meaning in the experience of illness (Lewis, 1995). Blaxter (1983) in a study of concepts of disease in a sample of working-class, middle aged women in Scotland, using unstructured interviews, found that the search for causal explanations was central to elicited accounts. The most commonly expressed causes of illness were categorised as follows: infection and the environment; heredity and family tendency; stress, strain and psychological explanations; disease secondary to trauma or surgery; behaviour, neglect and the constraints of poverty; individual susceptibility; the ageing process, ‘natural’ degeneration and stages of life; and diseases without a cause. While the beliefs represented in these categories share similarities with professional theories of disease and cause, they carried specific meanings that were rooted in the women’s social reality. Sources of infection, for example, were believed to reside in the environmental conditions of poverty – damp, dusty working environments, unclean water and environmental pollutants. Likewise, stress and illness arose from the difficulties of living, as illustrated in this example of a woman who had suffered a stroke: “I’d an awful lot of stress with my husband dying, and looking after my mum, and I went out to work ... I wasnae home here until evening and by the time I did housework and bed – I was up early in the morning again. I think it just began that it got too much” (Blaxter, 1983, p. 64). Interestingly, as respondents associated health and happiness, so they linked ill-health to sources of unhappiness in their lives, such as bereavement and burdensome chores. While some of the beliefs about causes of illness did incorporate notions of blame and individual responsibility, the emphasis was on external, uncontrollable features of the environment, which clearly invites comparisons with Snow’s (1983) conclusion that social position exerts a
significant influence on the form beliefs take. It further points to a possible influence of
gender on both beliefs and illness behaviour, in that the social roles and positions fulfilled in
such contexts differ between men and women. Studies in this area, however, have more often
focused on women (Calnan, 1987; Blaxter, 1983; Pill & Stott, 1983).

A comparable study by Pill and Stott (1982), this time with a sample of working class
women in South Wales, found interesting differences and similarities. Infection and germs
were again the most frequently mentioned cause of illness, followed by life-style, heredity
and stress. What is particularly interesting is that approximately half of the respondents (n =
20/41) invoked behavioural choices when discussing causes, in particular life-style choices,
and, significantly, those in this group of respondents were more likely to be home owners and
to have more formal education. A key distinction in lay beliefs, evident both in this study and
others, is between those in which individual behaviour is invoked as a major causal factor and
those in which factors external to the individual are central, the core issues being ones of
individual responsibility and control. As will be discussed later in this chapter, where
responsibility for illness is believed to rest will influence beliefs about what should be done
and by whom. Tentatively, Pill and Scott’s (1982) study hints at the possibility that social
position and education may be important factors separating these two types of causal
explanation.

Three further causal explanations are particularly evident in this and other research,
namely those invoking heredity, individual susceptibility and stress. These beliefs, as with
others, share much in common with professional theories of illness causation and no doubt
have in part been shaped by these through contacts with health services and the popularisation
of such theories via the media and other sources. The meanings attached to these causal
factors, however, have been shown to vary from those of professional medicine in important
respects. The concept of, and beliefs relating to, stress illustrate this well.

In academic discourse, the concept of stress was originally formulated by Seyle
(1936) as "the generalised response of the organism to environmental demands" (Helman,
1994, p. 296). Since then innumerable papers have been published on the subject of stress
and its role in the aetiology of a wide range of illnesses (Helman, 1994). Through this vast
body of research, Seyle’s original formulation has been modified and extended to take
account of the role of individual characteristics, physical environment, social supports,
economic status and cultural background in modifying the impact of external demands on the
functioning of the organism (Pearlin, 1999). What is important here, however, is that the
concept of stress has increasingly entered popular discourse and many studies of lay concepts
of illness have documented the pervasiveness of stress as a theme in theories of illness
causation (Shiekh & Furnham, 2000; Pollock, 1988). Helman has argued that: “The lay
The concept of stress can be regarded as one of the most pervasive—and multi-dimensional—folk illnesses of contemporary western society” (p. 314). He goes on:

“... lay notions of ‘stress’ blend together into a single image, a cluster of negative feelings, emotions, physical sensations, as well as certain social, cultural and economic circumstances. In doing so it has absorbed older, more traditional models of misfortune and unhappiness. It has become a secularised version of more supernatural concepts such as witchcraft, sorcery and other forms of interpersonal malevolence, and of ‘fate’, ‘divine punishment’ and possession by malign ‘spirits’. Modern images of ‘stress’ provide a fascinating illustration of how Seyle’s original concept has entered popular culture and blended there with older models of misfortune—becoming a point of overlap between popular, medical and religious explanations of suffering.” (p. 314)

Helman has further documented a number of images of stress that have been identified in studies of illness representations (see Box 4.1), all of which coalesce around the notion of stress as a diffuse, invisible force somehow linking the individual to the external world. Certainly, stress is invoked more often in lay explanations of illness than in professional medicine, particularly mental illness, as will be seen below, and, following Helman (1994) and Blaxter (1983), it can be seen as one way for people to make sense of illness by locating it in the circumstances of unhappiness. This need to give meaning to experience frequently creates a conflict of Explanatory Models between patient and doctor.


- **Stress as a heavy object**
  Examples: ‘to be under a lot of stress’, ‘to be under pressure’, ‘to have a lot on one’s mind’, to have things ‘piling up on top of me’.

- **Stress as a wire or line**
  Examples: some people are ‘highly strung’, ‘taut’, ‘tense’, ‘tightly wired’, while others have nerves that ‘snap’ or that become ‘frayed’.

- **Stress as internal chaos**
  Examples: ‘to be churned up’, ‘to be all mixed up’, ‘to have butterflies in the stomach’.

- **Stress as fragmentation**
  Examples: ‘to crack up’, ‘to fall apart’, ‘to go to pieces’, ‘to break’.

- **Stress as malfunctioning of a machine**
  Examples: ‘to have a nervous breakdown’, ‘to be burnt out’, ‘to need to recharge one’s batteries’, ‘to grind to a halt’.
• Stress as depletion of a vital liquid
  Examples: 'to feel drained', 'running on empty', 'to run out of steam'.

• Stress as inner explosion
  Examples: 'to get it off one's chest', 'to burst a boiler', 'to blow one's top'.

• Stress as interpersonal force
  Examples: 'my boss gives me a lot of stress', 'she gave me a nervous breakdown', 'he broke his mother's heart'.

4.1.3 Making the Familiar Strange (2): Beliefs about Mental Illness
The examples outlined above have been drawn primarily from sociological studies that are characterised by the use of in-depth interview techniques, with small numbers of respondents, and which are concerned to explore variations and similarities in lay concepts between social and ethnic groups, often focusing on how the structural position of respondents shapes these concepts and may underpin differences in beliefs and health practices between these groups. This work shares much with anthropology in attempting to understand folk beliefs from the perspective of their own internal logic and how this, meaningfully, underpins responses to episodes of illness. This, however, is but one perspective from which lay beliefs have been studied among western populations, and there are significant strands of research in social psychology and psychiatry that have utilised very different research methods and that are underpinned by different theoretical perspectives and aims (see Figure 4.1). Not surprisingly, much of this work has focused on beliefs about mental illness, and while it differs in perspective and method from that research considered so far it does provide some indicators as to variations in beliefs about mental illness among western populations. For purposes of clarity, research specifically considering beliefs about mental illness among western populations can be divided into three types: 1) that concerned primarily with attitudes towards the mentally ill; 2) that concerned with differences between lay beliefs and professional knowledge; and 3) that concerned with the content of beliefs on their own terms.

Attitudes towards mental illness, in contrast to beliefs about mental illness, refers to what people think about the mentally ill and how they respond to them. The key finding to emerge from the substantial body of research in this field, that is of relevance here, relates to what lay people believe are the characteristic attributes of people experiencing severe mental illness. It provides indications of what the prevalent images are of mental illness among western populations. In this there is considerable consistency. The predominant images are ones of violence, unpredictability and extreme and bizarre behaviour (Crisp et al., 2000; Bhugra, 1989; Rabkin, 1974, 1972). These are not the only images, and others hold much more psychological images of the mentally ill as emotionally disturbed, but it is this persistent image of severe mental illness and madness as violent and unpredictable that underpins
ongoing stigmatisation of the mentally ill and what appears to be widespread fear of contact with the mentally ill. Interestingly, there is some evidence that this stigmatisation of the mentally ill is even more marked in ethnic minority groups (Wolff et al., 1996a; 1996b). What is of particular relevance here is that this negative conceptualisation of severe mental illness creates a potential barrier to early help-seeking and engagement with mental health services. What is more, attitudes have been shown to be more positive towards those who are depressed compared to those with a more severe mental illness, but this does not necessarily translate into a greater willingness to seek medical help. Indeed, research further reveals there to be widespread distrust of anti-depressant medication and a preference for psychological and complementary therapies (Jorm et al., 2000), which may reflect the common conceptualisation of depression as a normal response to extreme stress or as a problem in coping (Rogers et al., 2001) or a mistaken belief that anti-depressants are addictive (Jorm, Korten, Rogers et al., 1997). The example of depression shows that attitudes are one component of broader concepts of illness and that these attitudes, and willingness to engage certain forms of help, are influenced by these broader concepts.

Much of the research that has investigated beliefs about mental illness among white western populations has been conducted by social psychologists and psychiatrists concerned primarily with discrepancies between professional knowledge and lay beliefs. Contained within this distinction is the assumption that professionals have access to objective, incontrovertible knowledge that stands outside of social and cultural contexts, while lay people merely hold beliefs about the world that derive from a variety of sources and which may or may not resemble what is "known". Indeed, in common usage, belief implies trust or faith in a world view irrespective of the empirical basis of such a view. This perspective fits with the aim of a significant proportion of research that has investigated beliefs about mental illness among western populations, namely that of understanding the ways in which beliefs about mental illness influence compliance and engagement with services. The central point here is that beliefs which diverge from psychiatric knowledge and hinder compliance and engagement are potential targets for educational interventions to increase lay knowledge and, consequently, willingness to engage and comply. This perspective is at the heart of the influential and widely researched Health Belief Model (Petrie & Weinman, 1997). Simply stated: "Compliance is adherence to an appropriate and prescribed treatment" (Bebbington, 1995, p. 41). According to the Health Belief Model, prospective and current patients engage in a cost-benefit analysis, weighing the perceived costs of compliance against the perceived benefits. Central to this process is the patient's beliefs about illness. General health beliefs, specific beliefs about an illness episode and treatment preferences combine, in this model, to shape all health related decisions, creating a "subjective evaluation of circumstances" and a "subjective state of readiness" to seek help in the event of illness. As it has developed, the
model has incorporated other factors, such as previous experience and social interactions, but it remains primarily psychological, privileging cognitive attributions over other factors and conceptualising the process of help-seeking as the outcome of a rational, cost-benefit analysis. Research focusing on mental health literacy shares much with that concerned with compliance and engagement, and in practice is very similar, particularly methodologically. Perhaps even more so than with compliance, the starting point of research conducted from this perspective is the question, how literate in matters of mental health are the public? Answering this question is the basis for the development of literacy campaigns through which it is hoped recognition of mental illness, early help-seeking and positive attitudes towards the mentally ill can be fostered. These approaches have limitations, not least that the use of structured questionnaires elicits only limited data about beliefs which lacks the depth evident in, for example, the data collected by Blaxter (1983) and Pill and Stott (1982). It has nonetheless contributed to the little that is known about beliefs among western populations, particularly in relation to beliefs about the causes and appropriate treatments for specified illnesses, such as depression and schizophrenia. The purpose is always to compare such beliefs to psychiatric knowledge.

The broad body of work by social psychologists and psychiatrists that has used structured questionnaires and quantitative analyses, often within the Health Belief Model or mental health literacy frameworks, has tended to confirm the negative conceptualisation of mental illness among western populations found in research focused primarily on attitudes. Furnham and Rees (1988), in their study of lay theories of schizophrenia, found that respondents identified the most common characteristics of people with schizophrenia as: 1) those alluding to dangerousness; 2) those referring to amorality (e.g. untrustworthiness); 3) those relating to egocentricity (e.g. no thought for others); and 4) those referred to by Furnham and Rees as "aspects of vagrancy regarding schizophrenia" (p. 217) (e.g. "many people with schizophrenia are vagrants and drop outs of our society"). In the main, however, research conducted from the perspective outlined in the previous paragraph has not been concerned with lay conceptualisations of what schizophrenia or depression are. The concern with comparing lay belief and professional knowledge has meant that subjects are usually given vignettes of cases labelled as schizophrenic, depressed, and so on, and asked about perceived causes and preferred treatments. This means that an important component of cultural conceptions of mental illness, madness, or whatever, is ignored, namely how non-professionals label behavioural and emotional disturbance.

Studies from these perspectives that have focused on white, or predominantly white groups, have found that the most common causes identified of both depression and schizophrenia are social (Jorm, 2000). Furnham and Rees (1988), for example, in a study of lay concepts of schizophrenia found stress to be the most significant cause identified by
respondents, particularly stress in the family, followed by biology, genes and brain damage. A further study, this time by Furnham and Bower (1992), comparing lay and professional concepts of schizophrenia showed that lay subjects stressed the importance of the patient’s environment in causing schizophrenia, in contrast to the greater emphasis on physiological malfunction among professionals. In a review of research focused on the mental health literacy of the public, Jorm (2000) concluded that schizophrenia was often viewed as being caused by the social environment, particularly recent stressors. The importance of social environment and stress in lay accounts of schizophrenia is also evident among other cultural groups. Furnham and Murao (1999) compared beliefs of British and Japanese respondents and found that among both stress was the main causal factor identified, followed by cognitive, genetic and biological factors. Using a similarly quantitative methodology, Srinivasan & Thara (2001) found that relatives of patients with schizophrenia in India identified psychosocial stress as a causal factor more frequently than others; these others including personality defect, heredity, brain dysfunction and, in a small minority, supernatural causes. In this latter study, researchers also investigated which causal factors tended to be invoked together and found that the most common combination was stress and heredity, a combination, as the authors point out, that is reminiscent of professional stress-diathesis models. This, moreover, serves as an important reminder that while social factors and stress may be the most common factors believed to cause schizophrenia, these form only one component of more complex and perhaps contradictory belief frameworks. Unfortunately, the use of structured questionnaires in much of this work has not allowed for the investigation of which factors tend to go together in respondents’ answers and, more importantly still, they do not allow for the exploration of how respondents see diverse factors as combining to cause or protect against mental illness.

It is particularly interesting to compare the findings of those studies that have considered only schizophrenia with those that have investigated beliefs about both schizophrenia and depression together. It is clear from research focusing on beliefs about depression that similar social factors to those identified above are very commonly believed to cause depression (Jorm, Korten, Jacomb et al, 1997). When considered together the emphasis on social factors in both disorders is confirmed, except that other factors, such as biology and genetics, tend to become more salient in expressed beliefs about the causes of schizophrenia. In a series of surveys of lay beliefs in Germany, for example, which included between 2-3,500 respondents in each study, Angermeyer, Matschinger and colleagues (Angermeyer & Matschinger, 1999; 1996; Angermeyer et al, 1999; 1998; Matschinger & Angermeyer, 1996), showed that while psychosocial factors were prominent for both schizophrenia and depression, this was more true for depression, and biological factors tended to be more common for schizophrenia. Jorm (2000) has also commented that in those studies where
vignettes are labelled schizophrenic more biological causes are preferred. This suggests that the lay public do perceive schizophrenia to be more severe than depression and that when considered side by side, more biological causes are invoked to differentiate the two and emphasise the seriousness of schizophrenia and/or its more appropriate status as an illness requiring medical intervention.

The suggestion that lay people differentiate depression and schizophrenia in terms of seriousness and status as an illness requiring medical intervention has some confirmation in reported differences in what lay respondents believe the appropriate treatments are for depression and schizophrenia. Angermeyer et al (1999), for example, reported that their respondents believed mental health professionals to be helpful in treating schizophrenia but not depression. For depression, close confidants, family physician and self-help groups were higher up the list of treatment preferences given by respondents. Similarly, Jorm, Korten, Rogers et al (1997) found that medical treatments were rated more negatively for depression than for schizophrenia, though in both cases non-medical treatments were rated more highly than medical treatments. In general, Jorm (2000) suggests the lay public tend to have negative perceptions of medication and other psychiatric interventions and prefer psychotherapies, self-help and complementary therapies.

Studies that have compared cultural and ethnic groups in multi-ethnic settings have reported interesting differences, as well as similarities. Research on ethnic minorities is methodologically more mixed than that detailed above, with some of it using qualitative methods to investigate beliefs on their own terms, i.e. the third type of study identified in the introduction to this sub-section, though the majority is still primarily quantitative. Eisenbruch (1990), for example, developed the Mental Distress Explanatory Model Questionnaire (MDEMQ), a fully structured questionnaire, with the aim of exploring "how people from different cultures explain mental distress" (p. 712). Using Murdock and colleagues' (1978) work on illness models throughout the world, a 45 item questionnaire of possible causes of mental illness was developed and administered to 261 people, mainly college students. Eisenbruch (1990) found a range of beliefs about the causes of mental illness and was able to group these into four categories – western physiological, non-western physiological, stress and supernatural. This confirms the cross-cultural relevance of concepts of stress and biogenetic factors, but it also shows that beliefs about the causes of mental illness extend wider than this to include non-western physiological factors, such as imbalance in body humours and eating the wrong food, and supernatural factors, such as witchcraft and spirit possession. The persistence of folk beliefs derived from cultures of origin and heritage among ethnic minority groups has been documented in other studies. In relation to mental illness, this has been most evident in beliefs about spiritual causes. Millet et al (1996), for example, in a study of the views concerning mental illness of black and white college students in the USA,

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found that Black Americans attributed greater significance to spiritual factors. Also in the USA, Alvidrez (1999) studied attitudes and beliefs among women from a range of ethnic groups attending a women’s clinic, and found that Latin-Americans in the sample endorsed medical causes of mental illness least, whilst African-Americans endorsed religious/supernatural explanations most. Not all studies have supported these general findings. Raybuck (1998) compared beliefs among African-Americans and Caucasians and found no significant differences. In developing countries, some researchers have failed to find the expected preponderance of spiritual beliefs, particularly in urban centres and among those with higher levels of education (Padmavathi et al, 1998).

Research exploring beliefs about mental illness among ethnic minority groups in the UK, particularly African-Caribbeans, is very sparse. In total, following a detailed literature search, only seven studies could be identified that included data on beliefs about or perceptions of mental illness among African-Caribbeans (Cinerella & Lowenthal, 1999; Lloyd et al, 1998; Callan & Littlewood, 1998; McGovern & Hemmings, 1994; Perkins & Moodley, 1993; Morely et al, 1991; Kiev, 1963). Lloyd et al (1998), using a semi-structured interview with women primary care attendees in the UK and Zimbabwe, found that both the Zimbabwean and UK African-Caribbean groups believed in spells and black magic as a cause of mental illness much more than the UK white and UK Indian groups. The Lloyd et al (1998) study aside, only the studies by Kiev (1963) and Cinerella & Lowenthal (1999) revealed strong beliefs in supernatural factors as causes of mental illness. Even then, Kiev’s (1963) study was conducted not long after many would have migrated to the UK, when it could reasonably be assumed that traditional beliefs would still be common, and was focused specifically on religious and spiritual belief, and Cinerella & Lowenthal’s (1999) study was conducted primarily with religious groups, including Africans and African-Caribbeans, which no doubt inflates the significance of spiritual factors beyond that likely to be found among a broader sample of either of these population groups. What is particularly interesting about this latter study is that, although a qualitative methodology was used, it found that schizophrenia was more stigmatized than depression and that more organic causes and fewer religion based interventions were proposed, which is in keeping with the findings outlined above. Limited as this research is, it suggests that while beliefs linking mental illness to spiritual and supernatural forces persist, they do so in attenuated form, and among those born in the UK to Caribbean parents it would be expected that such factors would be invoked even less in beliefs about mental illness.

Furthermore, the tendency to focus on differences between ethnic groups may result in more important similarities being ignored. It may well be that a significantly larger proportion of African-Caribbeans than Whites believe there to be spiritual causes of mental illness. However, this says nothing about how central such beliefs are to accounts of mental
illness, and whether it is these beliefs that are driving responses to mental illness. Indeed, the
use of quantitative methods, which focus on identifying variations between groups, may serve
to over-state differences. Such methods have little to say about how apparently contradictory
beliefs, for example stress and spiritual factors, held by the same respondent are reconciled by
that respondent, and which beliefs are the most salient in shaping decisions about what help to
seek. This of course cuts both ways. A common feature of all of the work on African-Caribbeans in the UK is the finding that beliefs linking social factors to mental illness are
much the most common (Lloyd et al, 1998; Perkins & Moodley, 1993). On the face of it, this
marks an important point of similarity between African-Caribbeans and Whites, but, as is
evident from more general research discussed above, what is meant by stress varies and folk
beliefs incorporate a range of metaphors to describe stress, each of which may have different
implications for help-seeking. For example, concepts of stress as arising from external,
uncontrollable events, such as bereavement or job loss, may lead to different help-seeking and
management strategies than, say, beliefs that stress arises from interpersonal difficulties.
These conceptualisations are not mutually exclusive, and indeed many people switch between
them in talking about illness. What is important here is that failure to explore what is meant
by stress among different groups runs the risk that important differences are missed. Again,
the predominantly quantitative methodologies of much research in this area have meant
existing research has little to say about these questions.

The limitations of previous research that has included data on beliefs about mental
illness among African-Caribbeans have meant that the potential impact of beliefs on different
patterns of service access and use has not been fully explored. Some of the seven studies
already referred to have tried to connect beliefs or perceptions to help-seeking, but findings
are equivocal and narrow in their scope. Perkins and Moodley (1993), for example, explored
perceptions of illness among a multi-ethnic sample of patients and found that African-
Caribbeans were significantly more likely than Whites to believe that they had no problem or
that their problem was social or physical, not psychiatric (63.6% v. 48.0%). These
perceptions were related to compulsory admission, but unfortunately the classification of
perceptions into no problem, social/physical and psychiatric is narrow and it is not clear
whether these findings are confounded by differences in levels of insight between the two
groups (see Chapter Two). McGovern and Hemmings (1994) used a broader set of categories
in their study of attitudes towards mental illness and psychiatric services in a sample of
patients with schizophrenia and relatives. They did not, however, find any differences
between African-Caribbeans and Whites in terms of satisfaction with services,
conceptualisation of illness and attitudes towards different types of treatment and
management. Morley et al (1991) similarly found no differences between relatives of
African-Caribbeans who had been admitted to hospital voluntarily and those who had been
admitted compulsorily, their conclusion being that there was no evidence to support the hypothesis that differences in beliefs among relatives was a factor in higher rates of compulsory admission among African-Caribbeans. The methodology used, however, is poorly specified in the paper, making it difficult to assess the validity of such conclusions. The remaining four studies did not attempt to consider directly the relationship between beliefs and help-seeking among African-Caribbeans.

While much of the research considering beliefs about mental illness among western populations is methodologically limited in its use primarily of structured questionnaires, a number of broad conclusions can be drawn:

- Lay people generally have negative views of severe mental illness, frequently linking it with violence and unpredictability
- Explanations of the causes of severe mental illness frequently include a range of factors, the most common, crudely grouped, being:
  - Social factors, especially stress
  - Heredity
  - Biology
  - Individual personality
- Depression, in general, is believed to be caused by social factors more than schizophrenia, which in turn is more often believed to result from heredity or biological factors
- Overall there appears to be considerable reluctance to resort to psychiatric services for help, though this is more marked for depression than for schizophrenia
- Among ethnic minority groups, beliefs linking spiritual and supernatural forces to mental illness have been documented in a number of studies both in the USA and, to a lesser degree, in the UK. There is a danger, however, that by focusing on such beliefs other key differences and important similarities may be obscured
- In the UK, the paucity of research on beliefs among African-Caribbeans makes it difficult to draw any conclusions about how such beliefs vary both within the African-Caribbean population and between African-Caribbeans and other ethnic groups

Research to date, then, offers important clues about the nature and variation of beliefs about mental illness among western multi-ethnic populations, but as a whole it lacks depth and there remain important gaps, most notably in the lack of research investigating beliefs about mental illness and pathways to care using more detailed, qualitative methodologies.
4.2 FRAMEWORKS FOR THE CROSS-CULTURAL COMPARISON OF BELIEFS ABOUT ILLNESS

There have been a number of frameworks proposed for classifying illness beliefs across cultures. In general, typologies of beliefs about illness have tended to focus on two features: i) responsibility for illness; and ii) presumed locus of origin of illness. These are important features of lay beliefs. Who or what is deemed responsible and where the illness is believed to originate are potentially key influences shaping what people do in response to illness. If, for example, illness is believed to arise because of poor lifestyle choices, (e.g. smoking, obesity, etc.) then the sufferer is potentially less likely to receive sympathy and support. That is, it may be more difficult for the sufferer to enter into a socially approved sick role (Parsons, 1951). Shame and stigma may attach to illnesses believed to arise from lifestyle choices (e.g. assumptions that HIV/AIDS is a disease of homosexuality), and this may inhibit help-seeking. Likewise, the believed source of illness will shape ideas about appropriate remedies. For example, if illness is believed to stem from spirit possession, it is likely that forms of exorcism or extraction will be deemed necessary to remove the spirit and the illness, as illustrated in the examples discussed by Leff (1988) outlined above, whereas a belief that illness is the product of physiological dysfunction is more likely to promote help-seeking from the medical profession. To reiterate, much of the interest in beliefs about illness arises from efforts to understand how and why people respond to illness and seek help. It is natural, given this, that typologies should focus on the characteristics of belief frameworks that shape responses to the experience of illness. Such classificatory frameworks facilitate cross-cultural comparisons, allowing differences and similarities in beliefs to be mapped more clearly.

Helman (1994), for example, distinguished beliefs according to whether the cause of the illness is believed to arise from within the individual, in the natural world, in the social world, or in the supernatural world, as illustrated in Figure 4.2.

Figure 4.2. Sites of illness aetiology (from Helman, 1994, p. 120).
Helman (1994) further suggested that, broadly, supernatural and social explanations tend to be features of non-industrial communities, particularly in rural areas, while natural and individual centred aetiologies are more common in the west. This apparent dichotomy in beliefs between industrial and non-industrial countries has led some to distinguish beliefs along a western – non-western dimension (Eisenbruch, 1990). Others have drawn the distinction more simply between those causal theories implicating internal and those implicating external factors (Young, 1976). A major component of this, and to some degree Helman’s (1994) classification, is the issue of individual responsibility, that is, of the degree to which illness is located in the intentional actions of individuals. The question of intentional action is at the centre of the personalistic-naturalistic dichotomy often used to classify beliefs about illness. In the former (personalistic), illness is due to the purposeful active intervention of an agent, such as a supernatural being (a god), a non-human being (ghost, ancestral spirit, capricious spirits), or human being (witch or sorcerer), while in the latter (naturalistic), illness is explained in impersonal, systemic terms; it can be due to natural forces or to conditions such as cold, wind or damp, or disequilibrium in the individual or in his social environment (Foster & Anderson, 1978; Foster, 1976). Such systems of classifying beliefs have been useful in cross-cultural studies, and offer potentially valuable frameworks for summarising and comparing beliefs between different cultures and different social groups. Littlewood (1993; 1988), for example, made good use of the personalistic-naturalistic classification of beliefs in his study of illness beliefs in Trinidad. Littlewood (1988), however, also showed that these frameworks have to be applied flexibly and modified depending on the data collected. Given that this research is part of the small body of work on illness beliefs in the Caribbean, it is worth considering in more detail.

While the distinctions drawn between different types of beliefs give the impression of clear dividing points between these types, Littlewood’s (1988) research illustrated how beliefs systems often incorporate factors that span more than one site of illness or contain both personalistic and naturalistic elements. What Littlewood (1988) found was that, in Trinidad, there are naturalistic theories of physical sickness and personalistic theories of madness, but these are not mutually exclusive, “there is not a total rupture between them” (p. 70). Bush medicine was seen primarily as a naturalistic system: “its efficacy does not depend on the individual’s state of mind, personality, behaviour or their interaction with others except in as much as these lead to a changed relationship with the body and the rest of nature” (p. 75). Madness on the other hand was believed to be caused most often by spirits or obeah. However, in relation to specific instances of madness, Trinidadians incorporated a much wider set of explanatory factors, which included personality, life-style, coping mechanisms and most notably pressures. As Littlewood (1988) comments:
“Whilst most villagers offer a rich lexicon of personality and psychological states, only pressure and its related notions of studiation, grinding and tabanka offers an accepted but rare pathway from everyday life to madness which involves an internalised set of mental attitudes or physiological processes”. (p. 83)

Pressure as understood here and its relationship to madness is not easily located within the naturalistic-personalistic framework. This leads Littlewood to argue: “as in all other medical systems, the two paradigms leave an ambiguous area where the constraints of human agency are debateable and uncertain” (p. 101). The result then is a complex map of beliefs, as in Figure 4.3, in which Littlewood elaborates the initial personalistic-naturalistic dimension with the introduction of three categories - mystical, psychological and physical – in order to make sense of Trinidadian beliefs. This serves to emphasise the point that individual beliefs rarely invoke causal explanations that are restricted to one type and indeed most theories or beliefs about illness are multi-causal, invoking causes drawn from a number of spheres – individual, social, supernatural and so on. Once again, this is likely to be particularly so of beliefs in multi-ethnic settings, given the complex cultural mix outlined earlier. This emphasises the need for flexibility in applying and developing categorical systems.

Figure 4.3. Trinidadian beliefs about mental illness (from Littlewood, 1988, p. 89).
4.3 THEORIES, MODELS, MAPS, AND ACCOUNTS: The structure and status of beliefs about illness

So far the discussion has concentrated on the content and classification of folk beliefs and the perspectives from which they have been studied. In terms of content, the descriptions of beliefs in the foregoing discussion show a remarkable complexity in how individuals make sense of illness. The women in Blaxter's (1983) sample, for example, employed multifactorial accounts of illness, frequently positing multiple alternative causes of diseases and factors working together to produce final pathways to a specific illnesses. This sophistication and complexity of lay beliefs has been commented on by a number of researchers (Blumhagen, 1980; Pill & Stott, 1982). However, this can be taken too far, and, at the same time, these and others have cautioned against attributing a greater degree of coherence and consistency to lay beliefs than is warranted.

In reality, while such beliefs have often been referred to as lay theories of illness (Fitzpatrick, 1984), the term theory implies a greater degree of coherence and logic than is often evident. Lay respondents often express parallel, contradictory ideas about the nature and origins of illness, with no sense of inconsistency. Blumhagen (1980), for example, in his study of beliefs about hypertension among a sample of 103 patients found that some respondents recounted parallel, unrelated models of hypertension at different points of the interview, with no sense of this as problematic. Pill & Stott (1982) also described their respondents as: “unsure of themselves and less articulate when discussing aetiological topics” (p. 46). Further, expressed beliefs about illness are likely to be unstable over time, particularly those relating to specific episodes of illness. Individuals are likely to explore and test a number of hypotheses when experiencing symptoms in the process of making sense of them and answering the questions: what is wrong, why me, why now and so on. In relation to Explanatory Models of illness, Kleinman (1980) has commented: “Since Explanatory Models involve tacit knowledge, they are not coherent and unambiguous. In responding to an illness episode, individuals strain to integrate views in part idiosyncratic and in part acquired from the health ideology of the popular culture. Hence, it is characteristic of Explanatory Models that they undergo change fairly frequently” (p. 109). Rather than being well-worked out, stable theories of illness, then, Explanatory Models and illness beliefs in general are likely to be characterised by “vagueness, multiplicity of meanings, frequent changes” (p. 107). What matters to the individual is not the theoretical consistency of beliefs, so much as the treatment options they give rise to. In this sense, individuals make sense of culturally available interpretations of symptoms pragmatically, being concerned primarily with how best to respond.

In response to these observations, Williams & Healy (2001) have argued that it is more accurate to think of respondents' expressed beliefs as exploratory maps, rather than
explanatory models, of illness. This argument was developed in the context of a study using in-depth interviews to explore beliefs about their illness of people recently diagnosed with depression. One of the striking findings was that individuals expressed a range of causes throughout the interview, such that even within the context of the interview beliefs could be characterised as changeable. Explanations given by respondents of their experiences could not, therefore, be considered definitive, but were rather better considered as attempts to make sense of experience by exploring a range of possible explanations. While Kleinman (1980) always acknowledged these characteristics of Explanatory Models, as indicated above, the concept of a "model" nonetheless implies a degree of coherence and stability that is rarely evident. Indeed, Kleinman (1997) himself has more recently expressed his ambivalence in relation to Explanatory Models, primarily because of the way in which he feels the concept has been taken up and applied by researchers:

"I introduced the idea as a way to get a rough and ready sense of what is at stake for participants in medical dramas. It has proved useful in the clinic, where time prevents even a mini-ethnography, and it continues to be applied in research. But I am extremely uncomfortable when it is misapplied as an entification of medical meanings as "beliefs": things that can be elicited, often outside the vital context of experience, like reading the pulse, and coded as clinical artifact." (p. 8)

The concerns expressed by Kleinman are shared, to some extent, by Prior et al (2000) in their argument that what is wrong with a focus on "belief" is that: "it implies an inner state of believing ...[it is] suggestive of a psychological state that is somehow locked in individual minds" (p. 817). Prior et al (2000) argue that while social researchers refer to beliefs few actually claim to have access to inner psychological states of believing. They argue, instead, that what social researchers in fact have access to is verbal accounts of what people believe. From this perspective, individuals recruit or enrol ideas and concepts that are lodged in a specific cultural context to account for an action or an emotional or behavioural state at any given point. Interviewers have access to these publicly available accounts, which may vary over time and space. Consequently: "what ought to be researched in the realm of health beliefs/knowledge is not what is believed or 'known', but rather what it is that is enrolled into people's accounts of health and illness" (p. 818). This neatly side-steps the issue of whether researchers can have access to inward psychological states of believing. At the same time, accounts elicited during the course of interviews or focus groups are derived from wider cultural ideas about the nature, causes and ideal treatments for specific illnesses, such that eliciting accounts of health and illness can still be seen as providing a window into culturally shared conceptualisations of illness.
This analysis is problematic in terms of connecting cultural beliefs and help-seeking activities. Just as has been argued by Prior et al (2000) and Williams and Healy (2001), beliefs about illness, particularly from a social psychological perspective, have often been researched with the implicit assumption that the data collected represent a fixed state of belief that can be used as a variable in research looking primarily at predictors of help-seeking and/or compliance with treatment. If beliefs were fixed, and the methodology used validly elicited such beliefs, this would be fine, but this position is difficult to sustain. Establishing a connection, then, between stated beliefs or accounts and behaviour is far from straightforward. The elicited accounts no doubt bear some relation to both what is believed and wider cultural concepts. However, there has to be caution in assuming such beliefs or accounts are fixed at each point on the pathway to care and have a consistent impact on what people do. Beliefs expressed at one-off points through interviews, on this analysis, should be considered imperfect representations of the cultural context in which help-seeking took place, a context that will be one of a range of influences shaping what individuals do at certain points. As Fitzpatrick (1984) has argued:

"In terms of general, fundamental themes, cultural beliefs about illness are quite stable. Nevertheless there is a danger of what might be termed reifying lay explanations of illness and viewing them as fixed frameworks in terms of which health and illness are experienced." (p. 261)

4.4 CONCLUSIONS
This review has been purposefully wide ranging, so that the study of beliefs about mental illness among different ethnic groups can be seen in the wider context of research on illness beliefs. A number of points have emerged. In general this research confirms two basic points:

1. There is a vast diversity, as well as important similarities, of beliefs about illness across and within cultures
2. Beliefs about illness play a significant, though not a sole, role in shaping illness behaviour

Specifically in relation to beliefs about mental illness two further, related points have emerged:

1. While beliefs about mental illness have been studied from a range of perspectives, in relation to western populations quantitative methodologies have dominated research.
This has important implications. While the broad content of beliefs has been mapped, the lack of depth means that important and subtle differences in beliefs, that may significantly affect help-seeking among different ethnic groups, may have been obscured.

2. Related to this first point, there is consequently a need for more qualitative research that can explore beliefs about mental illness and the impact of these on pathways to care among different ethnic groups in more detail.

These points have informed the focus, design, methodology and interpretation of data for this study.
PART 2

METHODOLOGY
CHAPTER 5

METHODOLOGY (1)

METHODOLOGICAL BACKGROUND
5 METHODOLOGY (1)

METHODOLOGICAL BACKGROUND

"It is with [the] assertion that a given method of collecting data – any method – has an inherent superiority over others by virtue of its special qualities and divorced from the nature of the problem studied, that I take sharp issue."

(Trow, 1969, p. 332)

The discussions in the previous three chapters have all pointed to the need for research considering pathways to, and mode of contact with, mental health services among African-Caribbeans and Whites to incorporate perspectives and methods from sociology and anthropology. The intention has not been to suggest such approaches offer the only means of researching this issue. Rather, the implication has been that an optimum strategy would involve use of both process and contingency approaches. Efforts to incorporate perspectives from sociology and anthropology with those from psychiatric epidemiology, however, inevitably present methodological difficulties. As already noted, the different perspectives of the contingency and process orientated approaches to health service use have necessarily involved the use of divergent methodologies, a fact that has further intensified differences between the two and which undermines efforts to develop an integrated model and approach. In short, the contingency approach has relied on a quantitative methodology, while the process approach has utilised a range of more qualitative methods, including semi-structured and unstructured interviews and observational approaches (Pescosolido, 1991). The question of whether and how to develop an integrated perspective consequently encounters the wider question of the desirability and feasibility of combining quantitative and qualitative methods (Murphy et al, 1998). Pescosolido (1991) has argued that it is necessary to integrate the two strands of research on the basis that both contribute to understanding how people come to use mental health services. So, “even if contingencies like age, race, and sex cannot help us understand how, when and why individuals enter services, they do mark important limits on the kinds of contacts people have ...” (Pescosolido et al., 1998, p.277). Identifying general patterns of service use, and associated contingencies, from this perspective, is a necessary prerequisite to the more detailed study of how, when and why people enter care. Not only does it mark the “limits on the kinds of contacts people have”, it identifies the types of help-seeking patterns in need of explanation, and the associated contingencies hint at possible factors in generating differences in routes to care. Moreover, certain factors that may shape illness behaviour may well be more effectively studied using qualitative methods, an obvious case in point being beliefs about mental illness. This suggests a methodological approach is needed that combines studies of general patterns with more in-depth inquiries about why the
observed patterns arise and the role played by, broadly, cultural factors. This study is
designed on this basis. This simple formulation, however, contains a minefield of
methodological issues. Consequently, prior to setting out the study design, it is necessary to
work through these methodological issues in order that the assumptions on which the study is
designed are made explicit. The central issue is that of combining qualitative and quantitative
methods within a single study design.

This chapter focuses, in turn, on three questions:

1. The question of whether qualitative and quantitative methods necessarily rest on
opposing philosophies of the nature of the world and knowledge, such that they are
fundamentally incompatible

2. The question of whether, practically, the aims, focus and procedures/strategies of
qualitative and quantitative methods are so distinct as to make combining methods
impossible. This will particularly focus on whether the two rest on distinct research
logics

3. The question of how such methods, if not incompatible, can be combined

On the basis that methods can be combined, and that this should be done according to how
successful particular methods are likely to be in addressing research questions, the chapter
goes on to discuss the view that qualitative methods allow researchers to successfully access
insider accounts of experience and belief, a view that is central to this study.

5.1 AND NEVER THE TWAIN SHALL MEET?: The (assumed) ontological and
epistemological differences between qualitative and quantitative research

To begin with, in contrasting and comparing qualitative and quantitative approaches to social
research there is a danger of giving the false impression that each methodological tradition
represents a distinct consensual theory about how the social world can be studied. This would
be a gross distortion. Particularly within the qualitative tradition there are considerable
differences in assumptions made about the nature of reality, the capacity of researchers to
"know" this reality, theoretical perspectives and choice of method. Tesch (1990), for
example, identified at least 45 different approaches to qualitative research, each of which
might operate from a distinct theoretical perspective and employ a range of sampling
strategies, data collection methods and analytic techniques. Any discussion of qualitative
methods, therefore, has to be conducted with an awareness of the diversity of methods
subsumed under this broad category. This is true to a lesser extent in relation to quantitative
methods. While such approaches are often characterised crudely as positivist, a term often used to imply criticism of certain research as overly mechanistic and reductive, a number of authors have been quick to point out both that the meaning of the term is contested and that there is research within the quantitative tradition that cannot accurately be described as positivist in any sense (Bryman, 1988). A key difference in practice, as Murphy et al (1998) point out, is that while quantitative researchers have reached “a working philosophical consensus”, qualitative researchers have not: “This means that quantitative researchers can treat methodology as a technical matter. The best solution is the one which most effectively and efficiently solves a given problem” (pp. 57-58). This is not true of qualitative research. That said, for all the diversity within each tradition, it has been strongly argued that each rests on a set of ontological and epistemological assumptions that gives a measure of unity to each and which fundamentally divides one from the other. This is summarised by Rist (cited in Bryman, 1988):

“When we speak of ‘quantitative’ or ‘qualitative’ methodologies we are in the final analysis speaking of an interrelated set of assumptions about the social world which are philosophical, ideological and epistemological. They encompass more than simply data gathering techniques.” (p. 67)

Debates concerning the relative strengths of qualitative and quantitative methods, and whether the two are fundamentally incompatible have produced a huge literature. The central issue of relevance here is whether methods from the two traditions can be used within a single study design. The remainder of this section addresses this briefly, to some degree summarising arguments that are well rehearsed elsewhere.

Pope and Mays (1995) have usefully set out the assumed points of divergence between qualitative and quantitative methods, along key dimensions (see Table 5.1). Missing from this outline, however, are perhaps the two fundamental points of division relating to the underpinning ontological and philosophical positions assumed to characterise each research tradition. On the one hand, quantitative methodologies have been associated with a realist ontology (i.e. that there is a world really existing beyond our perceptions of it) and a correspondence theory of truth (i.e. research has the potential to produce accounts that correspond to that reality). On the other, qualitative methodologies have been associated with an idealist ontology (i.e. that there is no world independent of individual perceptions of it) and a relativist theory of truth (i.e. there will be many competing accounts of the world, all of equal validity). From the assumption that each research tradition rests on each of these ontological and epistemological positions, and from the assumed divisions noted by Pope and
Mays (1995), it has been forcefully argued by many that the two are fundamentally opposed and incompatible, such that combining the two is a recipe for methodological confusion.

Table 5.1. *Key assumed differences between qualitative and quantitative research (from Pope & Mays, 1995, p. 43).*

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<td>Methods</td>
<td>Observation, Interview</td>
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<td>Question</td>
<td>What is X? (classification)</td>
<td>How many X's? (enumeration)</td>
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<td>Reasoning</td>
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<td>Sampling method</td>
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This very brief sketch oversimplifies, but it does capture the essence of the arguments that have fuelled this debate. What is important here is that there appears to be a growing consensus that this formulation of the two as incompatible is overstated, misleading and unhelpful. The main thrust of this developing consensus is that there is no necessary connection between quantitative and qualitative methods and the respective ontologies, epistemologies and methodological practices that are assumed to underpin each.

To take the supposed realist/idealist divide as an example. To begin with, a number of authors have commented that, in practice, many researchers utilising qualitative methods appear to hold realist assumptions, thus undermining the assumption of a necessary connection between idealism and qualitative research. Hammersley (1992), for example, has argued this in relation to those ethnographers who justify their chosen methods of data collection, such as participant observation, in-depth interviews and so on, on the basis that they allow access to the true nature of social phenomena – metaphors such as “lifting the veils” and “digging deeper” are frequently employed to justify the use of more in-depth methodologies and are suggestive of an assumed reality existing beyond the veil or under the surface. One of the key dividers usually assumed to separate qualitative and quantitative methods is that the former produces more valid data; that is, it allows researchers to get a more accurate representation of phenomena, a line of reasoning that again implies underlying realist assumptions. Interestingly, Hammersley (1992) has pointed to a tension in ethnographic studies in the apparent realist ontology underpinning the research enterprise and the idealist ontology adopted in respect of the people being investigated. As Murphy et al (1998) comment:

“There is, for Hammersley, a fundamental contradiction in treating the beliefs and perspectives of the social actors we are investigating as incommensurable, socially
constructed versions, while treating the accounts which ethnographers produce as more or less accurate representations of some externally existing reality.” (p. 68)

Phillips (1990), in contrast, rather than seeing this as contradictory argued that it is possible to retain a concern for truth as a regulatory ideal, while studying how individuals construct social reality and how this shapes behaviour, in that it is not necessary to accept that such constructs are true. From this point of view, while it may well be the case that researchers operating from an idealist position were at the forefront of establishing qualitative methods, it does not follow that qualitative methods require such an ontology; nor indeed have all researchers adhered to scientific idealism to guide their own research even where they have been concerned with how social actors construct and consequently act on the social world. By the same reasoning, it does not follow that quantitative methods, even if primarily utilised by those operating from a realist perspective, necessarily depend on such a realist ontology.

In practice, it has been forcefully argued that neither extreme forms of realism nor idealism offer a sound basis for social research. Indeed, for some the logical conclusion that follows from a position that the world is unknowable and that each perception or construction is as valid as another is that research is futile, that it leads to a “debilitating nihilism” (Hammersley, 1992). That said, the view, implicit in scientific realism, that researchers can have direct, objective, access to the social world, is, according to a number of authors, naïve. Perceptions of phenomena are the product both of the inherent qualities of the phenomena and the cultural-biological lens through which they are seen (Campbell, 1994), which suggests purely objective reproductions of phenomena, unmediated by the perspective of the investigator, are impossible. A way out of this is proposed by what Hammersley (1992) has termed subtle realism. In essence, this position accepts the reality of a world independent of individual perceptions of it, but concedes that it is impossible for the investigator to have unmediated access to and incontrovertible knowledge of that reality. From this position, the researcher should “search for knowledge about which we can be reasonably confident” (Murphy et al, 1998, p. 69). In short, the aim of research is to represent reality rather than to reproduce it. This middle position not only offers a way out of the difficulties presented to social research by both realist and idealist positions, but it also further undermines the already dubious claim that qualitative and quantitative research methods necessarily rest on opposing ontologies and epistemologies. Indeed, it provides a basis for social research using any number of investigative techniques, and as such provides a philosophical base that allows researchers to utilise whatever methods allow more accurate representations of the phenomena of interest. In short, there is a world out there and can we know it – to a degree.

A further example of how divisions between the two major research traditions have been overstated is in the assumed necessary connection between qualitative research and
inductive reasoning and quantitative research and deductive reasoning. Induction refers to the process of deriving theories and generalisations from empirical observations and deduction refers to the testing of previously formulated theories through the collection of relevant empirical data.

The link between qualitative and quantitative methods and, respectively, inductive and deductive logic has been cemented by two particular theories of the scientific or research process. Firstly, the association of deductive reasoning and quantitative methods is in its origins traceable to Popper's philosophy of science (Magee, 1985), in which the task of science, as distinct from pseudo-science, is to seek to falsify theories or hypotheses that are proposed to explain phenomena (Murphy et al, 1998). The origin of theories, from Popper's perspective, was largely irrelevant – they could come from anywhere. What was important was the logical procedure that followed and allowed theories to be rigorously tested. This hypothetico-deductive framework has been influential across the sciences and, in the social sciences, has translated into an insistence on the systematic collection of representative quantified data from which stated hypotheses can be tested and findings generalised. Research purporting to operate within this framework has consequently usually been quantitative. Secondly, the association between inductive research and qualitative methods is partly due to the influence of grounded theory, as developed by Glaser and Strauss (1967). This has had a significant impact on interpretative sociology and methodology. The starting point for Glaser and Strauss (1967) was what they saw as the neglect of theory formation in the focus on hypothesis testing that, up to the 1960's, had, they believed, dominated sociological research. They argued that rather than setting out primarily to test a priori theories, which could mean imposing theories on data, researchers should seek to develop theories grounded in the data and which, because they were derived from the data, would more accurately fit the data. This approach is certainly more inductive and, as Murphy et al (1998) note, the fact that Glaser and Strauss described the grounded theory approach as inductive is: "... no doubt, one of the reasons why many qualitative researchers claim that qualitative research is, by definition, an inductive process" (p. 71). The emphasis on induction in qualitative research has further led to the characterisation of these methods as exploratory or hypothesis generating.

It is doubtful, however, whether there is a necessary or practical dependence of either quantitative methods on deductive logic or qualitative methods on inductive logic. To begin with, the lack of interest in theory formation and rejection of inductive processes in the hypothetico-deductive model of research is problematic. In the first place, this conceptualisation of the scientific process is overly linear, thus obscuring the fact that in practice – in both the natural and social sciences – research is circular. Where the starting point for research is prior hypotheses, the observations made in the process of testing these
hypotheses often give rise to new theories that are subsequently tested; that is, somewhere in the process there is likely to be the use of observations to generate theory, i.e. induction. Similarly, grounded theory is built on an approach to data analysis that involves both inductive and deductive reasoning. Central to grounded theory is the constant comparative method of theory generation and refinement which involves constantly moving from data to theory and back in an iterative process. In other words, initial theories are derived from the data and then re-tested against the data and refined in order to further develop theories that most accurately account for the data – a process that clearly involves both inductive and deductive reasoning. Considered in these terms, the research process involving all forms of data is more usefully conceptualised as circular. In practice, then, the logic employed by researchers utilising qualitative and quantitative methods often involves both inductive and deductive reasoning, the difference being largely one of emphasis. Nor is it the case that the emphasis is always on, for example, inductive logic in qualitative research. Increasingly there are good instances of qualitative research that has sought to test prior hypotheses. Murphy et al (1998) give the example of work by Silverman and colleagues (1992) who set out to test hypotheses derived from prior research, concerning how the structure of counselling sessions shaped patient receptiveness to advice given. Conversely, quantitative research is frequently exploratory.

This discussion of the misleading representation of qualitative and quantitative research as either inductive or deductive, respectively, is a useful illustration of how in practice assumed differences break down. It is more useful, then, to view these perceived areas of difference as highlighting particular strengths of the two approaches, a view, moreover, which begins to conceive of the two types of research methods as complementary rather than contradictory, each one being particularly effective and efficient in answering different questions or in providing fuller accounts. This further ties into an instrumental approach to research in which the primary concern is with which methodological tools will most effectively answer the research question. This is particularly relevant in health services research, in which: “... because of its applied nature, much research is driven not by the theoretical stance of the researcher, but by a specific practical problem which is turned into a research question” (Pope & Mays, 1995, p. 44).

5.2 MIXED METHODOLOGIES: Combining Qualitative and Quantitative Approaches
The foregoing discussion argues against the view that qualitative and quantitative methods are fundamentally opposed and in favour of the view that the range of research methods from within each tradition are complementary, each potentially offering a more effective or fruitful
alternative perspective on given problems. It is this analysis that provides the theoretical and philosophical basis for combining methods.

In broad terms, three approaches to the combined use of both qualitative and quantitative methods can be identified: 1) quantitative research as senior partner; 2) equal status for both; and 3) qualitative research as senior partner (Tashakkori & Teddlie, 1998). The first of these is perhaps the most familiar in main stream medical and health research and derives from the perception of qualitative methods as particularly useful in hypothesis generation. The purpose here is generally to use qualitative methods at the exploratory or pilot stages of a project to generate or firm up hypotheses which are then tested using quantitative methods. Alternatively, qualitative interview data may be used to develop structured questionnaires that can yield quantitative data—an approach that has been employed for example in developing instruments to elicit beliefs about mental illness in large samples (Phillips et al, 2000). Implicit in this approach is the view that scientific rigour and increasing certainty in findings will only come via the subsequent use of quantitative methods, with qualitative methods being only a precursor to the more scientific, quantitative methodologies. Methods are organised according to a hierarchy, with qualitative approaches coming fairly low down the order. The second broad approach resists any ordering of methods into a hierarchy. It is this perspective that sits most easily with the argument above that methods should be judged according to their capacity to address the question at hand. The researcher, from this point of view, has a range of methodological tools at his/her disposal and simply selects the ones most suited to the task: “There are no principled grounds to be either qualitative or quantitative. It all depends on what you are trying to do” (Silverman, 1997, p. 14). The final broad approach is that in which qualitative methods are viewed as the primary, most effective, tools. Within this, moreover, it has usually been participant observation that has been proposed as the gold standard of research methods on the basis that it offers: “the most complete form of sociological datum” (Becker & Geer, 1969, p. 322). Other methods may be useful in certain circumstances where, for example, resources do not permit the intensive research involved in participant observation, but these are viewed as second best. It is interesting to note, moreover, that all of these instrumental approaches appear to adopt realist positions, be it extreme or subtle, in relation to research. The aim is, invariably, to reproduce or represent the social world more accurately, using a range of methods.

A particularly good and pertinent example of how combining methods can work to more fully capture social processes is given by Pope and Mays (1995) in their series on qualitative research in the British Medical Journal. They describe a study by Bloor et al (1976) that set out to investigate differences in the geographic incidence of operations on the tonsils and adenoids and local differences in specialists’ clinical practices. To address this
issue a two-staged approach was adopted, in which the first step was an epidemiological study of regional variations in operations and the second step was a sociological study, utilising qualitative methods, of clinical practices aimed at investigating how and why variations observed in the epidemiological stage came about. In this example, qualitative methods are used to illuminate differences observed at a population level: as Pope and Mays (1995) note, it is a case of qualitative methods “reaching the parts other methods cannot reach”. In general terms, this type of approach to combining methods can be illustrated diagrammatically, as in Figure 5.1.

Figure 5.1. Qualitative methods to explain quantitative methods.

The approach adopted by Bloor et al (1976) offers a useful template for studies of ethnicity and pathways to care, particularly from the perspective outlined in Chapter Three. That is, it offers one means of incorporating contingency and process orientated approaches to this issue. The qualitative component of such a design allows for either the meaning of associations identified in the initial quantitative stage to be explored in-depth or for factors potentially impacting on pathways to care to be probed more fully. In relation to understanding why there are differences in patterns of health service utilisation, therefore, the qualitative part of such a study can serve at least two functions. Firstly, the processes shaping patterns of help-seeking can be researched, which may allow for a more dynamic understanding of, for example, ethnic variations in pathways to care. Secondly, specific factors that may influence help-seeking can be more effectively investigated, such as beliefs about mental illness, stereotyping, and the like. It is this strategy that has formed the basis for the methodology adopted in this study (see below).

Methods, then, are chosen according to their strengths. As has already been suggested, quantitative methods are particularly strong in enumerating patterns in, for instance, pathways to care. Qualitative methods, again as suggested above, are more effective in capturing processes and what has been termed the “insider perspective”. This latter
apparent strength of qualitative methods is particularly relevant to this study and is considered in more detail below.

5.3 THE STRENGTHS OF QUALITATIVE RESEARCH: Eliciting the Insider Perspective

Bryman (1988) has identified six core characteristics of qualitative research:

1. Commitment to viewing events, actions, norms, values, etc. from the perspective of those being studied
2. Emphasis upon description of the setting being investigated
3. Emphasis upon context and holism
4. Emphasis on process
5. Flexibility of research design
6. Reluctance to impose a priori theoretical frameworks at the outset

Whether these do in fact represent the core characteristics of qualitative research is certainly contested (Murphy et al., 1998), though this is not the immediate concern here. Rather, these six characteristics indicate areas where qualitative research is particularly strong. The key point of interest to this study is the suggestion that qualitative methods are particularly strong in eliciting the perspectives, etc. of those being studied.

5.3.1 The insider perspective

Commitment to the “insider” perspective has commonly been identified as a key feature of qualitative research (Murphy et al., 1998). No doubt, this focus stems from the perspectives that have underpinned much qualitative research (i.e. phenomenological, relativist, symbolic interactionist, etc.) and which have at their heart an emphasis on understanding meaning as a basis for understanding motives and action. The concern running through much of this work is with making behaviour and belief comprehensible. This is evident, for example, in much of the work reviewed in the previous chapter on beliefs about illness and mental illness in which researchers have documented the internal coherence of beliefs systems and practices that otherwise appear bizarre to outside observers. This perspective recognises that belief and action are closely linked and acknowledges that what people believe to be true, in terms of motivating behaviour, is often more important than what is true – “If men define situations as real, they are real in their consequences” (Thomas & Thomas, 1927, p.572).

This emphasis on the perspectives of those being researched has parallels in anthropology, in which a distinction has often been drawn between emic (insider) and etic (outsider) perspectives. Much research in anthropology has been committed to elucidating
the emic or insider's/native's perspectives of reality, and Fetterman (1989) has argued that this emphasis is: "... at the heart of most ethnographic research" (p. 30). As in sociology, this emphasis arises from an understanding that individuals often act according to their perceptions of the world: "Native perceptions may not conform to an 'objective' reality, but they help the field worker understand why members of a social group do what they do" (Fetterman, 1989, p. 30).

McCraeken (1988) has argued that:

"The [qualitative] method can take us into the mental world of the individual to glimpse the categories and logic by which he or she sees the world." (p. 9)

Qualitative interviews are typically unstructured, or at most semi-structured, using most commonly prompts or open ended questions, the aim being to facilitate the respondent in talking in their own terms about the area of interest. The open and flexible character of such interviews is designed to avoid imposing researcher defined categories and concepts on the respondent and to draw out the respondent's own ideas, perspectives, beliefs and so on. These interviews are either tape recorded or extensive notes are taken, and this data is then subject to detailed analysis, which, in the case of grounded theory, will seek to derive theories from the data rather than imposing pre-existing categories. It is typically through these methods that researchers have sought to "glimpse" the world through the eyes of respondents. Implicit in these approaches is a critique of quantitative methods of interviewing. Quantitative interviews are typically structured, using predefined questions with a set range of responses, often using scales to record respondents' answers. That is, responses are quantified and, as such, can be subject to statistical analysis. The problems with this approach are that the range of possible responses are pre-ordained and their meanings fixed, leaving limited scope for respondents to develop their own ideas or for the possibility that the total range of possible responses has not been included in the questionnaire. Such approaches are, therefore, less able to access meanings in all their complexity. This was hinted at in the previous chapter in the discussion of those studies of White western populations that used predominantly structured questionnaires. Following this, it is useful to consider three examples of different approaches to eliciting beliefs about mental illness among western populations to illustrate the problems with such an approach and to further clarify the rationale for the choice of methods in this study.

Example (1) Structured Questionnaire
Eisenbruch (1990) developed the Mental Distress Explanatory Model Questionnaire (MDEMQ) with the aim of exploring "how people from different cultures explain mental
distress" (p. 712). Using Murdock and colleagues' work on illness models throughout the world, a 45 item questionnaire of possible causes of mental illness was developed and administered to 261 people, mainly college students. A five point Likert scale, ranging from not at all likely to highly likely, was used for each item. Multidimensional scaling analysis revealed four clusters of explanations for mental distress: stress, western physiological, non-western physiological, and supernatural. Eisenbruch's work represents an attempt to develop a widely useable questionnaire, which can be readily administered amongst large samples. However, it is limited in its ability to elicit the insider perspective. It is not always possible, for example, to interpret what a respondent might have meant when responding 'highly likely' to some of the items, for example 'astrological destiny', as a possible cause of mental distress. Because of this it is not clear on what basis certain categories of causation were fitted into one of the four clusters of explanations. "Doing something forbidden by social or cultural rules", for example, might be fitted equally into stress or supernatural, depending on how the respondent interpreted the potential consequences of doing "something forbidden". Moreover, the range of potential causes is prescribed, thereby excluding all beliefs not captured in the 45 item checklist. There are, then, clear limits to the MDEMQ's ability to meaningfully explore "how people from different cultures explain mental distress" (p. 712).

Example (2) Semi-structured interview using vignettes

A more recent, and very different approach, is the Short Explanatory Model Interview (SEMI), developed by Lloyd et al (1998). This explicitly uses Kleinman's (1980) concept of 'Explanatory Models' as the basis for a short questionnaire (taking about 30-40 minutes to complete), split into five sections: the subject's personal background, nature of presenting problem, help-seeking behaviour, interaction with physician/healer and beliefs related to mental illness. Beliefs are elicited by use of vignettes, followed by open-ended questions. The SEMI has been piloted amongst primary care attenders in London and Harare. In London three ethnic groups were included in the sample, African-Caribbeans (n = 56), Asians (n = 36) and Whites (n = 30). The initial report shows differences in responses between the three London groups and the Harare sample (n = 58) (Lloyd et al, 1998). The initial report, however, presents only quantitative data, and the nature of the qualitative data that the SEMI is able to elicit is not clear. The use of vignettes as the basis from which to explore beliefs about mental illness is also problematic. Previous research in the Social Psychiatry Section of the Institute of Psychiatry (Mallett et al, 1998) suggests that vignettes elicit limited responses compared with more open-ended approaches. Further, within the vignette there is an assumption of psychopathology, or at least it is evident to the respondent that this is where the questioner is leading them. This potentially undermines the extent to which the responses represent the 'insider's account'. These limitations, along with the fact that the whole SEMI
should take around 40 minutes to administer, raises doubts about the depth of accounts the schedule is able to elicit.

**Example (3) Semi-structured interview**

Weiss and colleagues, in developing the Explanatory Model Interview Catalogue, have retained a much more qualitative approach than either Eisenbruch or Lloyd et al (Weiss, 1997). "The Explanatory Model Interview Catalogue (EMIC) refers to a collection of locally adapted explanatory model interviews rooted in a common framework" (Weiss, 1997, p. 235). This represents a much more concerted effort to elicit emic accounts of mental illness than either the MDEMQ or the SEMI. Rather than attempting to develop a questionnaire with universal applicability, Weiss acknowledges that for a questionnaire to have validity it must be developed with reference to the particular cultural group(s) being studied. But, for comparison within and across cultural groups to be possible, the questionnaires used in differing cultural contexts have to share a common framework. The development of this framework has continued since the initial development of the EMIC for use in a study of leprosy and mental disorder (Weiss et al, 1995; Weiss et al, 1992). The EMIC aims to elicit Explanatory Models by probing patterns of distress, perceived causes, help-seeking and treatment, general illness beliefs, and disease specific queries. The use of open-ended questions, followed by probes, and then summaries of the importance attached to explanations in each section characterise the method of administering an EMIC interview. The depth of accounts elicited using an EMIC interview is consequently much greater than with either the MDEMQ or the SEMI, though naturally the level of resources required to deliver the interview is much higher than for the other two schedules. The difference between structured and less structured approaches, then, is also one of breadth versus depth. Certainly, the use of more qualitative interviews means that the numbers who can be interviewed is necessarily more restricted. While this limits generalisability, it retains a greater level of detail. It is arguable that the depth provided by the EMIC and other such interviews is the least that is required if interpretations of illness are to be meaningfully understood, particularly among groups whose beliefs and perspectives have rarely been researched.

5.3.2 Is it the insider perspective?

A penetrating criticism of what has been described above centres around the question of whether it is possible to access and reproduce respondents’ meanings and beliefs. Relying on respondents to explain their actions and/or beliefs raises two immediate problems: 1) respondents may not be able to articulate coherently experiences and beliefs; and 2) respondents are likely to produce an ‘account’ of experiences, beliefs and so on, which are devised to “make the system meaningful to an outsider” (Gould et al, 1974, p. xxiv). This
account, moreover, bears an indeterminate relationship to decisions to act. This second problem is precisely that raised by Prior et al (2000), discussed in the previous chapter, and which led Prior and colleagues to argue that instead of talking about eliciting beliefs, researchers should more properly consider interview responses relating to ideas about illness as accounts. Related to this, it has been pointed out by a number of authors that researchers do not simply reproduce accounts as intended by respondents. Researchers are inevitably selective in which aspects of accounts are focused upon and this process of selection is influenced by the theoretical perspectives brought by the researcher to the research process. As Emerson (1981) has noted: “Inevitably field workers comprehend, interpret and code in memory ongoing social activities in ways that depend upon their presuppositions, general cultural knowledge, prior experience in and particular knowledge of the setting” (p. 358). This applies equally to how researchers set about the task of interpreting interview data. In short, researchers interpret respondents’ interpretations, such that what emerges is the researcher’s account of the respondent’s account. This does not mean efforts to elicit respondent accounts are fruitless. It does, however, mean that claims about what is being elicited should be tempered and it further insists that the researcher should be as explicit as possible about how his/her own interpretations of the data have been made.

The consequence of these arguments is that a more moderate position is necessary, similar to the one adopted by Smith (1995), who argued: “... that what a respondents says in the interview has some ongoing significance for him or her and that there is some, though not a transparent, relationship between what the person says and beliefs or psychological constructs that he or she can be said to hold” (p. 10). This position shares much with subtle realism and the view articulated by Phillips (1990, see above) that it is possible to retain truth as a regulatory idea in the study of perceptions if, firstly, access to such perspectives is acknowledged to be imperfect and, secondly, those perspectives are not necessarily accepted as true accounts. It is this middle position that underpins those aspects of this study focusing on beliefs about mental illness.

5.4 CONCLUSIONS
A number of conclusions can be drawn from this discussion:

1. Subtle realism, as defined by Hammersley (1992), offers a sound philosophical basis for social research in: 1) its acceptance of the existence of an external world; and 2) its acceptance that knowledge of this world will be mediated by the historical and cultural lens through which it is studied.
2. Neither qualitative nor quantitative methods are necessarily predicated on either, respectively, idealist or realist philosophies. Likewise, for all the differences in the focus and practice of qualitative and quantitative research, these differences are not such as to make the two fundamentally incompatible. Choice of methods, therefore, should be determined by the research question rather than by pre-existing assumptions about 1) the incompatibility of the two research traditions; and 2) the superiority of one approach over another.

3. The first two conclusions pave the way for the use of methods from both research traditions within a single study design, if such an approach can be shown to be necessary and practical in addressing the research question.

4. Qualitative methods are particularly strong in eliciting the ‘insider’ perspective. However, the extent to which researchers are able to access ‘insider’ perspectives is limited by: 1) the ability and willingness of respondents to articulate such accounts; and 2) the inevitable influence of the theoretical, cultural, etc. perspectives of the researcher. On this basis, data relating to respondent beliefs and the like, and researchers’ interpretations of these beliefs, etc., are most usefully considered as imperfect representations of such phenomena.

This study rests on these conclusions.
CHAPTER 6

_____________________________________

METHODOLOGY (2)
STUDY DESIGN
6 METHODOLOGY (2)
STUDY DESIGN

The overall objective of this study is to investigate the impact of beliefs about mental illness on pathways to care among African-Caribbeans and Whites with a first episode of psychosis. To reiterate, this objective derives from the analysis of the literature set out in Chapters 2, 3 and 4. The conclusions drawn from these can be summarised as follows:

1. The reasons for the repeated finding that African-Caribbeans have a more coercive relationship with psychiatry than Whites are unclear, this being due largely to the methodological limitations that characterise previous research.

2. Pathways to care are the product of a social process involving a range of factors. Research in other areas has consistently pointed to the importance of beliefs about mental illness in shaping the pathway to care.

3. There is a vast body of research showing that: 1) beliefs about mental illness vary across cultures and between groups within multi-cultural settings; and 2) beliefs have a significant impact on the experiences of, and responses to, mental illness.

These three conclusions form the starting point for this study. In setting out the methodology, and indeed in order to contextualise the study, it is useful to provide a brief outline of the study context, focusing on the socio-economic context and the structure of the local Health Care System (Kleinman, 1980).

6.1 CONTEXTS
6.1.1 The Socio-economic Context
This study was conducted within the catchment areas of three hospitals in south London: the Maudsley, South Western and St Thomas’s. These cover the bulk of two London boroughs, Lambeth and Southwark (see Figure 6.1). The total population of the two boroughs is 506,700 (Lambeth, 273,700; Southwark, 233,000). Both have a high proportion of ethnic minority groups, particularly Africans (6.5% Lambeth; 7.2% Southwark) and African-Caribbeans (12.6% Lambeth; 8.3% Southwark). These two boroughs are among the two most deprived areas in the UK. On all indices of deprivation compiled by the Index Team at the University of Oxford for the Department of Transport, Local Government and the Regions (2000), both areas invariably fall into the top 10% most deprived. On indices of employment
deprivation\textsuperscript{1}, for example, Lambeth ranks 17\textsuperscript{th} most deprived out of 354 and Southwark 22\textsuperscript{nd}, and on indices of income deprivation\textsuperscript{2}, Lambeth ranks 21\textsuperscript{st} and Southwark 23\textsuperscript{rd}. Thus, the area from which participants in this study were drawn is one of substantial deprivation, on all measures, compared to the rest of the UK.

The migration of substantial numbers of African-Caribbeans to the UK, particularly to urban conurbations such as London and Birmingham, occurred largely in the 1940's and 1950's. Post-war economic prosperity in the UK and the consequent promise of work and income was the primary factor driving the decision of many to migrate, often with family migrating later. For many, England represented the "mother country", but rather than acceptance and prosperity, the overwhelming experience was one of rejection and discrimination, the majority securing only low paid, low status jobs and poor housing, the consequence being that while many migrants were dispersed throughout cities such as London and Birmingham, substantial numbers settled in the poorer areas where accommodation was cheap, but also poorly maintained. Chronic discrimination and racial prejudice has limited economic and educational opportunities, the result being that many African-Caribbeans continue to live in economically deprived areas such as Lambeth and Southwark. While indicators of social and economic position are limited at a local level, on a national scale it is clear that African-Caribbeans are socially and economically disadvantaged compared to the White majority. Modood at al (1997), for example, showed that, in 1990, the unemployment rate for African-Caribbeans was twice the national average, 18% compared to 9%, and the increase was fourfold among 16-24 year olds. There is little to suggest this disparity has improved since. The social and economic context of this study, then, is one of generally high levels of deprivation that are likely to be more marked among the substantial African-Caribbean population in the area. It is within this context that individuals make sense of and negotiate responses to illness.

\textsuperscript{1} Employment deprived: those who are unemployed and those unable to work due to illness or disability
\textsuperscript{2} Income deprived: those whose income is below the threshold for receiving Income Support
Figure 6.1. The study setting.

LAMBETH

St Thomas' Hospital

South Western Hospital

SOUTHWARK

Maudsley Hospital
6.1.2 The Local Health Care System

Taking Kleinman's (1980) framework of Health Care Systems, the immediate problem encountered when attempting to describe the structure and content of the three health care sectors that constitute the local health care system within which this study was carried out is that very little is known about the popular and the folk or traditional sectors, particularly in relation to mental health care. Indeed, in attempting to elicit and understand the belief frameworks of African-Caribbeans and Whites, the second stage of the study is the only research of its kind that has sought to compare this key aspect of the popular health care sector among these two broad ethnic groups. Beliefs about illness form a central component of the popular sector and have been consistently shown to influence movement from the popular sector into the folk and professional sectors. There are indications that beliefs prevalent in the African-Caribbean community diverge more from those embodied in psychiatry and mental health services than do White beliefs (Lloyd et al., 1998), though the research reviewed in Chapter 4 suggests lay beliefs about mental illness in general depart in important respects from the theories and ideas that underpin psychiatric practice. The content of the popular sector of both ethnic groups and how this potentially shapes interactions with other sectors of the health care system is, therefore, the focus of the second stage of the study and is explored in the final three chapters.

Perhaps less still is known about the folk or traditional sector of health care in the UK generally. Conceived broadly, this sector comprises services ranging from homeopathy to religious and spiritual healing. Interest in complementary therapies has certainly grown in recent times and there are increasing areas of overlap between this segment of the folk sector and the professional sector, with many GPs, for instance, increasingly providing or housing such therapies in their practices. The use made of such services, however, is still relatively unexplored; and this applies even more to those segments of the folk sector that stand wholly outside of mainstream services. This is a considerable gap in knowledge that needs to be filled, particular in relation to the questions posed in this thesis of how, when and why people from different ethnic groups come into contact with professional mental health services. Those who have speculated about the role of wider social and cultural factors in generating differences in pathways to care between African-Caribbeans and Whites have occasionally raised the possibility that some of these differences may arise because African-Caribbeans make more use of sources of help located in the popular and folk sectors (Harrison et al., 1989; Jarvis, 1998). The data from the second stage of the study will shed some light on this issue. Further, in an unrelated project, the author of this thesis and other researchers at the Social Psychiatry Section of the Institute of Psychiatry have conducted a preliminary mapping exercise designed to identify sources of help located in the folk sector in south east London. What this suggests is that there is a vast range of different types of help offered, much of it
rooted in holistic and what might be termed New Age theories of health (homeopathy, reiki, reflexology, etc.), but a significant number also of religious, spiritual and church based healing practices, often ethnically specific. This limited initial survey thus points to there being a substantial folk sector that is potentially available to people who develop mental health problems and their families. To fully understand the health care context of the help-seeking outlined in the next chapter, more work needs to be done to clarify the extent, and use of, such practices.

This study is essentially concerned with how people from different ethnic groups who develop, from the perspective of psychiatry, a psychotic illness come into contact with professional mental health services. The routes into this professional sector, and the broad legal framework, were outlined in Chapter 2 (see pp. 32-33). Two additional comments regarding the professional sector are relevant to this study. Firstly, in broad outline the make up of professional services is similar in south east London to the rest of the country, comprising a mixture of community based and hospital based services, including many run by voluntary organisations. Two specific differences set the services in this context apart: 1) part of the catchment area of the study is served by the Maudsley Hospital, perhaps the most well known psychiatric hospital in the UK and one that has a significant place in the knowledge of local people, often invoking suspicion and fear. There is unfortunately no research considering popular perceptions of the Maudsley Hospital in the immediate area, but it may be that these perceptions are such that many people resist seeking help for fear of ending up in the Maudsley; 2) more specifically, the Maudsley Hospital runs one of the very few 24-hour emergency psychiatric clinics in the country that operates both as a psychiatric Accident and Emergency department and as a place of safety for people with a suspected mental disorder found in a public place by the police. Such a service inevitably shapes how many people come into contact with services, such that patterns observed in this study may vary from those evident in studies in other areas.

6.2 AIMS, HYPOTHESIS, RESEARCH QUESTIONS, AND STRUCTURE OF THE STUDY

The study comprises two stages.

The first stage is designed to investigate, using a quantitative method, pathways to care in a cohort of African-Caribbean and White patients with a first episode of psychosis who presented to psychiatric services within the catchment areas of the Maudsley, South Western and St Thomas’s hospitals (total population 333,166) in south east London during an 18-month period, 1st June 1998 - 31st December 1999. This formed part of a larger, and longer, study of first episode psychosis among different ethnic groups, the AESOP project (see below). The aim of this first stage is to identify and analyse pathways to, and modes of
contact with, mental health services among patients from the two ethnic groups, addressing specifically the hypothesis that African-Caribbean ethnicity will be associated, independently of potential confounders, with higher rates of compulsory admissions and police contacts, and lower rates of GP referrals. In broad outline, this stage is not dissimilar to previous research in its reliance on cross-sectional quantitative data. It differs from that previous research, however, in four key respects: 1) it includes a larger number of first presentation cases from each ethnic group than any previous study; 2) data relating to a broader range of variables has been collected, including data relating to earlier stages on the pathway to care – and it is this data that paves the way for the third difference, namely - 3) the analysis has been conducted so as to model, within the limits of the data, pathways as a process involving key decision points; and 4) the data and analysis are not considered the end point, but rather the basis for the second stage of the study and for a potential follow-up study of engagement with services over time.

The second stage is a qualitative study of beliefs about mental illness in a sub-sample of those included in the first stage. The aim of this stage is to elicit and compare beliefs about mental illness among patients, relatives and community respondents from the two ethnic groups, and from this to assess the potential role of beliefs about mental illness in shaping the patterns of service access and use identified in the first stage of the project. In relation to this aim, three specific questions are addressed:

1. Do African-Caribbeans’ beliefs about mental illness differ from those of Whites?
2. Do beliefs about mental illness differ within the African-Caribbean group according to place of birth and/or age?
3. Do the beliefs evident among African-Caribbeans and Whites bear any relationship to the patterns of pathways to, and modes of contact with, mental health services observed in the first stage of the study?

There are, then, two primary aims with related hypotheses and research questions, each addressed in turn in the separate stages of the project. The overall structure of the project is shown in Figure 6.2.
The remainder of this chapter sets out the methodology for each stage, excluding how the data has been analysed. Data analysis for each stage is discussed in the following chapters in which the findings from each stage are also presented and discussed.

6.3 METHODOLOGY (1): Stage One

6.3.1 Inclusion and Exclusion Criteria
Patients were recruited for the study as part of the Aetiology and Ethnicity in Schizophrenia and Other Psychoses (ÆSOP) project, between 1st June 1998 and 31st December 1999. The ÆSOP project is an epidemiologically based study of all first onset cases of psychosis (F20-F29 and F30-F39 (psychotic codings) in ICD-10 (see Box 1.1 and Introduction)) presenting to mental health services between September 1997 and August 2000 within the catchment areas of the Maudsley, South Western and St Thomas’ hospitals in south London. A team of researchers was involved in regularly checking with points of contacts with mental health services in the catchment area in order to identify potential patients for inclusion in the study. All patients who came into contact with secondary and tertiary services for a first time within the catchment area during the study period were screened for inclusion using the Screening Schedule for Psychosis (see Appendix 2), which was completed by interview with the patient and/or using case notes and psychiatric staff. Each patient meeting inclusion criteria for the study was approached to take part and permission was sought to interview a relative or close friend who had had recent contact with the patient. Exclusion criteria were: aged under 16 or over 65; evidence of psychotic symptoms precipitated by an organic cause; and moderate or severe learning disability (i.e. IQ less than 50).

6.3.2 Sample Size
To determine the required sample size for the first stage of the project, a power calculation was conducted. This showed that, with an estimated frequency of compulsory admission of
20% in Whites, a sample of 60 Whites and 60 African-Caribbeans was necessary to detect a 25% difference in the rate of the compulsory admission between the two ethnic groups at a 5% significance level (two sided) with over 80% power. Differences of 25% or more have been reported in published studies (Harrison et al, 1989).

6.3.3 Data Collection

Data for this study were collected by the author and other researchers as part of the broader AESOP project. Specifically in relation to this study, all those patients and relatives agreeing to take part were interviewed using the schedules detailed in Table 6.1. Each of the schedules used has been validated in previous research, and copies of the full or relevant parts of the schedules are included in Appendix 2.

Table 6.1. Interview schedules.

<table>
<thead>
<tr>
<th>Schedule</th>
<th>Reference</th>
<th>Schedule Type</th>
<th>Comments</th>
<th>Data Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>MRC Sociodemographic Schedule</td>
<td>Mallett, 1997</td>
<td>Structured</td>
<td>Used with patients, relatives and community respondents</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Schedules for Clinical Assessment in</td>
<td>WHO, 1992</td>
<td>Semi-structured</td>
<td>Used with patients</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Neuropsychiatry (SCAN)</td>
<td></td>
<td></td>
<td>This is the main source of clinical data. Diagnoses were made by</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>consensus on the basis of this data</td>
<td></td>
</tr>
<tr>
<td>MRC Mental Disorder Beliefs Schedule</td>
<td>Mallett, 1997</td>
<td>Semi-structured</td>
<td>Used with patients, relatives and community respondents</td>
<td>Qualitative</td>
</tr>
<tr>
<td>(MDBS)</td>
<td></td>
<td></td>
<td>This is designed to explore beliefs in a multi-ethnic sample. It</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>has been used in previous studies in London and Barbados and has</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>been shown to be effective in eliciting detailed descriptions of</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>beliefs</td>
<td></td>
</tr>
<tr>
<td>Culture &amp; Identity Schedule 1</td>
<td>Mallett &amp; Bhugra,</td>
<td>Structured</td>
<td>Used with patients</td>
<td>Quantitative</td>
</tr>
<tr>
<td>(CANDID 1)</td>
<td>1996</td>
<td></td>
<td>This has been used to determine self-ascribed ethnicity in the</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>second stage of the project</td>
<td></td>
</tr>
<tr>
<td>Psychiatric and Personal History</td>
<td>WHO, 1996</td>
<td>Structured</td>
<td>Used with patients and relatives</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Schedule (PPHS)</td>
<td></td>
<td></td>
<td>This is the main source for dating onset of patients’ illness and</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>pathways to care. Where no relative or patient consented, this</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>was completed using case notes</td>
<td></td>
</tr>
</tbody>
</table>
These interview schedules elicited data relating to three key areas for the first stage of the study: sociodemographic characteristics, pathways to care and clinical presentation (see Table 7.1, Chapter 7). In addition, case notes for each patient were collected and scrutinised. Where the patient refused to take part in the study, cases notes were used to complete, as far as possible, the MRC Sociodemographic Schedule (Mallett, 1997), the Item Group Checklist (IGC) part of the SCAN (WHO, 1992) and the PPHS (WHO, 1996). Data relating to pathways to, and mode of contact with, services was collated from all sources (SCAN, IGC, PPHS, case notes) using the Pathways Recording Sheet (Appendix 2) that was devised by the author. In total, 123 patients (60 White, 63 African-Caribbean) screened positive and were included in the study. The number of patients and relatives agreeing to take part is detailed in Table 6.2 and the author’s contribution to patient and relative recruitment and the collection of data relevant for the first stage of the study is outlined in Table 6.3.

Table 6.2. Rates of patient and relative consent to take part in the study.

<table>
<thead>
<tr>
<th>Patients</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consented (Relative consent)</td>
<td>81 (34)</td>
<td>66</td>
</tr>
<tr>
<td>Refused</td>
<td>22</td>
<td>18</td>
</tr>
<tr>
<td>Not contactable</td>
<td>20</td>
<td>16</td>
</tr>
<tr>
<td>Total</td>
<td>123</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 6.3. Author’s contribution to patient recruitment and data collection for stage one.

**Patient Recruitment**

The author was responsible for checking new admissions to two wards at the Maudsley Hospital, twice weekly, and new referrals to two community team bases serving the Maudsley Hospital, once weekly. The author completed the Screening Schedule for Psychosis for all possible patients, and if screening positive, approached patients to take part in the study. If consent was given, permission was also sought to interview a close relative of the patient.

**Data Collection**

<table>
<thead>
<tr>
<th>Data Collection</th>
<th>Author Completed</th>
<th>Author Completed from Case Notes</th>
<th>Other Completed</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sociodemographic</td>
<td>65</td>
<td>42</td>
<td>16</td>
<td>123</td>
</tr>
<tr>
<td>SCAN (inc. IGC)</td>
<td>30</td>
<td>42</td>
<td>51</td>
<td>123</td>
</tr>
<tr>
<td>PPHS Patient</td>
<td>55</td>
<td>42</td>
<td>26</td>
<td>123</td>
</tr>
<tr>
<td>PPHS Relative</td>
<td>47</td>
<td>0</td>
<td>26</td>
<td>47</td>
</tr>
<tr>
<td>Pathways</td>
<td>123</td>
<td>0</td>
<td>123</td>
<td></td>
</tr>
<tr>
<td>Recording Sheet</td>
<td></td>
<td></td>
<td></td>
<td>122</td>
</tr>
</tbody>
</table>
Table 6.2. shows that there was a high rate of refusal and non-contact with patients (34%) and relatives. This rate of attrition is the same across the full ÅESOP study and is a combination of at least three factors: 1) the difficulty of engaging in research people with a first episode of psychosis, in which reluctance to accept mental illness, and therefore engage with a study purporting to investigate the causes of mental illness, is likely to be relatively high; 2) the nature of inner-London populations in which engagement with services and research projects is lower than in other areas; and 3) what can be termed “the Maudsley effect”, that is, the fact that the individuals in the target population are often approached to take part in more than one study. For those who did not consent to take part, data is more sparse and what data there is has been drawn exclusively from case notes. When those who were interviewed are compared to those who were not according to key sociodemographic, clinical and pathways data (see Table 7.1, Chapter 7 for variable definitions) there are no significant differences between the two groups (see Table 6.4). Further, the data extracted from case notes was largely factual, the major potential source of bias thus being non-recorded data in case notes.

Reliability
At this stage of the study, the issue of reliability in data collection and recording is important as data was collected by more than one researcher. This is particularly true in relation to the SCAN (WHO, 1992). Reliability was achieved and tested through training and a formal inter-rater reliability exercise. The ÅESOP researchers conducting the SCAN interviews were required to undergo a formal one-week WHO training course to ensure the SCAN was administered and rated in a standardised way. The successful completion of the training course was a prerequisite for researchers using the SCAN. Satisfactory inter-rater reliability was confirmed within the ÅESOP study with the scoring of four videotaped SCAN interviews. The videotaped interviews were rated for the presence or absence of a wide range of symptoms, with the ÅESOP researchers blind to the identity and diagnosis of the patients. Cohen's Kappa coefficients for inter-rater agreement ranged from 0.727 to 0.743 (p < 0.001). In relation to the other interviews relevant to this study, formal standardised training was provided prior to researchers administering the interviews to again ensure that interviews were administered and rated in a standardised way. The author collated all relevant data from case notes.

The analysis and results are set out and discussed in Chapter 7.
Table 6.4. Comparison of patients by whether data is primarily from interview or case notes.

<table>
<thead>
<tr>
<th>Key Sociodemographic Variables</th>
<th>Interviewed (n = 81) N (%)</th>
<th>Case Notes Only (n = 42) N (%)</th>
<th>df</th>
<th>χ²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>39 (48.1)</td>
<td>21 (50.0)</td>
<td>1</td>
<td>0.04</td>
<td>0.85</td>
</tr>
<tr>
<td>African-Caribbean</td>
<td>42 (51.9)</td>
<td>21 (50.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>39 (48.1)</td>
<td>24 (57.1)</td>
<td>1</td>
<td>0.90</td>
<td>0.34</td>
</tr>
<tr>
<td>Female</td>
<td>42 (51.9)</td>
<td>18 (42.9)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-29</td>
<td>37 (45.7)</td>
<td>23 (54.8)</td>
<td>1</td>
<td>0.91</td>
<td>0.34</td>
</tr>
<tr>
<td>30-65</td>
<td>44 (54.3)</td>
<td>19 (45.2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School</td>
<td>51 (65.4)</td>
<td>24 (63.2)</td>
<td>2</td>
<td>0.38</td>
<td>0.83</td>
</tr>
<tr>
<td>Further</td>
<td>11 (14.1)</td>
<td>7 (18.4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Higher</td>
<td>16 (20.5)</td>
<td>7 (18.4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>53 (65.4)</td>
<td>22 (52.4)</td>
<td>1</td>
<td>1.98</td>
<td>0.16</td>
</tr>
<tr>
<td>Other</td>
<td>28 (34.6)</td>
<td>20 (47.6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living circumstances</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>29 (35.4)</td>
<td>14 (33.3)</td>
<td>1</td>
<td>0.07</td>
<td>0.79</td>
</tr>
<tr>
<td>Others</td>
<td>52 (64.2)</td>
<td>28 (66.7)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>59 (72.8)</td>
<td>34 (81.0)</td>
<td>1</td>
<td>1.00</td>
<td>0.32</td>
</tr>
<tr>
<td>In a stable relationship</td>
<td>22 (27.2)</td>
<td>8 (19.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Key Clinical Variables

<table>
<thead>
<tr>
<th>Duration of Untreated Psychosis</th>
<th>Interviewed (n = 81) N (%)</th>
<th>Case Notes Only (n = 42) N (%)</th>
<th>df</th>
<th>χ²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short (&lt;1 year)</td>
<td>59 (72.8)</td>
<td>27 (64.3)</td>
<td>1</td>
<td>0.96</td>
<td>0.33</td>
</tr>
<tr>
<td>Long (&gt;1 year)</td>
<td>22 (27.2)</td>
<td>15 (35.7)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Diagnosis

<table>
<thead>
<tr>
<th>Schizophrenia</th>
<th>Interviewed (n = 81) N (%)</th>
<th>Case Notes Only (n = 42) N (%)</th>
<th>df</th>
<th>χ²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other psychoses</td>
<td>42 (51.9)</td>
<td>22 (52.4)</td>
<td>1</td>
<td>&lt;0.01</td>
<td>0.96</td>
</tr>
</tbody>
</table>

Key Pathways Variables

<table>
<thead>
<tr>
<th>Help-seeker</th>
<th>Interviewed (n = 81) N (%)</th>
<th>Case Notes Only (n = 42) N (%)</th>
<th>df</th>
<th>χ²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help-seeker present</td>
<td>65 (80.2)</td>
<td>32 (78.0)</td>
<td>1</td>
<td>0.08</td>
<td>0.78</td>
</tr>
<tr>
<td>No help-seeker</td>
<td>16 (19.8)</td>
<td>9 (22.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Referral to services

<table>
<thead>
<tr>
<th>Via GP</th>
<th>Interviewed (n = 81) N (%)</th>
<th>Case Notes Only (n = 42) N (%)</th>
<th>df</th>
<th>χ²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Via EC/home visit</td>
<td>31 (38.3)</td>
<td>13 (31.0)</td>
<td>4</td>
<td>3.27</td>
<td>0.51</td>
</tr>
<tr>
<td>Via A&amp;E</td>
<td>21 (25.9)</td>
<td>8 (19.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Via Criminal justice agency</td>
<td>11 (13.6)</td>
<td>8 (19.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>15 (18.5)</td>
<td>9 (21.4)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Mode of contact

<table>
<thead>
<tr>
<th>Non-compulsory</th>
<th>Interviewed (n = 81) N (%)</th>
<th>Case Notes Only (n = 42) N (%)</th>
<th>df</th>
<th>χ²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compulsory in-patient</td>
<td>26 (32.1)</td>
<td>13 (31.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 Missing values - 7
2 Missing values - 1
6.4 METHODOLOGY (2): Stage Two

6.4.1 Sub-sample, Relatives and Community Respondents

Patients who met the study inclusion criteria for stage one of the project and who agreed to be interviewed using the Mental Disorder Beliefs Schedule (MDBS) (see Table 6.1) were included in the second stage of the study, that addressing specifically questions relating to beliefs about mental illness and pathways to care. Where consent was given, a relative or close friend of the patient was also interviewed using the MDBS (see Table 6.1). The aim for this stage of the study was to collect qualitative data on 60 cases, 30 African-Caribbeans and 30 Whites, and on as many relatives of these 60 cases as possible. This number of patients was chosen as a target to ensure there were sufficient respondents to allow a full exploration of the range of beliefs within both ethnic groups, within the resource limitations of the study. Relatives are included because it allows differences and similarities between relatives and patients to be explored.

In addition to patients and relatives, twenty community respondents were interviewed with the MDBS (Mallett, 1997). These respondents were taken from the group of controls recruited for the ÆSOP project. The sampling frame for controls in the ÆSOP project is the same as that used successfully by the recent OPCS Psychiatric Morbidity Survey (Jenkins & Meltzer, 1995), namely the postal address file (PAF). The method is based upon that study in that the PAF was used to generate a random sample of target addresses for each case from which controls were recruited. The first ten African-Caribbeans (5 male, 5 female) and ten Whites (5 male, 5 female) who completed the MDBS were included in this stage. The purpose of including community respondents is to allow for a comparison of beliefs between these and those who have experienced a psychotic illness and had recent contact with mental health services (patients and relatives) in order to address the question of whether, in patients and relatives, contact with mental health services and the illness experience has shaped elicited accounts of mental illness. This is important given that the aim of this stage is to assess the potential role of beliefs in shaping responses to illness prior to, or at the point of, contact with services.

6.4.2 Data Collection

The MDBS was used to elicit beliefs about mental illness, or more accurately accounts of beliefs about mental illness. This is a semi-structured interview consisting of five sections: terminology, signs, causes, social distance and treatment (see Box 6.1). It has been developed over a number of years at the Social Psychiatry Section of the Institute of Psychiatry and has already been used in studies of multi-ethnic populations in London and in studies in the Caribbean (Mallett et al, 1998). It is designed primarily for use amongst a multi-ethnic population, including African-Caribbeans. The MDBS does not elicit explanatory models of
particular illness episodes. It seeks to understand the wider belief framework of respondents in relation to mental disorder. It aims to discover the cultural references used to make sense of 'unusual' behaviour. The capacity for the MDBS to obtain rich accounts has been demonstrated in previous research (Mallett et al., 1998), and this underpins the decision to use it for this project. The MDBS takes approximately one hour to complete. The approach adopted in the MDBS is closer to that of the EMIC, than either the MDEMQ or the SEMI (see previous chapter). The accounts elicited using this method provide a rich source of data, from which questions regarding the influence of beliefs on pathways to care can be fully explored. Interviews were conducted, when possible, outside of the hospital environment, either in the patient's or relative's home or other suitable venue. Consent was always sought to tape record the interviews for subsequent transcription and analysis. Taped interviews were transcribed verbatim according to the basic rules set out by Flick (1998), adapted from Drew (1995) (see Box 6.2). All interviews for this stage of the study were conducted and transcribed by the author.

For this stage, patients were also interviewed using the Culture and Identity Schedule I (Mallett & Bhugra, 1996; see also Bhugra et al., 1999). While this is an extensive schedule designed to assess the degree to which respondents identify with traditional or western cultures, for the purposes of this study, it has been used to elicit data on patient self-ascribed ethnicity. Respondents are asked both to state their own ethnicity and to choose from a list of 25 pre-defined categories the one that is closest to their ethnicity (see Appendix 2).

The analysis and findings are set out and discussed in Chapters 8 and 9.
Box 6.1. The Mental Disorder Beliefs Schedule (Mallett, 1997).

The Mental Disorder Beliefs Schedule (Mallett, 1997) (see Appendix 2)

Introduction
The introduction takes the form of a set of short instructions to the interviewer. The aim of these is to ensure the interviewer creates a relaxed and open atmosphere by reassuring the respondent that he or she is not being tested, that there are no right or wrong answers, and that it is the respondent's views that are important. This aims to minimise potential bias arising from the professional setting, if in hospital or the research institute, and the status of the interviewer. Weiss (1997) has referred to this type of approach as an 'empowering introduction', in which the respondent is reassured he/she will not be judged.

Terminology and signs
The first section aims to establish the respondent's own descriptive terminology, which is then used throughout the interview. This is to avoid imposing categories that have no meaning for the respondent. This is followed by questions asking whether the respondent considers this to be an illness and what the signs are by which someone could be identified who is * (subject's terms are used). This probes further what the respondent means by * and the features that characterise it. By comparing the responses in a multi-ethnic sample, the degree to which conceptualisations of mental disorder differ between and within groups can be explored.

Causes
The section on causes begins with an open-ended question asking what the respondent feels are the possible causes for someone becoming *. The aim is to elicit spontaneous responses, an account unclouded by interviewer suggestion. This is in sharp contrast to the structured questionnaire developed by Eisenbruch (1990). It is also more open and less directive than an approach based on vignettes. A series of possible probes are then listed in order that the respondent's beliefs can be explored more fully. Weiss (1997) has made the obvious point that "a researcher cannot assume that failure to mention a particular response means that it is irrelevant" (p. 247). The probes are grouped into seven general areas of possible causes: congenital/hereditary; physical; ingestion of food, drink, drugs; magico-religious; the individual; psychosocial; environmental/economic. The interviewer is required to be familiar with the probe areas, so that probes can be asked in different order depending on the responses. During the interview, notes are taken regarding the relative importance ascribed by the respondent to the possible causes.

Social distance and treatment
The sections on treatment and social distance again use relatively open, non-directive questions. For example, 'What or who helps people to get better if they are *?' or 'Who would be the first port of call?' Again these are followed by more focused questions to clarify and explore further the respondents' beliefs. For example, 'Would going to the doctor or hospital help?' and 'Would going to church or religious assembly help?'
<table>
<thead>
<tr>
<th>Transcription conventions (from Flick, 1998, p. 175.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overlapping speech: the precise point at which one person begins speaking whilst the other is still talking, or at which both begin to speak simultaneously, resulting in overlapping speech.</td>
</tr>
<tr>
<td>'Aw:::'</td>
</tr>
<tr>
<td>'fishi-':</td>
</tr>
<tr>
<td>WORD:</td>
</tr>
<tr>
<td>(words...)</td>
</tr>
</tbody>
</table>
PART 3

FINDINGS
CHAPTER 7

STAGE ONE
PATHWAYS TO CARE - ETHNICITY, SOCIAL CHARACTERISTICS AND CLINICAL PRESENTATION
The primary objective of this stage of the project is to identify and analyse routes into care among the full sample recruited to the study, as detailed in Chapter 6. In particular, it is designed to test the hypothesis that African-Caribbean ethnicity will be associated, independently of potential confounders, with higher rates of compulsory admissions and police contacts, and lower rates of GP referrals. This chapter sets out the analysis and results for this stage of the study.

7.1 ANALYSIS

As noted before, the analysis set out here is not an end point, but forms the basis for a more detailed enquiry in the second stage of the potential impact of beliefs about mental illness on shaping the patterns observed at this stage. The scope of data collected for this stage, and the analytic strategy, is also designed to move beyond previous research. Data has been collected and collated in three key areas: sociodemographic characteristics, clinical presentation and pathways to care (see Table 7.1). This allows for a detailed investigation of which factors are most strongly, and independently, associated with compulsory admission at first presentation to services. The collection of data relating to different outcomes on the pathway to care (i.e. duration of untreated psychosis, who initiated help-seeking, source of referral) further allows for each of these outcomes, and factors associated with them, to be investigated. Few previous studies have considered these earlier outcomes, and how these affect contacts with psychiatric services. In part, this is a function of the static model of pathways, with the focus on one outcome (i.e. compulsory admission), that has dominated research in this area (see Chapter 2). When considered as a process, earlier outcomes and decisions become central in understanding subsequent patterns of help-seeking. Therefore, while this stage of the study relies on cross-sectional data, analyses can be conducted that, within the limits of the data, attempt to reconstruct the pathway as a process by focusing both on the point of contact with services and earlier outcomes, such as who sought help, who from and who made the referral to psychiatric services.
Table 7.1. **Variables for stage one analysis.**

<table>
<thead>
<tr>
<th>Sociodemographic Variables</th>
<th>Categories</th>
<th>Source</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td>1. Male</td>
<td>Sociodem. Schedule (Q 1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Female</td>
<td>Case notes</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td>1. To school level</td>
<td>Sociodem. Schedule (Q 53)</td>
<td>School</td>
</tr>
<tr>
<td></td>
<td>2. To further education level</td>
<td>Case notes</td>
<td>1 No qualifications</td>
</tr>
<tr>
<td></td>
<td>3. To higher education level</td>
<td>Case notes</td>
<td>2 GCSEs</td>
</tr>
<tr>
<td></td>
<td>4. Further</td>
<td>3 O-Levels</td>
<td>Further</td>
</tr>
<tr>
<td></td>
<td>5. Higher</td>
<td>4 A-Levels</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6. Teaching etc</td>
<td>5 Vocational</td>
<td></td>
</tr>
<tr>
<td></td>
<td>7. University</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>1. 16-29</td>
<td>Sociodem. Schedule (Q 3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. 30-65</td>
<td>Case notes</td>
<td></td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td>1. Unemployed</td>
<td>Sociodem. Schedule (Q 62)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Other</td>
<td>Case notes</td>
<td></td>
</tr>
<tr>
<td><strong>Living circumstances</strong></td>
<td>1. Living alone</td>
<td>Sociodem. Schedule (Q 11)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Living with others</td>
<td>Case notes</td>
<td></td>
</tr>
<tr>
<td><strong>Relationship status</strong></td>
<td>1. Single</td>
<td>Sociodem. Schedule (Q 25)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. In a stable relationship</td>
<td>Case notes</td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td>1. African-Caribbean</td>
<td>CANDID 1 (Q 1)</td>
<td>See Introduction.</td>
</tr>
<tr>
<td></td>
<td>2. White</td>
<td>Case notes</td>
<td></td>
</tr>
<tr>
<td><strong>Type of accommodation</strong></td>
<td>1. Owned</td>
<td>Sociodem. Schedule (Q 23)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Rented</td>
<td>Case notes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Social network</strong></td>
<td>1. Supportive</td>
<td>Sociodem. Schedule (Q 104)</td>
<td>Supportive</td>
</tr>
<tr>
<td><strong>Supportive network</strong></td>
<td>2. Not supportive</td>
<td>Case notes</td>
<td>1 Very helpful</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>2 Fairly helpful</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>4 Critical but truthful</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Not supportive</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>3 Not very</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5 Too critical</td>
</tr>
<tr>
<td><strong>Close confidants</strong></td>
<td>1. Close confidants</td>
<td>Sociodem. Schedule (Q 97)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. No close confidants</td>
<td>Case notes</td>
<td></td>
</tr>
<tr>
<td><strong>Amount of contact with others</strong></td>
<td>1. Weekly</td>
<td>Sociodem. Schedule (Q 93 &amp; 95)</td>
<td>Amalgamation of two questions relating to contacts with friends, neighbours and family.</td>
</tr>
<tr>
<td></td>
<td>2. Less than weekly</td>
<td>Case notes</td>
<td></td>
</tr>
<tr>
<td>Clinical Variables</td>
<td>Categories</td>
<td>Source</td>
<td>Comments</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>---------------------------------</td>
<td>-----------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Duration of untreated psychosis</td>
<td>1. Short DUP (&lt;1 year)</td>
<td>SCAN PPHS (Q 1.2)</td>
<td>Date of onset was determined using the date at which first clear description of psychotic symptoms is made, from any of the sources. Time from onset to first contact with psychiatric services was calculated in days.</td>
</tr>
<tr>
<td></td>
<td>2. Long DUP (&gt;1 year)</td>
<td>Case notes</td>
<td></td>
</tr>
<tr>
<td>Mode of onset</td>
<td>1. Acute (&lt; 1 month)</td>
<td>SCAN PPHS (Q 1.5)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Insidious (&lt; 1 month)</td>
<td>Case Notes</td>
<td></td>
</tr>
<tr>
<td>Reason for admission</td>
<td>1. Risk to self</td>
<td>PPHS (Q 1.1)</td>
<td>Risk to self Q1.1.1 &amp; 1.1.2</td>
</tr>
<tr>
<td></td>
<td>2. Risk to others</td>
<td>Case notes</td>
<td>Risk to others Q1.1.3 &amp; 1.1.4</td>
</tr>
<tr>
<td>Previous non-psychotic illness</td>
<td>1. Previous non-psychotic illness</td>
<td>Case notes</td>
<td>Any report in the notes that the patient has experienced a previous non-psychotic mental illness, such as depression, anxiety, etc.</td>
</tr>
<tr>
<td></td>
<td>2. No previous non-psychotic illness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problem recognition</td>
<td>1. Problem denied</td>
<td>SCAN</td>
<td>A crude proxy for insight, though it is not possible to know whether this reflects lack of insight or different explanatory model of mental illness.</td>
</tr>
<tr>
<td></td>
<td>2. Problem recognised</td>
<td>Case notes</td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td>1. Schizophrenia</td>
<td>SCAN</td>
<td>Patient diagnoses were determined on the basis of consensus meetings involving one of the ÆSOP project’s Principle Investigators (Professor Julian Leff or Professor Robin Murray) and other members of the research team. The Principle Investigator was blind to ethnicity. Patients were given a diagnosis according to both ICD-10 and DSM-IV. There was an assessment for possible bias between the two principal psychiatrists. They both independently formulated a diagnosis for 20 patients based on the same summary SCAN information. There was 80% agreement on diagnostic category.</td>
</tr>
<tr>
<td></td>
<td>2. Other psychoses</td>
<td>Case notes</td>
<td></td>
</tr>
</tbody>
</table>
Chi-square tests were used to compare ethnic groups according to the variables of interest (Healey, 1996). The variables used in the analysis are set out in Table 7.1 (above). In analyses considering the main (compulsory admission) and other outcomes (source of referral, involvement of help-seeker), logistic regression was used to analyse the effect of ethnicity while controlling for potential confounders. In logistic regression analysis, a small number of variables should ideally be selected on the basis of prior research to form a model that is tested against the data. This has not been possible in this case. As has been seen, previous research has implicated a number of different factors, none of which have been consistently shown to predict compulsory admission, such that there is not a small number of variables suggested by this research on which to base final models. This study has also included new variables not previously considered, particularly those relating to pathways and social networks, and, unlike previous research, three outcomes have been considered: mode of contact with services, source of referral, and whether there was an active help-seeker involved. The analysis is, therefore, partly exploratory. Consequently, the logistic regression analyses have been conducted using the forward selection procedure to select variables for inclusion in final models (Bhornstedt & Knoke, 1994). While forward or backward selection

Table 7.1. Variables for stage one analysis (cont.).

<table>
<thead>
<tr>
<th>Variables</th>
<th>Categories</th>
<th>Source</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous contact for non-psychotic illness</td>
<td>1. Previous contact</td>
<td>Case notes</td>
<td>Confirmation in the notes that the patient has been in contact with psychiatric services in the past for help with a non-psychotic mental illness.</td>
</tr>
<tr>
<td></td>
<td>2. No previous contact</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help-seeker present</td>
<td>1. Help-seeker present</td>
<td>PPHS (Q 6)</td>
<td>“Help-seeker present”: patient or other(s) in social network sought help</td>
</tr>
<tr>
<td></td>
<td>2. No help-seeker present</td>
<td>Case notes</td>
<td>“No help-seeker present”: no active help-seeking until the involvement of external agencies, such as the police, and initiated by people unknown to the patient.</td>
</tr>
<tr>
<td>Source of referral</td>
<td>1. Via GP</td>
<td>PPHS (Q 6)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Via A&amp;E</td>
<td>Case notes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Via Emergency Clinic / Home Visit</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Via Criminal Justice System</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5. Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mode of contact with services</td>
<td>1. Non-compulsory in-patient</td>
<td>PPHS (Q 0)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Compulsory in-patient</td>
<td>Case notes</td>
<td></td>
</tr>
</tbody>
</table>
procedures can be useful when research is exploratory, the results have to be considered in light of the limitations of this approach to regression analysis (Pampel, 2000), the most important of these being difficulty in interpreting results. This is particularly so when a host of variables are unthinkingly entered into the analysis. In this case, however, each of the variables included in the analysis has been selected because of its theorised impact on pathways to care, making the interpretations less problematic.

The logistic regression analysis has followed three steps for each outcome considered. Firstly, for each outcome the unadjusted odds ratios and 95% confidence intervals for each independent variable were calculated. Secondly, each independent variable found to be significant at the 0.1 level was entered into a forward selection logistic regression analysis, the aim being to select the most significant factors for inclusion in the final model. The level of significance at these two points is set at 0.1 so that potentially important factors are not missed. Thirdly, the variables selected at the 0.1 level were refitted to provide the final model. The significance level for variables in the final model was set at 0.05 for the first outcome considered, i.e. compulsory admission, and 0.01 for subsequent outcomes. The more conservative significance level for subsequent models takes account of the increased possibility of chance associations at each stage, as the number of statistical tests applied increases.

The data is presented initially with limited comment and then discussed more fully in the final section of this chapter. All analyses were conducted using SPSS for Windows, version 10.

7.2 RESULTS (1): Sample Characteristics and Patterns of Service Access

7.2.1 Sociodemographic characteristics

During the 18-month period of recruitment 123 patients were identified, 63 African-Caribbean and 60 White. The sociodemographic characteristics of the two ethnic groups are compared in Table 7.2. The African-Caribbean group included more women and more patients in the older age group (30-65) than would be expected from previous research (Castle & Murray, 1991), a finding that is accounted for by the relatively high proportion of African-Caribbean women presenting with a late onset psychosis. There was a significant difference between the two groups in level of education, with 81.7% of African-Caribbeans having studied only up to school leaving age compared to 46.4% of Whites ($\chi^2 = 17.61$, df 2, $p < 0.01$). Likewise, within the context of high overall levels of unemployment, African Caribbeans were more likely to be unemployed (68.3% v. 53.3%), though this fails to reach significance ($\chi^2 = 2.88$, df 1, $p = 0.09$). Both these findings are consistent with prior research in this area (Mallett et al, 2002). On all indicators of social isolation (living circumstances, relationship status, social networks), African-Caribbeans were more socially isolated than
Whites. This comes through most strongly in the findings that significantly fewer African-Caribbeans had close confidants ($\chi^2 = 4.34$, df 1, $p = 0.04$) and regular weekly contact with others ($\chi^2 = 5.40$, df 1, $p = 0.02$). These differences in sociodemographic characteristics persist across both age groups (16-29 and 30-65) and gender, showing that poor educational achievement, high levels of unemployment and greater levels of social isolation are not more marked in young African-Caribbean men. Likewise, while the African-Caribbean group included a sizable proportion who were born in the Caribbean ($n = 22$ (34.9%)), there were no differences between Caribbean and UK born African-Caribbeans in terms of sociodemographic characteristics, other than that, predictably, the Caribbean born patients were significantly older than the UK born African-Caribbean patients.

Table 7.2. Sociodemographic characteristics by ethnicity.

<table>
<thead>
<tr>
<th></th>
<th>White (n = 60)</th>
<th>African-Caribbean (n = 63)</th>
<th>df</th>
<th>$\chi^2$</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Male</td>
<td>34 (56.7)</td>
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</tr>
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<td>Female</td>
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<td>34 (54.0)</td>
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<td>Age</td>
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<td>16-29</td>
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<td>1.81</td>
<td>0.18</td>
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<td>36 (57.1)</td>
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<td>49 (81.7)</td>
<td>2</td>
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<td>11 (19.6)</td>
<td>7 (11.7)</td>
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<td>19 (33.9)</td>
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<td>Unemployed</td>
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<td>43 (68.3)</td>
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<td>2.88</td>
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<tr>
<td>Other</td>
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<td>20 (31.7)</td>
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<td>Living circumstances</td>
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<td>Alone</td>
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<td>26 (41.3)</td>
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<td>2.26</td>
<td>0.13</td>
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<tr>
<td>Others</td>
<td>43 (71.7)</td>
<td>37 (58.7)</td>
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<td>Relationship status</td>
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<td>50 (79.4)</td>
<td>1</td>
<td>0.99</td>
<td>0.32</td>
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<td>In a stable relationship</td>
<td>17 (28.3)</td>
<td>13 (20.6)</td>
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<td>Type of accommodation</td>
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<td>Owned</td>
<td>17 (29.3)</td>
<td>14 (23.3)</td>
<td>2</td>
<td>0.90</td>
<td>0.64</td>
</tr>
<tr>
<td>Rented</td>
<td>38 (65.5)</td>
<td>44 (73.3)</td>
<td></td>
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<tr>
<td>Other</td>
<td>3 (5.2)</td>
<td>2 (3.3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social network (1) Support</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supportive network</td>
<td>31 (63.3)</td>
<td>26 (48.1)</td>
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<td>2.38</td>
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<td>No supportive network</td>
<td>18 (36.7)</td>
<td>28 (51.9)</td>
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</tr>
<tr>
<td>Social network (2) Close confidents</td>
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<td></td>
<td></td>
<td></td>
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<td>Yes</td>
<td>32 (64.0)</td>
<td>25 (43.9)</td>
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<td>4.34</td>
<td>0.04</td>
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<tr>
<td>No</td>
<td>18 (36.0)</td>
<td>32 (56.1)</td>
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</tr>
<tr>
<td>Social network (3) Amount of contact</td>
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<td></td>
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<td>Weekly</td>
<td>47 (85.5)</td>
<td>38 (66.7)</td>
<td>1</td>
<td>5.40</td>
<td>0.02</td>
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<td>Less than weekly</td>
<td>8 (14.5)</td>
<td>19 (33.3)</td>
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</table>

1 Missing values - 7  3 Missing values - 20  5 Missing values - 11
2 Missing values - 5  4 Missing values - 16
7.2.2 Clinical presentation

Data on clinical presentation by ethnic group is shown in Table 7.3.

Table 7.3. *Clinical data by ethnicity.*

<table>
<thead>
<tr>
<th></th>
<th>White (n = 60)</th>
<th>African-Caribbean (n = 63)</th>
<th>df</th>
<th>( \chi^2 )</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Previous history</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Yes</td>
<td>22 (37.3)</td>
<td>11 (17.7)</td>
<td>1</td>
<td>5.82</td>
<td>0.02</td>
</tr>
<tr>
<td>No</td>
<td>37 (62.7)</td>
<td>51 (82.3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Duration of Untreated Psychosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short (&lt;1 year)</td>
<td>45 (75.0)</td>
<td>41 (65.1)</td>
<td>1</td>
<td>1.44</td>
<td>0.23</td>
</tr>
<tr>
<td>Long (&gt;1 year)</td>
<td>15 (25.0)</td>
<td>22 (34.9)</td>
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</tr>
<tr>
<td><strong>Risk to self</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>23 (39.0)</td>
<td>19 (31.1)</td>
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<td>0.81</td>
<td>0.37</td>
</tr>
<tr>
<td>No</td>
<td>36 (61.0)</td>
<td>42 (68.9)</td>
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<td></td>
</tr>
<tr>
<td><strong>Risk to others</strong></td>
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<td></td>
<td></td>
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<td></td>
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<tr>
<td>Yes</td>
<td>15 (25.4)</td>
<td>29 (47.5)</td>
<td>1</td>
<td>6.32</td>
<td>0.01</td>
</tr>
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<td>32 (52.5)</td>
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<td><strong>Mode of onset</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute</td>
<td>26 (43.3)</td>
<td>23 (37.7)</td>
<td>1</td>
<td>0.40</td>
<td>0.53</td>
</tr>
<tr>
<td>Insidious</td>
<td>34 (56.7)</td>
<td>38 (62.3)</td>
<td></td>
<td></td>
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<td><strong>Diagnosis</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>29 (48.3)</td>
<td>35 (55.6)</td>
<td>1</td>
<td>0.42</td>
<td>0.47</td>
</tr>
<tr>
<td>Other psychoses</td>
<td>31 (51.7)</td>
<td>28 (44.4)</td>
<td></td>
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</tr>
<tr>
<td><strong>Problem recognition</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denied</td>
<td>16 (30.8)</td>
<td>19 (33.3)</td>
<td>1</td>
<td>0.08</td>
<td>0.78</td>
</tr>
<tr>
<td>Acknowledged</td>
<td>36 (69.2)</td>
<td>38 (66.7)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 Missing values - 2
2 Missing values - 3
3 Missing values - 14

Interestingly, significantly more of the White patients reported a previous history of a non-psychotic mental illness (37.3% v. 17.7%, \( \chi^2 = 5.82, df 1, p = 0.02 \)). The two factors that have previously been implicated as showing African-Caribbeans have a worse clinical presentation, namely perceived risk to others and poor insight (problem recognition), reveal conflicting results. While African-Caribbeans were much more likely to be perceived as posing a risk to others (47.5% v. 25.4%, \( \chi^2 = 6.32, df 1, p = 0.01 \)), rates of denial of illness were similar between the two groups. Elaboration of the findings on risk to others by age and gender showed that rates of perceived risk to others were highest among young African-Caribbeans. Indeed, 63.0% (n = 17) of African-Caribbeans in the 16 to 29 year old age group were perceived as posing a risk to others compared to 20.6% (n = 7) of Whites in the same age band (\( \chi^2 = 11.32, df 1, p < 0.01 \)). As with previous studies, it has not been possible to establish whether perceived risk is a function, and indicator, of illness severity or a result of stereotyping by predominantly White psychiatrists. Comparison of duration of untreated
illness, mode of onset and diagnosis between the two groups showed no significant differences. The decision to dichotomise duration of untreated psychosis at the one year point is based on previous research (Lincoln et al., 1998; Larsen et al., 1998). Other options were considered, including different cut off points (for example, 3 months) and using the log of duration of untreated psychosis, an option that normalises the distribution and allows for the use of more robust statistics but which produces results that are difficult to interpret. Whichever way this variable is considered there was no statistical difference between African-Caribbeans and Whites. However, it is worth noting that in terms of the distribution of this variable, the African-Caribbean group was more spread, with more experiencing extremely long delays, as illustrated in Figure 7.1.

Figure 7.1. Duration of untreated psychosis by ethnicity.

In terms of clinical presentation, there were no significant differences between African-Caribbeans born in the Caribbean and those born in the UK.

7.2.3 Pathways to care
There were important differences between African-Caribbeans and Whites on all pathways variables (Table 7.4).
Significantly more of the White group had had prior contact with mental health services for a non-psychotic mental illness (27.1% v. 8.2%, $\chi^2 = 7.44$, df 1, p < 0.01). Overall, a majority of patients came into contact with services either having sought help by themselves or having had someone close to them seek help on their behalf. However, a higher proportion of African-Caribbeans had no help-seeker and came into contact with services via the intervention of external agencies, a finding that borders significance (27.4% v. 13.3%, $\chi^2 = 3.71$, df 1, p = 0.05). This is, not surprisingly, closely reflected in the higher rates of referral by criminal justice agencies (i.e. police, courts, prisons) among African-Caribbean patients (27.0% v. 11.7%, $\chi^2 = 4.59$, df 1, p = 0.03). There were indications, moreover, that involvement of criminal justice agencies was particularly marked among young African-Caribbean men. Of African-Caribbean men in the 16 to 29 year old age group, 42.9% (n = 6) were brought into contact with mental health services by the police compared to 16.7% (n = 3) of White men in the same age band, though the numbers are small and the difference does not reach statistical significance. There are clear variations in the source of referral to services between the two groups. In addition to being more often referred by criminal justice agencies, African-Caribbeans were more likely to present via the Emergency Clinic at the Maudsley Hospital or via a home visit (30.2% v. 16.7%, $\chi^2 = 3.11$, df 1, p = 0.08), though this is only a strong trend, and less likely to be referred by a GP (22.2% v. 50.0%, $\chi^2 = 10.32$, df 1, p = 0.01). The finding that less than one-quarter of African-Caribbeans presented to services via a GP is perhaps the most striking. Furthermore, in contrast to Cole et al (1995) and

<table>
<thead>
<tr>
<th></th>
<th>White (n = 60)</th>
<th>African-Caribbean (n = 63)</th>
<th>df</th>
<th>$\chi^2$</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous contact</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>with services</td>
<td></td>
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</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help-seeker</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help-seeker present</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No help-seeker</td>
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<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Referral to services</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Via GP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Via EC/home visit</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Via A&amp;E</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Via Criminal justice agency</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
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<td></td>
</tr>
<tr>
<td>Mode of contact</td>
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<td></td>
</tr>
<tr>
<td>Non-compulsory</td>
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<td></td>
</tr>
<tr>
<td>Compulsory in-patient</td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

1 Missing values - 3
2 Missing values - 1

Table 7.4. Pathways data by ethnicity.
Burnett et al (1999), there was a significant difference in rates of compulsory admission between the two groups in this sample (44.4 % African-Caribbean v. 18.3 % White, $\chi^2 = 9.68$, df 1, $p < 0.01$), a difference that was even more marked among young African-Caribbean men. Of African-Caribbean men in the 16 to 29 year old age group, 71.4% (n = 10) were compulsorily admitted compared to 11.1% (n = 2) of Whites in the same age band ($\chi^2 = 12.22$, df 1, $p < 0.01$). In terms of pathways to care, there were no significant differences between African-Caribbeans born in the Caribbean and those born in the UK. It is evident, moreover, even from this basic analysis, that referral source is associated with mode of contact with services. This is illustrated in Figure 7.2, which shows that GP referral is more often followed by voluntary contact with services and that criminal justice referral is more often followed by compulsory admission.

Figure 7.2. *Mode of contact with services, referral source and ethnicity.*

The next stage of the analysis sought to probe these findings more closely. The first step focused on compulsory admission and sought to analyse whether ethnicity was independently associated with compulsory admission after controlling for potential confounders, thus addressing the primary hypothesis proposed at this stage.
7.3 RESULTS (2): Determinants of Pathways to Care

7.3.1 Compulsory admission

Table 7.5 shows the unadjusted odds ratios, 95% confidence intervals and p-values for each independent variable, with compulsory admission as the outcome variable.

Table 7.5. Odds of compulsory admission.

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Unadjusted Odds Ratio</th>
<th>95% CI</th>
<th>p-value</th>
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</thead>
<tbody>
<tr>
<td>** Sociodemographic **</td>
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<td></td>
</tr>
<tr>
<td>African-Caribbean v. White</td>
<td>3.56</td>
<td>1.57-8.10</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Male v. female</td>
<td>1.36</td>
<td>0.63-2.90</td>
<td>0.43</td>
</tr>
<tr>
<td>Age: 16-29 v. 30-65</td>
<td>0.99</td>
<td>0.47-2.13</td>
<td>0.99</td>
</tr>
<tr>
<td>Education:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School v. higher</td>
<td>2.03</td>
<td>0.68-6.07</td>
<td>0.21</td>
</tr>
<tr>
<td>Further v. higher</td>
<td>1.80</td>
<td>0.45-7.26</td>
<td>0.41</td>
</tr>
<tr>
<td>** Unemployed v. other</td>
<td>2.89</td>
<td>1.22-6.82</td>
<td>0.02</td>
</tr>
<tr>
<td>Living alone v. with others</td>
<td>1.25</td>
<td>0.57-2.75</td>
<td>0.58</td>
</tr>
<tr>
<td>Single v. in a relationship</td>
<td>0.91</td>
<td>0.37-2.18</td>
<td>0.83</td>
</tr>
<tr>
<td>Type of accommodation:</td>
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</tr>
<tr>
<td>Rented v. owned</td>
<td>0.92</td>
<td>0.38-2.24</td>
<td>0.86</td>
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<tr>
<td>Supportive network v. none</td>
<td>0.55</td>
<td>0.24-1.30</td>
<td>0.18</td>
</tr>
<tr>
<td>Close confidents v. none</td>
<td>0.58</td>
<td>0.26-1.32</td>
<td>0.20</td>
</tr>
<tr>
<td>Weekly contact v. less</td>
<td>0.63</td>
<td>0.25-1.58</td>
<td>0.32</td>
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<tr>
<td>** Clinical **</td>
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<td></td>
</tr>
<tr>
<td>Previous history v. none</td>
<td>0.47</td>
<td>0.18-1.21</td>
<td>0.12</td>
</tr>
<tr>
<td>Long DUP v. short DUP</td>
<td>1.05</td>
<td>0.46-2.34</td>
<td>0.91</td>
</tr>
<tr>
<td>Schizophrenia v. other psychoses</td>
<td>0.61</td>
<td>0.28-1.31</td>
<td>0.20</td>
</tr>
<tr>
<td>Risk to self v. no risk</td>
<td>0.67</td>
<td>0.30-1.54</td>
<td>0.35</td>
</tr>
<tr>
<td>** Risk to others v. no risk</td>
<td>7.70</td>
<td>3.25-18.22</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Mode of onset:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insidious v. acute</td>
<td>1.25</td>
<td>0.57-2.75</td>
<td>0.58</td>
</tr>
<tr>
<td>** Process denied v. acknowledged</td>
<td>5.24</td>
<td>2.18-12.61</td>
<td>&lt;0.01</td>
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<tr>
<td>** Process **</td>
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<td></td>
</tr>
<tr>
<td>Previous contact v. none</td>
<td>0.43</td>
<td>0.13-1.38</td>
<td>0.16</td>
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<tr>
<td>Help-seeker</td>
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<tr>
<td>No help-seeker v. Help-seeker</td>
<td>5.72</td>
<td>2.32-14.66</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>GP referral v. others</td>
<td>0.05</td>
<td>0.01-0.24</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>** Criminal justice referral v. others</td>
<td>21.05</td>
<td>6.4-68.79</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

* Significant at the 0.1 level
** Significant at the 0.05 level

This analysis shows that seven factors were associated with an increased or decreased risk of compulsory admission at the 0.1 level. What is surprising here is that, of the variables possibly indicative of social isolation, only unemployment is associated with compulsory admission. Other than this, the factors associated with compulsory admission are
unsurprising and reflect previous research (see Chapter 2 and Appendix 1). The significant factors were entered into a forward selection logistic regression analysis. The factors that emerged as significant at the 0.1 level were: ethnicity, GP referral, criminal justice agency referral, and conceptualisation of problem. These variables were re-entered into a logistic regression analysis, using the enter method. Table 7.6 shows the final model.

Table 7.6. Logistic regression for compulsory admission: Final model.

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Adjusted Odds Ratio</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>African-Caribbean v. White</td>
<td>2.61</td>
<td>0.84-8.11</td>
<td>0.1</td>
</tr>
<tr>
<td>GP referral v. others</td>
<td>0.16</td>
<td>0.03-0.77</td>
<td>0.02</td>
</tr>
<tr>
<td>Criminal justice referral v. others</td>
<td>10.60</td>
<td>2.48-45.29</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Problem denied v. acknowledged</td>
<td>3.11</td>
<td>1.01-9.57</td>
<td>0.05</td>
</tr>
</tbody>
</table>

3 missing cases

This reveals that, after adjusting for the other three variables in the model, the effect of ethnicity is weakened and is no longer significant. The two factors independently associated with increased or decreased odds of compulsory admission are GP referral (Adjusted OR = 0.16; 95% CI 0.03-0.77) and criminal justice referral (Adjusted OR = 10.60; 95% CI 2.48-45.29).

The finding that absence of GP referral and involvement of criminal justice agencies in bringing about referral have independent significant effects on the odds of compulsory admission poses the question of what factors predict these outcomes. Funnelling back to consider referral source, the next stage of the analysis sought to explore the relationship between ethnicity and GP and criminal justice referral.

### 7.3.2 Source of referral

The same procedure of analysis was followed firstly with GP referral as the outcome variable, and then with criminal justice referral as the outcome. This stage of the analysis, while specifically looking at the effect of ethnicity on referral source, is necessarily more exploratory. The use of more statistical tests also increases the possibility of a Type I error, and for the final models the significance level is set more conservatively at 0.01 to take account of this.

**GP referral**

Table 7.7 shows the unadjusted odds ratios, 95% confidence intervals and p-values for the relevant variables, with GP referral as the outcome variable.
Table 7.7. Odds of GP referral.

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Unadjusted Odds Ratio</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>** Sociodemographic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>** African-Caribbean v. White</td>
<td>0.29</td>
<td>0.13-0.62</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>* Male v. female</td>
<td>0.52</td>
<td>0.25-1.11</td>
<td>0.09</td>
</tr>
<tr>
<td>Age: 16-29 v. 30-54</td>
<td>0.94</td>
<td>0.50-1.20</td>
<td>0.86</td>
</tr>
<tr>
<td>Education:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School v. higher</td>
<td>0.46</td>
<td>0.18-1.18</td>
<td>0.11</td>
</tr>
<tr>
<td>Further v. higher</td>
<td>0.26</td>
<td>0.07-1.04</td>
<td>0.06</td>
</tr>
<tr>
<td>Unemployed v. other</td>
<td>0.57</td>
<td>0.27-1.21</td>
<td>0.14</td>
</tr>
<tr>
<td>Living alone v. with others</td>
<td>0.69</td>
<td>0.31-1.51</td>
<td>0.35</td>
</tr>
<tr>
<td>Single v. in a relationship</td>
<td>0.54</td>
<td>0.24-1.26</td>
<td>0.16</td>
</tr>
<tr>
<td>Type of accommodation:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rented v. owned</td>
<td>1.11</td>
<td>0.47-2.61</td>
<td>0.82</td>
</tr>
<tr>
<td>** Supportive network v. none</td>
<td>2.29</td>
<td>1.00-5.22</td>
<td>0.05</td>
</tr>
<tr>
<td>* Close confidants v. none</td>
<td>1.96</td>
<td>0.88-4.35</td>
<td>0.10</td>
</tr>
<tr>
<td>Weekly contact v. less</td>
<td>2.01</td>
<td>0.80-5.50</td>
<td>0.13</td>
</tr>
<tr>
<td>** Clinical</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous history v. none</td>
<td>1.58</td>
<td>0.69-3.60</td>
<td>0.28</td>
</tr>
<tr>
<td>Long DUP v. short DUP</td>
<td>0.68</td>
<td>0.30-1.56</td>
<td>0.36</td>
</tr>
<tr>
<td>Schizophrenia v. other</td>
<td>1.02</td>
<td>0.49-2.12</td>
<td>0.97</td>
</tr>
<tr>
<td>psychoses</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk to self v. no risk</td>
<td>1.36</td>
<td>0.63-2.95</td>
<td>0.44</td>
</tr>
<tr>
<td>** Risk to others v. no risk</td>
<td>0.26</td>
<td>0.11-0.63</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Mode of onset:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insidious v. acute</td>
<td>0.73</td>
<td>0.34-1.54</td>
<td>0.40</td>
</tr>
<tr>
<td>** Problem denied v. acknowledged</td>
<td>0.39</td>
<td>0.16-0.97</td>
<td>0.04</td>
</tr>
<tr>
<td>** Process</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous contact v. none</td>
<td>1.18</td>
<td>0.44-3.11</td>
<td>0.74</td>
</tr>
<tr>
<td>Help-seeker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>** No help-seeker v. Help-seeker</td>
<td>0.05</td>
<td>0.01-0.40</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

* Significant at the 0.1 level
** Significant at the 0.05 level

African-Caribbeans were significantly less likely to be referred by a GP than Whites, as already shown using chi-square tests, and a number of other sociodemographic variables were found to be associated with increased or decreased odds of GP referral: gender, education, supportive social network, and having close confidants. Of the clinical variables, denial of illness and perceived risk to others were significantly associated with GP referral, both reducing the odds of referral via this route. The absence of a help-seeker was also negatively associated with GP referral. When these variables were entered into a forward selection logistic regression analysis, the factors selected at the 0.1 level were: ethnicity and absence of a help-seeker. These variables were re-entered into a logistic regression analysis, using the enter method. Table 7.8 shows the final model.
Table 7.8. Logistic regression for GP referral: Final model.

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Adjusted Odds Ratio</th>
<th>99% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>African-Caribbean v. White Help-seeker</td>
<td>0.33</td>
<td>0.11-0.98</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Help-seeker</td>
<td>0.06</td>
<td>0.01-0.89</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

3 missing cases

This shows that after adjusting for the presence or absence of a help-seeker, ethnicity retains approximately the same effect on the odds of GP referral (Adjusted OR = 0.33; 99% CI 0.11-0.98). Absence of a help-seeker is also shown to have an independent effect on the odds of GP referral, again the adjusted odds being approximately the same as the unadjusted odds (Adjusted OR = 0.06; 99% CI 0.01-0.89).

GP referral and ethnicity can be probed further. More patients made contact with a GP at some point between the onset of symptoms and contact with services than were actually referred by a GP. Of the 123 patients, 64 (52%) sought help from a GP subsequent to the onset of psychosis, but only 44 (68.8% of those contacting a GP) were referred to services by a GP. This means that 20 (31.2%) patients who came into contact with a GP at some point after becoming ill were not referred to secondary services by the GP. At some point further on services were accessed via another route. What is particularly interesting is to compare rates of GP referral in this sub-group by ethnic group. This shows that only 56% (n = 14) of African-Caribbeans who sought help from a GP subsequently accessed services via GP referral, compared to 77% (n = 30) of Whites, a difference that borders significance ($\chi^2 = 3.1$, df 1, p = 0.08) (see Figure 7.3).

Figure 7.3. GP referral following GP contact by ethnicity.

That this finding does not reach statistical significance means this difference should be treated with caution, but it is suggestive and is considered in more detail in the next section.
Table 7.9 shows the unadjusted odds ratios, 95% confidence intervals and p-values for each independent variable, with criminal justice referral as the outcome variable.

### Table 7.9. Odds of criminal justice referral.

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Unadjusted Odds Ratio</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>** Sociodemographic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>** African-Caribbean v. White</td>
<td>2.80</td>
<td>1.06-7.34</td>
<td>0.04</td>
</tr>
<tr>
<td>* Male v. female</td>
<td>2.21</td>
<td>0.87-5.60</td>
<td>0.10</td>
</tr>
<tr>
<td>Age: 16-29 v. 30-54</td>
<td>0.70</td>
<td>0.28-1.73</td>
<td>0.44</td>
</tr>
<tr>
<td>Education:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School v. higher</td>
<td>0.98</td>
<td>0.31-3.04</td>
<td>0.97</td>
</tr>
<tr>
<td>Further v. higher</td>
<td>0.72</td>
<td>0.15-3.52</td>
<td>0.69</td>
</tr>
<tr>
<td>Unemployed v. other</td>
<td>2.21</td>
<td>0.81-6.05</td>
<td>0.12</td>
</tr>
<tr>
<td>Living alone v. with others</td>
<td>0.72</td>
<td>0.27-1.90</td>
<td>0.51</td>
</tr>
<tr>
<td>Single v. in a relationship</td>
<td>0.94</td>
<td>0.34-2.69</td>
<td>0.94</td>
</tr>
<tr>
<td>Type of accommodation:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rented v. owned</td>
<td>0.86</td>
<td>0.30-2.48</td>
<td>0.78</td>
</tr>
<tr>
<td>Supportive network v. none</td>
<td>1.19</td>
<td>0.41-3.40</td>
<td>0.75</td>
</tr>
<tr>
<td>Close confidents v. none</td>
<td>0.97</td>
<td>0.36-2.62</td>
<td>0.95</td>
</tr>
<tr>
<td>Weekly contact v. less</td>
<td>1.23</td>
<td>0.37-4.09</td>
<td>0.73</td>
</tr>
<tr>
<td>** Clinical</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous history v. none</td>
<td>0.47</td>
<td>0.15-1.49</td>
<td>0.20</td>
</tr>
<tr>
<td>Long DUP v. short DUP</td>
<td>1.21</td>
<td>0.47-3.13</td>
<td>0.70</td>
</tr>
<tr>
<td>Schizophrenia v. other psychoses</td>
<td>0.73</td>
<td>0.30-1.78</td>
<td>0.50</td>
</tr>
<tr>
<td>** Risk to self v. no risk</td>
<td>0.22</td>
<td>0.06-0.80</td>
<td>0.02</td>
</tr>
<tr>
<td>** Risk to others v. no risk</td>
<td>33.77</td>
<td>7.36-155.02</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Mode of onset:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insidious v. acute</td>
<td>1.07</td>
<td>0.42-2.72</td>
<td>0.88</td>
</tr>
<tr>
<td>** Problem denied v. acknowledged</td>
<td>6.38</td>
<td>2.28-17.90</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>** Process</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous contact v. none</td>
<td>0.37</td>
<td>0.08-1.71</td>
<td>0.20</td>
</tr>
<tr>
<td>** Help-seeker</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No help-seeker v. Help-seeker</td>
<td>27.32</td>
<td>8.75-85.30</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

* Significant at the 0.1 level
** Significant at the 0.05 level

This analysis revealed six variables to be associated with criminal justice referral, which again included ethnicity. Using the same model selection procedure outlined above, the variables selected for the final model were: absence of help-seeker, gender and perceived risk to others. Ethnicity did not have an independent effect on the odds of criminal justice referral. Results for the final model are shown in Table 7.10.
Table 7.10. Logistic regression for criminal justice referral: Final model.

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Adjusted Odds Ratio</th>
<th>99% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help-seeker</td>
<td>28.63</td>
<td>3.54-231.60</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Male v. female</td>
<td>4.08</td>
<td>0.52-31.92</td>
<td>0.08</td>
</tr>
<tr>
<td>Risk to others v. no risk</td>
<td>27.99</td>
<td>2.65-295.67</td>
<td>&lt;0.01</td>
</tr>
</tbody>
</table>

6 missing cases

This shows that absence of a help-seeker (Adjusted OR = 28.63; 99% CI 3.54-231.60) and perceived risk to others (Adjusted OR = 27.99; 99% CI 2.65-295.67) are the only two factors that have an independent significant effect on the odds of referral via a criminal justice agency. For each of these the adjusted odds ratios are high and the confidence intervals extremely wide. While on the face of it this is suggestive of a strong relationship between criminal justice referral and the absence of a help-seeker and perceived risk, the wide confidence intervals show the need for caution in interpreting these findings. In part, this is due to the fact that the numbers coming into contact with psychiatric services via criminal justice agencies are relatively small, and in this sample those following this route numbered 24 (19.5%).

In the analysis of both GP and criminal justice referral, the presence or absence of a help-seeker was found to be a significant factor. This raises the question of why some people only come into contact with services following intervention by external agencies or persons. In terms of capturing key points on the pathway to care, this is an important question, and the next stage of this analysis aimed to examine the factors associated with the absence of a help-seeker. Again the significance level for variables entered in the final logistic regression model is set at 0.01.

7.3.3 Absence of a help-seeker

Table 7.11 shows the unadjusted odds ratios, 95% confidence intervals and p-values for each independent variable, with no help-seeker as the outcome variable. This analysis revealed that six variables were associated with not having a help-seeker, including duration of untreated psychosis and ethnicity. Again following the same procedure as before, the variables selected for the final model were: ethnicity, duration of untreated psychosis, and perceived risk to others. When these variables were re-fitted to produce a final model (see Table 7.12), only duration of untreated psychosis and perceived risk to others remained significant.
Table 7.11. Odds of having no help-seeker.

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Unadjusted Odds Ratio</th>
<th>95% CI</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sociodemographic</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African-Caribbean v. White</td>
<td>2.46</td>
<td>0.77-6.23</td>
<td>0.06</td>
</tr>
<tr>
<td>Male v. female</td>
<td>1.25</td>
<td>0.52-3.02</td>
<td>0.63</td>
</tr>
<tr>
<td>Age: 16-29 v. 30-54</td>
<td>0.53</td>
<td>0.21-1.31</td>
<td>0.17</td>
</tr>
<tr>
<td>Education:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School v. higher</td>
<td>1.84</td>
<td>0.48-6.97</td>
<td>0.37</td>
</tr>
<tr>
<td>Further v. higher</td>
<td>2.56</td>
<td>0.52-12.59</td>
<td>0.25</td>
</tr>
<tr>
<td>**Unemployed v. other</td>
<td>4.20</td>
<td>1.34-13.01</td>
<td>0.01</td>
</tr>
<tr>
<td>Living alone v. with others</td>
<td>1.35</td>
<td>0.55-3.35</td>
<td>0.51</td>
</tr>
<tr>
<td>Single v. in a relationship</td>
<td>2.83</td>
<td>0.78-10.23</td>
<td>0.11</td>
</tr>
<tr>
<td>Type of accommodation:</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Rented v. owned</td>
<td>2.06</td>
<td>0.64-6.65</td>
<td>0.22</td>
</tr>
<tr>
<td>Supportive network v. none</td>
<td>0.65</td>
<td>0.23-1.86</td>
<td>0.42</td>
</tr>
<tr>
<td>Close confidants v. none</td>
<td>0.64</td>
<td>0.23-1.77</td>
<td>0.39</td>
</tr>
<tr>
<td>Weekly contact v. less</td>
<td>0.48</td>
<td>0.17-1.37</td>
<td>0.17</td>
</tr>
<tr>
<td><strong>Clinical</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous history v. none</td>
<td>0.60</td>
<td>0.20-1.75</td>
<td>0.35</td>
</tr>
<tr>
<td>Long DUP v. short DUP</td>
<td>3.49</td>
<td>1.39-8.69</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Schizophrenia v. other psychoses</td>
<td>0.68</td>
<td>0.28-1.65</td>
<td>0.39</td>
</tr>
<tr>
<td>Risk to self v. no risk</td>
<td>0.46</td>
<td>0.16-1.35</td>
<td>0.16</td>
</tr>
<tr>
<td>**Risk to others v. no risk</td>
<td>7.24</td>
<td>2.58-20.31</td>
<td>&lt;0.01</td>
</tr>
<tr>
<td>Mode of onset:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>* Insidious v. acute</td>
<td>2.43</td>
<td>0.89-6.67</td>
<td>0.08</td>
</tr>
<tr>
<td>**Problem denied v. acknowledged</td>
<td>3.29</td>
<td>1.25-8.63</td>
<td>0.02</td>
</tr>
<tr>
<td><strong>Process</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Previous contact v. none</td>
<td>0.58</td>
<td>0.16-2.14</td>
<td>0.41</td>
</tr>
</tbody>
</table>

* Significant at the 0.1 level
** Significant at the 0.05 level

This shows that the longer the time between onset of illness and contact with services, the greater the odds of there being no help-seeker involved in the pathway. Likewise, perceived threat is independently associated with increased odds of having no help-seeker. When controlling for perceived risk to others and duration of untreated psychosis, the effect of ethnicity is weakened. A further cautionary note is necessary at this point. To consider the presence or absence of a help-seeker as a fixed variable that holds constant throughout the
help-seeking process is undoubtedly misleading. The data here refers to whether there was a help-seeker, be it the patient themselves or others within the patient’s lay referral network, involved at any point in initiating contact with professional services. That is, a positive rating of help-seeker present is only made if the person seeking or facilitating the seeking of help successfully achieves consultation for the patient. It misses those instances where others within the patient’s lay referral network may have attempted to seek help with or on behalf of the patient and failed. Indeed, it may well be that it is the failed help-seeking that delays contact with services, rather than the absence of a help-seeker. Similarly, the direction of the relationship between absence of a help-seeker and perception of risk to others is unclear from this analysis, and indeed this observed correlation is difficult to interpret. This is common to all variables observed to be associated with perception of risk, because it is not possible to know whether perception of risk is based on actual risk or on stereotyping, and it is likely that this variable includes both. These difficulties replicate those that have been faced by previous research and serve to re-emphasise the need for broader, in depth approaches to supplement this data. That said, this data is important in raising questions for such broader research.

Given the observed association between duration of untreated psychosis and absence of a help-seeker it is perhaps surprising that a long duration of untreated psychosis was not associated with the other outcomes considered – compulsory admission, GP referral and criminal justice system referral. Consideration of the factors associated with a long duration of untreated psychosis is nonetheless useful.

7.3.4 Duration of untreated psychosis

At each stage of funnelling back to consider predictors of outcomes at earlier points on the pathway to care, the possibility of observing correlations that are due to chance increases as the number of statistical tests applied grows. There is a danger of stretching the data beyond what it is capable of. Each step then should be treated with increasing caution and the findings as more speculative, a caveat already apparent in relation to the analysis of factors associated with not having a help-seeker. With this in mind, this final aspect of the analysis of data from the first stage has been restricted to straightforward tests of association between duration of untreated psychosis and sociodemographic and clinical data. This is intended to be exploratory and indicative of the types of factors that may be important in predicting a longer duration of untreated psychosis. Table 7.13 reports findings from chi-square tests of association.
Table 7.13. Duration of untreated psychosis by sociodemographic and clinical variables.

<table>
<thead>
<tr>
<th></th>
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2 Missing values - 5  
3 Missing values - 11  
4 Missing values - 16  
5 Missing values - 2  
6 Missing values - 14  
7 Missing values - 3  
8 Missing values - 14

149
This shows a number of sociodemographic variables to be associated with duration of untreated psychosis. Age aside, these variables are all indicators of social isolation – unemployment, non-supportive social networks, no close confidants, and irregular contacts with others. Interestingly, there is also an association, bordering significance, between a diagnosis of schizophrenia and a long duration of untreated psychosis.

7.3.5 Negative and positive pathways to care

On the basis of the above analysis it is possible to identify two extreme types of pathway, one, a positive pathway, that at each stage increases the odds that contact with services will be voluntary and the other, a negative pathway, that at each stage increases the odds that contact with services will be compulsory. These two routes to care, and the key points on the pathway, are illustrated in Figure 7.4.

Figure 7.4. Types of pathways to care.

A. Negative pathway

B. Positive pathway

In this sample, 57 (46.3%) took one of these two pathways to care, a finding that emphasises the diversity of pathways that people can take to care, as over 50% of patients took alternative routes. It is interesting, in concluding the analysis, to compare these pathways by ethnicity. Of the forty-three patients who came into contact with services via the positive pathway to care, 28 (68.3%) were White and 13 (31.7%) were African-Caribbean, a significant difference ($\chi^2 = 9.37, \text{df} 1, p < 0.01$). Of the sixteen patients who came into contact with services via the negative route, 4 (25%) were White and 12 (75%) were African-Caribbean, again a significant difference ($\chi^2 = 4.16, \text{df} 1, p = 0.04$).

7.4 DISCUSSION

This study is based on two premises about how people come to use mental health services:
• Mode of contact with psychiatric services is the outcome of a social process involving a series of decisions made in the context of the sufferer's social network and the wider health care system

• Culturally shaped beliefs about mental illness are central to the whole process, influencing decisions made at each stage on the pathway to care

The analysis of data from the first stage of the project has been conducted in such a way as to attempt to capture, within the limits of the data, some of the decision points that might be important on the route to psychiatric care. This marks a change of perspective and analysis from previous research rather than a change in the type of data used. The data, in fact, is not dissimilar to previous research, particularly that of Burnett et al (1999), Cole et al (1995) and Harrison et al (1989). There is a limit to how far this type of data can be stretched – the more it is stretched the more cautious interpretations and conclusions have to be. That said, within these limitations, the data and analysis do offer potential insights into the factors that are generating differences in pathways to care and, from this, provoke questions that can be explored using more in-depth methodologies. Therefore, as much as this analysis has attempted to study pathways as a process, it is most usefully considered as a starting point, as offering clues about the factors that shape pathways to care at each point.

7.4.1 Sociodemographic characteristics, clinical presentation and pathways to care

Differences between the two groups of patients were observed in all three areas of interest: sociodemographic characteristics, clinical presentation and pathways to care. In relation to sociodemographic characteristics, two key differences were apparent. African-Caribbeans were less likely to be educated beyond school level and more likely to be socially isolated, as measured by amount of contact with others and whether patients had close confidants and/or supportive social networks. These differences are in expected areas, given previous research, though on this basis stronger differences might have been expected in rates of employment (Mallett et al, 2002). African-Caribbeans were more likely to be unemployed, but this did not reach significance.

Data relating to clinical presentation also produced expected and unexpected findings. Higher levels of perceived risk to others among the African-Caribbean groups is in line with some previous research (Pipe et al, 1991; Dunn & Fahy, 1990). As already noted, a rating of perceived risk to others was made on the basis of how others construed the patient's behaviour. This does not overcome the problem that has been a feature of previous research, namely the difficulty in knowing whether higher rates of perceived risk to others are a function of higher levels of violence and threatening behaviour or of a tendency among White
professionals to stereotype black people, particularly young men, as threatening and dangerous. This is an important distinction. The former possibility is suggestive of differences in clinical presentation that merit the use of compulsory powers while the latter hints at the inappropriate use of compulsion based on racist stereotyping. This question certainly merits more direct investigation. For this study, both possibilities remain. The measure of insight used in this stage of the study is no less crude than that used in previous research in simply distinguishing between those who denied they were mentally ill and those who acknowledged this. In this instance there were no differences between the two groups. One interesting finding that did emerge from the clinical data is that African-Caribbeans were less likely to report having a history of non-psychotic mental illness. This throws up interesting general questions concerning the course of mental illness and the relationship between neurotic and psychotic disorders that are not directly relevant to this study. What is noteworthy in relation to this study is that lower rates of reported non-psychotic mental illness may have two implications: 1) that White patients are more likely to conceptualise distressing experiences in psychological terms, allowing for a diagnosis of mental illness to be made more easily; and, particularly when considered alongside the data showing that Whites were also more likely to have contact with psychiatric services for a non-psychotic mental illness, 2) that Whites are more familiar with psychiatric services and how to access care, thus facilitating early and non-compulsory entry into care in the event of psychosis. Finally, in relation to clinical characteristics, there was no significant difference between the two groups in terms of duration of untreated psychosis when those presenting to services within a year of the onset of illness were compared with those presenting over a year after onset. That said, there were more African-Caribbeans presenting to services later, in particular a small number presented following a very long period of untreated symptoms, sometimes many years.

Perhaps the most striking differences between the two groups were in terms of pathways into, and mode of contact with, psychiatric services. In relation to the three key outcomes considered, African-Caribbeans were less likely to fall into categories indicative of voluntary help-seeking.

7.4.2 Compulsory admission
In contrast to recent first presentation research (Burnett et al, 1999; Cole et al, 1995), this study did find significant differences in rates of compulsory admission between African-Caribbeans and Whites. African-Caribbeans were over three times more likely to be compulsorily admitted than Whites. This is more in keeping with the majority of previous research, and the rates of compulsory admission in the two groups (18.3% Whites v. 44.4% African-Caribbeans) are remarkably similar to those reported in other studies that were conducted in different contexts and diagnostically diverse samples. Singh et al (1997), for
example, in a study of all consecutive hospital admissions, reported rates of compulsory admission of 18.8% among Whites and 43.2% among African-Caribbeans. However, the analysis suggested that ethnic status alone could not explain these differences. When controlling for the source of referral to services, ethnicity ceases to be significant, which suggests the relationship between ethnicity and compulsory admission is mediated by who makes the referral to services. That is, higher rates of compulsory admission among African-Caribbeans are, in part at least, a function of differences in rates of GP and criminal justice system referral. This suggests that outcomes at earlier points on the pathway to care are important in shaping ultimate mode of contact with services.

Of the other sociodemographic variables, only unemployment was associated with compulsory admission, a finding that is surprising in view of recent work showing indicators of social isolation and poor socio-economic status to be significantly associated with adverse pathways to care (Burnett et al., 1999; Cole et al., 1995). Of the variables considered, moreover, unemployment did not emerge as one of independent significance. These findings may in part be due to the crude nature of the variables used. Unemployment, living alone, and so on do not necessarily distinguish those who are and those who are not socially isolated. That said, more direct measures of social isolation and networks, i.e. amount of contact with others and presence of close confidants and/or supportive networks, were also not associated with compulsory admission. The problem in drawing any firm conclusions from this, however, is that there were relatively large numbers of missing variables for these more direct indicators of social isolation, as this data could not readily or reliably be extracted from case notes for those patients not interviewed.

Of the clinical variables considered, perceived risk to others and denial of illness were both associated with compulsory admission, findings that again mirror previous research (Moodley & Perkins, 1991). Mechanic (1968) has throughout emphasised that while entry into care is shaped by a number of social and cultural factors, the nature and quality of the illness will also impact on how and when help is sought. Given that perceived risk to others and unwillingness to enter hospital voluntarily are two of the primary grounds for compulsory admission it is not surprising that these should emerge as a relevant factors. However, as noted before, the role of racial and cultural stereotyping in shaping perceptions of risk remains unclear here, as does the extent to which a crude variable such as denial of illness or not represents lack of insight or differences in explanatory models of illness. Whether it be due to lack of insight or conflicting explanatory models, denial of illness did emerge as one of the key factors independently associated with compulsory admission. This finding is returned to in subsequent chapters.

Of the factors considered in relation to the three areas — sociodemographic characteristics, clinical presentation and pathways to care — it is source of referral that had the
strongest independent effect on the odds of compulsory admission. Criminal justice referral and absence of GP referral significantly increased the odds that admission would be compulsory, after controlling for possible confounders, a finding that is consistent with the results of Burnett et al (1999) and Cole et al (1995). This is not surprising. The fact of having sought help from a GP and accepted referral to mental health services is already an indication of voluntary help-seeking, while the need for police or other criminal justice involvement is strongly suggestive of resistance to any form of intervention. What becomes important then is why it is that some people seek help from a GP and accept referral and others only enter care following the intervention of external agencies, such as the police.

7.4.3 Source of referral

There are clear differences in patterns of referral to psychiatric services between ethnic groups, with African-Caribbeans being referred more frequently via routes that are associated with compulsory admission (see Figure 7.2). These patterns of referral suggest help is sought or intervention occurs more often at times of crisis for African-Caribbean patients, a possibility that has been suggested before (for example, Harrison et al, 1989). Specifically in relation to criminal justice referrals, the logistic regression analyses revealed that ethnicity did not emerge as a key explanatory variable. In other words, the higher rates of criminal justice involvement among African-Caribbean patients were a function of perceived risk to others and absence of a help-seeker. The difficulty of interpreting this finding is again that ethnicity and perceptions of risk may be closely entwined, leading African-Caribbeans to be perceived as more of a risk. The wider context of higher general levels of contact between African-Caribbeans and the police and other criminal justice agencies is also relevant to these findings. Indeed, previous researchers have speculated that excess rates of police involvement in the pathways of African-Caribbeans may arise from a combination of factors that include both higher levels of contact with the police and, partly because of this, the perception many African-Caribbeans have of the police as the emergency service to be called upon at times of crisis, including those involving difficult-to-explain disturbed behaviour. It may further be the case that animosity between the police and the African-Caribbean community creates a pattern of communication that makes conflict more likely in the course of interactions, whether the basis for contact is suspected criminal activity or mental illness. Central to such speculations are presumed perceptions African-Caribbeans have about the nature of mental illness and which agencies should be involved in managing mental illness.

The strongest difference between ethnic groups in terms of referral to services was in rates of GP referral. African-Caribbeans were much less likely to be referred by a GP, a finding that remained significant after controlling for potential confounders. In total, only 22% of African-Caribbeans came into contact with services via a GP. The finding of low
levels of GP involvement in pathways to care among African-Caribbeans in this and other studies raises important questions. Koffman et al (1997) suggested that African-Caribbeans might not identify their GP as a relevant source of help for the types of behavioural and perceptual disturbances characteristic of psychosis. It is possible that these types of disturbance are conceptualised differently by patients and their relatives, such that they are not perceived as signs of illness requiring medical intervention. Indeed, both higher rates of police involvement and lower rates of GP referral may be partly determined by how these experiences are conceptualised and understood and what are perceived to be appropriate responses, an issue that is the subject of the second stage of this study. Focusing on the beliefs and actions of patients and relatives, however, is likely to be only one side of the story. The finding that even those African-Caribbeans who do make contact with GPs are less likely than Whites to be successfully referred raises further important questions about the role of GPs in recognising severe mental illness in this group and in successfully engaging patients as a basis for referral (Bindman et al, 1997). This finding could be a product of either poor GP detection rates or unwillingness to accept referral to psychiatric services, both of which have potentially important implications for service delivery and certainly merit further study.

7.4.4 Help-seeker and duration of untreated psychosis

One of the key points to emerge from the sociological literature on help-seeking is the importance of significant others in determining the route to care (Pescosolido, 1991; Zola, 1973). This study found that both criminal justice referral and GP referral were significantly associated with the presence or absence of a help-seeker, a finding that remained after controlling for potential confounders. If a person seeks help themselves or someone close seeks help for him/her, the odds that referral will be via a GP and contact will consequently be voluntary are significantly increased, whereas the opposite route, via criminal justice agencies to compulsory admission, is more likely without a help-seeker. This hints at the importance of having a network of family or friends who can either reinforce decisions to seek help or can assume a measure of control in seeking help for a patient. However, in considering the factors associated with absence of a help-seeker, again only unemployment, of the indicators of social isolation, was significantly associated with not having a help-seeker, and this effect disappeared after other factors were controlled for. The other factors found to be associated with absence of a help-seeker were: ethnicity, perceived risk to others, denial of illness, and a long duration of untreated psychosis. After controlling for other variables, ethnicity was no longer significant and the only two retaining a significant effect on the odds of not having a help-seeker were perceived risk to others and duration of untreated psychosis. There is, however, a difficulty of teasing out cause and effect here.
The more limited analysis of the duration of untreated psychosis data hints at the possibility that social isolation is a factor in delaying help-seeking. This is particularly important in view of the finding that the key differences between African-Caribbeans and Whites in terms of sociodemographic characteristics were in indicators of social isolation; that is, they showed African-Caribbeans to be more socially isolated. This hints at a complex interplay of factors, including social isolation, that serve to increase the length of time between onset and help-seeking, which in turn increases the risk of outcomes that are associated with compulsory admission, i.e. no help-seeker, no GP contact, and so on.

Harrison et al (1989) and Owens et al (1991) hypothesised that higher rates of compulsory admission among African-Caribbeans could, in part, be a function of how the patient's family and friends responded to the early stages of illness, an explanation that is hinted at in these findings. However, it is not clear from the data and analysis presented in this chapter why some people are able to draw on resources from their social network to facilitate early entry into care and others are not. Indeed, it is at this type of stage where the use of crude variables such as help-seeker present or not fails to capture the dynamic processes at work in the lay referral network in shaping responses to illness. However, while this analysis may not capture the process, it nonetheless confirms the validity of conceptualising pathways as social processes.

7.5 SUMMARY

The data from the first stage of the project, then, emphasise the extent to which help-seeking should be viewed as a process, even if this data cannot fully capture the processes. The key finding is that decisions at one stage significantly impact on subsequent outcomes. The finding that at each stage African-Caribbean ethnicity is associated with outcomes that increase the risk of compulsory admission, and that African-Caribbeans are more likely to follow a wholly negative route to care, suggest that the relationship between ethnicity and compulsory admission is the end product of a series of complex processes taking place within a specific social, cultural and service delivery context. This type of analysis, however, can only go so far, and a fuller understanding of the processes underpinning the observed associations are only possible with more detailed methodologies. This is the broad aim of the second stage of this study in focusing on the potential impact of beliefs about mental illness in shaping the associations observed here. The first step in this is the full exploration of beliefs among the two ethnic groups, which is the subject of the next two chapters.
CHAPTER 8

STAGE TWO (1)
BUILDING BLOCKS
8 STAGE TWO (1) BUILDING BLOCKS

"You can't make an omelette without breaking eggs. And – to extend the aphorism – you can't make an omelette without beating the eggs together. 'Analysis' too involves breaking the data down into bits, and then 'beating' the bits together again."
(Dey, 1993, p. 30)

Three specific questions are considered in this stage of the study:

- Do African-Caribbeans' beliefs about mental illness differ from those of Whites?
- Do beliefs about mental illness differ within the African-Caribbean group according to place of birth and/or age?
- Do the beliefs evident among African-Caribbeans and Whites bear any relationship to the patterns of pathways to, and modes of contact with, mental health services observed in the first stage of the study?

This and the next chapter are concerned with the first two of these questions, that is, with assessing whether, and to what extent, beliefs about mental illness vary between and within the two ethnic groups. This provides the basis from which to consider, in the final chapter, the third question. This chapter describes, firstly, the sample of patients, relatives and community respondents who were included at this stage and, secondly, sets out in detail the approach adopted to analyse the data.

8.1 SUB-SAMPLE CHARACTERISTICS: Patients, Relatives and Community Respondents

8.1.1 Patients

Sixty patients, 30 White and 30 African-Caribbean, completed the Mental Disorder Beliefs Schedule (MDBS) Interview, as intended. This sub-sample comprises 49% of the 123 patients identified during the 18-month research period. However, of the 60 patients included in the sub-sample eight were subsequently excluded. This was because there was evidence that these patients were actively psychotic at the time of interview, such that the beliefs elicited could not be said to be independent of the patient's illness. Every effort was made to interview patients when they were not actively psychotic. However, in these cases, it only became evident during the course of the interview that the patient was still experiencing psychotic symptoms that had a tangible impact on the accounts provided. Of those who
completed interviews but were excluded, three were African-Caribbean (1 male, 2 female) and five were white (4 male, 1 female). The total number of coherent, non-illness related beliefs transcripts, then, is 52 (42.3% of the full sample).

Tables 8.1, 8.2 and 8.3 compare those patients included in this stage with the rest of the cohort included in the first stage by key clinical, sociodemographic, and pathways variables.

Table 8.1. Completion of MDBS by sociodemographic characteristics.

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<tr>
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<td></td>
</tr>
<tr>
<td>Male</td>
<td>22 (42.3)</td>
<td>41 (57.7)</td>
<td>1</td>
<td>2.86</td>
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</tr>
<tr>
<td>Female</td>
<td>30 (57.7)</td>
<td>30 (42.3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-29</td>
<td>25 (48.1)</td>
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<td>0.89</td>
</tr>
<tr>
<td>30-65</td>
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<td></td>
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</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School</td>
<td>28 (56.0)</td>
<td>47 (71.2)</td>
<td>2</td>
<td>3.99</td>
<td>0.14</td>
</tr>
<tr>
<td>Further</td>
<td>8 (16.0)</td>
<td>10 (15.2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Higher</td>
<td>14 (28.0)</td>
<td>9 (13.6)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>34 (65.4)</td>
<td>41 (57.7)</td>
<td>1</td>
<td>0.74</td>
<td>0.39</td>
</tr>
<tr>
<td>Other</td>
<td>18 (34.6)</td>
<td>30 (42.3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Living circumstances</strong></td>
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<td></td>
</tr>
<tr>
<td>Alone</td>
<td>15 (28.8)</td>
<td>28 (39.4)</td>
<td>1</td>
<td>1.48</td>
<td>0.22</td>
</tr>
<tr>
<td>Others</td>
<td>37 (71.2)</td>
<td>43 (60.6)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Relationship status</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Single</td>
<td>36 (69.2)</td>
<td>57 (80.3)</td>
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<td>1.99</td>
<td>0.16</td>
</tr>
<tr>
<td>In a stable relationship</td>
<td>16 (30.8)</td>
<td>14 (19.7)</td>
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<td></td>
</tr>
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<td><strong>Type of accommodation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Owned</td>
<td>14 (26.9)</td>
<td>17 (25.8)</td>
<td>2</td>
<td>4.13</td>
<td>0.13</td>
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<td>Rented</td>
<td>38 (73.1)</td>
<td>44 (66.7)</td>
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<td></td>
</tr>
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<td>0 (0.0)</td>
<td>5 (7.6)</td>
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</tr>
<tr>
<td><strong>Supportive social network</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td>Supportive</td>
<td>31 (62.0)</td>
<td>26 (49.1)</td>
<td>1</td>
<td>1.74</td>
<td>0.19</td>
</tr>
<tr>
<td>Not supportive</td>
<td>19 (38.0)</td>
<td>27 (50.9)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Close confidants</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>32 (64.0)</td>
<td>25 (43.9)</td>
<td>1</td>
<td>4.3</td>
<td>0.04</td>
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<tr>
<td>No</td>
<td>18 (36.0)</td>
<td>32 (56.1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Amount of contact</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weekly</td>
<td>39 (76.5)</td>
<td>46 (43.9)</td>
<td>1</td>
<td>0.02</td>
<td>0.90</td>
</tr>
<tr>
<td>Less than weekly</td>
<td>12 (23.5)</td>
<td>15 (24.6)</td>
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</tr>
</tbody>
</table>

1 8 Missing Values
2 5 Missing Values
3 20 Missing Values
4 16 Missing Values
5 11 Missing Values

159
Table 8.2. *Completion of MDBS by clinical characteristics.*

<table>
<thead>
<tr>
<th>Beliefs Complete (N = 52)</th>
<th>Beliefs Not Complete (N = 71)</th>
<th>df</th>
<th>( \chi^2 )</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Previous history</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16 (31.4)</td>
<td>17 (24.3)</td>
<td>1</td>
<td>0.75</td>
</tr>
<tr>
<td>No</td>
<td>35 (68.6)</td>
<td>53 (75.7)</td>
<td>1</td>
<td>0.01</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>27 (51.9)</td>
<td>37 (52.1)</td>
<td>1</td>
<td>3.98</td>
</tr>
<tr>
<td>Other psychoses</td>
<td>25 (48.1)</td>
<td>34 (47.9)</td>
<td>2</td>
<td>0.25</td>
</tr>
<tr>
<td><strong>Risk to self</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>23 (45.1)</td>
<td>19 (27.5)</td>
<td>1</td>
<td>2.66</td>
</tr>
<tr>
<td>No</td>
<td>28 (54.9)</td>
<td>50 (72.5)</td>
<td>1</td>
<td>0.07</td>
</tr>
<tr>
<td><strong>Risk to others</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>20 (39.2)</td>
<td>24 (34.8)</td>
<td>1</td>
<td>1.01</td>
</tr>
<tr>
<td>No</td>
<td>31 (60.8)</td>
<td>45 (65.2)</td>
<td>1</td>
<td>1.45</td>
</tr>
<tr>
<td><strong>Mode of onset</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acute</td>
<td>25 (49.0)</td>
<td>24 (34.3)</td>
<td>1</td>
<td>0.10</td>
</tr>
<tr>
<td>Insidious</td>
<td>26 (51.0)</td>
<td>46 (65.7)</td>
<td>1</td>
<td>0.07</td>
</tr>
<tr>
<td><strong>Duration of untreated psychosis</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Short DUP</td>
<td>37 (71.2)</td>
<td>49 (69.0)</td>
<td>1</td>
<td>2.33</td>
</tr>
<tr>
<td>Long DUP</td>
<td>15 (28.8)</td>
<td>22 (31.0)</td>
<td>2</td>
<td>1.00</td>
</tr>
<tr>
<td><strong>Problem recognition</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denied</td>
<td>12 (25.0)</td>
<td>23 (37.7)</td>
<td>1</td>
<td>2.00</td>
</tr>
<tr>
<td>Acknowledged</td>
<td>36 (75.0)</td>
<td>38 (62.3)</td>
<td>1</td>
<td>1.00</td>
</tr>
</tbody>
</table>

1 2 Missing Values
2 3 Missing Values
3 14 Missing Values

Table 8.3. *Completion of MDBS by pathways variables.*

<table>
<thead>
<tr>
<th>Beliefs Complete (N = 52)</th>
<th>Beliefs Not Complete (N = 71)</th>
<th>df</th>
<th>( \chi^2 )</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Previous contact with services</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11 (21.6)</td>
<td>10 (14.5)</td>
<td>1</td>
<td>1.01</td>
</tr>
<tr>
<td>No</td>
<td>40 (78.4)</td>
<td>59 (85.5)</td>
<td>1</td>
<td>1.45</td>
</tr>
<tr>
<td><strong>Help-seeker</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self/Family/Friends</td>
<td>44 (84.6)</td>
<td>53 (75.7)</td>
<td>1</td>
<td>4.64</td>
</tr>
<tr>
<td>External person/agency</td>
<td>8 (15.4)</td>
<td>17 (24.3)</td>
<td>4</td>
<td>4.64</td>
</tr>
<tr>
<td><strong>Referral to services</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Via GP</td>
<td>21 (40.4)</td>
<td>23 (32.4)</td>
<td>4</td>
<td>1.00</td>
</tr>
<tr>
<td>Via EC/home visit</td>
<td>14 (26.9)</td>
<td>15 (21.1)</td>
<td>4</td>
<td>2.00</td>
</tr>
<tr>
<td>Via A&amp;E</td>
<td>9 (17.3)</td>
<td>10 (14.1)</td>
<td>4</td>
<td>0.10</td>
</tr>
<tr>
<td><strong>Mode of contact</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community patient</td>
<td>17 (32.7)</td>
<td>22 (31.0)</td>
<td>2</td>
<td>2.66</td>
</tr>
<tr>
<td>Voluntary in-patient</td>
<td>21 (40.4)</td>
<td>24 (33.8)</td>
<td>2</td>
<td>1.00</td>
</tr>
<tr>
<td>Compulsory in-patient</td>
<td>14 (26.9)</td>
<td>25 (35.2)</td>
<td>2</td>
<td>1.00</td>
</tr>
</tbody>
</table>

1 3 Missing Values
2 1 Missing Value
The only statistically significant difference (at the 0.05 level) between the two groups (beliefs complete v. beliefs not complete) in terms of sociodemographic characteristics is that those completing the MDBS were more likely to report having close confidants, an indicator of having more supportive social networks. In relation to clinical presentation, there is one significant difference, namely that those completing the MDBS were more likely to be perceived as a threat to themselves ($\chi^2 = 4.4$, df 1, $p = 0.04$). With regard to pathways to care, there are no significant differences between those included in this second stage and those who are not. All groups, then, are reasonably represented in those completing the MDBS, such that the group is on the whole representative of the full first presentation cohort from which they are drawn. The break down of the sub-group by ethnicity and gender is shown in Table 8.4.

Table 8.4. *Number of cases completing the MDBS by ethnicity and gender.*

<table>
<thead>
<tr>
<th></th>
<th>White</th>
<th></th>
<th>African-Caribbean</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
<td>50</td>
<td>16</td>
<td>66.7</td>
</tr>
<tr>
<td>Male</td>
<td>14</td>
<td>50</td>
<td>8</td>
<td>33.3</td>
</tr>
</tbody>
</table>

All those included at this stage also completed the Culture and Identity Schedule I (CANDID I) (Mallett & Bhugra, 1996), which allows the initial categorisation of patients into one of two crude ethnic categories to be probed. Using this schedule, patients both self-ascribed ethnicity and ascribed ethnicity according to an extensive list of categories, and answered a question relating to whether they identified themselves as British (see Appendix 3). Table 8.5 compares patients' self-ascribed ethnicity to the original categorisation of patients as either White or African-Caribbean.

Table 8.5. *Self-ascribed ethnicity by original ethnic categories.*

<table>
<thead>
<tr>
<th></th>
<th>White</th>
<th></th>
<th>African-Caribbean</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>British</td>
<td>20</td>
<td>71.4</td>
<td>5</td>
<td>20.8</td>
</tr>
<tr>
<td>Black British</td>
<td>-</td>
<td>9</td>
<td>37.5</td>
<td></td>
</tr>
<tr>
<td>African-Caribbean</td>
<td>-</td>
<td>3</td>
<td>12.5</td>
<td></td>
</tr>
<tr>
<td>Jamaican</td>
<td>-</td>
<td>4</td>
<td>16.7</td>
<td></td>
</tr>
<tr>
<td>Barbadian</td>
<td>-</td>
<td>1</td>
<td>4.2</td>
<td></td>
</tr>
<tr>
<td>Guyanese</td>
<td>-</td>
<td>1</td>
<td>4.2</td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>1</td>
<td>3.6</td>
<td>1</td>
<td>4.2</td>
</tr>
<tr>
<td>Irish</td>
<td>1</td>
<td>3.6</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>European</td>
<td>6</td>
<td>21.4</td>
<td>-</td>
<td></td>
</tr>
</tbody>
</table>

This confirms the expectation that the often used crude categories of African-Caribbean and White hide differences in how individuals perceive themselves. Particularly within the
African-Caribbean group there are a number of different ways in which people identify themselves. Interestingly, those born in the Caribbean, in this sample, tend to identify with their place of birth, while those born in the UK to Caribbean parents tend to identify themselves as either British or Black British. The majority of those born in the UK to Caribbean parents, moreover, said that they felt British (12 (66.67%)). In the analysis of beliefs it has been possible, using this data, to probe whether beliefs differ according to self-ascribed ethnicity and/or place of birth within the original crude categories, in particular whether those identifying with the Caribbean have more traditional, distinctly Caribbean beliefs than those born in the UK. Further, the ethnic composition of the White group is clarified, showing a small number to identify themselves as Irish or European.

8.1.2 Relatives

Eighteen relatives were interviewed using the MDBS. This means that beliefs data is available for relatives of 34.6% of the patients (n = 52) included in this stage. Of the eighteen, twelve were White and six were African-Caribbean. The basic sociodemographic characteristics of the relatives are shown by ethnicity in Table 8.6.

<table>
<thead>
<tr>
<th>Table 8.6. Relatives' sociodemographic characteristics by ethnicity.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>16-29</td>
</tr>
<tr>
<td>30 and over</td>
</tr>
<tr>
<td>Education</td>
</tr>
<tr>
<td>School</td>
</tr>
<tr>
<td>Further education</td>
</tr>
<tr>
<td>Higher education</td>
</tr>
<tr>
<td>Relationship status</td>
</tr>
<tr>
<td>In a relationship</td>
</tr>
<tr>
<td>Widowed/divorced</td>
</tr>
<tr>
<td>Single</td>
</tr>
<tr>
<td>Employment</td>
</tr>
<tr>
<td>Unemployed</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Place of birth</td>
</tr>
<tr>
<td>UK</td>
</tr>
<tr>
<td>Caribbean</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

Most of the relatives are female, the majority being patients' mothers. The number of relatives interviewed is small, particularly the African-Caribbean group. Many researchers have in the past encountered difficulties in recruiting relatives and this study was no
exception. Three steps are involved. Firstly, a patient has to have a close relative with whom he/she is in regular contact. Secondly, the patient has to consent to the relative being contacted. Thirdly, the relative has to agree to participate. Each step creates obstacles to recruitment and explains why, in this case, it was only possible to interview relatives of a third of the patients. Nonetheless, the relatives who were interviewed provide a comparison group that enables cross-generational differences and similarities in beliefs to be analysed, albeit with the capacity to generalise reduced, and, along with the group of community respondents, it allows for comparisons between the beliefs of patients and those of non-patients (see below). This is central to determining to what extent the beliefs of patients are similar to those of people within their social networks and the wider community.

8.1.3 Community Respondents

As intended, twenty community respondents (5 White female, 5 White male, 5 African-Caribbean female, 5 African-Caribbean male) were identified (as detailed in Chapter 6) and interviewed using the MDBS. The basic sociodemographic characteristics of the community respondents are shown by ethnicity in Table 8.7.

Table 8.7. Community respondents' sociodemographic characteristics by ethnicity.

<table>
<thead>
<tr>
<th></th>
<th>African-Caribbean (n = 10)</th>
<th>White (n = 10)</th>
<th>Total (n = 20)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-29</td>
<td>3</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>30 and over</td>
<td>7</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>School</td>
<td>8</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Further education</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Higher education</td>
<td>1</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>Relationship status</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>In a relationship</td>
<td>3</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Widowed/divorced</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Single</td>
<td>4</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td><strong>Place of birth</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UK</td>
<td>6</td>
<td>9</td>
<td>15</td>
</tr>
<tr>
<td>Caribbean</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

The purpose of including a group of community respondents is set out in Chapter 6.

In total, 90 MDBS interviews were completed (40 African-Caribbean, 50 White (52 Patients, 18 Relatives and 20 Community Respondents)). The primary focus of the analysis
has been the patient groups and the relative and community respondent groups have been used mainly as comparisons to address the questions noted above relating to differences and similarities of patients' beliefs to those evident in their social networks and wider communities.

8.2 ANALYSIS: Theoretical Assumptions
The theoretical premises underpinning the collection and analysis of the beliefs data are set out in Chapter Five and closely mirror the position established by Smith (1995). Research utilising qualitative interview data has often adopted one of two extreme theoretical positions. Some researchers have made the assumption that in the process of the interview accurate accounts of the phenomena under study, be it of past events or of subjective beliefs about illness, are being elicited. Others have considered the responses to be primarily a function of the interview situation, such that the data cannot be held to represent a reality beyond the immediate context within which it was generated. Just as the apparent ontological and philosophical divisions between qualitative and quantitative research have broken down giving rise to a middle, pragmatic position, so it is possible to adopt a position concerning the epistemological status of this type of interview data that falls between the two extremes:

"... one may consider that what the respondent says does have some significance and 'reality' for them beyond the bound of this particular occasion, ... but it will also be affected by the requirements of this particular interaction" (Smith, 1995, p. 10).

This midway point accepts that the specific context of the interview and the characteristics of the interviewer and respondent will, in part, shape the responses given, but it also assumes that what is said bears some relationship to events or what the person believes outside of that immediate setting. This ties in with the view that such interviews elicit accounts that are shaped by the context within which they are generated, but which also draw on culturally available symbols and beliefs in the wider community. This fits with the subtle realist position outlined in Chapter Five and is the perspective adopted here.

Recently, as the dichotomy between qualitative and quantitative methodologies has been questioned, concern with how the quality of qualitative research might be independently judged has come to the fore. While efforts to develop criteria for assessing how good a piece of qualitative research is have met with resistance, there have nonetheless been a number of attempts at explicating the key features of a good qualitative study. In these a common requirement is that the whole process of the research – data collection, analysis, interpretations, etc. – should be open to independent scrutiny (Blaxter, 1983). For this to be possible, the methodology of the research must be more clearly set out than has been usual in
the past, including accounts of how data has been analysed. In light of this, Chapter 6 set out the study design and methods of data collection and the next section of this chapter sets out the process of analysis of the MDBS interview transcripts.

8.3 BUILDING BLOCKS: Developing the Category Set and Advancing the Analysis

8.3.1 Preliminary Comments

The creation of a set of categories and sub-categories that allow the data to be broken down, classified and compared provides the building blocks of qualitative data analysis, particularly that concerned with the thematic content of interview transcripts, as here (Silverman, 2000). Dey (1993) likens this process to a jigsaw puzzle in the sense that individual bits of data are cut from the interview, categorised and re-assembled to produce a picture or account of the data. Classifying the data according to its characteristics allows comparisons between cases to be made more efficiently, just as the grouping of pieces from a jigsaw into blue, red, edge, and so on provides the most expedient method for completing the puzzle. Using another metaphor, Dey (1993) suggests categorisation can be visualised as a process of funnelling the data into relevant categories for analysis. Using, as an example, the broad categories for grouping beliefs about illness aetiology suggested by Helman (1994) (see Chapter 4), this is illustrated in Figure 8.1.

Figure 8.1. Sorting data into categories (modified from Dey, 1993, p. 43).

Beliefs about the causes of mental illness

Put more simply still, categorising is a process of grouping like with like. Bits of data that seem similar are separated into piles and the bits within each pile can then be compared.

Categories can be developed in advance of or during the analysis. In grounded theory analysis (Glaser & Strauss, 1967; see Chapter 5), where the primary purpose is to develop theory from the data, the imposition of prior categories is resisted. However, as has been
discussed in Chapter Five, there is no a priori reason why qualitative analysis should not begin with theoretical categories that are tested against the data. Researchers, as is the case in this study, may want to explore whether expected themes, suggested by other sources, are evident in elicited accounts. The approach adopted here then is much more circular, as set out in Chapter 5, in that the data provides both a testing ground for prior theories and themes and a source of new themes. For this study, thematic categories were anticipated in the methods used to collect the data, as is usually the case with semi-structured interviews. While the anticipated categories may be conceptually meaningful, they still require empirical confirmation in the data, and consequent refinement and revision. Further, each category requires a set of criteria defining the basis on which a bit of data can be ascribed to a specific category, such that a) it is clear to an independent observer what the category represents, and b) in theory others can apply the category scheme reliably to this and similar data. These thematic categories can be created at a number of levels, depending on the degree of abstraction from the data. As categories become more abstract the analysis inevitably moves further from the data, but what is lost in detail is made up for in increased clarity and comparability.

8.3.2 Process of Analysis

In outline, the analysis of the MDBS transcripts followed the process for analysing the thematic content of semi-structured interviews suggested by Smith (1995). This involves, to start with, the following steps:

- Looking in detail at one, or a small number, of transcripts
- Reading the transcript(s) a number of times, on the basis that each new reading is likely to throw up new insights
- When reading the transcripts, using one side of the margin to note down observations of interest and the other side to document emerging theme titles, i.e. categories
- On a separate sheet, listing the emerging themes and looking for connections between them
- Producing a master list of themes ordered coherently

(Smith, 1995, p. 19-20)

In developing the analysis, the subsequent steps are:

- Producing a category name for each theme

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• Going through the remaining transcripts, looking for instances of themes and ascribing the category
• Where necessary producing new categories for themes that emerge from the remaining transcripts
• Re-arranging the material by category
• Refining the categories by examining each in turn and using the raw material to define more clearly what the theme is
• Producing an index of themes

(Smith, 1995, p. 21-22)

The qualitative data analysis software WinMAX was used to facilitate this analysis, assisting primarily with the mechanics of annotating transcripts, creating and assigning categories, and comparing material by category. WinMAX was chosen because it has the necessary features and uses a windows style format, making it the most user-friendly software available. It is, thus, through the iterative process of classifying, connecting and describing that the MDBS interview transcripts have been analysed. Drawing on Smith's (1995) suggested approach, the overall process of analysis is represented in Figure 8.2.

Figure 8.2. The process of analysing the MDBS transcripts.

Transcribe taped interviews using accepted conventions

Select 5 interview transcripts at random

Read and annotate interview transcripts

Develop initial category list or, if necessary, add to list

Compare beliefs (themes, types, etc) between groups

Explore connections

Select 5 interviews at random

Assign categories to the data

Produce a thematic structure and case description for all

Refine categories and produce a definition for each category

It is now possible to turn to the thematic category set that developed from the initial stage of the analysis.


8.3.3 The Thematic Category Set

The structure of the MDBS provides an incipient categorical system. The framework for the MDBS was drawn from prior research (Mallett et al, 1998) and the expertise of researchers. The interview is separated into five sections: terminology, signs, causes, social distance and treatment (see Box 6.1, Chapter 6, p. 126). These are the five main areas of interest, addressing the questions what terms respondents use to identify someone who has lost control (*), what are the characteristic signs of *, what causes *, how would the respondent deal with someone who is * in certain situations, and how should someone who is * be treated. While this schedule aims to elicit general beliefs about mental illness, the structure of the interview loosely follows the series of questions suggested by Kleinman (1980) to elicit specific beliefs about illness episodes, Explanatory Models (EM) (see Chapter 4, p. 76). The section on causes, in addition to an open question of what causes *, has a series of probes designed to elicit beliefs about causes in seven areas: congenital/hereditary; physical features; ingestion of food, drinks, drugs, etc.; magico-religious; activities of individuals themselves; psychosocial factors; and environmental/economic factors (see Appendix 3). While these probe areas suggest initial thematic categories for the analysis of beliefs about causes, they have undergone significant modifications during the course of the analysis, such that the subcategories of causes bear only a vague resemblance to these probe areas. Further, in developing the initial frame for analysing beliefs about mental illness, existing research and theoretical work was particularly relevant in developing higher order categories, that is categories at a more abstract level (see Chapter 4 and see below). Applying previous frameworks for organising lay beliefs about illness to new data is potentially useful in two respects. Firstly, it allows the validity of previous frameworks to be assessed in relation to the new data. Secondly, it increases the potential comparability of this study with previous work, thereby adding to its cross-cultural relevance.

Beginning with this prior research and the framework of the MDBS, the category set was developed and refined through the iterative process detailed in Figure 8.2. Transcripts were read and re-read, annotated, and initial categories were developed and/or modified and assigned to the data. Categories were developed, with tight definitions, according to the five areas of interest, i.e. terms, signs, causes, social distance and treatment. The category names and definitions are listed in Appendix 3 and the formal relationships between categories are shown graphically in Figure 8.3a (signs), Figure 8.3b (causes), Figure 8.3c (social distance), and Figure 8.3d (treatment). At this point, it is useful to make some brief comments about the development of the thematic categories in each of the key areas of interest.
**Terminology and Signs**

The general approach adopted was to first develop categories that remained close to the data, which were then grouped into overarching categories at a higher level of abstraction and removal from the data. An example from the development of thematic categories for believed signs of *severe mental illness* will illustrate this. The response below is to a general question about what the characteristic signs are of someone who, in this respondent's terms, is "unstable":

1351: Line 72-76 (Patient, African-Caribbean, Male)

Sometimes slow speech, eyes look a bit gaunt, appearance maybe not looking after themselves very well, fidgeting, shaking and unable to keep still, I think you'll find that if someone's walking up and down they're worried or something, or unstable or something and pacing up and down.

A number of signs are identified here: slow speech, gaunt eyes, appearance, agitation, worry. Each of these signs was classified in a category that remained very close to what was said, i.e. "speech", "eyes/face", "agitated" and "worried". Such first order categories allow the breadth of signs identified to be captured. In terms of making comparisons and distinguishing identified signs by type, second and higher order categories are necessary. In this case, higher order categories were created that classified identified signs according to their focus, i.e. whether on behaviour, appearance, emotional state, and so on. Conceptually, these are important distinctions. It clarifies whether respondents perceive severe mental illness in terms of, for example, behavioural or emotional disturbance. As previously noted, there are some indications from the cross-cultural literature that western societies foster a more psychological concept of mental illness, which focuses on internal emotions, in contrast to that typical of non-industrial societies where severe mental illness is viewed more as behavioural disturbance, often with moral overtones. So, continuing this example, "worried" forms a sub-category of a broader category "emotional state", and "agitated" is a sub-category of "visibly disturbed", which in turn is part of the more general category still, "behaviour" (see Appendix 3 and Figure 8.3a).

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1 As respondents are asked to provide their own terms, in discussing the data it is necessary to use a generic term that summarises what respondents' beliefs are about. For this, "severe mental illness" has been chosen (see Chapter 9).
Questions and probes relating to beliefs about the causes of mental illness are the most numerous in the MDBS and beliefs about causes generated the most diverse range of themes. Again, there are different levels of thematic category. The three overarching categories of "individual", "social" and "supernatural" have been derived from Helman's (1994) schema, though with important modifications. To begin with, no one believed that severe mental illness could be caused by factors emanating from the natural world, according to Helman's (1994) definition, hence the use of three rather than four primary categories. The types of factors subsumed under these three categories, moreover, do not exactly map onto Helman's (1994) definitions of the types of factors that each represents. There are two main reasons for this. Firstly, it is not clear from Helman's (1994) definitions where causal factors related to socio-economic conditions and an individual's place in the social structure should be placed. On the face of it they fall naturally within the "social" category, but Helman's (1994) definition of this focuses much more on social interactions. For the purposes of this study the "social" category is extended to explicitly include impersonal socio-economic, socio-structural and situational factors. Secondly, beliefs relating to obeah (see Chapter 4), under Helman's (1994) formulation, would be located in the "social" category, as obeah is usually invoked in interpersonal disputes. However, to include these beliefs in the "social" category would group together widely different beliefs about the origins of severe mental illness that imply very different treatment responses. In any case, it is questionable whether beliefs that invoke the workings of supernatural entities, whether they be used in interpersonal disputes or not, should be grouped with those locating illness within the social world. While obeah is invoked in interpersonal disputes, the locus of causation rests in the supernatural realm, and for this reason beliefs relating to obeah have been grouped under the "supernatural" category.

This of course necessitates a final modification to the schema developed by Helman (1994), namely a broader definition of the "supernatural" category to include any beliefs in which supernatural or spiritual causes are invoked, whether these relate to the direct activities of spirits, demons, and the like, or to the invoking of supernatural forces, through ritual and the like, in the course of interpersonal disputes.

It has also been necessary to introduce a middle level between these more abstract categories and the first level categories that closely reflect the data. This is to allow for a more fine-grained analysis than is possible using the most abstract categories, but which at the same time groups causes into categories that are potentially more instructive in comparisons between respondents than the first order categories. These middle categories represent important thematic distinctions, both conceptually and empirically. For example, causes locating the source of illness in the individual may or may not focus the blame on the individual, depending on whether the cause is believed to arise from biological processes over
which the individual has no control or from intentional behaviour. Differences here may underpin beliefs about appropriate treatment and may shape responses to mental illness. Similarly, grouping structural-situational explanations into the broad "social" category means that these sit alongside causes that are believed to arise from interpersonal interactions, causes that are often referred to as psychosocial. Again, whether illness is believed to arise from interpersonal and intrapersonal processes or from external socio-economic and situational factors may affect what treatments and responses are believed to be appropriate, hence the distinction between psychosocial and structural-situational factors within the broad social category. For clarity, "social" causes were also distinguished according to whether they represent "chronic difficulties" or "life events", though respondents did not make these distinctions themselves.

Social Distance
Classifying responses to questions about attitudes towards people with a severe mental illness has been simpler, with first order categories grouped by whether they represent negative or positive attitudes (full criteria for all categories are set out in Appendix 3).

Treatment
Thematic categories relating to beliefs about appropriate treatments were grouped, for clarity, according to what, when, by whom and where treatment should be given (see Figure 8.3d). It has, however, proved useful to present and discuss data relating to beliefs about treatment, following Kleinman (1980), by the sector in which the proposed response is located, i.e. whether popular, folk/traditional or professional (see Chapter 9).

8.3.4 Developing the Analysis: substantive connections, thematic structures and typologies
Once data has been sorted into thematic categories according to a set of criteria, the data can be looked at afresh according to the categories developed during the initial stages of the analysis: "this shift in focus has been described as 'recontextualisation' of the data ... as it can now be viewed in the context of our own categories rather than in its original context" (Dey, 1993, p. 129). Again, computer software makes this fairly easy through the use of retrieve options that allow data to be scrutinised by category. At the same time, the software provides a link between categorised data and the original text, so that assigned data bits can

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2 The distinction between life events and chronic difficulties has been made in the academic literature assessing the impact of such problems on various mental health problems (Brown & Harris, 1978).

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always be seen in context, thus reducing some of the fragmentation that inevitably occurs during the process of categorisation.

Dey (1993) draws a distinction between the formal connections linking categories on the basis of similarities and differences and the substantive connections that can be observed between categories that may or may not be similar, but which are suggestive of causal association, interaction and the like. To take an example from Dey (1993):

"... in formal terms we can distinguish 'dentists' and 'patients' as two distinct categories based on differences between these social roles. However, there is also a substantive connection between these two roles ... Dentists have skills and patients need treatment. Indeed, one cannot be a dentist without a patient, nor a patient without a dentist. To understand these social roles we have to recognise the substantive relationship that exists between them.” (p. 152)

It is through the identifying of substantive connections, by observing associations both between categories and cases, that research questions can be addressed. Exploring substantive connections in the data is possible in two main ways: one, examining associations between categories; and, two, examining associations between categories and cases. Each of these inevitably requires enumeration in one form or another, an implication often resisted by qualitative researchers. Enumeration allows patterns in the data to be clarified and thus is crucial and unavoidable in analysing the MDBS interview transcripts. Of course, this is not sufficient in itself. Returning to the original data in order to interpret the meaning of any patterns observed forms the next essential step in the analysis. Enumerating is an aid to analysis rather than an end point and although important in helping to establish substantive connections, returning to the data allows the meaning and validity of associations to be explored.

Further, it is by identifying themes within individual interviews and making connections that it becomes possible to describe the data. One approach to describing beliefs or “subjective theories of illness” is through mapping the thematic structure of each interview (Flick, 1998). Such descriptive outlines of individual beliefs serve a number of functions. Firstly, they provide overall representations of how individuals’ beliefs fit together, as illustrated in Figure 8.4.
Figure 8.4. Thematic structure of beliefs – 1333.

Terms
1. Mad

Signs
1. Change of character, behaviour, etc.
2. Agitation, etc born of frustrations.
3. Eyes
4. Appearance
5. Withdrawn
6. Ranting
7. Erratic
8. Odd

Causes
1. Stress
   a. Caring for children, especially if there are other pressure, e.g. lone parent, lack of money, etc
   b. Lack of money
   c. Unemployment
   d. Disadvantages, e.g. institutional disadvantage
   e. Racism
   f. Ethnic minorities more prone, ‘cos subject to more pressures, inc. racism
2. Early childhood experiences
3. Thinking too much
4. Envy
5. Failure to succeed
6. Parental pressure
7. Studying too hard
8. Relationship problems
9. Too much religion
10. Loss of faith, and associated guilt
11. Protected by resources

Treatment
1. Where
   a. Hospital, in a crisis
   b. Community, otherwise
2. What
   a. Respect
   b. Support
   c. Medication
   d. Prayer
   e. Talking
3. Who
   a. First: GP
   b. Second: specialist
   c. Family
   d. Friends
   e. Church
   f. Pastor

"I think it’s more to do with the person’s character, their disposition, how they cope with changes and with stress, how they cope with relationships really.”

Secondly, they form the basis for identifying typologies, a strategy common in qualitative research (Mumby & Clare, 1997), as they enable similarities and differences between individual beliefs frameworks to be explored and, as with the development of categories for individual themes, beliefs frameworks sharing similar characteristics can be grouped, producing a small number of beliefs types.
8.3.5 Summary

Breaking the data down using thematic categories has provided the basis for comparisons of beliefs about mental illness between the groups of interest in this study. It allows for the data to be explored fully for connections, similarities, differences, and so on, and for a detailed description of the data, particularly in the form of descriptions of the thematic structure and content of individual beliefs (thereby following the process represented in Figure 8.2. (see above)). Specifically in relation to this study, breaking down (categorising) and describing (mapping thematic structures) the data in this form opens up a number of analytic possibilities that have been utilised in addressing the study research questions. It allows for:

1. Comparisons of thematic content between respondent interviews
2. Identification, from comparisons of themes and thematic structures, of beliefs typologies
3. Comparison of beliefs typologies between respondents

These analytic strategies have been used to move the analysis forward and address the three research questions posed in this stage of the study. The findings from this analysis are set out and discussed in the remaining chapters.
Figure 8.3a. Formal relationships between categories for signs.

- Behaviour
  - Introverted
  - Visibly disturbed
  - Unpredictable
    - Aggressive / violent
    - Agitated
    - Body language
    - Disturbed public behaviour
    - Loud
    - Odd / bizarre
    - Unpredictable
    - Bad / wrong

- Appearance

- Eyes / face

- Speech

- Emotional state
  - Angry
  - Anxious
  - Bereft
  - Confused
  - Frightened
  - Frustrated
  - Mood changes
  - Over sensitive
  - Sad
  - Tense
  - Tired
  - Worried

- Outside norms
- Loss of control / sense
- Psychiatric symptoms

---

Depends on ...
Figure 8.3b. Formal relationships between categories for causes.

- **INDIVIDUAL**
  - Biological
    - Brain injury
    - Brain dysfunction
  - Substance abuse
    - Genetic
    - Constitutional weakness
    - Drug
  - Chronic difficulties
    - Childhood learning failure
    - Interpersonal problems
    - Jealousy / envy
    - Loss of faith
    - Not having a friend
    - Parental pressure
    - Religion
    - Self-esteem
    - Social pressure
    - Striving to outdo others
    - Studying too hard
    - Thinking too much
    - Guilt
  - Life events
    - Bereavement / loss
    - Relationship break up
  - Stress
    - Group exposure
  - Occupational
    - Abuse / assault
    - Accident
    - Job loss
    - Loss of home
    - Trauma
  - Chronic difficulties
  - Accumulation of difficulties / events

- **SOCIAL**
  - Social network
  - Structural / situational
  - Ghosts / spirits / demons

- **SUPERNATURAL**
  - Obeah

- **DEPENDS ON THE INDIVIDUAL CONTEXT**
Figure 8.3c. Formal relationships between categories for social distance.

- **Negative**
  - Apprehensive
  - Ignore / avoid / not help
  - Antipathy / intolerance

- **Positive**
  - Give / get help
  - Tolerant

- **Stigma**

---

Depends on ...
Figure 8.3d. Formal relationships between categories for treatment.

- **NO CURE**
  - General care / support
  - Medical care
  - Practical care
  - Talking therapy
  - Traditional / alternative care

- **WHAT**
  - Advice
  - Care
  - Change of environment
  - Love
  - Patience
  - Respect
  - Self
  - Support
  - Sympathy

- **WHEN**
  - First, second, third

- **WHERE**
  - Community
  - Drop in centre
  - Hospital

- **WHO**
  - Professional
  - Traditional / alternative
  - Lay

- **Depends on...**
  - Ambulance
  - Doctor - GP, psychiatrist, nurse
  - Counsellor
  - Police
  - Phones
  - Help
  - Psychologist
  - Social worker
  - Support worker
  - Spiritual healer
  - Own doctor
  - Alternative doctor
  - Fellow
  - Shout
  - Monk
  - Close friends
  - Family
  - Friends
  - Self
  - Fellow patients

- **Activities**
  - Living circumstances
  - Problem solving

- **Depends on...**
CHAPTER 9

STAGE TWO (2)
BELIEFS ABOUT MENTAL ILLNESS
This chapter sets out the findings from the analysis of the Mental Disorder Beliefs Schedule (MDBS) interview transcripts, built on the foundations described in the previous chapter. The presentation and discussion of these findings is organised around the structure of the MDBS, covering terminology, signs, causes, social distance and treatment in turn. For each of these, the key themes that emerged from the analysis are presented, focusing firstly on findings across the groups of respondents (patients, relatives and community respondents), and secondly on differences and similarities between patients and relatives and community respondents from both ethnic groups. From this, for each area a small number of belief types have been identified and these are presented at the end of each section. Discussion of these findings has been woven into the presentation of the data, though the conclusion to this chapter will attempt to tease out the salient findings, preparing the way for the final chapter in which are discussed the implications of these findings for help-seeking and their potential relationship with the patterns of service access observed in the first stage.

It is already clear from the large number and diverse range of thematic categories developed during the analysis that respondents' accounts of the nature, causes and appropriate treatments of severe mental illness were varied, and in many cases remarkably full and coherent. It is important to note, however, that the level of depth and coherence of elicited accounts was mixed, and the findings from previous research that lay respondents often express parallel, contradictory ideas about the nature and origins of illness, with no sense of inconsistency, held firm among at least a proportion of this sample (Fitzpatrick, 1984; Pill & Stott, 1982). Some respondents provided very little elaboration in response to questions and indeed struggled to formulate responses. Such interviews inevitably result in accounts that are fragmented, and it is in these types of interview that contradictions and illogicalities are most evident. The data takes the form more of a list of expressed possible signs, causes and so on. In others, beliefs are presented by respondents with a high degree of consistency and coherence, such that the ideas elicited start to resemble integrated theories. Indeed, the clarity and sophistication of some accounts is greater than would be expected from the frequent caveat about the coherence of lay beliefs made in much previous work (Pill & Stott, 1982). In such accounts, the relationships between specific beliefs are clearly set out and preferred treatment responses follow logically from formulations of the nature and causes of severe mental illness. Not surprisingly, the majority of interviews elicited accounts that fell between these extremes. This variability has implications for interpreting and comparing beliefs, and should serve to temper any conclusions drawn both about the generalisability of findings from this sample and about the relationship between stated beliefs and help-seeking strategies.
A brief note is required about terminology. The MDBS asks respondents to provide their own terms to describe someone who has lost control of their actions or senses, and this is used throughout the interview. In presenting the data, this necessitates use of a generic term for these types of problems, as respondent terms differ. For this severe mental illness has been used. This is not intended to suggest this is the legitimate way of conceptualising these problems: it is simply a necessary short hand.

9.1 “THEY'RE RAMBLING ... THEIR BEHAVIOUR'S BIZARRE”: TERMINOLOGY AND SIGNS

The aim of the first two sections of the MDBS is to elicit the respondents’ conceptualisations of behaviours and experiences that are constructed by psychiatry as psychosis or severe mental illness, focusing on respondents’ preferred terms and signs believed to characterise severe mental illness. Respondents identified a wide range of terms to refer to someone who had lost control of their actions or their senses, and many reported more than one. The range of terms is listed in Appendix 3. By far the most frequently used terms were crazy, mad, and mental illness/disorder. Respondents were asked to choose a preferred term from those they had listed. Table 9.1 lists the preferred terms chosen by ethnicity.

Table 9.1. Terms preferred by ethnicity.

<table>
<thead>
<tr>
<th>Term</th>
<th>White Respondents (n = 50)</th>
<th>African-Caribbean Respondents (n = 40)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Bewildered</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Confused</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Crazy</td>
<td>3</td>
<td>6.0</td>
</tr>
<tr>
<td>Deranged</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Disordered</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Disoriented</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Disturbed</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Lunatic</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Mad</td>
<td>11</td>
<td>22.0</td>
</tr>
<tr>
<td>Mental illness / disorder</td>
<td>24</td>
<td>58.0</td>
</tr>
<tr>
<td>Mentally unstable</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Nervous breakdown</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>No term</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Nuts</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Nutter</td>
<td>2</td>
<td>4.0</td>
</tr>
<tr>
<td>Out of control</td>
<td>3</td>
<td>6.0</td>
</tr>
<tr>
<td>Out of sync</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Pushed too far</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Schizophrenic</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Sick</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Sick in the head</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Unstable</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Unwell in the head</td>
<td>2</td>
<td>4.0</td>
</tr>
</tbody>
</table>
The majority of terms used by respondents were colloquial and have long been
generic terms across cultures for referring to people whose behaviour, beliefs, and so on are
non-understandable (crazy, mad, lunatic, nutter, deranged). Other terms used equate severe
mental illness with a loss of balance, confusion or breakdown (out of sync, unstable, nervous
breakdown, pushed too far, bewildered, disorientated), while some draw on a language of
sickness and illness (unwell in the head, sick in the head, disordered), but without explicitly
using the professional terminology of mental illness. These are distinguishable from those
clearly utilising the language of psychiatry (mental illness, mental disorder, schizophrenic). It
is no surprise that the majority used either common colloquial terms (n = 36 (40.0%)) or
terms derived from psychiatric discourse (n = 31 (34.4%)). It is particularly interesting that
White respondents used psychiatric terms (mental illness or schizophrenia) more frequently
than African-Caribbeans (24 (48.0%) v. 7 (17.5%), $\chi^2$ 9.16, df 1, p < 0.01). This pattern was
common across all respondents – patients, relatives and community respondents - thus adding
weight to the conclusion that African-Caribbeans in general utilise psychiatric discourse less
to make sense of unusual behaviours and experiences, either because of unfamiliarity or
rejection of this framework of understanding. The difference between Whites’ and African-
Caribbeans’ use of the term mental illness is reflected in responses to the question whether the
behaviours and experiences summarised by the respondents’ chosen term constituted an
illness or not, with White respondents being significantly more likely to respond positively to
this question (42 (84%) v. 22 (55%), $\chi^2$ 9.10, df 1, p < 0.01) (see Table 9.2). This further
suggests that African-Caribbeans are more likely to reject an illness framework for making
sense of these experiences. That said, those who responded positively to the question, is it an
illness?, often failed to articulate any clear ideas about what they meant by illness, as is
evident in the following example:

1288: Line 30-43 (Patient, African-Caribbean, Male)

QU
When you say that someone who has lost control of their actions or their senses is
someone who is mental, do you think that being mental is some form of an illness?

RES
Yes.

QU
In what sense?

RES
It is as if you are not completely in charge of your faculties, it's hard to describe really.

A small number of respondents were reluctant to specify a term or were uncomfortable with terms that they did use, a discomfort that was invariably rooted in a perception of psychiatric and other labels as unfairly stigmatising. One respondent expressed this in relation to ethnicity, suggesting that Black people are more likely to be subject to such labelling processes:

1189: Line 66 – 73 (Patient, African-Caribbean, Female)
RES
... so if I saw a black person carrying on in a certain way I wouldn’t automatically say they were crazy I would more say they was vexed and upset. But somebody European would see them as crazy. And as I have grown up to know this myself I would also be calling them crazy, because I am not educated away from that fact, I am more educated to know that if someone is carrying on funny, that is not the norm, then they are crazy, that is the way I have been raised, taught in school. From what I know within myself they are not crazy, they are not mad, they are just vexed.

This response shows an awareness of the impact labels can have. The implication here is that "crazy" is a term with negative connotations, a term that disguises vexation and upset and stigmatises people, particularly Black people; and, in the comments about how Europeans misconstrue Black people's vexation as craziness, there are echoes of the argument that psychiatry pathologises Black people's distress (Fernando, 1991). This reluctance to adopt what are perceived as negative terms is evident again in this example:

1246: Line 22 – 40 (Patient, African-Caribbean, Female)
QU
Would you ever refer to these people as being mad or anything like that?
RES
I think everybody has their eccentricities about them and just because your way is different to somebody else's way I don't think anybody has the right to say they are mad.
QU
Do you think there is such a thing as madness?
I think there is such a thing as people with over-active minds.

Here there is no state of madness, only people whose behaviour is on the extremes of what is considered normal, people who, as the respondent later says, may have been "pushed too far". The terms respondents use, and their attitudes towards commonly used terms, begin to reveal how it is they make sense of unusual behaviour and experiences. In these two examples, there is a reluctance to reify what are viewed as the difficulties and distresses of life into a disorder or illness that can be readily summarised using what are viewed as negative terms. Both the examples are from interviews with African-Caribbean women. It has already been noted that African-Caribbeans were less likely to use psychiatric terms, and these two examples can be seen as reflecting a more general difference that revolves around the issue of whether such experiences are signs of illness and fall legitimately within the clinical ambit of medicine and psychiatry. This can be explored further by considering what respondents believed the key identifying signs were of severe mental illness.

A wide range of signs and characteristics believed to be indicative of severe mental illness were identified by respondents. These fell into eight broad thematic categories: 1) appearance; 2) eyes/face; 3) speech; 4) emotional state; 5) behaviour (introverted, visibly disturbed, unpredictable, bad/wrong); 6) loss of control; 7) outside norms; and 8) psychiatric symptoms. The definitions for each of these categories are given in Appendix 3. Table 9.2 shows the frequency with which respondents identified signs within each of these categories, by whether the response was prompted or unprompted. Overall, the most frequently identified signs were: disturbed speech, behaviour (introverted and visibly disturbed), and signs couched in psychiatric language (hallucinations, delusions, etc.).
Table 9.2. Signs. Number of respondents believing each feature to be a sign of mental illness by ethnicity.

<table>
<thead>
<tr>
<th></th>
<th>White Respondents (n = 50)</th>
<th>African-Caribbean Respondents (n = 40)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unprompted</td>
<td>Prompted</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Appearance</td>
<td>10</td>
<td>20.0</td>
</tr>
<tr>
<td>Eyes / Face, etc</td>
<td>5</td>
<td>10.0</td>
</tr>
<tr>
<td>Speech</td>
<td>18</td>
<td>36.0</td>
</tr>
<tr>
<td>Emotional State</td>
<td>15</td>
<td>30.0</td>
</tr>
<tr>
<td>Behaviour</td>
<td>12</td>
<td>24.0</td>
</tr>
<tr>
<td>introverted</td>
<td>10</td>
<td>20.0</td>
</tr>
<tr>
<td>Violent</td>
<td>21</td>
<td>42.0</td>
</tr>
<tr>
<td>Unpredictable</td>
<td>2</td>
<td>4.0</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>8.0</td>
</tr>
<tr>
<td>Loss of Control</td>
<td>11</td>
<td>22.0</td>
</tr>
<tr>
<td>Outside Norms</td>
<td>15</td>
<td>30.0</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>21</td>
<td>42.0</td>
</tr>
</tbody>
</table>

Yes  No  Yes  No
Illness? 42  84.0  8  16.0  22  55.0  18  45.0

The degree of coherence in conceptualisations of severe mental illness varied. Some patients offered only a restricted number of possible signs of mental illness, often only on prompting, and struggled to formulate a clear picture of severe mental illness. This is evident in the following example:

1281: Line 41 – 60 (Patient, White, Male)

QU
If you are thinking about somebody who is not well in their mind, what do you think would be the telltale signs by which you and your friends could identify someone who is not well?

RES
Probably stressed out, I don’t know.

QU
What about their behaviour, would they be doing things that would allow them to be identified as being not well?

RES
If they were doing strange things yes.
QU
What sort of strange things?

RES
I don’t know.

QU
Do you think that someone who is not well in their mind, do you think they are more likely to be violent than other people?

RES
Maybe I don’t know.

In such interviews, while prompting and probing yielded responses relating to perceived signs of mental illness, these did not form a coherent account of the perceived nature of such phenomena, a finding that mirrors previous research showing many lay people to have poorly formulated notions of health and sickness (Fitzpatrick, 1984; Pill & Stott, 1982). In this study, those patients and relatives who did not fully respond to questions and probings regarding perceived signs of severe mental illness may have been uneasy specifying phenomena that might imply he/she or a relative was mentally ill at a time of coming to terms with a first episode of psychosis. Still, the number of such fragmented and limited accounts was small (n = 9 (10%)) and many other respondents, in contrast, identified a range of signs, in what were multi-faceted formulations of severe mental illness, involving disturbances in a number of spheres.

By far the most common themes, across all groups, were those conceptualising severe mental illness as behavioural disturbance. The types of behavioural disturbance specified fell into two categories: introverted and visibly disturbed. When considered together, only one respondent did not identify a form of behavioural disturbance as a sign of severe mental illness. However, the emphasis given to specific disturbances varied, as did the extent to which such signs were prominent features of respondents’ accounts. In only a small number of instances was introversion believed to be a sign of severe mental illness in the absence of other outwardly visible signs of behavioural disturbance (n = 7 (7.8%)) and respondents rarely introduced this idea themselves. This is in sharp contrast to the more extroverted behaviours that were frequently identified as key signs of severe mental illness, including agitation, odd and bizarre behaviour, and publicly disturbed behaviour, which were often
introduced unprompted by respondents in response to the initial question of what the tell tale signs were of severe mental illness, as illustrated in these two examples:

1351: Line 117 – 125 (Patient, African-Caribbean, Male)
QU
And what other things about schizophrenia, what are the tell tale signs?

RES
Temper, I definitely know that one, again moving up and down a lot, body language, a person's not very calm and maybe constant swearing and also whatever it is that you might be saying to that person they're not actually listening, they're talking about something completely different and that's when you know that person isn't focussing on what's happened.

4018: Line 29 – 35 (Patient, White, Male)
QU
What are the tell tale signs by which you could identify someone who is mental, out of control?

RES
They're rambling, uncontrolled. Their behaviour's bizarre; they dress shabbily. That kind of thing.

This second example focuses entirely on outward signs – behaviour, speech ("rambling") and appearance ("they dress shabbily"), and when both disturbance of speech and unusual appearance are included it becomes clear that overwhelmingly conceptualisations of severe mental illness, across both groups, focus on outward manifestations of disorder. Indeed, a central idea running through many accounts was that severe mental illness could be observed from a distance: it could be identified by unusual and unpredictable behaviour, often occurring in a public place, by appearance, by what is said and its lack of sense, and by "something about" the eyes: "By the stare of their face, their eyes, you can see that the person is really sick" (1329: Line 45 (Patient, African-Caribbean, Female)).

The most common single theme among respondent accounts in which visible disturbance was the defining characteristic was that linking severe mental illness with violence and/or threatening behaviour:

1247: Line 27 – 39 (Patient, White, Male)
QU
What about their behaviour?

RES
Aggressive. In your face, it means no one is going to stop them.

QU
So more likely to be violent?

RES
Yes like me. I was a nutter.

There are numerous examples of unprompted references to violence as a key distinguishing feature of severe mental illness, and such ideas often permeated the interview and were reintroduced in relation to questions about social distance:

1348: Line 816 – 831 (Patient, African-Caribbean, Female)
QU
And what about if someone who was mad came to live next door to you, how would you feel about that?

RES
I’d be scared.

QU
Why?

RES
Let’s say … mad people can harm you, and if they harm you nothing will come out of it. So, I’d just be scared, whereas if I’m with my little three year old daughter, I wouldn’t feel comfortable.

Other respondents were more ambivalent on the question of a link between severe mental illness and violence, as illustrated in the following example, in which the respondent draws a distinction between verbal and violent aggression, being careful to distance mental illness from the latter:
So they are not more likely than anybody else to be aggressive?

RES
No ... they can be aggressive, but not violently aggressive. They can be just closed within themselves, but you start at them, there are just verbally aggressive, not violently aggressive, there's a difference.

Others either rejected any connection or reasoned that violence was dependent on factors other than severe mental illness, thereby rejecting a necessary link between the two. The rejection of a necessary connection between mental illness and violence among patients may well be a product of initial experiences both of mental illness and of contacts with other patients.

As already noted, these themes connecting severe mental illness and violence and visible behavioural disturbance were common across the sample, but within this there were important differences between African-Caribbean and White respondents, particularly in the centrality of such themes to overall conceptualisations of severe mental illness. These differences are evident in at least two respects. Firstly, African-Caribbeans were more likely to identify violence as a key characteristic of severe mental illness and, secondly, African-Caribbeans were less likely to identify non-behavioural signs as indicative of severe mental illness. Taking the link between violence and severe mental illness first, there was a clear difference in the frequency with which violence and/or threatening behaviour was believed to be a core feature of severe mental illness between the two ethnic groups. Close to 50% of respondents believed violence was a core feature of severe mental illness. This belief, however, was much more common among the African-Caribbean groups (28 (70.0%) v. 18 (36.0%), χ² 10.28, df 1, p < 0.01). This difference was also evident in the strength with which the link was made in individual accounts. The following is typical of the ways in which African-Caribbean respondents talked about violence and severe mental illness:

QU
What about if someone like that wanted to marry a member of your family?

RES
Well I wouldn't advise it.
QU
Why would you not advise it?

RES
Well I think it could be a danger for, every disturbed person you have to say there is a streak of violence behind that situation, there's a streak of violence and you never know when it's going to happen.

This is in contrast to the following example which was more typical of White respondents:

2157: Line 49 – 60 (Relative, White, Female)
QU
So say for example do you think they're more likely to be violent?

RES
They can be, not all of them, but they can be.

In short, the linking of violence and mental illness was not only less common among White respondents, it was also more equivocal and less forceful.

Further, while both groups frequently identified behavioural signs as key features of severe mental illness, White respondents were more likely to include other signs falling outside of the behavioural category, such as “emotional state” and “psychiatric symptoms”, in their conceptualisations. References to internal emotional states were relatively uncommon overall (n = 29 (32.2%)), and in no accounts were they central, but they were virtually absent from the accounts of African-Caribbeans, with only six respondents identifying disturbed internal emotions unprompted as a feature of severe mental illness. In describing the signs of severe mental illness a number of respondents utilised the language of psychiatry, referring to delusions, hallucinations, hypomania and the like. The use of this discourse was, again, more common among the White group (23 (46.0%) v. 11 (27.5%), $\chi^2$ 3.24, df 1, p = 0.07) and in a small number of cases permeated the account, as was the case in this example:

1341: Line 24 – 44 (Patient, White, Male)
QU
So if you were picking out a one word term to refer to someone who's suffering in this way what would it be?

RES
I suppose it would be schizophrenia, but that means so many different things doesn't it?

QU
What does it mean to you?

RES
Hearing voices, maybe lose control of my actions, seeing and hearing things that aren't there, believing things that aren't true, imagining things and those things that you imagine are real at that time, and those voices it's almost as if there's someone else there and there's no arguments with it you can't argue that it's there and you're so convinced that it's there that you will write a written statement to say that those voices were true even in your rational state of mind you'd try so hard to say no this isn't happening but you cannot do it because it's so strong and you believe wholeheartedly that those things are happening to you and there's nothing you can do to stop it.

In this example the respondent is no doubt drawing on personal experience, but it is telling that the experiences of voice hearing are readily interpreted as signs of mental illness. Together these findings show that signs derived from psychiatric discourse or focusing on internal emotional states are more common among White respondents, and that White patients more readily accept and incorporate into their understandings the language of psychiatry. However, what this suggests is not that these themes predominate, but rather that the signs identified by Whites were wide ranging and varied, drawing on emotional and behavioural states and utilising both colloquial and psychiatric discourse. From this angle, what distinguishes conceptualisations of severe mental illness among these two groups is not that one is psychiatric and emotional and the other behavioural, but that in the White group there is a wide array of different notions, drawing from popular and professional discourse giving a much more varied set of conceptualisations than in the African-Caribbean group.

This diversity was apparent not just across the group, but in a number of individual accounts in which a range of possible signs, drawing from all spheres – behavioural, emotional, psychiatric, and so on – were posited as indicators of severe mental illness. This was most evident among the small number of respondents who believed severe mental illness could be manifested in a wide variety of ways, often depending on a sufferer's personality and traits prior to the onset of illness. The following segment gives a clear example of this type of conceptualisation:

1280 Line: 38 – 61 (Patient, White, Female)
QU
Do you think that madness is a form of mental illness?

RES
Yes I suppose so. I think it is not just internally it is externally, if people don't have the level of support around them it is important as what is going on in your brain.

QU
Do you think there are any different types of madness?

RES
Yes I think there is an aggressive, and there is more morose, introverted. I am no expert but I would have thought there were very many different types of ways in which madness can manifest itself, whether it be self mutilation or aggression towards others.

QU
So any kind of sorts of behaviour which are not normal, is that what you are saying?

RES
Well, yes anything that doesn't subscribe to the sort of law abiding, accumulating, caring society.

This segment introduces the idea of “madness” as a disorder that can be manifested in any number of different ways, ranging from violence to self-mutilation. This is extended to “anything that doesn't subscribe to the sort of law abiding accumulating, caring society”, which is reminiscent of the idea that social norms define abnormality and as such abnormality is changeable and fluid. Moreover, there are suggestions in what is said further on that the form madness takes depends on what type of person the sufferer was prior to the onset of “madness”. So, madness and violence are not necessarily connected, rather “madness” manifested as violence is a product of someone having "been like that before" (1280: Line 68 (Patient, White, Female)).

This degree of complexity was not evident in most of the elicited accounts, but among White respondents there was a greater diversity of identified signs than among the African-Caribbeans. These patterns were evident across all groups – patients, relatives and community respondents – which points to these being rooted in the wider cultural contexts of each ethnic group. Furthermore, there were no marked differences evident in
conceptualisations between those born in the Caribbean or who identify themselves as African-Caribbean and those who self-ascribed ethnicity as Black British or British, the majority in all being behavioural.

9.1.1 Typologies
The data, thus, revealed a small number of different types of conceptualisations of severe mental illness, as illustrated in Table 9.3.

Table 9.3. Typologies: conceptualisations of severe mental illness.

<table>
<thead>
<tr>
<th>Typology</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behavioural</td>
<td>Outward appearance and disturbance are the key themes, with other themes figthing no more than twice</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>Psychiatric terms and language are the key themes, with other themes figthing no more than twice</td>
</tr>
<tr>
<td>Mixed</td>
<td>A range of themes located in more than one of the categories of signs are evident, with no clear predominance of one over the other</td>
</tr>
<tr>
<td>No clear concept</td>
<td>It is not possible from the responses to identify a clear conceptualisation of severe mental illness</td>
</tr>
</tbody>
</table>

In setting out types of beliefs like this there is the obvious danger of over-formalising accounts and ascribing to them a degree of coherence they lack. These typologies are also remote from the data and represent complex ideas expressed by respondents. They do, however, allow for such ideas to be summarised and compared, allowing patterns to be observed. Table 9.4 compares beliefs organised according to these typologies by ethnicity.

Table 9.4. Types of conceptualisations of severe mental illness by ethnicity.

<table>
<thead>
<tr>
<th>Typology</th>
<th>White Respondents (n = 50)</th>
<th>African-Caribbean Respondents (n = 40)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Behavioural</td>
<td>16</td>
<td>32.0</td>
</tr>
<tr>
<td>Psychiatric</td>
<td>5</td>
<td>10.0</td>
</tr>
<tr>
<td>Mixed</td>
<td>25</td>
<td>50.0</td>
</tr>
<tr>
<td>No clear concept</td>
<td>4</td>
<td>8.0</td>
</tr>
</tbody>
</table>

This supports the conclusion that there are broad differences between African-Caribbeans and Whites in the cultural references that are recruited to account for the nature of severe mental illness, differences that hold for patients, relatives and community respondents, and which cut across generations and place of birth. Indeed, when all respondents are considered together,
significantly more African-Caribbeans hold primarily behavioural conceptualisations compared to Whites (25 (62.5%) v. 16 (32.0%), $\chi^2$ 8.34, df 1, $p < 0.01$).

9.2 “YOU BLOW A FUSE, DON’T YOU?”: CAUSES

The aim of the third section of the MDBS is to elicit accounts of the causes of severe mental illness, as conceptualised by respondents. As already noted, this is the most extensive section of the MDBS and it generated the most themes. Broadly, all respondents in the study located the origins of severe mental illness in one or more of three spheres: the individual, the social world, and the supernatural world. Beliefs relating to each of these spheres will be considered in turn, beginning with beliefs locating the causes of mental illness in the social world.

9.2.1 “Well, I just think pressure, stress”: Social Causes

Themes subsumed under the social category were by far the most common (see Figure 8.3b and Appendix 3 for definitions of the themes subsumed under this broad category) and merit detailed consideration. This section firstly sets out a brief overview of the range of social factors identified as a prelude to focusing on: 1) the relative emphasis respondents placed on psychosocial and structural-situational factors and 2) the perceived nature and role of stress.

Themes locating the causes of severe mental illness in the social world were virtually ubiquitous in respondents’ accounts. In all but one interview (1341) social factors were identified as possible causes of severe mental illness, and in only two others (1316, 1354) were social factors not prominent either as primary causes or as significant causes among others. Table 9.5 shows the frequency with which individual social factors were identified as a potential cause by ethnic group, according to whether the positive response was unprompted or prompted by the interviewer. This affirms the prominence and breadth of social factors identified in accounts of the causes of severe mental illness.

A number of key themes were evident, the most salient being: financial difficulties, living circumstances, bereavement/loss, childhood learning and/or experiences, and absence of social networks. What is noticeable about each of these is the frequency with which they were introduced by respondents unprompted, particularly financial difficulties. Indeed, the belief that severe mental illness could be caused, at least partly, by a lack of financial resources was perhaps the single most prominent theme throughout the interviews. This is particularly interesting among a sample drawn from two of the most deprived local boroughs in the UK, in which a lack of material resources is a daily reality for a majority of local inhabitants, the most tangible form of this being lack of money. This links back to the research of both Blaxter (1983) and Pill and Stott (1982) that showed ill health in general, among relatively impoverished working class communities, was frequently believed to arise from sources of unhappiness, particularly those located in the social and environmental
conditions of poverty. A range of other factors broadly relating to socio-economic conditions were also evident – poor living conditions, unemployment, racism and general disadvantage. It was not just themes locating the origins of severe mental illness in structural sources of unhappiness, however, that figured prominently and other themes relating severe mental illness to lack of emotional resources (absence of social network, loss, childhood experiences) and interpersonal problems were common, with many respondents incorporating factors from all of these areas – both psychosocial and structural-situational – into their accounts.

Table 9.5. Social Causes. Number of respondents believing each factor to be a cause by ethnicity.

<table>
<thead>
<tr>
<th></th>
<th>White Respondents (n = 50)</th>
<th>African-Caribbean Respondents (n = 40)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unprompted</td>
<td>Prompted</td>
</tr>
<tr>
<td>Psychosocial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Childhood experiences</td>
<td>18</td>
<td>36.0</td>
</tr>
<tr>
<td>Failure to achieve</td>
<td>6</td>
<td>12.0</td>
</tr>
<tr>
<td>Guilt</td>
<td>4</td>
<td>8.0</td>
</tr>
<tr>
<td>Jealousy / envy</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Loss of faith</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Too much religion</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Self esteem</td>
<td>8</td>
<td>16.0</td>
</tr>
<tr>
<td>Studying</td>
<td>1</td>
<td>2.0</td>
</tr>
<tr>
<td>Thinking too much</td>
<td>7</td>
<td>14.0</td>
</tr>
<tr>
<td>Interpersonal problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>4</td>
<td>8.0</td>
</tr>
<tr>
<td>Friends</td>
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<td>2.0</td>
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<tr>
<td>Neighbours</td>
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<td>0.0</td>
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<tr>
<td>Relationships</td>
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<tr>
<td>At work</td>
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<tr>
<td>No relationship</td>
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<td>Parental pressure</td>
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<tr>
<td>Social pressures</td>
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<td>12.0</td>
</tr>
<tr>
<td>Outdoing others</td>
<td>6</td>
<td>12.0</td>
</tr>
<tr>
<td>Bereavement</td>
<td>16</td>
<td>32.0</td>
</tr>
<tr>
<td>Relationship break-up</td>
<td>10</td>
<td>20.0</td>
</tr>
<tr>
<td>Absence of social network</td>
<td>23</td>
<td>46.0</td>
</tr>
<tr>
<td>Structural-Situational</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caring for children</td>
<td>7</td>
<td>14.0</td>
</tr>
<tr>
<td>Disadvantage</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Financial difficulties</td>
<td>27</td>
<td>54.0</td>
</tr>
<tr>
<td>Living circumstances</td>
<td>9</td>
<td>18.0</td>
</tr>
<tr>
<td>Migration</td>
<td>7</td>
<td>14.0</td>
</tr>
<tr>
<td>Racism</td>
<td>5</td>
<td>10.0</td>
</tr>
<tr>
<td>Society</td>
<td>6</td>
<td>12.0</td>
</tr>
<tr>
<td>Unemployment</td>
<td>9</td>
<td>18.0</td>
</tr>
<tr>
<td>Work problems</td>
<td>8</td>
<td>16.0</td>
</tr>
<tr>
<td>Abuse / assault</td>
<td>9</td>
<td>18.0</td>
</tr>
<tr>
<td>Accident</td>
<td>4</td>
<td>8.0</td>
</tr>
<tr>
<td>Job loss</td>
<td>7</td>
<td>14.0</td>
</tr>
<tr>
<td>Loss of home</td>
<td>4</td>
<td>8.0</td>
</tr>
<tr>
<td>Trauma</td>
<td>5</td>
<td>10.0</td>
</tr>
</tbody>
</table>
In such accounts, severe mental illness was usually believed to be caused, at least in part, by life events and difficulties or stresses in general, with the specific factors being examples. The following is typical:

1241: Line 96 – 101 (Patient, White, Female)
QU
Can you give me examples?
RES
Well like a bereavement, and then you have a horrible job, you have no money, and then you get sacked and things like that. A lot of things probably.

Often respondents who saw the causes of severe mental illness in these terms accepted the possibility that any number of social factors could cause mental illness, the result being that probes asking about the possible causal role of specific social factors, such as failure to achieve or unemployment, frequently elicited positive responses, the interview often following the pattern in this example:

1266: Line 131-141 (Patient, African-Caribbean, Female)
QU
And finances?
RES
Yes, financial pressures are the top key, the main thing.
QU
Unemployment?
RES
Yes, unemployment does cause stress.

The clearest example of a theme given prominence through prompting is parental pressure - the idea that young people can be subjected to excessive pressure from parents to do well. Very few respondents introduced this unprompted (n = 3 (3.3%)), but a majority responded positively to a direct question on this potential causal factor (n = 61 (67.8%)), often strongly. While there is always a danger that interviewer prompts lead the interviewee, in the context of this study the prompts were essential, as the example of parental pressure shows, in
identifying the range of possible factors respondents believed could contribute to the onset of severe mental illness, factors that might otherwise have remained unexplored. Still, in terms of understanding the strength and prominence of factors in respondents' accounts it is important to make the distinction between those that were unprompted and those that were prompted.

Many of the themes incorporated under this broad social category, then, were anticipated in the suggested probes for this section of the MDBS, though these themes were often introduced unprompted by respondents. Importantly, a number of non-anticipated themes emerged from respondents' accounts, these being: bereavement; childhood learning and/or experiences; guilt; social pressures and expectations; absence of social networks; caring for children; abuse/assault; accident; and trauma. Of these, the most prominent were bereavement, childhood learning and/or experiences and absence of social networks (see Appendix 3). That the MDBS was able to elicit themes beyond those anticipated in advance was crucial to a full exploration of patients' and other respondents' beliefs about severe mental illness, with some key themes being revealed as a result. In particular, themes relating to bereavement, loss and social supports proved central in a number of accounts, themes that illustrate the importance attached by many respondents to social relationships in sustaining good mental health and their breakdown – by whatever means – in causing severe mental illness.

These latter themes – of loss and isolation – are particularly interesting from the point of view of ethnic differences. Significantly more White respondents introduced themes relating the absence of supportive social networks to the onset of severe mental illness than did African-Caribbeans (23 (46.0%) v. 9 (22.5%), $\chi^2$ 5.36, df 1, $p = 0.02$) and, while not statistically significant, a higher proportion of Whites also introduced bereavement and loss as themes (16 (32.0%) v. 10 (25%), ns). Beyond this, the only other factor on which the two ethnic groups differed significantly was childhood learning and experiences (18 (36.0%) Whites v. 6 (15.0%) African-Caribbeans, $\chi^2$ 5.01, df 1, $p = 0.03$). Interestingly, the ideas subsumed under this latter thematic category often echoed professional theories, particularly those rooted in psychoanalysis, linking early adversity and later emotional disturbance. Otherwise, the specific social factors identified by respondents were similar across the two ethnic groups. Likewise, there were no substantive differences between patients, relatives and community respondents, findings that point to the ubiquity of social factors as believed causes among this sample and, by extension, among the wider communities from which they are drawn.

These similarities, however, are evident at a fairly broad level, and when accounts are probed more closely important differences emerge. These differences can be teased out by addressing three questions: 1) were there any differences between respondents in the types of
social factors emphasised (i.e. psychosocial or social-structural/situational)?; 2) what was the mechanism by which respondents believed social factors caused severe mental illness, and were there differences between respondents with regard to this?; and 3) was the impact of social factors believed to be independent of other factors? The first two of these questions are addressed in this section and the third is considered in the next section, Individual Causes.

9.2.1.1 Types of social factors

Both psychosocial and structural-situational causes were prominent in elicited accounts across all groups, and in the majority of interviews neither figured more prominently than the other. This is largely due to how social factors were believed to cause severe mental illness. Many respondents conceptualised social factors, i.e. significant life events or chronic difficulties, as stressors, such that each specified event or difficulty was simply an example of a stressor, as noted above, with stress being the primary causal factor. Even when stress was not implicated, respondents often believed social factors caused severe mental illness in combination, through a build up of difficulties and adversity over time, such that, again, the specified factors were only examples of events or difficulties that together could cause severe mental illness. These themes, stress and accumulation of difficulties, are discussed more fully below. What is noteworthy here is that the examples of stressors or adverse social factors given by respondents usually included both psychosocial and structural-situational factors. This can be seen most clearly through the thematic structures developed for each interview, in which the specified beliefs are summarised visually. Figure 9.1 is a typical, straightforward example in which the respondent, while believing social factors to be central, places no particular emphasis on one type of social factor over another.

Figure 9.1. *Thematic structure of beliefs (causes) – 1241.*

<table>
<thead>
<tr>
<th>Causes</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Accumulation of painful events</td>
<td>i. Bereavement</td>
</tr>
<tr>
<td></td>
<td>ii. Relationship break-up</td>
</tr>
<tr>
<td>2. Pressure from the environment</td>
<td>i. Work problems</td>
</tr>
<tr>
<td></td>
<td>ii. Financial pressures</td>
</tr>
<tr>
<td></td>
<td>iii. Failure to achieve</td>
</tr>
<tr>
<td></td>
<td>iv. Stressful occupations</td>
</tr>
<tr>
<td></td>
<td>v. Living circumstances</td>
</tr>
<tr>
<td></td>
<td>vi. Racism</td>
</tr>
<tr>
<td></td>
<td>vii. Loss of faith</td>
</tr>
<tr>
<td>3. Genes – but also the transmission of spiritual themes through families</td>
<td></td>
</tr>
<tr>
<td>4. Soul</td>
<td></td>
</tr>
<tr>
<td>5. Alcohol</td>
<td></td>
</tr>
<tr>
<td>6. Cannabis</td>
<td></td>
</tr>
<tr>
<td>7. Bad karma</td>
<td></td>
</tr>
<tr>
<td>8. Labelling / misdiagnosis</td>
<td></td>
</tr>
</tbody>
</table>
However, while the majority of respondents did not attach greater importance to psychosocial or structural-situational factors, there was a significant minority in which structural-situational factors were clearly more prominent than psychosocial factors. Consider the following example. Firstly, Figure 9.2 shows the thematic structure of 1189’s beliefs about the causes of severe mental illness, with structural-situational factors highlighted in bold:

**Figure 9.2. Thematic structure of beliefs (causes) – 1189.**

**Causes**

1. **The system – Society**
   - a. Rules
   - b. Injustice
   - c. Being labelled

2. **Stress of life**
   - a. Living circumstances
   - b. Neighbours
   - c. Failure to achieve
   - d. Occupation
   - e. Studying too much
   - f. Parental pressure
   - g. Women more prone
   - h. Young more prone

3. **Cultural**
   - a. Misdiagnosis due to cultural differences
   - b. Loss of community
   - c. Community disunity

While there are certainly both psychosocial and structural factors identified, the emphasis is very much on the “system”, that is on the wider societal structures and pressures that constrain people’s lives. Secondly, returning to the interview text, this is evident in what the respondent says about both how society imposes diagnoses of mental illness on people in a structurally weak position and how this position is the source of stress:

1189: Line 38-57 (Patient, African-Caribbean, Female)

QU

What do you think are possible causes of someone going crazy?

RES

The system..

QU

You mean society?
RES
Yes the whole of the make up of society, the rules and regulations, the injustice, the negligence which starts in hospital, there is a long list.

QU
Injustice, what kind of areas, what kind of things do you mean?

RES
For instance being diagnosed or being labelled as a certain schizophrenic or whatever, the label sticks and it categorises people. So there is an injustice going on.

QU
How about even before then, before they are labelled, what do you think actually caused them to have some problems?

RES
Stresses of life.

This dual emphasis on the system as a cause of stress and as a source of injustice persists throughout the interview. It is clear that while this respondent accepts the potential for certain psychosocial factors to cause stress and contribute to the onset of mental illness, the primary emphasis is on the role of wider societal forces. Moreover, it will be recalled that this respondent resisted the use of the term crazy, arguing that such terms are often wrongly applied to Black people who are simply “vexed” (see p. 182).

This emphasis on the system and structural-situational factors in causing severe mental illness was evident in seven other accounts, all of them from African-Caribbean respondents. Financial difficulties, unemployment, living circumstances and racism were among the key factors believed to cause mental illness by these respondents, as in the following example:

1225: Line 164 – 172 (Patient, African-Caribbean, Female)
QU
What else might cause madness?

RES
I think bad social economic conditions, if you are a person who is very intelligent and you can't move forward, it could cause you to get very ill. If you know you are in
such a position like in black America where they have a lot of brilliant people who don't have money and they don't have ways of moving forward, they can become very violent.

The potential for ethnic minorities to experience disproportionate levels of distress and mental illness due to their structural position in the UK was also a prominent theme in the following account:

1333: Line 234 – 246 (Patient, African-Caribbean, Female)

QU
Do you think that, I mean the sort of pressure that you talk about, do you think that people, ethnic minority groups are more likely to face those pressures and are consequently more likely to experience madness?

RES
Yes I do because the ethnic community do not have equal access to the nicer housing, nicer areas to live in, they may be qualified but they’re clustered at the lower rungs of their careers and they don't ordinarily have the money to do what they want to do …

The emphasis in these accounts on socio-economic disadvantage as a source of severe mental illness particularly calls to mind Snow’s (1983) comments about how the beliefs of African-Americans in the American Deep South were rooted in their precarious social position (see Chapter 4). Certainly, the finding that these types of accounts are restricted to African-Caribbeans suggests a conclusion along these lines, namely, that a significant minority of African-Caribbeans explain emotional and psychological distress in terms of wider sources of unhappiness, such as socio-economic disadvantage, poor housing and chronic discrimination. Of course, it has already been noted above that structural-situational factors, particularly financial difficulties and poor living conditions, were prominent themes across all the respondents. What sets this group apart, however, is the degree of emphasis on these factors, an emphasis that is almost political in the focus on injustice and discrimination as potential causes of severe mental illness. Moreover, this sits alongside the finding that White respondents more often invoked factors relating to loss and social isolation, factors which are much more psychosocial in their focus, though in individual accounts these often sat alongside beliefs that structural-situational factors could contribute to the onset of severe mental illness. There are, however, limits to how far the specifically structural-situational belief frameworks evident among this group can be said to reflect beliefs evident in the wider community, as all eight respondents were patients. It could be, for example, that these beliefs
are in part a product of initial interactions with mental health services and a sense of injustice fostered by dissatisfaction with the service provided. The numbers are too small to discern any patterns within this group in terms of place of birth or age or self-ascribed ethnicity: two were born in the Caribbean and identified with their island of birth, Jamaica and Barbados, and five were born in the UK and identified themselves either as Black British or British.

9.2.1.2 Stress: mechanism, concepts and mediators
Stress was linked to severe mental illness in two ways in patients' accounts: 1) as a cause in itself; and 2) as the mechanism by which social factors impacted on the individual to cause severe mental illness. Overall, stress was a pervasive theme throughout the interviews, with only a small number of respondents not believing stress had any role to play in causing severe mental illness. Indeed, of the 87 (96.7%) respondents who believed social factors are central, 78 believed stress plays a role, 18 as one factor of many and 60 as the key mechanism connecting adverse events and difficulties and severe mental illness, with no clear ethnic variations. In accounts not implicating stress, and in those in which stress was viewed as one of a number of social factors, the mechanism whereby external events or interpersonal problems impacted on the individual to cause severe mental illness was unclear. The prominence of stress as a theme is emphasised further by the fact that 52 (57.8%) of the 90 respondents introduced the theme unprompted. The following two examples were typical:

2163: Line 207 – 220 (Relative, White, Female)
QU
So what other sorts of things can happen to people that cause mental illness?

RES
Well I just think pressure, stress.

QU
And what types of pressure and stress?

RES
Well I mean if you take a man who's under a lot of pressure, he's got a family to keep and he's got to work all the hours God sends to provide for that family, that stress can get too much and it can make them go into possibly a nervous breakdown or into a mental illness, that's the way I look at it.

1266: Lines 59-64 (Patient, African-Caribbean, Female)
What do you think are the possible causes of someone becoming mad?

Lots of stress, you know, splitting up with someone, bills not paid, just uncontrollable things happening.

In these examples, as in all others, stress is viewed as arising from negative experiences and ongoing difficulties, that is from the social factors outlined above. The prominence of stress as a theme in beliefs about the causes of mental illness in this study both mirrors previous research (Sheikh & Furnham, 2000; Pollock, 1988) and reflects the pervasiveness of this concept as an explanation for illness and misfortune in modern western societies (Helman, 1994, 1985). While in broad terms the use of stress to account for severe mental illness again marks an important similarity in beliefs about the causes of severe mental illness, what respondents meant by stress, and the metaphors utilised to describe it, varied. These merit further discussion.

Of the 78 who believed stress was a cause, 18 (19.4%) did not articulate a clear concept of stress. In those who did express coherent accounts of what they meant by stress, two distinct models were evident:

1. Stress as increasing pressure (n = 52: African-Caribbean, 20; White, 34)
2. Stress as worry or ‘thinking too much’ (n = 8: African-Caribbean, 6; White, 2)

**Stress as increasing pressure**

The concept of stress as increasing pressure contained three components: 1) adverse social and interpersonal events and difficulties cause stress and pressure; 2) an accumulation of such difficulties, particularly over a short space of time, place an increasing burden on the individual, pushing him/her towards a breaking point; and 3) this breaking point differs between individuals according to certain factors.

Helman’s (1994) comment that lay concepts of stress often contain within them the idea of stress as a “... diffuse and invisible ‘force’, somehow mediating between individuals (and their mental and physical state), and the social environment in which they live and work” (p. 314) captures the essence of how stress was talked about by the majority of respondents, i.e. stress as exerting increasing pressure on the individual through some vague invisible “force”. The variability of concepts and metaphors of stress in lay beliefs about illness has been documented by Helman (1994) (see Chapter 4) and many of these were evident among the accounts provided by respondents in this study. For example, stress, for many patients,
arose from the everyday travails of life, a common metaphor being that of events and difficulties as heavy objects bearing down ("I think everything gets on top of somebody" (1355: Line 295-299, Patient, African-Caribbean, Female)) on people, overloading them:

1153: Line 193 – 199 (Patient, White, Female)
QU
You said before that stress can possibly lead to madness. What kind of stresses do you think?

RES
Stress? Doing too much too soon, too much workload, too much problems, overload - it could happen to anyone, overloading.

A further common metaphor was that of stress as an electrical current and the body or mind as an electrical circuit capable of withstanding only so much electricity (stress) before again becoming overloaded and blowing, a metaphor evident in often heard phrases that the mentally ill have "blown a fuse", and which was most clearly articulated among the respondents in this study in the following example:

1226: Line 230 – 242 (Patient, White, Female)
RES
I am trying to think what really is it that really causes this to happen? I don't know how bizarre this is but I have this idea that because of all the ... like the brain is like all electric and chemicals and stuff, so I just think that if you have a hell of a lot of pressure on an electrical circuit it is going to blow isn't it? And things are just going to go off here and there and it is not going to patch up properly, you blow a fuse don't you, that is what they say isn't it.

Less often respondents talked about stress as arising from interactions with others (Helman's (1994) notion of stress as an interpersonal force (see Chapter 4)), though this metaphor was often mixed with others, as in the following segment:

1218: Line 429 – 435 (Patient, White, Male)
QU
And when you think about stress and pressure, can you say anything about what you mean?
When you are having people with unrealistic expectations upon you, I think in any sort of area, or if they are overloaded with too much to do, etc.

In this example, the notions of stress as an interpersonal force ("when you are having people with unrealistic expectations upon you") and as a build up of pressure ("if they are overloaded with too much to do") are both evident.

The metaphors utilised among the majority of respondents served to characterise stress as a nebulous force, placing increasing demands or pressures on the individual, making it increasingly likely that the individual would be unable to stand the pressure, such that beyond a certain point the individual would "break", "explode", "blow" and so on. This notion of a "breaking point" shares much with academic discourse on stress, which, as indicated in Chapter Four, has documented a range of factors that potentially mediate the impact of stress on individuals, making a pathological reaction more or less likely. These include: individual characteristics; physical environment; available social supports; economic status; and cultural background (Pearlin, 1999). The primary mediating factors identified among the respondents in this study were: 1) the strength of an individual's personality; 2) the ability to cope with stress; and 3) biological or genetic predisposition. The latter of these is discussed in detail in the following section, Individual Causes. In relation to the other two mediators, the following is a particularly articulate example capturing the essence of stress as increasing pressure, in which the metaphors of breakdown and explosion, and differences in personal strength and capacity to cope, are all combined in a lucid account of how stress is believed to cause severe mental illness:

1246: Line 445 – 462 (Patient, African-Caribbean, Female)

I think any kind of person can break down. It is just people have different levels of what they will be able to tolerate. Some people they will get a gas bill and it will be the end of their world, some people will get a gas bill and get their cat knocked over, will experience a death in the family and then they will break down. Some people will go through all the previous things I have mentioned and it will escalate and some people will get a chipped nail and it will depress them, I have seen it happen. It is a personal thing. I can take a lot, I can take a hell of a lot, I have a very high strain level and that is why it will then be the smallest thing that will finally blow and it is usually the simplest thing.
The focus, in some accounts, on ability to cope implies that individual's learn how to cope with, or develop strategies for managing, life stresses with varying degrees of success. Some people cope better than others. These ideas are closely tied in with those in which various factors are identified that can protect people from "breaking" under the pressure of external and interpersonal difficulties. The most common of these protective strategies was that of talking to others. Indeed, from this viewpoint, not talking about problems can be damaging as it ensures the built up pressure remains internalised. Talking, then, was often seen as a safety valve, as a means of relieving the pent up pressure. Within this, there is an element of individual responsibility ("Maybe they've bottled things up" (1345: Line 51-52, Patient, African-Caribbean, Female)), though some respondents focused more on the absence of the "right type of friends to discuss that type of problem" (1220: Line 143, Patient, African-Caribbean, Female). While explanations in terms of stress, particularly stress arising from external social factors, are, on the face of it, primarily explanations that locate the causes of severe mental illness in the external social world, the caveat that the impact of these events is dependent on the person's ability to cope and/or utilise available supportive networks adds a complexity to the beliefs. From this perspective, it is the interaction between individual capacity, supportive resources and environmental adversity that ultimately leads to severe mental illness.

The focus on personality as a mediating factor was much stronger in those cases where personality type, whether weak or strong, was believed to be a key factor determining why some people, when facing similar levels of stress to others, became mentally ill. Such accounts, which imply an inherent characteristic of strength or weakness in people's personalities, were common:

1329: Line 416 – 422 (Patient, African-Caribbean, Female)
RES
Yes I think so because I'm very weak in that sense, and strong physical going out working, but when it come to trouble I'm weak because even my niece used to say "auntie you must be strong" but I'm not that sort of person, I can't go in flare off like some people flare up I take it all in and I keep it there, everything and even my husband said to me don't keep these things in come out with it because I'm hurting myself, meaning if it will come out and I will get help.

1355: Line 359 – 362 (Patient, African-Caribbean, Female)
RES
Maybe, I think it's how you are, if you're a strong person, what you can take on, what you can't take on, or maybe you can take on something for a little while but then after a while it starts getting to you.

These beliefs begin to hint at the notion of increased susceptibility both to stress and mental illness by virtue of inherent characteristics, beliefs that shade into those that conceptualise stress and social factors primarily as triggers provoking severe mental illness in those with genetic or biological predispositions.

**Stress as worry or 'thinking too much'**

A distinct, but less common, conceptualisation of stress was also evident, namely stress as arising from worry or thinking too much. This is a much more straightforward, and individual focused, concept than the one outlined above. The basic idea is that worrying or “thinking too much” about problems causes stress and pressure, from which severe mental illness can result, as illustrated in the following example:

1348: Line (Patient, African-Caribbean, Female)

RES

... or some people ... for instance if something went wrong in their life or their family, if they start thinking too hard, that can drive them crazy as well. So Dr or no one can't help them. Got to get help by them own self, by start concentrating and putting things better.

From this perspective, the individual is at least partly responsible and the onus is consequently on the individual to “start concentrating and putting things better”. The primary causal mechanism resides in the individual who thinks too much. While in this example the respondent suggests that the individual has to find a solution, that he/she “Got to get help by them own self”, later in the interview she accepts that talking to others can help to alleviate the pressure from thinking too much (much in the same way talking was believed by others to relieve built up pressure), but again the emphasis is on the individual's responsibility to seek out others:

1348: Line 644-654 (Patient, African-Caribbean, Female)

RES

It depends, not really. It could be any problem. Could be money problem, could be love life problem, could be deaths in the family, could cause by any problem where you just think by yourself and don’t talk. It's best when you have a problem to
associate with somebody, that will help your nerves more better than keeping it to yourself.

This conceptualisation of stress and pressure has parallels in the Caribbean, where notions of “studiation madness” and pressure as a cause of mental illness sit alongside other beliefs implicating supernatural forces including obeah (Littlewood, 1993, 1988; Laguerre, 1987; Fisher, 1985; see also Chapter 4). Given this, it is particularly noteworthy that, of the eight interviews in which stress and pressure were conceptualised primarily in terms of worry or thinking too much, six were with African-Caribbeans, four of whom were first generation African-Caribbeans who identified ethnically with their island of origin. Not surprisingly, it is in these four accounts that the links with notions of studiation and pressure common in the Caribbean are most apparent and, as will be seen later, two of these respondents (1348 and 1354) further revealed parallel beliefs relating “madness” to obeah and the interjection of spiritual or supernatural forces. Examples from the interviews with these respondents will illustrate the emphasis placed on “thinking” or worry as a primary factor. In this first example, the respondent makes it clear that it is those who worry “about the slightest thing” who are most likely to develop problems:

1354: Line 220 – 232 (Patient, African-Caribbean, Female)
QU
Apart from the possible spiritual aspects that you’ve mentioned, anything else that might cause it?

RES
Worry, if you're worried over something, some people can be worrying about the slightest thing, it can get you emotionally.

This worry is a source of pressure and stress:

1354: Line 399 – 404 (Patient, African-Caribbean, Female)
QU
What sorts of things cause stress?

RES
Worry, some people find that they’re not in a job, you know, or, studying. That could cause stress.
Similar ideas are evident in the other accounts from first generation African-Caribbeans, as illustrated in the following segments:

1288: Line 599 – 616 (Patient, African-Caribbean, Male)
QU
You've mentioned in particular and a lot of what you say seems to come back to it this idea of pressure.

RES
Yes the pressure on yourself.

QU
What do you understand by pressure, what do you mean when you say pressure?

RES
What I mean is worrying about certain things, I mean yes maybe I had been putting too much pressure on myself, like going to bed at night and sometimes not having a good nights sleep for 3 or 4 nights ...

1348: Line 727 – 741 (Patient, African-Caribbean, Female)
QU
What about stress and pressure in life, do you think that can cause madness?

RES
Yes.

QU
How does that work?

RES
When you have stress, stress make you think, you think too hard, and pressure a thing make you think as well, you getting too much pressure, like someone, you doing more than you can manage. It can lead you to madness.

The belief that worrying causes stress and leads to mental illness is not peculiar to the Caribbean, as is clear by the fact that two of the White respondents in the sample believed this to be the case. There is, however, a particular way of constructing this belief in terms of
“thinking too hard on it” or “studiation” that is evident in the Caribbean and in the previous examples. In these examples, moreover, the responses that follow from these ideas, namely that the individual has “got to get help by them own self, by start concentrating and putting things better” further mirrors beliefs about appropriate responses documented in the Caribbean (Littlewood, 1993, 1988; Laguerre, 1987; Fisher, 1985). In the other two interviews with younger, second generation African-Caribbeans it is not so clear that the conceptualisation of stress in terms of worry is derived specifically from beliefs widespread in the Caribbean, though it may well be that such beliefs reflect diluted, residual ideas picked up from older family that have been merged with wider notions about stress.

Consequently, while relatively uncommon, the belief that stress and pressure and, from this madness or severe mental illness, stem from individuals ruminating excessively on problems contrasts with the concept of stress as a build up of pressure due to external factors and interpersonal difficulties. In the former, the origins of stress and pressure reside very much in the individual, whose responsibility it is to resolve the problem, while in the latter stress is viewed much more, though not entirely, as originating in factors external to the individual. The broad model of stress as increasing pressure was the most common across all groups – patients, relatives and community respondents. This model was more singularly evident among White respondents compared to African-Caribbeans (34 (68%) v. 20 (50%), 3, df 1, p = 0.08), a difference accounted for by the small number of older, mainly first generation African-Caribbeans, who conceptualised stress as “thinking too much” and the fact that more African-Caribbeans did not provide a coherent account of what they meant by stress (11 v. 4).

Discussing beliefs about social causes first makes sense because of their ubiquity in respondent accounts. It provides a basis from which other causes, and how they were believed to relate to social factors, can be considered.

### 9.2.2 “It’s nature-nurture, isn’t it?”: Individual Causes

The individual category incorporates two sub-categories: biological and substance use (see Appendix 3 and Figure 8.3b). While these categories are not as wide-ranging as those for social causes, the themes they capture nonetheless form significant components of the beliefs of many respondents in this study. The predominant themes were biological, rather than substance use, and this section focuses primarily on beliefs about biological causes and how these were believed to relate to, and interact with, social factors. Table 9.6 shows the frequency with which each individual factor was identified as a potential single or contributory cause by each ethnic group, according to whether the response was unprompted or prompted by the interviewer.
Table 9.6. Individual Causes. Number of cases believing each factor to be a cause by ethnicity.

<table>
<thead>
<tr>
<th></th>
<th>White Respondents (n = 50)</th>
<th>African-Caribbean Respondents (n = 40)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unprompted n</td>
<td>%</td>
</tr>
<tr>
<td>Biological</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain dysfunction</td>
<td>12</td>
<td>24.0</td>
</tr>
<tr>
<td>Brain / head injury</td>
<td>2</td>
<td>4.0</td>
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<tr>
<td>Genes / hereditary</td>
<td>9</td>
<td>18.0</td>
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<tr>
<td>Constitutional weakness</td>
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<tr>
<td>Substance abuse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drugs</td>
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<td>Alcohol</td>
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</tbody>
</table>

9.2.2.1 Biological Causes

The two main themes that emerged in this area were those that implicated genes or inheritance and those that implicated brain dysfunction in the causation of severe mental illness. Respondents who believed genes or inheritance (n = 49 (54.4%)) and/or brain dysfunction (n = 59 (65.6%)) were potential causes of severe mental illness, in all but one case (1341), envisaged them interacting in some form with social factors or at the very least believed that both biological and social factors could independently cause mental illness. In this, these beliefs very much resemble professional models that posit an interaction between the environment and biology in the aetiology of mental illness (Warner, 2000; see Introduction). Certainly, many were aware of this professional discourse.

There were two main ways in which respondents talked about the interaction between biology and social factors: 1) in terms of nature-nurture; and 2) in terms of social factors triggering mental illness in those who had an underlying genetic or biological predisposition. A number of respondents, for example, talked about severe mental illness as being the product of an interaction between nature and nurture. The following provides an example of this:

1226: Line 185 – 193 (Patient, White, Female)

QU
Moving on to think what might cause this, what do you think might be the possible causes of these types of illnesses?

RES
You have to think about it from scratch. If somebody was born, so they might be born with a certain chemical type, that could cause chemical reactions in their brain under certain circumstances, so there is that chemical, it is nature nurture isn't it.

Where the nature – nurture theme was introduced, respondents invariably used this as a framework through which the potential influence of all factors was assessed, such that the idea of a biology – environment interaction permeated the whole account. Implicit in most of these accounts is the idea that both are necessary to cause severe mental illness. A small number of respondents did, however, believe that the relative contribution of biology and environment could vary between individuals, as in the following example:

4034: Line 159 – 169 (Patient, White, Male)
QU
Does someone always have to have this predisposition, is that kind of necessary for someone becoming mad?

RES
I would say it was a combination of nature and nurture, yes, predisposition, your genetic makeover, your father, your granddad had, the type of irrational behaviour as well as your nature. I do think it's a combination, also in some individual is totally the genetic side, nature will deal, with some it's much more the nurture, but I have a feeling that genetic makeup also has to be the there to some extent.

In this account, while genes alone can be sufficient to cause severe mental illness, for social factors – nurture – to cause severe mental illness there has to be a genetic component. Social factors are only aetiologically significant in the vulnerable. The similarities with stress-diathesis models of mental illness are clear.

Other patients expressed essentially similar ideas in viewing social factors as triggers that sparked some form of brain dysfunction or biochemical imbalance, sometimes in those who were genetically predisposed, as is evident in these two examples:

1289: Line 335 – 348 (Patient, White, Female)
QU
What about if the man or woman leaves their partner for another person, do you think that the shame of that can bring someone down?

RES
Yes I think anything can trigger it off if you're predisposed to it anyway, there are certain things that could trigger it off, it doesn't really matter what, stress of any kind.

1247: Line 219 – 257 (Patient, White, Male)
QU
Is there anything else that might cause it, I mean these are all kinds of stresses?

RES
I don't know. Those are the main things, erm, failure of partnership, losing a job, having a bad accident, anything can cause it, you can kill a child, run over a child or anything, anything can set it off. They reckon that everyone of us has a counter inside, don't they, and if you have a bad bang that will set the counter off. So whatever triggers it you don't know.

QU
So you think there is something waiting ...

RES
There's a trigger, the mechanism is there. It is just waiting to be triggered, init.

In these accounts the presence of some underlying, genetically based, susceptibility explains both how social factors contribute to the onset of severe mental illness and why similar stresses in different people result in different mental health outcomes. What is clear, then, is that overwhelmingly biological causes were posited only in conjunction with social factors. In this model of the aetiology of mental illness, social factors remain important, but how they contribute to mental illness is qualified. They are either relegated to a more subsidiary role of triggering brain dysfunction and from that mental illness, or they operate in conjunction with genetic and biological factors.

In only one of the 90 interviews did a respondent – a patient – believe that the sole cause of severe mental illness was biological. In this, the patient was unequivocal:

1341: Line 141 – 156 (Patient, White, Male)
QU
What do you think might be the possible causes of someone becoming schizophrenic?

RES
I don't think it's got much to do with their upbringing I think it's got more to do with some chemicals that's going on in the brain because you can have a family of five children, each brought up in the same way and only one develops schizophrenia so it's the chemicals inside your brain that have gone wrong I think.

In this instance, the observation that not all people who are apparently exposed to similar forms of social adversity go on to develop mental illness is used to dismiss social factors altogether in favour of an account that implicates brain chemistry alone.

When beliefs relating to biological factors are compared between ethnic groups, perhaps the most striking difference in beliefs about the causes of severe mental illness is evident. Considering crude frequencies, White respondents were much more likely to believe brain dysfunction (40 (80.0%) v. 19 (47.5%), \( \chi^2 10.4, df 1, p < 0.01 \)) and/or genetics (33 (66.0%) v. 16 (40.0%), \( \chi^2 6.1, df 1, p = 0.01 \)) played a role in causing mental illness. This difference is more striking still when it is considered that most of the African-Caribbeans who accepted a possible role for biology did so only on prompting and then without working it into their overall understanding of the aetiology of mental illness. In contrast, White respondents who believed biological factors to be important invariably linked the social and biological into a single model, as in the examples outlined above. This shows that not only were there crude differences between the two groups in the frequency with which the possibility of biological factors causing mental illness was put forward or accepted, for White respondents biological factors were much more central to overall accounts and in many instances were accorded equal weight to social factors, the belief being that both were necessary for severe mental illness to develop. For some, these beliefs arose from education in which they had been exposed to professional theories of mental illness, as in this following example from a respondent who was a trained nurse:

5300: Line 172 – 188 (Community Respondent, White, Female)

RES

Well I have looked, I think with schizophrenia they've actually looked and there is a slight difference in the make up of the brain of people who do suffer from schizophrenia so that is actually saying there could be a difference, they've related it to all sorts of things, they've related it to women getting the flu when they're pregnant I think, they're trying to find a reason especially nowadays it's become so advanced they can actually look into the brain and they are actually trying to find things, I mean it's a nature nurture thing to a degree I mean I'm a believer you might be born with a predisposition towards something but then triggers in your life possibly trigger it off so it's environmental as well.
In the majority, such beliefs were not so clearly derived from professional discourse, and were consequently often more vague (“I think you could be born with it, but I think what happens to you triggers it off” (5115: Line 97, Community Respondent, African-Caribbean, Male)).

Consequently, while African-Caribbeans and Whites, on the face of it, both attributed mental illness to social factors in equal measure, when considered more closely it was clear that this obscured a key difference. African-Caribbeans believed much more in straightforwardly social models of the cause of severe mental illness, while Whites tended to offer accounts that more closely resembled the bio-psycho-social models, in broad outline if not in sophistication, that are common within clinical and academic psychiatry (Warner, 2000; see Introduction). What is more striking still is that these differences were evident across all groups – patients, relatives and community respondents. The one area where it might be expected that patients’ and relatives’ beliefs would differ from those of community respondents is in the perceived role of biological factors. Both exposure to professional theories through contact with mental health services and the lesser degree of individual or familial blame implied by biological theories of severe mental illness have the potential to modify patients’ and relatives’ beliefs, making them more accepting of biological explanations. However, there was no evident difference from community respondents. African-Caribbean patients and families provided similarly non-biological accounts to African-Caribbean community respondents, and White community respondents incorporated biological theories into their accounts in similar proportions to White patients and relatives. This points to the conclusion that the differences observed in this sphere reflect variations rooted in the wider social and cultural communities of these respondents.

9.2.2.2 Substance use

Beliefs relating substance misuse to severe mental illness differed markedly between patients and relatives and community respondents. While the belief that use of alcohol or other drugs could contribute to the onset of severe mental illness was fairly common among the patient groups, this did not form a prominent theme in any of the interviews, and there were no obvious differences between the two ethnic groups of patients in terms of beliefs about the role of substance use in the aetiology of severe mental illness. In contrast, the majority of relatives and community respondents from both ethnic groups believed substance use, in particular drug use, was a potentially key factor in causing severe mental illness.

Using simple frequency counts, 15 (68.2%) White relatives and community respondents and 12 (75%) African-Caribbean relatives and community respondents believed
drug use could cause or contribute to the onset of severe mental illness, with a substantial number introducing the theme unprompted (16 (42.1%)), as in the following segment:

5065: Line 84 – 94 (Community Respondent, White, Male)
QU
What do you think are the possible causes of someone going mad?

RES
Possibly I think substance abuse I think, I don't have any evidence on that at all it just seems to me from what I can gather from the news and some people but some of suicides there's usually drugs involved somewhere along the line and if they're not on them at the time they may have used them long term I think but so strongly I feel that long term substance abuse leads to depression and even though you may not be affected by the drug at the time you may have depression which would cause you not to perhaps not act in the way you might want to.

Once again, looking beyond the simple frequency count it is clear from the interview texts that substance use is more central to some relative and community respondent accounts than any patient accounts. This is important. The belief that substance use leads to severe mental illness also carries with it the implication that the individual is, at least in part, responsible and that the illness stems from bad or immoral behaviour. This is evident in the following example in which the respondent expresses the belief that severe mental illness is more common among young people because “getting in with the wrong sort of people” can lead to use of drugs and, from that, mental illness:

2192: Line 188 – 200 (Relative, White, Female)
RES
Well I don't know I would have thought that young people were more likely to suffer from psychosis than a very old person.

QU
Why would you think that?

RES
Because I think a young person could be vulnerable getting in with the wrong sort of people that affect them in some way, affect the way they think or the use of things like drugs, alcohol and just the kind of experiences that they are likely to have might
be different than an old person who's slowed right down in their life and is spending a lot of time at home.

The linking of substance use and mental illness blurs the boundary between illness and risky behaviour, leading to the perception of mental illness more in moral than biological terms, as is implicit in the following example:

2303: Line 260 – 268 (Relative, White, Female)
QU
What do you think?
RES
I think drugs have a lot to contribute or do contribute a lot, that's the way of life, looseness of society, not having a strict family life as it was perhaps a 100 years ago, discipline, they have less discipline now, that might contribute to illness because it's all spread out, floating, not being contained within a group of people.

Thus, it is a loosening of discipline and morals that have contributed to the spread of mental illness.

The beliefs of relatives and community respondents in relation to drug use and mental illness mark an important difference from patients. Certainly, such beliefs among relatives and the wider community have the potential to hinder sympathetic responses towards people exhibiting the kinds of behaviours believed to be indicative of madness, craziness and the like.

9.2.3 “Witchdoctor … sent them to be that way”: Supernatural Causes

In distinguishing lay beliefs between developed and developing countries, much has been made of the continued prevalence of beliefs in the spiritual and supernatural origins of ill-health in developing countries (Helman, 1994). This was evident in the review of relevant literature in Chapter Four. Similarly, the limited research that has compared beliefs about mental illness among ethnic minorities in multi-cultural societies has often focused on and reported that ethnic minority groups are more likely than the majority population to believe that spiritual or supernatural factors or forces can cause mental illness (Millett et al, 1996). The limited research that has considered the beliefs of African-Caribbeans in the UK has similarly identified a continuing spiritual component to many respondents’ beliefs (Lloyd et al, 1998; Cinnirella & Lowenthal, 1999; Kiev, 1963). These spiritual and supernatural elements derive from beliefs common in the Caribbean linking obeah and madness (see
Chapter Four) and the research suggests there is a continuity in belief between the Caribbean and UK. Two questions are consequently posed: 1) is there evidence of beliefs implicating spiritual and supernatural forces in the accounts of respondents in this study?; and 2) are such beliefs more common among African-Caribbeans?

Of the three broad thematic categories, the spiritual/supernatural one was the least common. The section in the MDBS relating to this sphere begins with an open question: “do you think * [respondent’s term] could be caused by anything spiritual or supernatural?” A positive response was probed further, and in particular, the MDBS sets out a number of specific probes designed to explore beliefs relating to obeah, the aim being to assess to what degree such beliefs persist among African-Caribbeans in the UK. While overall beliefs linking mental illness and the spiritual or supernatural worlds were uncommon, in thirteen accounts they were prominent (9 (22.5%) African-Caribbean (4 patients, 1 relative and 4 community respondents) v. 4 (8%) White (2 patients and 2 relatives)), and in a further five African-Caribbean accounts obeah was identified as a possible cause. Crudely, then, African-Caribbeans were significantly more likely to believe spiritual or supernatural forces could cause severe mental illness (14 (35%) v. 4 (8%), Fishers exact test p < 0.01).

The four White respondents who identified such factors as potential causes drew very much on Christian theology. One of the patients, for example, who was a practising Anglican and actively involved in her local church, strongly believed mental illness could be the consequence of spiritual or demonic possession:

1253: Line 465 – 481 (Patient, White, Female)

QU
Do you think that someone for example can be possessed by a spirit?

RES
Yes bloody right I do.

QU
And that that is the cause of them being bewildered?

RES
Yes. But nobody understands. If you get .... People who saw me before Christmas, my vicar was convinced I was being possessed. A lot of people ... some people say that, how can I put this, if you are hearing voices then it must be a demon, they would not believe it was a mental illness, they would say it must be demonic. During my
illness I was taken to King's hospital twice with demonic stomach pains which went when people prayed over it - explain that, how do you explain that?

The patient, in expressing these beliefs, was aware of how they may be considered beyond the community of her church and how experiences caused by, from her perspective, demonic possession could, through another lens, be taken as signs of mental illness. In setting out these beliefs, therefore, there is an effort to justify their legitimacy by reference to others and actual events – “my vicar was convinced I was being possessed”, “… some people say that … if you are hearing voices then it must be a demon” – and by making the challenge “explain that, how do you explain that?” at the end of her account of the effect of prayer in relieving what she termed “demonic stomach pains”. The patient also broadened this out, making reference to how she thought the beliefs of ethnic minorities, that were often spiritual, were misdiagnosed as schizophrenia:

1253: Line 453 – 463 (Patient, White, Female)

QU
Do you think that spirits can send people into a state of being bewildered?

RES
Yes, how can you question what someone is hearing, how do you know that someone's not been chosen to hear messages. I think we have to be very careful about what people say and just because you are not hearing it, how do you know it is not true, and in the other ethnic groups spirits come to people, it can be a normal thing for them because they have grown up with these spirits in their ears, and they get over to this country and they are labelled as schizophrenic and I think that is bang out of order.

Interestingly, this patient’s account comprised two parallel narratives about the nature and causes of severe mental illness. As well as being heavily involved in her local Anglican church, the patient was a trainee social worker, and the initial responses to questions put during the course of the interview were broadly within a bio-psycho-social frame, such that a dual, non-overlapping account was provided. The respondent said that she could see these problems from two perspectives, her own and that of a professional expected to interpret such problems in particular ways:

1253: Line 560 – 570 (Patient, White, Female)

QU
It is exactly that, it is your beliefs that I am after, what we might ....

RES
I can't go into social work and see this dysfunctional family and say it is because you are not a Christian, because there's demons in your house, let me go and bless your bedroom. I have got to look at it, the parents are alcoholics, you are under stress, you are quite poor, so I can look at it both ways. To be honest I don't know why I had this sort of breakdown - it has really opened my eyes to a lot of things and I think that I will be a stronger person because of this, because I can see it from both sides now.

Apart from this, and three other accounts in which demonic possession within a Christian frame was implicated as a key factor in causing severe mental illness, no other White respondent believed such factors were important and indeed most were summarily dismissive.

Most African-Caribbeans who accepted a potential role for supernatural or spiritual forces in causing mental illness did so through the belief that obeah could cause madness. Obeah was discussed in Chapter Four, the essence being that obeah practitioners are believed to have the power to invoke supernatural forces to cause madness, often at the request of individuals who seek out obeah practitioners to work "something" against a person whom they dislike or are in dispute with. These beliefs are clear in the following example from an interview with a Jamaican patient:

1348: Line 191 – 199 (Patient, African-Caribbean, Female)
QU
You say in Jamaica that there's a lot of shame about being mad, and they're sent away to Belle View and there's a lot of stigma, why is that?

RES
'Cos people that are mad is like people went to witchdoctor and sent them to be that way, like people pay money for people to be sick, turn them mad, so they can't get back.

1348: Line 229 – 255 (African-Caribbean, Female)
QU
You mentioned someone paying for someone to work witchcraft against someone to make them mad, is this the same thing as obeah?

RES
Yes.

QU
How does that come into it?

RES
It’s like some people in Jamaica are so jealous and they envy, if they see you wear nice clothes they think you making too much money, they just get bad mind and envy you and take their money to a obeah doctor, and take your picture, your photograph or your clothes that you sweat in and ask them to turn this person mad or destroy them or kill them, ‘cos it can reach that stage as well.

The details of obeah practices provided in this account resemble many traditional African beliefs in which hair, nail clippings or the like are thought to be used in rituals to cause harm and illness (Leff, 1988). While the reference points for this respondent are Jamaica and her account refers to the working of obeah in Jamaica, she nonetheless makes it clear that she believes such practices can and do work in the UK, and uses her own experiences to illustrate this:

1348: Line 287 – 301 (Patient, African-Caribbean, Female)
QU
Some people have said to me when I’ve talked to them before that they know that obeah can work in Jamaica or the Caribbean, but they are not so sure it can work over here …

RES
It work here. It do. ‘Cos when my husband came to me when I was in hospital, when he take me the first of January and I was transferred from the JBU ward to King’s College, he came and picked me up and he was saying Mr R [the witchdoctor], and that the witchdoctor have give him something for me to drink. I said get off my face. I didn’t drink it.

This respondent’s account, in fact, provides the only instance in the interviews in which recourse to, and descriptions of, the practices of an obeah doctor or witchdoctor operating in
the UK are provided\(^1\). The veracity of this account is supported by the family and was reported consistently by the patient independently of the presence of delusional beliefs, suggesting the story is reliable. This will be returned to when the impact of beliefs on help-seeking is considered more directly, but for now this stands as the clearest example of the continuation of specifically Caribbean beliefs about obeah among this group of respondents. It is evident, moreover, that these beliefs are held by the patient’s family and friends, both from their actions, particularly the husband’s, and what the patient says:

1348: Line 270 – 279 (Patient, African-Caribbean, Female)

QU

Who does believe in obeah?

RES

Other people. My husband do. I’ve got friends who do, like this girl, [address], she’s a believer as well. My sister in law’s church in [place name] they believe. I know people who believe in them things.

Beliefs relating to obeah, moreover, run right through the interview, such that all questions are interpreted within this belief frame. When asked about whether madness may be caused by the brain not working properly, the patient interprets this within her own frame:

1348: Line 440 – 460 (Patient, African-Caribbean, Female)

QU

Is it anything to do with the brain not working properly?

RES

No. Though they can play with your thoughts, so you can’t remember nothing. So what the obeah doctor do, he can’t take away your soul, he not that powerful, he not God. So what he can do is just to play with your mind. Try to let you play fool, or turn you to an idiot, turn you stupid, that you don’t know what you doing.

This patient’s account is yet more interesting because, alongside the beliefs relating obeah and madness, she provides a parallel account that thinking too much can cause madness, again an account rooted in Caribbean folk beliefs, as already discussed above.

\(^1\) In a further example, another African-Caribbean woman (1204) talks about visiting a spiritual healer, but it is not clear from the account whether this is an obeah doctor or not.
Within this single account, then, the two primary causes of severe mental illness that are consistently reported from the albeit limited research on lay beliefs in the Caribbean are evident. The appropriate responses that flow from these theories of causation are likewise rooted in Caribbean folk beliefs. This dual belief system was equally evident in three other accounts in which obeah was a central factor, such that, in four interviews, accounts were elicited in which respondents conceptualised madness, its causes and, as will be seen below, appropriate treatments, in ways that are indistinguishable from the reported conceptualisations evident in the Caribbean. It is no surprise that these respondents were older (all over 30) and, with one exception, born in the Caribbean.

In the remaining 10 interviews in which obeah was believed to be a potential causal factor, the parallel beliefs that madness could result from “thinking too much” were not evident, though more generally stresses and pressures were invariably identified as potential causes. In these accounts obeah was usually viewed as one of a range of possible causes and respondents offered very little elaboration on what they meant beyond a positive response to questions about obeah. This may reflect a reluctance to talk about obeah in the contexts of the interviews, which were conducted by a White male and were part of a project concerning the nature and causes of mental illness. Listening to the tape recordings and closely reading the transcripts, there are few direct indications that this was the case. There were, for example, no clear indications that questions relating to obeah made respondents uncomfortable and less open than in other sections of the interview. This is not to discount the context of the interview as a factor shaping these findings, but it is to suggest that an equally reasonable reading of the data is that the limited elaborations on the questions of obeah reflect the fact that such beliefs were not central to the respondents’ understandings of severe mental illness. The impression was that either the limited responses were characteristic of the whole interview or that the respondent accepted the possibility that such factors may cause mental illness, but had very limited worked through ideas about how this would operate. Interestingly, of this group of 10, 8 were born in the UK, a finding that opens up the possibility that such beliefs were derived from older family members, but in only limited detail. It suggests a residue of belief acquired through family, as is apparent in the following segments from the same respondent:

1275: Line 512 – 554 (Patient, African-Caribbean, Female)
QU
Have you heard of things like obeah and black magic?
RES
Yes.
QU
Do you believe in any of that?

RES
Yes.

QU
Can you tell me a bit about what it is because I am a bit ...

RES
I believe in obeah, it is like witchcraft.

QU
What happens, how does it work?

RES
I don't know how it works but I know it is a form of evil. It's erm ... black magic.

QU
What do people do to bring about ....

RES
I don't know but I have heard of it.

QU
It is something you have heard about through parents?

RES
Yes.

Accounts in which respondents expressed ambivalent ideas relating to obeah were common among both Caribbean born and UK born respondents (n = 12). This ambivalence may reflect a fear of obeah, and a consequent reluctance to talk about it, and/or a lack of knowledge. Certainly, for the younger, second and subsequent generation, African-Caribbeans this ambivalence further reflects the dilution both of knowledge and strength of belief in the context of the UK, where such beliefs and practices are less common. The
following example confirms the transmission of knowledge through family and hints at how such beliefs fail to take root in contexts where such beliefs are not widespread:

1189: Line 278 – 292 (Patient, African-Caribbean, Female)
QU
How about things like black magic?
RES
I believe yes they can do something, but I don't believe in that so ... I hear lots of stories about it but I am not one to indulge, I am not one to take that on too hard. I don't fully understand it.

QU
You think there might be possibly something going on ...

RES
There is because my elders have told me about things that have happened and I believe things do happen but I don't believe in using them forms or methods, I don't believe in that at all. I think that's rubbish. It is evilness.

To reiterate, this pattern of belief among African-Caribbeans is suggestive, unsurprisingly, of stronger beliefs about obeah in the older generations with some residual knowledge derived from the older generations among the younger UK born African-Caribbeans, manifested as uncertainty or rejection of the power of obeah. Many of the respondents themselves were aware of this patterning of belief:

1355: Line 613 – 621 (Patient, African-Caribbean, Female)
QU
Who does believe it?
RES
I think quite a lot of Black people believe in things like that, the older generation tell the younger generation then it's up to the younger generation if they believe the older generation or not but I think that even if they don't believe it I think they do have it in the back of their minds still, 'cos I don't know if I believe it but sometimes I think I wonder if it's true.
The patterns of beliefs about obeah, by place of birth, among African-Caribbeans in this sample are shown in Table 9.7.

Table 9.7. Beliefs about obeah by place of birth among the African-Caribbean respondents.

<table>
<thead>
<tr>
<th></th>
<th>Obeah a central cause</th>
<th>Obeah a potential cause</th>
<th>Ambivalence</th>
<th>Obeah not a cause</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caribbean born</td>
<td>3</td>
<td>2</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>UK born</td>
<td>1</td>
<td>8</td>
<td>5</td>
<td>10</td>
</tr>
</tbody>
</table>

The pattern of beliefs about obeah evident in this sample is instructive. While in crude terms beliefs relating obeah and severe mental illness are common among African-Caribbeans, in only four cases are these beliefs central and fully worked out. In others such beliefs are either not central or show ambivalence. The use of qualitative methods has allowed these more fine grained distinctions in the nature and strength of such beliefs to be clarified. It is possible that previous quantitative studies, in failing to identify these nuances, have overstated the importance of these beliefs in general in the African-Caribbean community (Lloyd et al, 1998). Such studies create the impression that these beliefs are a major distinguishing feature of beliefs between Whites and African-Caribbeans, while the data presented here suggests this holds for, at most, a minority of older, first generation African-Caribbeans. A final point. This patterning held across patients, relatives and community respondents, though numbers were of course small. Tentatively, this suggests that the nature and distribution of beliefs about obeah observed in this sample reflect wider cultural patterns of belief in the African-Caribbean community.

9.2.4 Typologies

Data relating to beliefs about the causes of severe mental illness revealed themes locating the origins of mental illness in three broad spheres: the social, the individual, and the spiritual/supernatural. What is striking about this data is the range of believed causes and, in many cases, their complexity. The data revealed a small number of different types of causal explanations, as illustrated in Table 9.8.
Table 9.8. Typologies: causes of severe mental illness.

<table>
<thead>
<tr>
<th>Typology</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biological</td>
<td>The key causes are biological, to the exclusion of others</td>
</tr>
<tr>
<td>Bio-psycho-social</td>
<td>The key causes are biological and social, either independently or in some form of interaction</td>
</tr>
<tr>
<td>Social</td>
<td>The key causes are social, to the exclusion of others</td>
</tr>
<tr>
<td>Dual (Spiritual / Other)</td>
<td>The key causes are both spiritual and others unrelated to spiritual causes. These other causes fit one of the three models above</td>
</tr>
<tr>
<td>Spiritual</td>
<td>The key causes are spiritual, to the exclusion of others</td>
</tr>
<tr>
<td>Traditional Caribbean</td>
<td>The key causes are obeah and pressure due to worry or thinking too much</td>
</tr>
</tbody>
</table>

Each of these is recognisable from the data presented above. The two most common were the “social” and “bio-psycho-social” models. The caveat expressed in relation to typologies for conceptualisations of mental illness hold, but once again these typologies usefully capture and summarise the range of beliefs about severe mental illness, and allow for fruitful comparisons between groups. Table 9.9 compares beliefs organised according to these typologies by ethnicity.

Table 9.9. Types of causes of severe mental illness by ethnicity.

<table>
<thead>
<tr>
<th></th>
<th>White Respondents</th>
<th>African-Caribbean Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 50</td>
<td>n = 40</td>
</tr>
<tr>
<td>Biological</td>
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</tr>
<tr>
<td>Bio-psycho-social</td>
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<td>5</td>
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<tr>
<td>Social</td>
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<td>25</td>
</tr>
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<tr>
<td>Spiritual</td>
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<tr>
<td>Traditional Caribbean</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>No clear model</td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

This summarises clearly the differences between the two ethnic groups in terms of believed causes. While more African-Caribbeans across all groups revealed beliefs that included spiritual factors (10 (25%) v. 2 (4%), Fisher's exact test p < 0.01), the more striking difference is in relation to beliefs incorporating biological factors. Across all the groups, African-Caribbeans were significantly less likely to believe biological factors played a key role (5 (12.5%) v. 27 (54%), Fisher's exact test p < 0.01). The differences all point to the conclusion that beliefs about causes that diverge from psychiatric theories of mental illness are more common among African-Caribbeans and that consequently African-Caribbeans are potentially less receptive to psychiatric explanations.
The aim of the fourth section of the MDBS is to probe respondents' attitudes towards those with a severe mental illness through a series of questions concerning how respondents would deal with certain situations in which they came into contact with people with a severe mental illness. These situations were: 1) being approached in the street for help or money; 2) having a hostel for people with a severe mental illness opened in the street where the respondent lived; 3) having someone with a severe mental illness move next door; and 4) a member of the respondent's family marrying someone with a severe mental illness. These four situations represent increasing levels of likely contact with someone with a severe mental illness. In analysing the data relating to this section, two patterns could reasonably have been expected to emerge: 1) that overall attitudes would be more positive among patients and relatives than community respondents, given recent personal experiences; and 2) that attitudes would be more negative among African-Caribbeans, given the harsher, more behaviourally focused, conceptualisations of severe mental illness evident among this group. This section discusses the data in relation to each of these expectations.

9.3.1 Overall attitudes
The data overall revealed mixed attitudes towards people with a severe mental illness, the majority of respondents expressing both negative and positive attitudes depending on the specified situation. Surprisingly, in individual accounts it was often difficult to discern any clear logic to the attitudes expressed. For example, while it might be expected that those situations implying a greater degree of contact with and commitment to someone with a severe mental illness would generate more negative responses, many respondents expressed more positive attitudes in relation to such situations, for example marriage, than in others, for example the opening of a hostel. Thus, attitudes were mixed in various combinations in 62 (68.9%) of the interviews. In the remaining 28 accounts, 16 were wholly positive and 12 were wholly negative.

What is particularly striking is that negative attitudes among patients and relatives were as common as among community respondents. This is surprising, and perhaps reflects the pervasiveness and strength of such attitudes among the communities from which these patients and relatives are drawn. Certainly, at the early point following contact with mental health services it is clear that many negative attitudes and stereotypes persist. In many cases these attitudes were clearly rooted in the conceptualisation of severe mental illness as extreme behavioural disturbance, often associated with greater degrees of violence. A number of respondents explicitly acknowledged a fear of the mentally ill. The following is a particularly
telling example in which the respondent struggles both with her own fears and the possibility that she may be “in the same boat as them”:

1355: Line 735 – 750 (Patient, African-Caribbean, Female)
QU
The next question is what would you do if someone who was mentally ill came to live next door?

RES
Oh God, just the thought of it, because even when I go to the clinic, I go to the Network, I just go as early as possible and just pray to God that no one else comes in and I seem to have this sort of face where they stick to me, they start talking to me and then I start to get all dried mouth, but I don't want to be like that because at the end of the day maybe they was at a stage when they was like me just having these horrible thoughts and they never saw the doctor and it went out of control and I think at the end of the day I'm in the same boat as them maybe on a different scale you know so I don't know being thrown into it like this is going to help me, help me see it in a better way, not to be scared because I have to go the doctors, I have to go the Network Team because I need to be better.

Others were more forthright still:

1351: Line 841 – 850 (Patient, African-Caribbean, Male)
QU
What would you feel if something like a hostel was opened at the bottom of your street?

RES
No way, absolutely no way, no it should be somewhere in an open field somewhere where there is some grounds so there's a bit of distance between them and the public and if someone should escape then at least the people who are looking after them would be able to get to them first before they do themselves some harm.

The harshness of this response is tempered slightly by the focus, at the end, on the sufferer as a potential harm to him/herself, but the overall tenor, that people with a severe mental illness should be separated from the community, is extremely negative. This level of animosity was not common in the interviews, but a negative response in one form or another to at least one
of the questions was evident in 39 (75.0%) patient interviews, though in only 4 were attitudes wholly negative, and in 12 (66.7%) relative interviews, 4 of which were wholly negative.

Similar patterns were evident among community respondents, with 16 (75.0%) accounts including at least one negative response, 4 of these being entirely negative. Again, these negative attitudes stemmed, in many cases, from an association between severe mental illness and violence:

5014: Line 746 – 753 (Community Respondent, African-Caribbean, Female)
QU
What about if someone who had mental health problems came to live next door?

RES
Anyone with half a brain would not feel very safe you would feel a little bit well you're going to be on your guard all the time, mental disorder as I understand sometimes people act normal and whether it's the moon or changes in the moon or what there are periods that they're not alright, they can harm you.

While in this example the respondent clearly believes mental illness and violence are inextricably linked, others suggested mental illness carried with it a greater potential for violence, and it was when the mentally ill became violent that social distance was desired:

5061: Line 490 – 497 (Community Respondent, African-Caribbean, Male)
QU
What about if someone like that came to live next door to you?

RES
It wouldn't bother me up to a point if they start to get aggressive or whatsoever then I start to think about, but if he's the type of person when he's alone or he's out in the back garden doing his thing, all I have to do is come in and close the door.

The data could equally be considered from the alternative angle that many respondents expressed positive attitudes in relation to the hypothetical situations, such that to focus on only the negative responses biases the interpretation. Indeed, there are probably more positive attitudes evident in the data than would be expected from other research (Crisp et al, 2000; Bhugra, 1989), a finding that suggests lay people do not always indiscriminately group people with a mental illness together, as cause for fear and suspicion, but rather modify their attitudes and responses according to the situation. In 69 (76.6%) interviews positive
attitudes were evident in relation to at least one of the questions and in 16 (17.7%) interviews attitudes were wholly positive. Interestingly, the most positive attitudes were expressed by those respondents who had been reluctant to specify a label for people with a severe mental illness and who at times had implied there was no such thing as madness or the like (see above, p. 182), a perspective that in the segment below was only reinforced by initial experiences of services and extended contacts with people experiencing a severe mental illness:

1246: Line 537 – 557 (Patient, African-Caribbean, Female)
QU
If we think now about people who have been pushed too far, and you are in a position where they may or may not have to go into hospital, if people in that kind of state, if someone who is like that came up to you in the street and asked you for help or money, what would you do?

RES
I always give them money. I had nothing in that place and I was giving cigarettes, I was basically ... I had people coming in and giving me money for fags, everybody who came to visit me I asked them for 20's, 10's and 50's and had a little black money bag and if people needed to make a call I would give them money for it. I had people coming in and bringing me cigarettes. That is the difference you see, I had people coming to see me, a lot came to see me, if you look at the span of the time I was there and the visitors for [patient’s name], and the amount of time we had for visitors [another patient’s name]. [The other patient’s name] had in the same period of time I was there, he had the same visitor [visitor’s name] and he had [visitor’s sister] and brother come and that was it. I had a lot of people come visit me and based on that I therefore gained what I could, used the resources that I had, I learnt a lot in that place. These are just unhappy people who basically just need a bit of time to get themselves sorted and do not need prescribed drugs, and it is ridiculous.

It is not surprising that the most positive attitudes should be evident in those respondents whose conceptualisations of severe mental illness were the least harsh. This leads into the question of whether negative attitudes were more common among African-Caribbeans, who as a group held more behaviour focused conceptualisations of severe mental illness than Whites.
9.3.2 Attitudes and ethnicity

In crude terms, negative attitudes were more common among the African-Caribbean group. The number of text segments in which negative themes were expressed was 75 among African-Caribbeans and 53 among Whites, bearing in mind there were ten more White respondents than African-Caribbean. In other words, 58.6% of the text segments in which negative attitudes were expressed came from African-Caribbean respondents, who comprised 44.4% of the respondent sample. Further, when the number of respondents who expressed predominantly negative attitudes (i.e. negative attitudes in response to at least three of the four relevant questions), or who at least expressed negative attitudes as much as positive attitudes (i.e. negative attitudes in response to two of the four relevant questions), are compared by ethnic group, African-Caribbeans are significantly more likely to fall into this category (26 (65.0%) v. 13 (26.0%), $\chi^2 13.7, df 1, p < 0.01$), a striking difference.

When the data is considered more closely it is clear that many African-Caribbeans expressed much more negative attitudes than was evident among White respondents. This has already been seen in one example above (1351: Line 841 – 850), and was evident in a number of others. The following examples further illustrate this:

1345: Line 333 – 341 (Patient, African-Caribbean, Female)
QU
How would you feel if a half-way home or hostel for people with mental problems was opened at the bottom of your street?

RES
I wouldn't like it. Kids have got to play somewhere, and there may be kids around when they flip. Older people can defend themselves, but kids can't.

1352: Line 760 – 773 (Patient, African-Caribbean, Male)
QU
What about if someone like that wanted to marry a member of your family?

RES
That's already happened. Before I didn't know that this person had mental problems but just say I'm coping with it, I'm just like worried about it, very worried about the situation.

QU
Why are you worried, what is it?
Because the person is very violent and you never know, he's unpredictable, you don't know what he's going to do next.

In general terms these findings support previous suggestions that the stigmatisation of severe mental illness is greater among the African-Caribbean population than generally (Wolff et al, 1996a, 1996b; Harrison et al, 1989), and further suggests that this stigma, at least in part, arises from out of culturally shared models of madness or severe mental illness as characterised by behavioural disturbance and violence.

9.4 "KINDNESS AND SUPPORT AND A BIT OF PRODDING": TREATMENT

The types of responses and treatments identified by respondents as appropriate in cases of severe mental illness ranged from those involving lay support networks, through those involving alternative practitioners and/or religious institutions, to those provided by professional psychiatric services, such that preferred responses incorporated interventions located in all of the three health care sectors identified by Kleinman (1980). The section of the MDBS concerned with beliefs about treatment is designed to focus on four basic questions: what treatment is appropriate?; who should provide treatment?; where should treatment be provided?; and when should treatment be provided? The formal relationships between the thematic categories developed from the analysis are shown in Figure 8.3d and the definitions for the categories are specified in Appendix 3. Table 9.10 shows the frequency with which specific treatment options were identified by ethnic group according to whether the response was prompted or unprompted.

Table 9.10. Treatment. Number of cases believing each treatment to be appropriate by ethnicity.

<table>
<thead>
<tr>
<th>What</th>
<th>White Respondents (n = 50)</th>
<th></th>
<th>African-Caribbean Respondents (n = 40)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unprompted</td>
<td>Prompted</td>
<td>Unprompted</td>
<td>Prompted</td>
</tr>
<tr>
<td>General Care</td>
<td>31</td>
<td>62.0</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Talking</td>
<td>27</td>
<td>54.0</td>
<td>16</td>
<td>32.0</td>
</tr>
<tr>
<td>Practical</td>
<td>10</td>
<td>20.0</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Traditional</td>
<td>6</td>
<td>12.0</td>
<td>21</td>
<td>42.0</td>
</tr>
<tr>
<td>Medication</td>
<td>26</td>
<td>52.0</td>
<td>15</td>
<td>30.0</td>
</tr>
<tr>
<td>Where</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital</td>
<td>11</td>
<td>22.0</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>Community</td>
<td>2</td>
<td>4.0</td>
<td>n/a</td>
<td></td>
</tr>
<tr>
<td>Depends</td>
<td>37</td>
<td>74.0</td>
<td>n/a</td>
<td></td>
</tr>
</tbody>
</table>
Table 9.10. *Treatment. Number of cases believing each treatment to be appropriate by ethnicity (cont.)*

<table>
<thead>
<tr>
<th>Who</th>
<th>White Respondents (n = 50)</th>
<th>African-Caribbean Respondents (n = 40)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unprompted n</td>
<td>%</td>
</tr>
<tr>
<td>Lay</td>
<td>26</td>
<td>(52.0)</td>
</tr>
<tr>
<td>Traditional Medical</td>
<td>3</td>
<td>(6.0)</td>
</tr>
<tr>
<td>Medical Professional</td>
<td>31</td>
<td>(62.0)</td>
</tr>
<tr>
<td>Non-medical</td>
<td>24</td>
<td>(48.0)</td>
</tr>
</tbody>
</table>

While the categories were organised around the questions set out above, it is useful to present the data in this section according to the three health care sectors proposed by Kleinman (1980): popular, folk/traditional and professional.

9.4.1 The Popular Sector

The popular health care sector, from Kleinman’s perspective, comprises all forms of advice or treatment provided by friends or family, self medication and the like. The vast majority of illness episodes are managed within the popular sector and the pathway to health care services is navigated through the lay referral network (see Chapter 3). It is important, then, to understand what role potential and actual users of mental health services believe this sector has in managing severe mental illness. The data from this study suggest this area is perceived as a source of considerable value. The two most common themes that emerged in this sphere were: 1) the value of the involvement of family and friends; and 2) the importance of talking. These obviously overlap in that the family and friends were often believed to be the most helpful people to talk to. To begin with, however, it is useful to consider each of these themes in turn.

*Family and friends*

The majority of respondents (n = 67 (74.4%)) believed that family or close friends were an important source of help and support for people with a severe mental illness, and in most cases family or close friends were suggested as the first person(s) someone should turn to for help (“I think you go to family before you get outside help” (1163: Line 682, White, Female)). The type of help that family and friends could offer was often expressed in vague terms, such as support, being there and so on (“A lot of support from family and friends, being there” (1275: Line 685, African-Caribbean, Female)). In some cases, respondents believed this kind of support could be sufficient in itself for people to “get better”:
Who or what do you think helps people to get better if they are mad?

If the person is fortunate enough to have family and friends like the illness hasn't driven away family and friends if they're fortunate enough to have those relations I think with kindness and support and a bit of prodding they'll probably get better even without any medical intervention. It might take longer but it can be done …

For others, the main role of family and friends was that of listening and offering advice. The belief that talking is helpful for people with a severe mental illness is discussed briefly in the next sub-section, though it is important to note here that family and friends were often seen as the best people to talk to. In yet other accounts the primary role of friends and family was that of facilitating access to professional services. In this there was the suggestion that people with a severe mental illness were not always able, or in a position, to seek help themselves. Most respondents, then, in one form or another believed that people within a sufferer's social network were important, particularly in the early stages. This maps on to the more general work within medical sociology that has shown that the overwhelming majority of people who experience any illness episode will have discussed their complaints with family or friends first (Scambler, 1997). There seems, however, to be more to the proposed involvement of family and friends in these accounts than them simply being a source of reassurance prior to help-seeking. There is a strong suggestion in many of the accounts that the quality of relationships with others – the support, just being there, talking and so on – is therapeutic and, in some instances, sufficient to promote recovery in the absence of other interventions. There were, moreover, no clear differences between or within the two broad ethnic groups on this. In both groups a majority saw family or friends as being the appropriate first source of help for severe mental illness (29 (58.0%) White v. 24 (60.0%) African-Caribbean, ns).

Talking

The belief that talking is helpful for people suffering from a severe mental illness was almost ubiquitous among respondents, with only 13 respondents believing talking could not help. The idea that talking, either informally or in therapy, is of value in resolving mental health problems of all types is certainly widespread among western populations (Jorm et al, 2000; Angermeyer et al, 1999; Furnham & Smith, 1988). This is confirmed here. The belief in the value of talking appears, in many cases, to arise out of the belief that mental health problems stem from the problems and difficulties of life and people’s ability to manage such problems.
It was seen, for example, in relation to supposed causes how talking was believed, by some, to be a preventive factor, acting as a kind of safety valve relieving pent up pressure. In much the same way, talking was believed by many patients to be a means of enabling sufferers to overcome the difficulties that underpin and sustain severe mental illness:

1280: Line 635 – 642 (Patient, White, Female)
QU
How do you think someone who is mad should be treated?
RES
I think with a lot of patience and be extremely careful towards patronizing them. Just being very calm and finding out what they like doing, what makes them happy and making sure that they do what makes them happy. You can talk about the reasons why they fell into depression.

Others were less clear about the precise way in which talking to others could help and the impression given was that talking as a process in itself had some kind of therapeutic effect, through the offering of sympathy or simply the existence of a supportive, listening relationship. Not surprisingly, it was those who saw talking in these terms who emphasised more the role of family and friends, or who believed what was important was the nature of the relationship between the sufferer and the person offering support:

1163: Line 648 – 655 (Patient, White, Female)
QU
Who is the best person to talk to?
RES
I think it is anybody, you can click with somebody and then that person is someone they might find genuine or strong, or has the right expression back. Apart from that you can talk to as many people as you can. You might not say as much because you are not talking to the right person.

Interestingly, one patient took the next step and spoke about how talking to and receiving or giving support to fellow patients could be helpful:

1246: Line 596 – 611 (Patient, African-Caribbean, Female)
QU
In that sense then, what or who helps people to recover from being pushed too far?

RES
People that will listen. I spoke to a lot of people and all I did was sit in the room, in the living areas, and if you go to Charter Clinic now, I went to every single floor and I met loads. I have met loads of people and talked to them and say you have to get yourself sorted out, I was counselling them. I seriously was.

In the main, respondents saw the primary role of people within a sufferer’s social network as being one of offering support, advice and as being someone to talk to. This role, however, was not restricted to people within the sufferer’s social network, and often respondents believed professionals were both more appropriate and better placed to offer “talking cures”. This was based primarily on notions of competence, with family and friends being viewed as lacking the expertise to offer support and advice. This is evident, for instance, in the following examples:

1307: Line 730 – 738 (Patient, White, Female)
QU
And friends?

RES
Yes, like the thing is you can have your family and friends but they don't know what to say, they don't know how to answer or respond to what you're talking about so that's why you have to go outside, not that you want to, you need someone higher than you're actually getting, who reciprocates what you're talking about.

1345: Line 391 – 400 (Patient, African-Caribbean, Female)
QU
Who's the best person to talk to?

RES
A psychologist or counsellor. They know, they understand. It's not the same as talking to friends or family. They don't give nothing constructive. Counsellors understand more about the illness. Family and friends just say you'll get better soon. They've not been through it themselves.
For others, professionals were seen as offering a more detached perspective than those who were more closely involved with the sufferer, a perspective that allowed them to be more objective and effective. The professionals who it was believed could provide more formal counselling and therapy included both those trained specifically for this task (counsellors, psychologists and so on), medical professionals (doctors, psychiatrists, nurses and so on), and those operating phone services (such as Saneline, The Samaritans, and so on). Still others believed that both close confidants and professionals could provide help through talking and listening, the determining factor simply being a question of whom the sufferer felt most comfortable with.

The belief that talking is therapeutic, then, was a pervasive theme in respondents' accounts, though the people considered to be the most useful in providing this support varied, as did beliefs about how such talking could help. Moreover, the value of talking was similarly prominent among the two broad ethnic groups, both that provided by friends and family and that provided by professionals. However, it was in how talking fitted in with other treatments – in the folk and professional sectors – that differences between the two groups emerged. There were, indeed, two key differences between the ethnic groups, centring on the perceived benefits of traditional or folk sources of help and medication.

9.4.2 Folk or Traditional Sector
The folk or traditional sector incorporates all non-professional sources of help located outside of a person's network of family and friends, including alternative and complementary therapies, faith healers, religious institutions and the like. Interest has grown recently in this sector of health care in western societies, though little is known about the extent and variety of healing practices that stand outside of mainstream medicine and less still about who makes use of such services and why. That there is a large and varied traditional or folk sector in the UK is nonetheless clear and alongside more mainstream complementary therapies, such as homeopathy, there are certainly a host of religious, spiritual and other practitioners operating, many originating in developing countries. Alongside this, churches of various denominations have always offered forms of healing to their communities and, again, this seems particularly true at present among churches dominated by ethnic minority groups, such as Pentecostal churches. It is this, then, that raises questions about how such forms of help are perceived and what use is made of them.

Broadly conceived, folk or religious sources of help were viewed as helpful by a sizeable proportion of respondents (n = 63 (70.0%)). The majority of sources of help captured by this broad thematic category were religion or faith based (church, prayer, God, laying on of hands, faith, pastor), while others were more rooted in Caribbean folk medicine (herbs, obeah doctor, witchcraft), though these were much less common. Only two patients
(1 African-Caribbean and 1 White) talked specifically about complementary therapies being helpful, in both cases homeopathy. Perhaps not surprisingly, there were clear ethnic differences in relation to beliefs both in the utility of religion and associated practices and in the value of herbs and obeah doctors.

Many of the respondents believed that religious faith and practice were potentially helpful for people with a severe mental illness. The following is a forceful example:

1189: Line 366 – 372 (Patient, African-Caribbean, Female)
QU
What or who do you think helps people to get better if they have gone crazy?
RES
I think God. If they can pray hard enough I believe God. Forget the medication I don't really agree with medication. I believe if they have a strong meditation with God they will come through.

In overall terms, 60 (66.7%) respondents believed religion based sources of help were valuable, with a clear difference between Whites and African-Caribbeans (25 (50.0%) White v. 35 (87.5%) African-Caribbean ($\chi^2$ 14.1, df 1, $p < 0.01$). These differences, however, are more striking still when strength of belief in these factors is considered. Many patients, in saying that faith and/or religious practice could help, were not so much saying that these sources of help and support were central and useful in all cases, but rather that they may be useful for people who were religious or had a strong faith, as illustrated in the following examples:

1218: Line 660 – 664 (Patient, White, Male)
QU
What about going to church, do you think that would help?
RES
It depends if someone is religious or has religious beliefs.

4018: Line 306 – 310 (Patient, White, Male)
QU
Would going to church or a religious assembly help?
RES
Yes, perhaps, if you are that way inclined.

The implication is that the church or religion may help others, but not the respondent. In a similar vein, others saw churches of any kind as offering a supportive community that might provide the type of talking therapy and support discussed above:

1192: Line 638 – 652 (Patient, White, Male)
QU
When you said that you’re a Christian, do you think that going to church can help?
RES
Yes, I think so.

QU
In what way?
RES
Meeting other people with similar beliefs. And having …talking to people. I think talking to people always helps, and going to a Christian congregation you get to talk to people, that would help.

There was, then, a difference between those who believed the church was helpful for others or as providing a supportive community at a difficult time and those who saw the church or religion as playing a much more central and definitive role in resolving severe mental illness. This latter belief was seen in the first example given above (see p. 238), and it is again clear in the following segment in which the patient draws on his own experiences to emphasise his belief in the utility of religious practices:

1351: Line 964 – 987 (Patient, African-Caribbean, Male)
QU
Do they have any kind of healing rituals or healing practices, I mean some churches in the congregation people who are not feeling too well or have problems they might get that healing practice within, does anything like that happen?
RES
Yes sometimes they put their hands on you.
QU
Is that something that happens at your church?

RES
It happens at that church, I've never actually had it done to me, but I'll tell you something if I'd gone on Sunday instead of being here more than likely if the pastor had said come up the front and I'll pray for you I would have done it because of the way I was feeling.

When beliefs about the utility of religion or faith in recovery from severe mental illness are considered in these terms (i.e. between belief that it can help others and belief that it is a key factor in recovery) the differences between African-Caribbeans and Whites are even more marked, with only 7 White respondents strongly believing such factors were helpful, three of whom had identified spiritual factors as key potential causes of severe mental illness, making their belief in the power of faith and the like unsurprising. In contrast, the overwhelming majority of African-Caribbeans who believed such sources of help were important in recovery had not considered spiritual factors to be central in causing severe mental illness, though many were aware of, and ambiguous about, beliefs relating obeah and mental illness. What these findings suggest is that among the African-Caribbean group there was a much more generalised belief in the power and utility of God, faith and religion in recovery from severe mental illness. While social factors may be the main causes, religion and faith, according to many African-Caribbeans, had the power to help people through times of such distress and unhappiness, making church, the pastor, God, and so on valuable in a number of ways in promoting recovery and return to good mental health:

1225: Line 919 – 930 (African-Caribbean, Female)
QU
What sorts of things do they do to help?

RES
I don't know. When you go in there [church], there is a sense of community, everybody is welcome, regardless of race, creed or colour and it is just the way the people talk. If you are upset you can actually find people who will take the time to talk to you and help you as well, encouraging you to come to the services or maybe they will lead you to people who can help you out. A very good sense of community, when you come out you feel a lot better. The churches I am talking about, especially
the Jesus Christ Arena, they are not like the Church of England, these churches use a lot of music, very vibrant and active.

In terms of these general beliefs there were no clear differences within the African-Caribbean group, partly because such beliefs were so common. There were, however, four patients who identified spiritual healers or practitioners outside of organised churches as important sources of help, these four being those who also strongly believed that obeah was a potential cause of "madness". The clearest example of this comes from the Jamaican patient already quoted extensively above (see pp. 219-222) who strongly believed obeah could send people mad. In her account, madness caused by obeah could only be cured by one means, namely recourse to an obeah doctor:

1348: Line 926 – 934 (Patient, African-Caribbean, Female)

QU
Can people who are mad get better?

RES
Yes ... It depends. Depends if your mad off your own then that's a bit harder than if someone set you to be mad. If someone went to their obeah doctor for you to be mad, then they can go back to the obeah doctor and release the madness. But if you're mad from your own, it takes a while for you to get back.

In this example, the connections between what is believed to cause "madness" and the appropriate response are clear. If an obeah doctor was involved in causing "madness", then an obeah doctor has to release the "madness". Here the patient implies it has to be the same obeah doctor, though she later says that any obeah doctor could cure the "madness". If "madness" was caused by thinking too much, then cure is more difficult relying, as it is believed to, on the individual to get themselves "back". Thus, "madness" in this account takes on two distinct forms, defined by the cause, which require distinct responses. This example provides an unusually coherent and lucid account that in almost all respects shares the characteristics of beliefs about "madness" identified in research in the Caribbean (Littlewood, 1993, 1988; Laguerre, 1987; Fisher, 1985). While the other three accounts in which obeah was believed to be both cause and cure were not as coherent as this, the consistency between cause and cure was equally evident, and sets these accounts apart as distinctly Caribbean. Incidentally, all four patients also believed that more generally religion, the church, faith and so on could aid recovery from severe mental illness.
9.4.3 The Professional Sector

In Kleinman's (1980) original formulation the professional sector comprised the legally sanctioned medical establishment and allied services. Others have since divided the professional sector in two to distinguish between professional medical services and allied services, such as social services, housing agencies and so on, what Pescosolido and Boyer (1999) have referred to as the "human-social service sector" (p. 393). Basically, this modification to Kleinman's original model distinguishes between medical and non-medical professional services. Patients in this study certainly identified professionals from a range of agencies as potentially helpful for someone with a severe mental illness, and the data fell into these two broad areas: 1) medical professionals (specialist mental health services, general medical services); and 2) non-medical professionals (the police, teachers, housing workers, and social services). This section focuses on beliefs relating to: 1) who, within the professional sector, if anyone, should provide treatment; 2) the usefulness of medication; and 3) where treatment should take place, i.e. in hospital or in the community.

Who should provide treatment?

Overall, only 10 respondents did not believe that medical services or professionals had a role in the treatment of severe mental disorder, though the majority did not believe such professionals should be involved unless it was unavoidable or until other strategies had been tried. Of the 80 respondents who believed medical professionals had a role, only 25 (31.3%) believed that either a GP or psychiatrist should be the first source of help sought by a sufferer, while the remaining 55 believed that medical help should be sought only if other strategies had failed, such as talking, religion, and so on:

1303: Line 619 – 634 (Patient, White, Male)
QU
So let's say someone is becoming mad, who is the first port of call?

RES
Get good friends, get friends who talk good sense and not talk a load of rubbish and listen to a load of rubbish. If you can't go to your friends then. I never heard of Maudsley and Bethlem Hospital, I never even knew it was so close to home, so I would say friends, relatives and anyone who talks sense that you can agree with and agree with you and can steer you in the right way sometimes or give you something to think about so you can work your mind.

QU
And if that doesn't work?

RES  
Doctor, hospital.

While many respondents did believe that psychiatrists were necessary, at least after a certain point, only a proportion had a clear idea of what it was psychiatrists could do to help. For these the role of psychiatrists was often seen either as a dual one of prescribing medication and offering specialist counselling or as providing one or the other. Others struggled when asked what it was psychiatrists could do, offering vague responses that they were unable to elaborate on:

1164: Line 559 – 565 (Patient, African-Caribbean, Male)  
QU  
What do you think these people can do to help?

RES  
Just help you out with what problems you've got. Just help you out with your troubles and that. And every time you see your friends and that, the chances are it'll be worked out and it'll be alright.

A much smaller proportion of patients identified non-medical professionals as potentially helpful in the treatment of severe mental illness. These included: counsellors, phone lines, social workers, psychologists, support workers, and in five interviews, the police. In no interview, however, did such sources of help figure prominently.

Medication  
Not surprisingly, given the number of respondents who believed medical professionals had a role in the treatment of severe mental disorder, and that many of these believed the primary role of such professionals was the prescription of medication, a majority of respondents expressed positive views about the usefulness of medication (n = 57 (63.3%)). While every effort was made to interview patients as close as possible to first contact with services, it was inevitable that by the time of the interview most would have had some personal experience of medication, and this seems to have shaped the positive perspective of some of the patients:

1309: Line 766 – 777 (Patient, White, Female)  
QU
Do you think there is any type of medication that can help?

RES
The ones what there's giving me, I don't know what they're giving me, but it has actually helped me.

QU
So do you generally think medication is useful?

RES
Yes it helps you calm down.

Unfortunately it is not possible to know what attitudes towards medication were prior to contact, though willingness to take medication and interpretations of its effects may have been shaped by whether prior attitudes were positive or negative, such that attitudes were reinforced rather than overturned. This is, however, speculative. What is clear is that many of the patients who viewed medication positively did so on the proviso that it formed part of a broader package of care which should, according to a number of accounts, include non-medical interventions, including talking therapy:

1289: Line 671 – 693 (Patient, White, Female)
QU
Do you think someone who's mentally ill can be helped to get better just by talking and the experience of sharing their problems with someone?

RES
I think that's a quarter of the battle really, I think there's a lot of other stuff, stimulation as well as talking about it with other people, mixture of drugs, therapy.

QU
So in a sense that people need a package of various things which would include talking, which would include medication, include the kind of activities, stimulations, activities and therapy.

RES
Yes.
Medication, then, was only rarely believed to be sufficient in itself and a number of respondents believed a combination of medication and more socially orientated interventions, particularly talking, was essential. This again relates back to beliefs that invoke both biological and social factors in causing severe mental illness, and indeed it is in these accounts that this proposed package of care was most evident. The following, for example, is from an interview in which the respondent believed mental illness was the product of a combination of nature and nurture:

1218: Line 641 – 646 (Patient, White, Male)
QU
When someone is mentally ill what or who helps them to get better?
RES
It can be a combination of drugs and therapy. Although in some cases you have to wait for the drugs to kick in.

Beliefs in the benefits of medication, even within the context of other interventions, were not universal and some patients were sceptical or anti medication. These beliefs ranged from ambivalence (“It can help, it may not ... I personally don't like drugs and medication but it can help. I don't know how but they do.” (1182: Line 387-388, Patient, African-Caribbean, Female)) to rejection (“They can talk to you and talk to you but after all that talk they're gonna give you medication. And I don't agree with that, I don't like that at all.” (1189: Line 422-423, Patient, African-Caribbean, Female)). Again, some of those who rejected the idea that medication could help did so on the basis of personal experience:

1246: Line 626 – 639 (Patient, African-Caribbean, Female)
QU
Any other types of medication other than medication to help you sleep?
RES
I can only comment on the medication that I was given.

QU
You don't think that helped at all?
RES
Not at all because I am very clever and I took note of what the medication was doing to me and I knew that I didn't need the medication in the first place from the time that I was in there but I was pumped full of procyclidine, haloperidol, risperidone, zopiclone, etc., I was on a cocktail of drugs.

When considered by ethnic group, unlike with general beliefs about the potential role of medical professionals, there was a greater number of Whites who believed medication was beneficial compared to African-Caribbeans (41 (82.0%) v. 16 (40.0%), $\chi^2$ 16.8, df 1, $p < 0.01$). This is striking. While overall positive attitudes towards medication were found, in over 50% of African-Caribbeans medication was not believed to be beneficial. Evidently, while many African-Caribbeans believed the medical profession had a role in the treatment of severe mental illness, fewer believed this should involve the prescription of medication. This suggests that a sizeable minority believed the medical profession was helpful, but either had no clear idea in what way – other than that it was not to provide medication – or only in terms of providing specialist talking therapies.

*Where should treatment take place?*

When asked about whether treatment should be provided in hospital or in the community, the majority believed that time in hospital had a role, albeit often only on certain conditions. There were some respondents who believed that hospital was a first resort, the only place for people who had a severe mental illness (n = 22 (24.4%)). This was occasionally based on a conceptualisation of severe mental illness as visible disturbance and aggression or violence:

Patient, African-Caribbean, Female

Q: Do you think that someone should remain at home, stay in the community rather than going to hospital?

R: That's a hard one. After listening to one or two things I've seen on TV, someone who's schizophrenic and has murdered people they can be in the community but they should be with someone who knows how they are. I do not think that someone who is schizophrenic should be allowed to walk freely amongst anybody, among children...

In such cases the rationale for hospitalisation appears to be more one of containment and protection than of help and care, as in the following example:
In such accounts there is at least the implication that severe mental illness is of a nature that it will always provoke the types of behaviours that require containment, that the public need to be protected from. The other main reason given by respondents who believed hospital was always appropriate was that it provided a respite from the problems that had caused severe mental illness, it was seen as a place of rest, as a sanctuary from the "cruel world" (1246: Line 594, Patient, African-Caribbean, Female).

For those patients who did not believe all instances of severe mental illness required hospital admission, the major determinant of need for hospital admission was the level of risk posed by the sufferer to others. That is, many patients believed hospitalisation was only
necessary in cases where the sufferer was threatening or violent. The following is fairly typical:

1182: Line 351 – 359 (Patient, African-Caribbean, Female)

QU
Why wouldn't going to hospital help?

RES
It wouldn't help because ... it all depends on that person's mentality first, if they are going out to harm people they should be hospitalised or if it just a minor mental health problem they don't need to be because hospitals are depressing places. If someone is to get better they are not to be stuck in an institute or wherever.

Here hospital is not considered to be a therapeutic environment and recovery is only possible outside of an institution. The hospital is reserved for those who are “going out to harm people”. This belief is similar to that in which hospital was always believed to be necessary, the difference being that this perspective does not require a necessary connection between violence and mental illness. Simply, mental illness can result in violence, and it is at these times that hospital is necessary. Within these accounts, as seen in the example above, there are two ideas about the nature and utility of hospital care: 1) hospitals are not the best place for people with a severe mental illness; and 2) hospitals are useful to contain people with a severe mental illness who become violent. Related to this, a smaller number of patients focused on severity of illness as the key factor determining whether hospital admission was necessary and helpful (n = 5), though this was often expressed in vague terms (“Depends on how bad they are” (1352: Line 826, Patient, African-Caribbean, Male)). Severity was also occasionally equated with violence.

Those respondents who did not believe hospital should invariably be a resource for the treatment of severe mental illness, and who did not believe violence or severity were the factors determining when hospitalisation should be used (n = 23 (25.6%)), revealed a number of different contingencies that distinguished those requiring hospital treatment from others, including: crises (n = 1); unable to function (n = 3); poor self-care (n = 2); refusal to take medication (n = 2); and harm to self (n = 4). For 3 respondents hospital was a last resort to be used when no other means of treatment were available (“If there’s nobody then it’s the hospital” (1220: Line 1150, African-Caribbean, Female)) and 6 respondents rejected hospital all together, saying that treatment should be provided in the community. The basis for this is that the hospital is again seen as a non-therapeutic environment, as illustrated in the following two segments:

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Beliefs about appropriate treatments for severe mental illness reveal two notable patterns among the groups of respondents. Firstly, there are clear ethnic differences, as outlined above. Secondly, these differences persist across the three groups – patients, relatives and community respondents. This is perhaps surprising, as it suggests the initial contacts that patients and relatives have with mental health services have at most a limited impact on what sources of help are believed to be the most appropriate. Once again, patient beliefs can be seen as reflecting those evident both across generations and in the wider community.

9.4.4 Typologies

The key issue here is the question of whether professional mental health services are perceived to be helpful for those with a severe mental illness. The data presented here shows clear differences between respondents in the degree to which such services were perceived to be appropriate and effective, and in the types of alternatives to professional help that respondents identified. Amidst the diverse range of beliefs it is possible to delineate three types of beliefs regarding professional services and medical treatments: 1) those that were
positively, and primarily orientated towards professional services; 2) those that were orientated towards a range of treatment options, including professional services; and 3) those that were orientated primarily towards non-professional services. The characteristics of these three belief types are outlined in Table 9.11.

Table 9.11. Typologies: treatment of severe mental illness.

<table>
<thead>
<tr>
<th>Type of Orientation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional orientation</td>
<td>The specified treatment options are either professional services as a first resort or a second resort after talking to family or friends, and include positive attitudes towards medication</td>
</tr>
<tr>
<td>Mixed orientation</td>
<td>The specified treatment options include a range of interventions or responses located in all three health care sectors, and include professional services</td>
</tr>
<tr>
<td>Non-professional orientation</td>
<td>The specified treatment options are non-professional and fall into either the popular or folk sectors, and include negative attitudes towards medication</td>
</tr>
</tbody>
</table>

Once again the utility of summarising beliefs in this way is to allow ready comparisons, at a fairly general level, between groups according to the key characteristics of beliefs that may influence help-seeking and interactions with mental health services. Table 9.12 compares these belief types by ethnicity.

Table 9.12. Types of treatments by ethnicity.

<table>
<thead>
<tr>
<th>Type of Orientation</th>
<th>White Community Respondents n = 50</th>
<th>African-Caribbean Community Respondents n = 40</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Professional orientation</td>
<td>33</td>
<td>53.5</td>
</tr>
<tr>
<td>Mixed orientation</td>
<td>13</td>
<td>32.1</td>
</tr>
<tr>
<td>Non-professional orientation</td>
<td>3</td>
<td>10.7</td>
</tr>
<tr>
<td>No clear orientation</td>
<td>1</td>
<td>3.6</td>
</tr>
</tbody>
</table>

The differences between the predominant orientations of respondents towards treatment options, by ethnicity, are striking. African-Caribbeans were significantly less likely to believe treatment should be undertaken predominantly by professional mental health services (9 (22.5%) v. 33 (66%), 16.89, df 1, p < 0.01).

9.5 CONCLUSIONS

This chapter has presented and discussed data concerning beliefs about mental illness collected from African-Caribbean and White patients, relatives and community respondents. This section aims to pull together the salient findings, revisiting the first two research
questions set out at the beginning of Chapter 8, and preparing the way for consideration of the final study question in the next chapter.

9.5.1 General Conclusions

The data collected for this stage of the study revealed a wide ranging, complex and sophisticated set of beliefs among patients, relatives and community respondents. In terms of the overall coherence of accounts, there were examples both of interviews in which responses were inconsistent, fragmented and lacking coherence and of interviews in which respondents presented complex, coherent and sophisticated accounts of mental illness.

Across all the areas considered, a number of general themes emerged that were evident in the accounts of respondents from both ethnic groups. In relation to terminology, colloquial terms, such as mad and crazy, and psychiatric terms, such as mental illness and mental disorder, predominated, with the majority of respondents viewing severe mental illness in terms of disturbed behaviour that was often threatening and bizarre. In relation to causes, the most salient themes were those implicating social factors in general and stress in particular. These themes were virtually ubiquitous, signifying an important commonality between accounts. The emphasis on social adversity in various forms as a key cause of severe mental illness mirrors much previous research both in relation to ill health generally and mental health in particular (Furnham & Rees, 1988; Blaxter, 1983; Snow, 1983). Indeed, it was this persistence of beliefs in the social aetiology of mental illness that Jorm (2000) identified as a target for mental health literacy campaigns designed to educate the lay public of the biological roots of severe mental illness. What this study demonstrates is how ingrained and pervasive such beliefs are across cultural groups. The interest here, however, is not with the legitimacy or feasibility of modifying lay beliefs, but more with the responses and treatment options they give rise to and underpin. The previous research that has considered lay beliefs about mental illness among western populations has been dominated by the use of structured questionnaires and statistical analysis. Undoubtedly, this has obscured the sophistication of lay beliefs, and what has emerged from the data collected in this study is that the general belief that social factors cause severe mental illness may hide greater variations in how such factors are believed to cause mental illness, with their impact often being held to depend on a number of factors that may increase or reduce vulnerability, such as genetic predisposition and supportive social networks. It is in these areas that differences between respondents were most evident.

There has been much previous research considering attitudes of the lay public towards people with a mental illness, most of it indicating the existence of widely held negative attitudes (Crisp et al, 2000; Bhugra, 1989). Few, if any, have considered the attitudes of people with a mental illness. There has been some research suggesting that
proximity to and/or contact with people with a mental illness promotes more positive attitudes (Wolff et al, 1996a; 1996b; Malla & Shaw, 1987), and from this perspective, it could reasonably be expected that those diagnosed as mentally ill and their relatives would have more positive attitudes than those evident in the wider community. This was not borne out in the data. Respondents across all groups most commonly expressed mixed attitudes with no clear pattern in terms of the situations provoking negative or positive responses. That said, the continuation of negative attitudes, particularly related to beliefs linking violence and mental illness, among both patients and relatives, as well as community respondents, was striking. One interpretation of this is that both patients and relatives, being at an early stage of coming to terms with the experience of a psychotic illness, held on to long-established attitudes and by doing so distinguished themselves or their close relative from the "properly mentally ill".

In relation to treatment, the three key themes that were common across all groups were: importance of family and friends, importance of talking, and need for medical help at some stage. The belief that people could be helped to recover through the giving of informal support and talking, usually by relatives and friends, was again almost ubiquitous in accounts. This ties into beliefs that mental illness results from social and interpersonal difficulties, such that improvement is possible through the support of others who can help individuals cope more effectively with the travails of life. While this was, for the majority, the most desirable response, at least initially, if this, or indeed other strategies, should fail to bring about any improvement then recourse to professional medical services was considered appropriate. There was, however, only a limited understanding by most respondents of what these medical services could offer, beyond the prescription of medication, and a significant number were sceptical of the utility of medication despite believing professional mental health services had a potential role to play. As for location of treatment, very few believed that this could or should always take place in the community, with a majority believing hospital admission formed a crucial component of a package of care, particularly if a sufferer was violent, but also as a place of respite, a last resort and so on.

There were, then, clearly a number of commonly held beliefs that spanned the two ethnic groups and different generations. Alongside this there were also notable ethnic variations. Before summarising these, it is important to acknowledge that, in its focus on ethnicity, the analysis has neglected the issues of gender and social class. During the analysis, respondents were grouped by gender, but no striking differences emerged that overrode those evident between ethnic groups or which suggested the observed ethnic differences were largely a function of gender. In relation to social class, the White respondents, across the full sample, were more likely to be employed and better educated than the African-Caribbean group, both crude proxies of higher socio-economic status. Again,
however, the beliefs documented in this chapter were not patterned according to these respondent characteristics in any obvious way. That said, these characteristics were not at the forefront of the analysis and it may be that future research needs to pay more attention to these factors. With these caveats in mind, differences between ethnic groups can now be considered.

9.5.2 Ethnic Variations

Terminology and Signs

The key differences in relation to terminology and signs are shown in Box 9.1.

Box 9.1. Summary of key differences between African-Caribbeans and Whites in relation to terminology and signs.

- African-Caribbeans used terms derived from psychiatric discourse less often than Whites
- African-Caribbeans held more singularly behavioural conceptualisations of severe mental illness than Whites, who more often incorporated emotional states and psychiatric discourse into their conceptualisations
- African-Caribbeans more often linked violence and mental illness than Whites, a difference that further underscores the more general difference noted regarding conceptualisations
- African-Caribbeans less often believed that madness, craziness, or the like was an illness than Whites

Each of these differences point in the same direction. That is, each suggests that African-Caribbeans more commonly conceptualise severe mental illness in terms of outward visible disturbance and likely violence, suggesting a harsher view, with a higher threshold for the types of behaviours and disturbances signifying severe mental illness. Conversely, African-Caribbeans were less likely to view mental illness in terms of emotional disturbance or as an illness requiring medical intervention, a perspective further reflected in the much less frequent use of psychiatric discourse among African-Caribbeans compared to Whites.

Causes

The key differences in relation to causes are shown in Box 9.2.
Box 9.2. Summary of key differences between African-Caribbeans and Whites in relation to causes.

- Overall, social factors were the ones most commonly identified by respondents across the ethnic groups, and both psychosocial and structural-situational factors were usually posited equally as examples. A small number of patients did clearly implicate structural-situational factors above others, often referring to the “system” as the cause of severe mental illness. All of these respondents were African-Caribbean (n = 8).

- The majority of respondents who believed social factors played a central role in the aetiology of severe mental illness further believed the key mechanism linking social and interpersonal factors and mental illness was stress, conceptualised either as increasing pressure or worry/thinking too much. While the number conceptualising stress as worry/thinking too much was relatively small, it was more common among African-Caribbeans, particularly first generation respondents, and shared much with beliefs documented in the Caribbean of “studiation madness”.

- African-Caribbeans were much less likely than Whites to believe biological factors were key potential causes of severe mental illness. This means that African-Caribbean models of the causation of severe mental illness were almost invariably social. In contrast, White respondents often believed both social and biological factors were important, many linking the two into coherent accounts that, in outline, resembled bio-psycho-social models evident in academic and clinical psychiatry.

- Spiritual/supernatural beliefs were the least common across all groups. However, among African-Caribbeans there was a much greater familiarity with, and acceptance of, wider cultural beliefs linking obeah and madness. Were this a quantitative study, this may have resulted in the conclusion that a major point of difference between the two ethnic groups was in the sphere of spiritual/supernatural beliefs. However, in only a small number of mainly older and first generation African-Caribbeans were these beliefs strong and coherent enough to suggest they might impact on health behaviour. The majority, while aware of obeah, in fact expressed ambivalent or sceptical views regarding the capacity for such forces to cause severe mental illness.

In terms of believed causes, the key difference between the two groups, then, was in the extent to which biological factors were believed to play a role. African-Caribbeans more often believed that severe mental illness originated in the social world, either from interpersonal interactions and/or structural-situational factors, or, less often, in the supernatural or spiritual realm. If beliefs about illness were plotted on a continuum from spiritual/supernatural through social to biological, then it is evident that African-Caribbean beliefs more often fall towards the spiritual and social ends of this continuum. Within professional psychiatry there are ongoing controversies about the aetiology of severe mental illness, though it is fair to say that these debates take place within a broad bio-psycho-social framework, in which the role of both biological factors and psycho-social factors is accepted, the dispute being about the relative contribution of each. To the extent that White
respondents more often posited both biological and social factors, often within a coherent framework, these beliefs share much more in common with psychiatric discourse. The distance from psychiatric models of the causes of severe mental illness is therefore less, across the groups, among White than among African-Caribbean respondents. Considered another way, the accounts of African-Caribbeans more often located the causes of mental illness in factors external to the individual – the structural-situational or supernatural realms, in contrast to Whites whose accounts more often invoked factors internal to, or within the control of, individuals – genetics, biology, and interpersonal interactions. In broad terms, then, these findings map on to previous research suggesting White western beliefs are more internalised (Helman, 1994; Young, 1976). In so far as psychiatric accounts of mental illness are individually focused, these more readily fit with the general way in which White respondents in this study accounted for the onset of severe mental illness. This should not be overstated, however. Littlewood (1988) has commented that “... in the absence of any developed ethnopsychiatry of Western Europeans, we may doubt whether ‘popular’ Western notions of madness are especially biomedical ...” (p. 70). While data from this study suggests that a sizable proportion of White respondents conceptualise severe mental illness and its causes in ways that resemble those common in psychiatry, there is still a significant number who hold predominantly social beliefs, which overlap with psychiatry less.

**Social Distance**

The key differences in relation to social distance are shown in Box 9.3.

**Box 9.3. Summary of key differences between African-Caribbeans and Whites in relation to social distance.**

- Overall, respondents in all groups expressed predominantly mixed attitudes towards those with a severe mental illness, negative or positive attitudes depending in individual cases on the situation described. Within this, African-Caribbeans were more likely to express negative attitudes than Whites, these attitudes often arising from the perceived link between violence and mental illness.

The finding that African-Caribbeans more often held negative attitudes towards those with a mental illness is not surprising given that they also more often conceptualised severe mental illness in terms of behavioural disturbance. This supports what has been previously suggested that African-Caribbeans more heavily stigmatise severe mental illness than do Whites, though this is within the overall context of high levels of stigmatisation across all groups.

**Treatment**

The key differences in relation to treatment are shown in Box 9.4.

- African-Caribbeans were more often sceptical about the potential value of medication in treating people with a severe mental illness.
- African-Caribbeans more frequently believed that sources of help located in the folk or traditional sector were valuable, particularly those related to religious faith and practice.
- Paradoxically, African-Caribbeans more often believed that people with a severe mental illness should be admitted to hospital. This is understandable when it is considered that admission to hospital was frequently believed to be necessary for containment rather than for its therapeutic potential, a belief that ties in with the harsher conceptualisations of severe mental illness among many African-Caribbeans.

The key difference between African-Caribbeans and Whites, then, in terms of preferred treatments or interventions, is that African-Caribbeans believed more in the therapeutic benefits of sources of help located in the popular and folk sectors and saw psychiatric institutions as primarily places of containment for those who were violent and/or threatening. White respondents, on the other hand, believed that popular sources of help were important, but more often believed the next step, for therapeutic benefits, particularly medication, was to professional medical and psychiatric services.

9.5.3 Research Questions

The striking feature of the accounts of severe mental illness elicited for this study was the similarities between patients, relatives and community respondents, both in terms of the range of beliefs elicited and the patterning of beliefs between the two ethnic groups. This is such as to strongly suggest that the beliefs of patients are derived from and rooted in the wider communities. There is no evidence that patient beliefs were substantially shaped either by the illness or initial contacts with psychiatric services. Indeed, in only one area is it possible to say there was a clear difference, i.e. in beliefs relating substance misuse to severe mental illness. This is not a trivial difference, as it suggests those within sufferers' social networks and wider communities may more frequently interpret the early signs of illness as the consequences of substance abuse and respond morally and punitively rather than sympathetically. However, the overall similarities increase confidence in the conclusion that the accounts elicited from patients are indicative of the cultural notions of severe mental illness prevalent among their respective communities and which guide and shape interpretations of, and responses to, experiences of severe mental illness.
The data and discussion presented in this chapter relate to the first two questions set out at the beginning of Chapter 8. From the summary and conclusions outlined above it is clear that, in relation to the first question, the beliefs of African-Caribbeans and Whites did, on a group level, differ. Of course, a number of African-Caribbeans held beliefs that were indistinguishable from the majority of White respondents and vice-versa, such that this general conclusion has to carry the important caveat that it relates to the group and does not hold for all respondents. This emphasises the variability of beliefs about illness among any group of respondents and further serves to temper any rush to link such beliefs with action.

Awareness that potential variability within, as well as between, groups, particularly cross-generationally among African-Caribbeans, underpinned the second research question, that asked whether beliefs about mental illness differed among African-Caribbeans according to place of birth and age. The answer is yes and no. While there were many commonalities in beliefs across generations, a small number of older, first generation African-Caribbeans held very distinctly Caribbean beliefs in which madness was accounted for by two parallel narratives, one of pressure and thinking too much and the other of obeah and spiritual factors. These beliefs about causes, moreover, gave rise to distinct ideas about appropriate treatments: on the one hand, talking or self-help, and on the other, recourse to an obeah doctor or more generally faith and God. Among younger and some of the older African-Caribbeans, there were clear residues of such beliefs, though these had been fused with beliefs derived both from the dominant culture of the UK and their socio-structural position.

Having examined the beliefs data and addressed two of the questions proposed for this stage of the study, the next chapter draws both stages together and addresses the final question: Do the beliefs evident among African-Caribbeans and Whites bear any relationship to the patterns of pathways to, and modes of contact with, mental health services observed in the first stage of the study?
CHAPTER 10

BELIEFS ABOUT MENTAL ILLNESS AND PATHWAYS TO CARE

The Cultural Context of Help-Seeking
The overall objective of this study is to assess the potential role of beliefs about mental illness in shaping pathways to care among African-Caribbeans and Whites with a first episode of psychosis. To achieve this, this chapter seeks to relate the findings from the second stage to those from the first, addressing specifically the final research question: Do the beliefs evident among African-Caribbeans and Whites bear any relationship to the patterns of pathways to, and modes of contact with, mental health services observed in the first stage of the study? This question is addressed in this chapter at two levels, the community and the social network/individual. Some preliminary comments relating to this are necessary.

It will be recalled that two primary conclusions were drawn from the literature reviewed in Chapter 3, namely that:

1. Mode of contact with psychiatric services is the outcome of a social process, involving a series of decisions made in the context of the sufferer’s social network and the wider health care system.

2. Culturally shaped beliefs about mental illness are central to the whole process, influencing decisions made at each stage on the pathway to care.

Further, two specific frameworks for the study of health service use were discussed, the Network Episode Model (Pescosolido & Boyer, 1999) and the Health Care System (Kleinman, 1980). Both emphasise the importance of conceptualising help-seeking as a process, though it is in Kleinman’s model of the Health Care System that the importance of beliefs about illness are emphasised and in which the wider social and cultural context is conceived as setting the parameters within which help-seeking takes place. This makes Kleinman’s (1980) model of the health care system, as an interconnected cultural system incorporating all health related beliefs and activities in specific cultural contexts, a particularly useful model for considering the relationship between beliefs about mental illness and pathways to care (see Chapter 3, p. 62 and Figure 3.3). Indeed, the beliefs data presented in the previous chapter can be viewed as providing a window into the popular health care sectors of two broad ethnic communities, Whites and African-Caribbeans. As Kleinman (1980) notes, the popular sector “... can be thought of as a matrix containing several levels: individual, family, social network, and community beliefs and activities”, and “... when people resort to folk or professional practitioners, their choices are anchored in the cognitive and value orientations of the popular culture” (p. 50). Kleinman (1980) goes on:
“In the popular sector, individuals first encounter disease in the family. We can think of the following steps occurring, at least initially: perceiving and experiencing symptoms; labelling and valuating the disease; sanctioning a particular kind of sick role …; deciding what to do and engaging in specific health care seeking behaviour; applying treatment; and evaluating the effect of self treatment and therapy obtained from other sectors of the health care system. The sick person and his family utilise beliefs and values about illness that are part of the cognitive structure of the popular culture” (pp. 51-52)

Beliefs about illness, rooted in popular cultures, are thus integral to the whole process of making sense of, and responding to, unusual experiences and behaviours, setting limits on what is and is not possible. How far such beliefs, embedded in what Kleinman (1980) terms the “cognitive structure of popular culture” (p. 52), overlap with and relate to those of the folk and professional sectors will, consequently, have a bearing on the extent to which help is voluntarily sought from services within these sectors. That is, the greater the congruence and overlap between the popular and other health care sectors, the greater the points of interaction, making entrance easier. In relation to this study, it is possible to address this issue of congruence directly, posing the question: to what extent do the popular sectors of African-Caribbeans and Whites, as embodied in accounts of beliefs about mental illness, overlap with the folk and professional sectors? Examining the extent of congruence between the different health care sectors, thus allows consideration of whether help-seeking patterns at a group or community level, observed in the first stage of the study, reflect differences in beliefs about illness. This is the focus of the first section of this chapter. Building on this, the second section goes on to look directly, through individual cases, at the role of beliefs in shaping the pathway to, and mode of contact, with mental health services.

10.1 THE CULTURAL CONTEXT OF HELP-SEEKING (1): The Community Level

The key points of divergence between the beliefs of African-Caribbeans and Whites are all such as to suggest that early help-seeking from, and voluntary engagement with, professional mental health services are less likely among African-Caribbeans. That is, the points of overlap and interaction between the popular sector of African-Caribbeans, as signified by elicited accounts, and the professional sector are smaller and fewer than for Whites. These differences can be discussed under two headings: 1) severity and stigma; and 2) divergences from psychiatry. Inevitably, in exploring this question, it is necessary to reiterate some of the findings outlined in the previous chapter.
10.1.1 Severity and Stigma

One of the key differences noted in the previous chapter was that African-Caribbeans more often conceptualised severe mental illness in terms primarily of visible behavioural disturbance and more often linked violence and mental illness. This more severe conceptualisation of mental illness was paralleled both by more negative attitudes and a more frequent belief that those who were severely mentally ill should be contained in institutions to protect the public. Such beliefs may shape interpretations and responses in at least two ways.

Firstly, a more severe conceptualisation of mental illness raises the threshold of disturbance required before someone is considered to be "mad" or mentally ill. The potential consequence of this is that early indicators of mental illness – for example, social withdrawal, suspiciousness, lack of attention to personal hygiene, and even hallucinatory experiences unaccompanied by frank behavioural disturbance – are interpreted outside of the framework of "madness" or mental illness. Based on the data discussed in the previous chapter, two alternative explanations for these early symptoms are possible. On the one hand, particularly from the perspective of the sufferer, changes in mood and unusual experiences and behaviours, such as feelings of paranoia or hearing voices, may be interpreted as the product of stress or social or interpersonal adversity. The appropriate response is seen to be the alleviation of stress through various means, including recourse to family and friends and to healers and therapists operating in the folk sector. On the other hand, and this time particularly from the perspectives of others in the sufferer's social network or the wider community, it may be that the early signs of severe mental illness are more often interpreted within a moral frame, as bad behaviour, or as the result of drug use. One of the African-Caribbean community respondents was particularly aware of this latter possibility:

5014: Line 262 – 269 (Community Respondent, African-Caribbean, Female)

RES

Well young West Indian people a lot of them are experimenting with drugs, so basically the majority of young people like teenager and or older, say 30 something, if I see them acting a bit mad I just automatically think it's a possibility they've been messing with drugs and West Indian people from what I know it's mainly the weed they smoke and some of them into smack and other drugs, I'm not very knowledgeable on all the types of drugs and thank God my four children as far as I know they're drug free and they're functioning normally.

It is particularly noteworthy here that one of the few differences between relatives and patients was that relatives, across both ethnic groups, more often believed mental illness could be caused by drug use. The implications of such beliefs are obvious. Gradual, subtle changes
in personality and functioning are more likely to be perceived as the result of intentional
behaviour requiring moral and punitive responses. Only when behaviour becomes grossly
disturbed is it likely that outside agencies will become involved, at which point the likelihood
of police involvement and contact with services being compulsory are substantially increased.
The possibility that African-Caribbean families and others within the community respond to
the early signs of severe mental illness in such a way as to make both police contact and
compulsory admission more likely was raised by Harrison et al (1989) some time ago (see
Chapter 2). They suggested that family members, interpreting unusual behaviours within a
moral framework, more often tended to distance themselves from the sufferer, isolating them
and increasing the risk that the pathway to care would be negative. The data for this study
both supports the assertion that African-Caribbeans more often require frank behavioural
disturbance before mental illness is considered and intentional behaviour ruled out, and
suggests that this does work, in some cases, to delay contacts and make adverse pathways
more likely (see below).

Secondly, the more severe and perhaps harsher conceptualisation of mental illness
that is common among African-Caribbeans underpins the considerable stigma that attaches to
mental illness in this community. Once again Harrison et al (1989) hypothesised that greater
levels of stigma relating to mental illness among African-Caribbeans may be a key factor
underpinning differences in help-seeking patterns, but they did not have data to support either
the suggestion that mental illness was more heavily stigmatised among African-Caribbeans or
the contention that this may underpin pathways to care. The data from this study does relate
to both these questions and broadly supports what Harrison et al (1989) proposed over a
decade ago. It has already been shown that African-Caribbeans in general hold more negative
attitudes towards people with a severe mental illness (see Chapter 9) and a number of
respondents were aware of the severe stigma that attaches to mental illness among this
community, as was clearly articulated by this relative:

2246: Line 53 – 74 (Relative, African-Caribbean, Female)
RES
It's a stigma, mental illness is a stigma or any breakdown like that, hence I also feel,
I'd say the Caribbean on the whole, Afro-Caribbean it's a stigma, it's something that's
not talked about, if it has happened, or if it's happening in family and if it's to the
point where it cannot be hidden that person is more or less ostracised if you know
what I mean.

QU
So there is an attempt to keep it in the home?
This example is instructive both because it emphasises the stigmatisation of mental illness among African-Caribbeans and because it hints at the potential for this to hinder help-seeking and lead to sufferers being ostracised and isolated. Not only this, such stigma may limit voluntary engagement with mental health services because any contact with such services brings with it the label of being mentally ill. Recent research by the Sainsbury Centre for Mental Health (2002) further supports the conclusion that mental illness is severely stigmatised among the Black and African-Caribbean communities, such that willingness to engage with services is eroded. Indeed, fear of mental illness was part of what the Sainsbury Centre have called “circles of fear” that characterise the relationship between African-Caribbeans and mental health services – fear of mental illness, fear of the mentally ill, fear of mental health services and so on.

It is interesting, moreover, that one of the ten factors identified by the Sainsbury Centre research as sustaining misapprehensions and fears on the part of both African-Caribbean services users and service providers was “… a divergence in professional and lay discourse on mental illness/distress” (p. 9), which undermined efforts at successful communication and further reduced willingness to engage voluntarily with services, an issue discussed in the next section.

10.1.2 Points of Convergence, Points of Divergence

The concept of “clinical horizons” was used by Koo (1987) in work with Chinese respondents to distinguish “… the kinds of things that lay … people included within the realm of medicine and illness and the kinds of things that they excluded” (Prior et al, 2000, p. 830). In each of the four areas of beliefs about mental illness considered in the previous chapter – terms and signs, causes, social distance and treatments – African-Caribbeans were more likely to provide accounts that diverged from those, broadly, of clinical and academic psychiatry; that is, they were less likely to view severe mental illness as falling within the “clinical horizon”.

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This was most apparent in three key areas, each of which is considered in relation to their potential impact on pathways to care below.

Concepts: Emotional signs, psychiatric discourse and mental illness
The concepts of mental illness evident in White respondents’ accounts were more often closer to those of psychiatry than were the concepts of African-Caribbean respondents. This was evident in the greater prevalence of emotional signs, albeit within an overall context of low prevalence, the more frequent use of psychiatric discourse, and the almost invariable acceptance that such experiences and behaviours constituted an illness. This is the flip side of the finding that African-Caribbeans held more behavioural conceptualisations. The potential implications of this, similarly, are the converse of those outlined above in relation to the African-Caribbean community.

Firstly, the varied conceptualisations outlined by White respondents are more congruent with those of psychiatry, though for many outward behaviour was still the key defining feature. Perhaps more importantly, the use of psychiatric language indicates both a degree of familiarity with and acceptance of psychiatry that was not evident among African-Caribbeans, a finding that suggests White respondents more often saw severe mental illness as falling within the “clinical horizon”. Importantly, together these findings suggest White respondents did not always require gross behavioural disturbance before the possibility of severe mental illness and the need for intervention from general medical and specialist mental health services was considered.

Secondly, not only is this more likely to promote voluntary help-seeking, both by the sufferer and crucially by others within the sufferer’s social network, it also facilitates communication with mental health professionals. When confronted with psychiatric explanations for experiences and behaviours in the course of seeking help or when in contact with services, these explanations are more congruent and therefore acceptable. This is not to say that the label of mental illness, particularly of schizophrenia, will not be resisted. Stigma, while perhaps not as marked as in the African-Caribbean community, is nonetheless extensive and will no doubt pull in the opposite direction, working against acceptance and engagement. However, there is this potential counter-balance for a significant number of Whites, with psychiatric explanations being more familiar and consonant with their own.

Causes: The role of biological factors
Perhaps the most striking finding from the second stage of the study was that Whites, across all groups – patients, relatives and community respondents – were much more likely than African-Caribbeans to believe biological factors, i.e. brain dysfunction and/or genes, played a potential role in the aetiology of severe mental illness. Further, almost invariably such factors
were posited as potential causes alongside social factors, making many accounts appear similar, at least in outline, to broad bio-psycho-social or stress-diathesis models of severe mental illness; models that are common in clinical and academic psychiatry.

This difference is crucial. The common perception of medicine as primarily concerned with physical illness, as dealing with disorders of the body, means that where distress is believed to arise from social and interpersonal difficulties (or other factors external to the individual), independent of any underpinning biological susceptibility or dysfunction, recourse to medicine is probably less likely. That is, once again, such distress is more likely to be perceived as being beyond the "clinical horizon". That White respondents more often incorporated biological components into their understandings of severe mental illness once again points to a greater degree of overlap with professional theories. Indeed, the conceptualisation of such experiences and behaviours as an illness with an underlying biological cause inevitably points to professional medical services as the legitimate source of help for such problems, including GPs, psychiatrists and hospitals. Perhaps more pertinent, the reverse of this is that those who do not conceptualise such problems as an illness and who believe the causes lie in the external social and/or supernatural realms, beliefs more common among African-Caribbeans, are less likely to seek help from GPs, psychiatrists and so on, and less willing to accept and engage with services once contact is made, by whatever route.

While African-Caribbeans less often believed biological factors were important, the causal factors they did believe were important varied, though the unifying feature, as noted in Chapter 9, is the tendency for causal explanations to invoke factors external to the individual. The majority of African-Caribbean respondents believed severe mental illness was caused mostly by social factors, and while these excluded potential biological causes, they do not intrinsically preclude the use of professional mental health services, a point that is emphasised in the fact that a majority of African-Caribbeans still saw professional services – at some point – as having a potential role to play in managing and treating severe mental illness. There were, however, two noticeable sub-groups whose beliefs imply greater barriers to help-seeking from, and engagement with, professional mental health services.

One group of eight patients believed that structural-situational factors were the key causes, essentially locating the origins of severe mental illness in adverse social and living circumstances; conditions that for ethnic minorities are both worse and compounded by chronic discrimination. There was a sense in some of these accounts that it was societal injustices that caused severe mental illness, injustices that psychiatry contributed to rather than resolved in its pathologisation of distress, particularly Black people's distress. Awareness of this discourse was also evident in the people interviewed for the Sainsbury Centre (2002) research introduced above, such that professional services were often equated with other coercive agencies such as the police and prisons, with the concomitant fear that
services are primarily forces of control rather than sources of therapy. The potential for such beliefs to hinder both help-seeking and voluntary engagement are clear, and will be discussed more in relation to a specific example in the next section. For now it can be noted that such beliefs are characterised more by a distrust of psychiatry and an insistence that distress arising from structural-situational stresses should not be pathologised – both of which are likely to provoke resistance to psychiatric intervention. There is not, however, an obvious alternative strategy for the alleviation of distress, other than recourse to supportive social relations within the popular sector.

A further small group of older, predominantly first generation respondents (n = 4) provided accounts of the causes of severe mental illness that were distinctly Caribbean in their dual emphasis on thinking too much as a source of pressure and cause of madness and on the potential for obeah practitioners to both cause and heal mental illness by harnessing supernatural forces. Once again, such beliefs locate “madness” outside of the clinical ambit, but this time point directly to sources of help located in both the popular and folk sectors – in the case of “thinking madness”, talking to others, and in the case of obeah madness, recourse to an “obeah doctor” or other spiritual healer. How such beliefs shaped the pathways to care of this small group, and how these differed from those of the group briefly discussed above, is considered directly in the next section.

*Treatments: Hierarchies of resort and the role of medication*

Overall, most respondents in both ethnic groups believed that professional mental health services had a role in the treatment of severe mental illness, a finding that, on the face of it, is surprising given that the concepts and causes provided in African-Caribbean accounts point away from recourse to professional services, as outlined above. However, the timing of help-seeking from, and the perceived role of, professional mental health services differed between the two groups in such ways as to again suggest African-Caribbeans are less inclined to voluntarily seek help early from such services. These differences centred on: 1) the timing of help-seeking from professional services; and 2) the value of medication.

It has long been established that the pathway to professional medical services often includes a series of sequential or concurrent attempts to manage and alleviate symptoms by recourse to popular or folk sources of help (Scambler, 1997). That is, sufferers often follow a hierarchy of resort, trying sources of help located in both the popular and folk or traditional health care sectors before seeking help from professional services. Beliefs about appropriate responses to severe mental illness showed that most respondents in all groups believed a number of sources of help should be employed with professional services being involved only when other options failed. Overwhelmingly, respondents believed that the initial resort should be to family and/or friends. However, while White respondents predominantly
believed the next step should be professional help, and indeed often saw the role of family and friends merely as one of facilitating access to professional services, African-Caribbeans almost invariably believed that sources of help located in the folk or traditional sector should be employed, either alongside or after family help, but always before professional services were involved. That is, there was an extra layer of help that was identified more often by African-Caribbeans than Whites, one usually involving religious faith or institutions in some form. Professional services, moreover, were often viewed as a last resort or as a source of containment for the violently mentally ill, rather than as a positive therapeutic option.

It is interesting that while many African-Caribbean respondents identified doctors as an appropriate source of help, albeit after others had failed, only a minority believed medication was valuable in the treatment of severe mental illness, again in contrast to Whites. This is potentially problematic in at least two possible ways. It suggests that those who believed doctors were helpful, but not medication, either had no clear idea of what doctors could do to help or saw the role of doctors as one of providing talking therapies not prescribing drugs. Both possibilities have the potential to impact on help-seeking and influence initial interactions with GPs and psychiatrists. Lack of clarity about what psychiatrists and mental health services in general can do may limit help-seeking from these sources, while the belief that doctors can provide forms of help other than medication – along with a scepticism about the value of medication – has the potential to create conflict in initial interactions between doctor and patient when faced with the reality that medication is the primary means of treatment for people with a psychotic mental illness. In particular, in situations where patients voluntarily seek help or accept help-seeking by family or friends, such initial experiences may undermine willingness to engage, thus increasing the likelihood of compulsory admission. This is particularly relevant given that a small body of research suggests African-Caribbeans are less likely to receive psychotherapies and more likely to receive higher doses of neuroleptic medication (Sainsbury Centre for Mental Health, 2002; Chen et al, 1991; Littlewood & Cross, 1980).

10.1.3 Cultural Differences and Pathways to Care

The differences in beliefs between African-Caribbeans and Whites identified in the second stage of the study – relating to stigma, concepts, causes and treatments – all point to there being greater divergences between the beliefs of African-Caribbeans and those embedded in mental health services than is the case with Whites. Using Kleinman's original model as a template, the differing relationships between the popular, folk and professional health care sectors for each ethnic group can be summarised graphically (see Figures 10.1 and 10.2).
Figure 10.1. *Relationship between different health care sectors: Whites.*

**Popular Sector**
- Lower levels of stigma
- More psychiatric concepts of MI
- More biopsychosocial causes
- Fewer folk/traditional remedies
- More positive attitudes re: medication

**Folk Sector**
- Limited overlap with the popular sector

**Professional Sector**
- Greater overlap with the popular sector

Points of interaction, entrance and exit
Figure 10.2. Relationship between different health care sectors: African-Caribbeans.

- **Folk Sector**
  - Considerable overlap with the popular sector

- **Popular Sector**
  - Higher levels of stigma
  - More severe concepts of MI
  - Fewer biological causes
  - More folk/traditional remedies
  - Greater scepticism re: medication

- **Professional Sector**
  - Limited overlap with the popular sector

Points of interaction, entrance and exit
In summarising the differences between African-Caribbean and White beliefs, and their potential impact on help-seeking, there is again a danger of overstating the degree of homogeneity within the two ethnic groups. To suggest the there are two distinct popular sectors ignores overlaps in health related beliefs and practices among the two groups and it may be more correct to think of a single popular sector incorporating a diverse range of beliefs and practices. To summarise the data in this way, therefore, inevitably simplifies a complex reality. However, the diagrams do capture the points made above and, with the foregoing caveats in mind, can help to summarise the central conclusions that have been made from the data collected for this study. Indeed, these diagrams serve to illustrate the potential effects of the different beliefs evident among the two groups on interactions with folk and professional services. For Whites, the greater overlap with the professional sector makes the points of interaction and entrance greater and more permeable, allowing for earlier and more voluntary contacts with professional mental health services. This is in contrast to the very limited overlap with the folk sector, such that this sector figures to a very limited degree in the range of potential options available to Whites who develop severe mental illness. For African-Caribbeans, the convergence of the popular sector with the professional sector is much less, reducing the common ground that helps to facilitate early and voluntary help-seeking. Alongside this, the folk sector figures much more prominently making this a more natural and accessible source of help. Recourse to the folk sector, moreover, raises a further barrier to early contact with professional services. These diagrams, then, outline the potential influences of beliefs among the two groups on the process of interpreting and responding to the symptoms of severe mental illness. Of course, beliefs that, on the face of it, hinder early and voluntary help-seeking were evident among both ethnic groups, as were those that theoretically promote early and voluntary help-seeking. The point here is that those potentially hindering help-seeking were more prevalent among African-Caribbeans, and to the extent that such beliefs reflect the wider cultural contexts within which help-seeking takes place, they suggest that for African-Caribbeans these contexts are such as to work against recourse to professional mental health services.

The different beliefs, and by extension cultural contexts, of the two ethnic groups are consistent with the patterns of pathways to, and modes of contact with, mental health services observed among the two groups in the first stage of this study. That is, for African-Caribbeans, the greater divergence of beliefs from psychiatry are consonant with the more negative routes to, and modes of contact with, psychiatric services, namely:

- Less frequent involvement of an active help-seeker on the pathway to care
- Less frequent GP referrals
• More frequent police and other criminal justice agency referrals
• Higher rates of compulsory admission

The next section focuses directly on the impact of beliefs on pathways at the family/social network and individual levels.

10.2 THE CULTURAL CONTEXT OF HELP-SEEKING (2): The Family/Social Network And Individual Levels

The focus of this section is on five brief case examples in which the types of beliefs outlined in Chapter 9 and discussed further above evidently influenced the pathway into care in the ways expected, with other examples brought in to support or question what can be inferred from the five case examples. In each, both family/social network and individual beliefs are, to a greater or lesser extent, evident in shaping the interpretation of and responses to symptoms. These cases serve to further illustrate the potential for such beliefs to shape how people from different ethnic groups come to use mental health services, and establish a more direct link in individual cases between beliefs and pathways. The details concerning pathways to care are taken from the Mental Disorder Beliefs Schedule interviews, the Psychiatric and Personal History Schedule and case notes (see Chapter 5).

10.2.1 Not Mad, Just Bad

1230

1230 was a 23 year old, second generation African-Caribbean male, who lived with his mother. His mother (2230) was 65 years old and had been born in Jamaica, coming to England when she was 25 years old. 1230 was admitted to hospital under Section 2 of the Mental Health Act (MHA) 1983 having been brought into contact with services by the police, who were called to his house by his mother, because the patient had “smashed the whole lot [the house]” (2230: Line 61, Relative, African-Caribbean, Female). This crisis situation was preceded, according to the patient’s mother, by a three month deterioration in which the patient was “acting up, acting silly ... acting a bit strange” (2230: Line 53 – 54), a deterioration that was the culmination of approximately three years of increasing social withdrawal. His mother explained the changes in 1230’s behaviour as the consequence of drug use – “I more put it down that he was smoking drugs” (2230: Line 153 – 154) – and consequently when he began to become aggressive and violent she called the police from a neighbour’s house – “When [patient’s name] started you know I had to get the police because ... he started in the middle of the night, the police takes him in” (2230: Line 815 – 816). This is a case
where the role of a significant other within the sufferer's social network is important and in which her interpretations drive the pathway to care. From 2230's beliefs it is clear that, for her, madness is typically characterised by severe behavioural disturbance, does not fall within the "clinical horizon", and that the police are a potential source of help, their purpose being to convey the mad to places where they can be contained.

In this example, behaviours that retrospectively, and from the perspective of psychiatry, can be seen as the beginning of a psychotic episode are interpreted by the patient's mother as signs of drug use. The patient's behaviours are thus made sense of within a moral frame and the need for intervention from mental health services is never considered. This delays contact with mental health services or any helping agency until a crisis ensues, at which point the police are called. It is only at this late stage, when there is clear behavioural disturbance, that the mother considers madness or mental illness to be a possible explanation for her son's behaviour. In this example the sufferer plays no role in seeking help and it is not clear that 1230 believed there was any problem; he certainly resisted admission to hospital once conveyed to the Emergency Clinic by the police, resulting in his admission under Section 2 of the MHA 1983. What is important about this example, for illustrative purposes, is the interpretation of symptoms by the patient's mother, which are such that when her son's behaviour becomes unmanageable, the agency to which she turns is the police. This contrasts with the following example.

1281

1281 was a 19 year old White male, who lived with his mother, step-father and three siblings. 1281 was referred to his local Community Mental Health Team (CMHT) by the Emergency Clinic of the Maudsley Hospital, having been referred there by his GP. 1281's mother (2281) had taken him to his GP following a period of approximately 6 months of increasing social withdrawal, obsessional behaviours and in which his behaviour was reported by his mother to have become increasingly odd. He was treated by the CMHT and not admitted to hospital.

The process of accessing care is much more straightforward in this example than in the previous one. There are both similarities and differences. In terms of age, living circumstances and initial symptoms there are similarities. Both are young men, living with family, who become withdrawn and whose behaviour becomes increasingly unusual over a relatively long period. What is noticeable, however, is the different responses of the patient's mother in each case. In the first the changes in behaviour are attributed to drug use and no

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help-seeking is attempted until a crisis ensues. In the latter the changes in behaviour are considered cause for consultation with a GP, from where referral to psychiatric services is accepted by both the patient and the mother. It is not clear precisely what influences the compliance of 1281 compared to the non-compliance of 1230. It may be that the lead is taken from significant others, such that 1281 is accepting of his mother's interpretations about what help to seek and accept, while 1230 has no lead from his mother. It is interesting that 1230's account of his beliefs is one of the eight in which structural-situational factors were prominent among the perceived causes. It may be, then, that unwillingness to engage with services reflected both the belief that his own difficulties arose from discriminatory social structures and a distrust of authority arising from this, a distrust manifested in resistance to both police involvement and admission to hospital.

In each of these examples, the role of significant others is clear. The data from the first stage of the study showed that having an active help-seeker involved in the pathway was a significant factor predicting more positive routes to care. These examples show that the availability of a supportive social network alone does not ensure active help-seeking by others. While sufferers may live with others, it is how these others interpret and respond to changes in the sufferer's behaviour that is crucial in determining what role they play in facilitating or delaying contact with mental health services. Further, the first example illustrates how such delays can lead to the development of crisis situations in which the police become involved and compulsory admission is more likely.

10.2.2 Not Mad, Just Vexed

1189 was a 26 year old, second generation African-Caribbean female, who lived with her partner and her two children. She had previously been in contact with the Emergency Clinic of the Maudsley Hospital five months prior to the presentation that led to her admission. At that time she complained of feeling depressed. She was prescribed fluoxetine and referred to her local CMHT, but did not attend any follow up appointments and had no contact with services in the intervening five months. She eventually re-attended the Emergency Clinic having been persuaded to do so by her family who were concerned about her behaviour. At presentation her mood was elated and she expressed grandiose delusions. She refused admission and was consequently detained under Section 2 of the MHA 1983. The emphasis in this patient's account of her beliefs is very much on how psychiatry is perceived to pathologise distress and vexation, particularly among Black people, that arises from structural-situational stresses (see Chapter 9, pp. 198-199). She said that she had resisted attending the
Emergency Clinic for fear she would be “given tablets and locked up”, and only did so under pressure from family. In the intervening five months between contact with services for depression and contact for elated mood, 1189 reports having tried a variety of herbal remedies given to her by her mother. She said that she was angry and vexed, but not mad.

This example is particularly interesting because it illustrates a number of important issues. To begin with, the striking feature of this is how the role of significant others in attempting to facilitate access to care ultimately fails in that the patient is admitted under a section of the MHA 1983. The patient’s family, in this case, evidently interpret her behaviour as signifying problems that can be dealt with by professional mental health services. However, 1189 throughout believed that she was “vexed” and did not need medication or to be in hospital, and only attended the Emergency Clinic to appease her family. Further, in the months between contact for depression and contact for mania and delusions, there was evidently an attempt to manage symptoms within the popular and folk sectors through the use of herbal remedies. The involvement of others, as this shows, does not ensure voluntary engagement – other factors are clearly at play.

In this case, the question of what determines the patient’s refusal to accept treatment revolves around whether non-engagement is illness or belief driven. That is, 1189’s refusal to accept that she is mentally ill can be considered either as arising from a lack of insight or as the product of a different explanatory model to that of psychiatry. This brings into focus a controversial debate about the legitimacy of insight as a concept in psychiatry (Johnson & Orrell, 1995; David, 1990); a debate that was discussed briefly in Chapter 2 when considering research that has shown a relationship between lack of insight, crudely measured, and compulsory admission. What is notable about this example is that 1189 accepts that there is a problem, that she is “vexed”, which at least allows for the alternative explanation that unwillingness to accept the interpretations of assessing psychiatrists stems from a conflicting explanatory model. This is further supported when her beliefs are considered. As was described in Chapter 9 (see pp. 198-199), 1189 believes that people do not become mad or crazy or schizophrenic, rather they may become vexed in the face of stresses that primarily arise from structural-situational factors and it is psychiatry that mistakenly pathologises this distress. This set of beliefs, which logically eschew the need for professional treatment, is consistent with her stated beliefs at the time of admission. This consistency suggests, at the very least, that her refusal to accept that she was ill was in part based on her own perceptions of the nature of such problems. It may be that such a perspective emerged to some degree in the course of her experiences, and in part as a consequence of interactions with psychiatry, but this still points away from an explanation of compulsory admission in terms of poor
insight. Indeed, it points towards a somewhat politicised perspective in which Black people, and thus the patient, are both more stressed and vexed and more likely to have such distress pathologised. What is more, the Sainsbury Centre (2002) research discussed above found that while many African-Caribbeans accepted that they were experiencing problems, they did not see these as medical. To dismiss these alternative accounts as due to poor insight may compound feelings that services are unresponsive and irrelevant, further reducing willingness to engage.

It is interesting, leading on from this, that of the eight patients whose causal beliefs were dominated by structural-situational factors, five were compulsorily admitted, two of whom have already been discussed (1189 and 1230). In three of these cases (1220, 1266 and 1352) family were involved in bringing the patient into contact with services, but it was reluctance to engage on the part of the patient that necessitated compulsory admission. One of these cases (1352) further illustrates how expectations of mental health services and beliefs about what is appropriate in terms of treatment can shape willingness to engage. This is considered next.

10.2.3 Not Medication, Just Counselling

1352

1352 was a 26 year old, second generation African-Caribbean male, who lived with his mother and his two brothers. 1352 was admitted to hospital under Section 2 of the MHA 1983 having been brought into the Emergency Clinic at the Maudsley Hospital by members of his family, who were increasingly concerned about his erratic and unpredictable behaviour. There appears to have been a long period of approximately three years of increasing withdrawal and isolation, followed by a six week period of behavioural disturbance that prompted help-seeking. During the period of withdrawal the patient reports having seen a counsellor on his own initiative, though the details provided were limited. A week before admission to hospital 1352’s family contacted the Emergency Clinic and a home visit was arranged, but the patient was not at home at the time of the visit. Five days later the family took the patient to the Emergency Clinic, though he would not agree to be admitted and at that time he was not felt to be detainable under the MBA 1983. 1352 further deteriorated over the next two days and was again taken to the Emergency Clinic, this time being admitted under Section 2 of the MHA 1983. 1352 saw his problems as stemming from his living environment and lack of work: “I noticed I wasn’t my usual self ... that’s when I thought Jesus this is hell, I’m living in hell and I can’t get out of it ... [got to] get myself a job” (1352: Line 1026-1030, Patient, African-Caribbean, Male). He described the process of help-
seeking and his expectations of mental health services as follows: "My brother came with my cousin and he said we're going to Maudsley, ... because the doctor said to go for the counselling at Maudsley, they will counsel you and the most you stay there for is two days, but, oh no, when I went down there, wasn't it different" (1352: Line 1037-1042, African-Caribbean, Male). Rather than counselling, however, 1352 was given medication: "And medication makes you look mad, makes your body act back that's what medication does, that's what I'm saying, when I get out of here I'm not using the medication, I'm not touching the medication" (1352: Line 1056-1060, African-Caribbean, Male).

This example once again is illustrative of a number of issues. The pattern of a long process of withdrawal and increasing social isolation followed by acute behavioural disturbance, which precipitates intervention, closely resembles the pattern evident in 1230. Unlike in that case, however, family do initiate help-seeking from mental health services. However, the patient's belief that his problems arise from living circumstances and lack of work, for which he believes he needs counselling, are contradicted by the implication of madness or mental illness in the help offered, and then the compulsory treatment with medication and hospitalisation.

10.2.4 Obeah Madness, Thinking Madness: "... doctor can't help them"

1348 was a 32 year old, first generation African-Caribbean female who moved to England from Jamaica when she was 19. Her first contact with mental health services occurred when she was picked up by the police, having been found naked in the street, and taken to the Maudsley Hospital, with clear psychotic symptoms. The duration of untreated psychosis was unclear. In relation to the episode that brought her into contact with psychiatric services, she said that she had felt “different” from November-December 1999 onwards. She also said, however, that she had felt like this before, once in Jamaica around about 1989-1990 and a further time during 1993 when she was in the UK. At the time she was feeling “different” in Jamaica she visited a spiritual woman, “Mother Ramsey”, but received no psychiatric help, and her unusual experiences appear to have remitted. During the 1993 “episode” 1348 said that she was taken by members of her family, the main help-seeker being her husband, to see someone 1348 referred to interchangeably as an obeah man and witchdoctor. This was because her family believed she was “mad”. Again her symptoms remitted, and this time 1348 attributed this to the intervention of the obeah doctor, though she did not
specify what it was the obeah doctor had done. Immediately prior to 1348’s first contact with mental health services, her husband was being investigated by the police, and her husband feared that she, the patient, would inform on him to the police. Because of this she believed that her husband and the obeah man, whom it seems her husband sought help from regularly, worked something against her, to send her “mad” (her words), to stop her talking to the police. Initially, 1348’s family sought help from their Pentecostal Church and then again from the same obeah doctor visited in 1993. This time 1348 resisted this. It is evident that at this time 1348’s mood was elated and following an argument with her husband she was found wondering the streets naked by the police, who transferred her to the Maudsley Hospital Emergency Clinic. She refused to be admitted and so was compulsorily detained under Section 2 of the MHA 1983. This patient provided one of the four accounts of beliefs that can be characterised as distinctly Caribbean. 1348 believed there were two types of madness, each defined according to the causes: “’Cos people that is mad is that someone went to the witchdoctor … and pay money to turn them mad, or some people, for instance, if something went wrong in their life or their family, if they start thinking too hard, that can drive them crazy as well” (1348: Line 197-203, African-Caribbean, Female). The signs were the same for each type of madness: violence, unpredictability, and so on. But one is caused by worries about external pressures, e.g. financial, relationship, etc., and the other is caused by obeah. What is important here is that the appropriate remedy in each form of madness stems from the perceived cause. So for the first type of madness, talking over a period of time is the preferred response, whereas the other form of madness requires the intervention of another obeah doctor to reverse the sorcery that has caused the madness. As 1348 said: “…if someone went to their obeah doctor for you to be mad then you can go back and the obeah doctor will release the madness” (1348: Line 931-934, African-Caribbean, Female) (see p. 241). It is important to note that the patient’s family shared her beliefs and both she and her family attributed her excitability and erratic behaviour, during the episode that led to contact with mental health services, to an enemy who had been to an obeah man to “set her to be mad”.

This is the clearest, and in certain respects the most extreme, example in which the way that madness or mental illness is conceptualised by patients and significant others within their social networks influences the interpretation and response to symptoms. At each point, the beliefs of the patient and her family and friends work against recourse to professional mental health services: madness is beyond their “clinical horizons”. What is particularly remarkable about this example is that there appear to have been two previous psychotic episodes that
were dealt with within the folk sector, both times by practitioners styled as spiritual healers or obeah doctors. It is only when such an episode became publicly visible in a UK context that outside agencies, in this case the police, intervened to effect a referral to mental health services, a referral that resulted in compulsory admission.

In three other cases beliefs similar to those of 1348, i.e. distinctly Caribbean, were evident, which raises the question of whether the pathway to care followed by these three patients was similar to that of 1348. This question can be considered in terms of four outcomes: 1) duration of untreated psychosis; 2) recourse to alternative sources of help located in the folk sector; 3) help-seeking from GPs; and 4) compulsory admission. To begin with, each of the three patients experienced long periods of untreated psychosis, over a year, and in one case this was exceptionally long, possibly as much as ten years. It certainly appears that these delays were, at least in part, a product of the way in which experiences were conceptualised. Both 1204 and 1354 attributed their experiences to the interjection of supernatural forces and sought help from a spiritual healer and church leaders, respectively. None of the three patients accessed services via a GP. 1164 was referred to mental health services by social services after they had received a referral from his tenancy support worker due to the appallingly poor state of his flat. 1204 was admitted after attending the Emergency Clinic at the Maudsley Hospital with a friend, after a series of alternative sources of help had been tried, including a spiritual healer. 1354 also attended the Emergency Clinic, this time with her brother-in-law who had paid a rare visit and had recognised her need for help. He was a public health doctor. In each of these three cases admission was voluntary. This serves to emphasise the complexity of the processes underpinning the end outcome of either voluntary or compulsory contact.

In each of the four cases, then, in which patients held distinctly Caribbean beliefs about mental illness, these beliefs played a key role in shaping the pathway to care, in particular serving to delay contact and make voluntary help-seeking from professional sources less likely. In two of these cases others within the patient's social network intervened to bring about contact and facilitate voluntary engagement. This once again emphasises the importance of the lay referral network in determining routes into care. In the case discussed in detail, 1348, the patient's close family and friends shared her beliefs, hindering any possibility of voluntary contacts with professional services. The complexity of the help-seeking process is apparent in these examples. Each suggests that the beliefs of all those involved in the process of interpreting and responding to changes in experiences and behaviour can exert a key influence on when and how contact is made with psychiatric services. That the same beliefs do not necessarily lead to the same outcomes should further serve to temper any generalisations beyond this. However, what is clear from these, and the other examples discussed, is that the beliefs more common among African-Caribbeans —
which diverge more from psychiatry – make accessing professional services more problematic.

10.3 CONCLUSIONS

This chapter set out to address the question of the potential relationship between beliefs about mental illness and pathways to care among African-Caribbeans and Whites. This question has been explored at both a community and family/social network and individual levels. In broad terms, the areas of differences in beliefs between African-Caribbeans and Whites all point towards the conclusion that African-Caribbeans more often hold beliefs about mental illness that inhibit early and voluntary help-seeking from professional mental health services. In terms of Kleinman’s framework, areas of overlap and interaction are fewer, making access less easy (see Figures 10.1 and 10.2). These findings closely parallel the patterns of pathways to care observed among the full cohort of patients included in this study. That is, African-Caribbeans were found to:

1. Less often have an active help-seeker involved in the pathway
2. Less often be referred via a GP
3. More often be referred via a criminal justice agency
4. More often be compulsorily admitted

Patterns, moreover, that would be predicted on the basis of the beliefs data, at a community level. The second part of this chapter, in considering specific examples, illustrated the potential for beliefs to have a direct impact on the timing and nature of help-seeking in the ways expected. These findings all point in the same direction, suggesting that the cultural context of help-seeking exerts a significant impact on observed differences between the two ethnic groups in pathways to care.
CHAPTER 11

CONCLUSION
CONCLUSION

“What alternative is there for Black people who develop mental illness in the UK? Either to subjugate themselves to a failing statutory sector that claims to do the best it can but which is more likely to detain them than their White peers, or to disengage and try to make it on their own – risking forensic service contact.” (Bhui, 2003, p. 11).

Clarifying why African-Caribbeans have a more coercive relationship with psychiatric services is crucial to the development of services and practices that promote engagement and reduce delays in service contacts. Recently, the issue of service provision for ethnic minority groups in the UK has come to the fore, particularly with the NHS Plan and National Service Framework for Mental Health (Department of Health, 1999) placing explicit emphasis on the need for services to be culturally competent and equally accessible to all. Within this policy context, the debate about whether specialist services for ethnic minorities should be established, separate from the mainstream, is particularly relevant and indeed has become more prominent (Bhui, 2003; Sashidharan, 2003; Bhui et al, 2001). While forceful arguments have been put both for and against separate services, this debate is not informed by an evidence base either about what factors influence service accessibility or what can be done to reduce compulsory admissions and promote engagement among members of certain ethnic minority groups. Sashidharan (2003) has argued that: “We are at a critical point in the reform of our mental health services. We cannot afford to miss the opportunity to achieve fair and equal access for all …” (p. 12). Research is crucial to informing this process of reform and, overall, this thesis is intended as a contribution to what has to be a substantial programme of clinically relevant research in this area. This conclusion briefly summarises the findings from each stage of this study, before moving on to consider the limitations of the study and the implications of the research for mental health services and future research.

11.1 SUMMARY AND LIMITATIONS

Data from the first stage of the study once again showed that African-Caribbeans were significantly more likely than Whites to follow negative routes to care (more often without a help-seeker, more often via criminal justice agencies, and less often via a GP) and to be compulsorily admitted to hospital. Considered as a process, it was clear that outcomes at earlier stages on the pathway to care significantly affected outcomes at later stages. So, police and criminal justice involvement and absence of GP referral significantly increased the odds of compulsory admission, independently of ethnicity, suggesting higher rates of compulsory admission among African-Caribbeans were, in part at least, a function of low
rates of GP referral and high rates of police and criminal justice involvement. The data suggested that the role of GPs was particularly important, but that African-Caribbeans were both less likely to seek help from a GP and, when they did, less likely to be successfully referred to mental health services. In short, African-Caribbeans more often followed pathways to care that, at each point, increased the likelihood that admission would be compulsory, a finding that focuses attention on the context within which potential patients experience, make sense of and respond to symptoms. The second stage of the study, in focusing on beliefs about mental illness, offered a way into the cultural contexts of help-seeking among the two broad ethnic groups.

Data from the second stage revealed key differences in beliefs about mental illness between the two ethnic groups, differences that persisted across all respondent groups – patients, relatives and community respondents – suggesting these variations were rooted in broader cultural contexts. In relation to all spheres considered – conceptualisations, causes, social distance and preferred treatments – African-Caribbeans, at a group level, more often held beliefs that diverged markedly from those embedded in mental health services. Considered within the framework of Health Care Systems developed by Kleinman (1980), these differences all suggest that movement from the popular sector into the professional sector is potentially more difficult for African-Caribbeans. That is, the ways in which a significant proportion of African-Caribbeans conceptualise and explain severe mental illness is such that recourse to, and voluntary engagement with, professional services is less likely. Simply, severe mental illness is beyond the “clinical horizon” of more African-Caribbeans than Whites. This is consistent with the patterns of help-seeking and engagement identified in the first stage – absence of active help-seeking, low rates of GP consultation and high rates of compulsory admission. When considered more closely in relation to individual cases, the potential for such beliefs to shape the observed patterns of pathways to care was borne out. All of this points to beliefs about mental illness, and by extension the cultural context, being an important factor shaping differences in pathways to and mode of contact with mental health services among African-Caribbeans and Whites with a psychotic mental illness.

This study has moved beyond previous research in two key respects. Firstly, in attempting to draw on research in the social sciences and, from this, conceptualising the pathway to care as a social and cultural process, this thesis moves away from the somewhat narrow focus of much previous research that simply sought to investigate the contingencies of one end outcome, compulsory admission. Secondly, in utilising qualitative methods and attempting to assess the potential impact of beliefs about mental illness on pathways to care this study has both broadened the methodological tools brought to bear on this issue and considered the impact of the cultural context in considerably greater detail than before.
Related to this, such a detailed study of the beliefs of patients with a psychotic illness is unique in the literature.

There are, however, at least three important limitations to this study and the conclusions that can be drawn, which are set out below:

1. **The pathway as a process**
   While data for the first stage was analysed in such a way as to attempt to capture the pathway to care as a process, the data was still cross-sectional and consequently shared many of the limitations of previous studies. The findings consequently hint at, but do not fully reveal, the processes shaping differences in pathways to care. The second stage of the study did specifically consider the potential impact of beliefs about illness and, by extension, the cultural context in shaping these processes, but more research is necessary that: a) studies pathways and interactions with services over time; and b) focuses more directly and longitudinally, using detailed methodologies, on a wider range of factors, in particular the role of social networks.

2. **Assumptions about the beliefs data**
   A number of assumptions have been made in this thesis about the nature of the beliefs data and what it represents, notably that the accounts respondents give do bear some relationship to beliefs held beyond the interview context and that these accounts offer one means of accessing and researching the cultural context of help-seeking. The validity of such assumptions is the subject of debate (see Chapters 4 and 5) and this should serve to temper the certainty with which conclusions are drawn from this data.

3. **Connecting beliefs and pathways**
   The connections drawn between beliefs and pathways in the final part of the thesis were, to some extent, indirect. The focus was on level of consistency between respondent beliefs, expressed in the interviews, and psychiatric theories and practices, and the potential impact of expressed beliefs on observed patterns of pathways to, and modes of contact with, mental health services. The conclusions suggested from this were supported in individual cases. However, the next step has to be to consider more directly the role of beliefs, also focusing on differences by gender and social class. Thus, again, the findings from this study are suggestive rather than conclusive.

The findings from this study, taking account of these limitations, have implications both for future research and service provision.
11.2 FUTURE RESEARCH

At least three specific avenues for future research are suggested by the findings from this study.

1. Mapping service access and use and associated contingencies over time
   As yet, there are no studies that have considered pathways to, and through, care over time. Most have simply considered all patients, regardless of diagnosis, at one point in time, or, as in this study, have focused on patients with a psychotic mental illness at the point of first contact with services. Thus, the impact of initial contacts with services on subsequent engagement among different ethnic groups remains unclear, and certainly merits further study. The data collected for this study provides potentially valuable baseline data that could be used to supplement longitudinally collected follow-up data and address important questions regarding service use over time.

2. Qualitative studies of specific illness episodes
   This study has considered pathways in relation to a first episode of psychosis and the impact on these of beliefs about mental illness. In order to overcome the limitations that this study does not fully capture the process of help-seeking and to further explore the role of beliefs about mental illness, research is needed that uses qualitative methodologies to consider in detail the processes at work in shaping responses to specific illness episodes, focusing in particular on the role of Explanatory Models and significant others in a patient’s social network.

3. Direct observation of patient interactions with mental health and other services
   Related to the previous suggestion, a particularly fruitful avenue for future research would be direct observations of interactions between patients from different ethnic groups and mental health and other services. The research detailed in this thesis has demonstrated the importance of earlier decisions and outcomes on the pathway to care in determining mode of contact with services. Direct observations of what happens at these earlier points, for example GP and police contacts, and at the end point of contact with mental health services, will further clarify what factors are important in generating the differences in pathways to, and modes of contact with, psychiatric services among African-Caribbeans and Whites.

These suggestions imply a significant programme of future research that both incorporates the perspectives of the social sciences and is methodologically diverse. Indeed, this study should be seen as an initial step in what has to be broad programme of research.
11.3 IMPLICATIONS FOR SERVICES

Given the limitations outlined above, any proposals for service and practice development made on the basis of the data presented in this thesis have to be considered as tentative. Three proposals do, however, appear merited on the basis of the data and can be considered under the headings: points of entry, GP detection and points of interaction.

1. Points of entry

The central conclusion drawn in Chapter 10 was that entry into professional mental health services was more difficult for many African-Caribbeans because of the ways in which severe mental illness is understood within their wider community. This points to the need for services to be developed that facilitate entry into care for African-Caribbean patients. One response to the conclusion that beliefs about mental illness undermine engagement with services is to educate the relevant communities about the nature of mental illness and appropriate responses (Jorm, 2000). The data from this study raise doubts about the potential for literacy campaigns to have an impact where beliefs about illness are so closely tied to wider cultural understandings of health, misfortune and the world. An alternative approach is to develop services that can acknowledge the perspectives of, and work with, African-Caribbean patients. This relates back to the debate about whether specialist services should be developed. In support of specialist services, Bhui (2003) argues that they offer a genuine alternative: "Culturally informed staff develop innovative ways of engaging and working with distressed people from Black and ethnic minority groups ... They focus on personal contact and relationship building in the context of culturally congruent thinking" (p. 11). The key question is whether such services could be developed and integrated into mainstream services or whether they need to stand outside in order to provide a genuinely non-stigmatising alternative that can engage people from ethnic minority groups.

The Sainsbury Centre for Mental Health (2002) has set out two recommendations to facilitate access to services for ethnic minorities that are particularly pertinent here and which hint at a mixture of specialist and integrated service development. Firstly, they recommend "gateway organisations" that can build bridges between the Black community and patients and mental health services. Such organisations could also fulfil a role of providing a first point of contact for Black people experiencing mental health problems, thereby providing an alternative to mainstream services by offering a non-stigmatising, culturally sensitive, point of entry. Given the findings from this study, such a service may serve to both increase willingness to seek help and reduce the potential for misunderstanding and conflict at the point of contact that often leads to the use of
compulsory powers. Secondly, and related to the first recommendation, the Sainsbury Centre (2002) suggest services should take steps to “encourage early access in non-stigmatising or generic community settings” (p. 10). The research conducted for this thesis supports the need for service and practice developments, such as these set out by the Sainsbury Centre (2002), that can more successfully engage African-Caribbeans. The next step from here is implementing and evaluating such services.

2. GP detection and referral

The foregoing implication for service development is broad and the specifics remain to be fully worked out. The finding that African-Caribbeans are not only less likely to seek help from GPs, but are also less likely to be referred to specialist services when they do raises an important issue that has direct implications relating to the ability of GPs to both detect psychosis among African-Caribbeans and to engage such patients in ways that enable successful referral to psychiatric services to be made. This points to the need for improvements in GP training in relation to these issues, particularly in areas where there are large numbers of African-Caribbeans and other ethnic minorities.

3. Points of interaction

Related to GP detection and referral, the data from this study suggested a more general problem in interactions between African-Caribbean patients and mental health professionals. That is, because beliefs about severe mental illness among the African-Caribbean community more often diverged from those that underpin mental health services, the potential for a conflict in the Explanatory Models of African-Caribbean patients and psychiatrists is greater, the potential consequence being misunderstanding and distrust and reduced willingness to engage with services voluntarily. By conceptualising this process of doctor-patient interaction as a coming together of Explanatory Models, one of the factors potentially hindering engagement is clarified. To promote more successful communication Kleinman (1980) suggested that clinicians elicit their patients’ Explanatory Models as a basis for negotiating interventions. The dual benefit of this is to acknowledge the patient’s perspective and to involve the patient in the process of determining the most effective strategy for managing his/her illness. This cannot always be possible, particularly with psychotic mental illness. However, where possible this may help prevent the deteriorations in communication that can lead to the use of compulsion. Bhui & Bhugra (2002), in exploring the potential value of routinely eliciting Explanatory Models, noted the many difficulties that are faced, particularly those of time and resources, and concluded more research was necessary before the case for such routine use could be justified. While this study may not establish such a
justification, it does add weight to the suggestion that their use should, at least, be more seriously evaluated.

The proposals set out here are tentative and significantly more research is needed to move from proposals to implementation and evaluation. It is hoped, however, that this thesis, both in the approach adopted and the data presented, offers one template for the conduct of future research, from out of which mental health services can be developed that fully meet the needs of the African-Caribbean and other ethnic minority communities.


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APPENDIX 1

SUMMARY OF LITERATURE ON ETHNICITY AND PATHWAYS TO CARE
<table>
<thead>
<tr>
<th>Author (Date)</th>
<th>Sample &amp; Data</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Sims & Symonds, 1975 | Sample: All referrals via the police during 1 year (n = 224) (comprising 252 referral episodes) | Ethnicity of referrals over 1 year (population figures are in brackets):  
|                     |                                                                                | 72% (87%) White  
|                     |                                                                                | 10% (2.5%) Caribbean born  
|                     |                                                                                | 2% (0.7%) Asian born  
|                     | Data source: Hospital case register                                            |                                                                                                                                  |
| Hitch & Clegg, 1980 | Sample: All first admissions over a 3-year period (1968-70) of persons resident in Bradford (n = 1130) | 1) Police referral:  
|                     |                                                                                | 3% UK  
|                     |                                                                                | 11% New Commonwealth  
|                     |                                                                                | 10% Foreign  
|                     | 2) Mental Welfare Officer referral:  
|                     |                                                                                | 9% UK  
|                     |                                                                                | 27% New Commonwealth  
|                     |                                                                                | 15% Foreign  
|                     | Data source: Case notes                                                        |                                                                                                                                  |
|                     |                                                                                | 3) Hospital emergency admissions:  
|                     |                                                                                | 34% UK  
|                     |                                                                                | 11% New commonwealth  
|                     |                                                                                | 32% Foreign  
|                     | All of these differences between UK and New Commonwealth patients are significant.|                                                                                                                                  |
| Rwegellera, 1980    | Sample: Patients making contact with psychiatric services over a three-year period (African-Caribbean n = 290; African n = 73) | 1) GP referral to psychiatric services:  
|                     |                                                                                | 61% of Whites referred by GP  
|                     |                                                                                | 49% of African-Caribbean referred by GP  
<p>|                     | 2) &quot;Many West Indians were brought to psychiatric services by Mental Welfare Officers or the police; the rest were self-referred or brought by relatives. The police and Mental Welfare Officers were involved in only very few English cases.&quot; |                                                                                                                                  |
|                     | 3) &quot;There was a strong association between disturbed behaviour and formal admission among West Indian patients (p &lt; 0.0001), which was not found in the English or West African groups.&quot; |                                                                                                                                  |</p>
<table>
<thead>
<tr>
<th>Author (Date)</th>
<th>Sample &amp; Data</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Littlewood &amp; Lipsedge, 1981a (London)</td>
<td>Sample: Consecutive patients with a psychotic illness admitted to hospital (n = 250)</td>
<td>“West Indian and West African schizophrenics were twice as likely to have been admitted under s. 29, 60, or 136 of the 1959 MHA (40% of them) as other ethnic groups in the sample (p &lt; 0.025) or the national average … independent of sex, diagnosis, or religious and paranoid ‘flavour’.”</td>
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<td></td>
<td>Data source: Admissions sheets and case notes</td>
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</table>
| Szmukler et al, 1981 (London) | Sample: All consecutive compulsory admissions over a one-year period (n = 150) Randomly selected group of informal patients (n = 100) Patients were also followed up over 1 year | 1) No ethnic differences in rates of compulsory admission.  
2) Social isolation and dislocation: Compulsory group were more likely to be:  
- Unemployed  
- In transitory accommodation or of NFA  
- Living alone  
- No contact with relative in past 6 months  
- Friendless  
- Not in contact with a social organisation  
3) Use of services: Compulsory group were less often in contact with a GP  
4) State on admission: Compulsory patients were more severely disturbed on most measures, reflecting differences in diagnosis between the two groups. Compulsory patients were more likely to believe they did not need to be in hospital  
5) One year follow-up: Compulsory patients were:  
- More often readmitted, and under section  
- Saw less of GPs  
- Were less likely to attend out-patient clinics  
- Less likely to be taking medication |
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<tr>
<th>Author (Date)</th>
<th>Sample &amp; Data</th>
<th>Findings</th>
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<tr>
<td>Harrison et al, 1984</td>
<td>Sample</td>
<td>GP referral:</td>
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<tr>
<td></td>
<td>203 compulsory admissions over one year in Bristol</td>
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<td>Data Source</td>
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<td></td>
<td>Case notes</td>
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<tr>
<td>Ineichen et al, 1984</td>
<td>Sample</td>
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<tr>
<td></td>
<td>All patients admitted from 4 'immigrant' wards to 3 hospitals covering Bristol</td>
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<td></td>
<td>during 1980 and 1981</td>
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<td>Data Source</td>
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<tr>
<td></td>
<td>Case notes</td>
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<tr>
<td>Fahy et al, 1987</td>
<td>Sample</td>
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<tr>
<td></td>
<td>All s. 136 admissions to an urban (n = 248) and a rural hospital (n = 140) over a 2-year period, and all s. 4 admissions to the urban hospital (n = 91) over the same period.</td>
<td>1) Of all admissions:</td>
</tr>
<tr>
<td></td>
<td>Data Source</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Case notes</td>
<td></td>
</tr>
</tbody>
</table>

| Findings | 1) Total admissions to all hospitals:                                         |                                                                          |
|          | 1980 - 2,352 admissions                                                       |                                                                          |
|          | 1981 - 2,152 admissions                                                       |                                                                          |
|          | 2) Compulsory admissions:                                                    |                                                                          |
|          | 1980 - 153 (6.3%) compulsory admissions                                       |                                                                          |
|          | 1981 - 182 (8.4%) compulsory admissions                                       |                                                                          |
|          | 3) There was a 10-fold difference in rates of compulsory admission between wards. |                                                                          |
|          | 4) Ethnic minority wards had particularly high rates of compulsory admission. |                                                                          |

1) Of all admissions: 7% of urban were s. 136 3.9% of rural were s. 136 2) Ethnicity: In the urban area 25.4% of the population was from the New Commonwealth, but 34% of s. 136 admissions came from this group (27% African-Caribbean) 32% of s. 4 admissions were African-Caribbean.
<table>
<thead>
<tr>
<th>Author (Date)</th>
<th>Sample &amp; Data</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>McGovern &amp; Cope, 1987b</td>
<td>Sample Three samples:</td>
<td>1) Rates per 10,000 for civil sections (i.e. risk of being detained at least once over study period): 11.5 White 69.7 African-Caribbean – Caribbean born 73.6 African-Caribbean – UK born</td>
</tr>
<tr>
<td></td>
<td>(Birmingham) 1) All male patients admitted under criminal sections over 8-year period (n = 67)</td>
<td>2) Differences are most marked for 16-29 group: 8.8 White 148.8 African-Caribbean – Caribbean born 77.9 African-Caribbean – UK born</td>
</tr>
<tr>
<td></td>
<td>2) All male patients admitted under civil sections over 4-year period (n = 217)</td>
<td>3) Rates per 10,000 for criminal sections (i.e. risk of being detained at least once over study period): 3.4 White 41.1 African-Caribbean – Caribbean born 15.2 African-Caribbean – UK born</td>
</tr>
<tr>
<td></td>
<td>3) Alternate informal admissions over 4-year period (n = 574)</td>
<td>4) Differences are most marked for 16-29 group: 3.7 White 90.9 African-Caribbean – Caribbean born 16.4 African-Caribbean – UK born</td>
</tr>
<tr>
<td></td>
<td>Data source Case notes</td>
<td>5) When account was taken of all admissions and diagnosis, differences for civil sections reduced, leading to the conclusion: “The … results suggest the high rate of West Indian detentions can be explained by the excess of admissions with schizophrenia&quot;.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6) The excess of criminal sections does not appear to be explicable in these terms.</td>
</tr>
<tr>
<td>Macmillan &amp; Johnson, 1987</td>
<td>Sample Patients with a first episode of psychosis admitted to nine medical centres (The Northwick Park Study) (n = 253)</td>
<td>“There were no important differences between the police contact group and the non-police contact group in terms of race or mother tongue.&quot;</td>
</tr>
<tr>
<td></td>
<td>Data source Patients, relatives and case notes</td>
<td></td>
</tr>
<tr>
<td>Author (Date)</td>
<td>Sample &amp; Data</td>
<td>Findings</td>
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</tbody>
</table>
| Rogers & Faulkner, 1987 | Sample: All police referrals to 3 places of safety (an emergency clinic, psychiatric hospital and police station) over a two-year period (n = 273 (326 referrals)) | 1) Ethnicity of referrals: 68.9% White 18.3% New Commonwealth  
2) The area where there is a sizeable African-Caribbean population was covered by the emergency clinic. The ethnicity of referrals was: 58.7% White 31% African-Caribbean  
African-Caribbeans form 10.7% of Emergency Clinic catchment area.  
3) During the same period, 18.3% of compulsory admissions made to the hospital served by the emergency clinic were African-Caribbeans. |
| Moodley & Thornicroft, 1988 | Sample: All consecutive patients detained under the Mental Health Act (n = 100) | 1) Violence a reason for admission: 38% White 58% African-Caribbean  
2) Police referral: 0% White 36% African-Caribbean  
3) Admissions to locked wards: 56% White Male 58% White Female 100% African-Caribbean Male 31% African-Caribbean Female  
4) Authors also report data from a one-day census carried out by the Maudsley Hospital showing: 55% of African-Caribbean in-patients were detained compared with 22% of White in-patients |
<table>
<thead>
<tr>
<th>Author (Date)</th>
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<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harrison et al, 1989</td>
<td>Sample Patients with a first episode of psychosis (n = 130) and relatives (n = 82)</td>
<td>1) Compulsory admission: 45% African-Caribbean, 21% General population</td>
</tr>
<tr>
<td>(Nottingham)</td>
<td>Data source Patients, relatives, and case notes</td>
<td>2) Reasons for admission: African-Caribbeans more likely to be perceived as danger to self, and greater incidence of violence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3) Duration of untreated psychosis: African-Caribbeans take longer to get to any helping agency, whereas the period is longer for Whites between contact with first helping agency and psychiatric services</td>
</tr>
<tr>
<td>Author (Date)</td>
<td>Sample &amp; Data</td>
<td>Findings</td>
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<tr>
<td>----------------------</td>
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<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Noble &amp; Rodger, 1989</td>
<td>Sample</td>
<td>1) Total assaults:</td>
</tr>
<tr>
<td>(London)</td>
<td>All in-patients committing an act of violence during a single year, identified from a register of violent incidents at the Maudsley Hospital (n = 137), were compared with a control group (n = 137)</td>
<td>470 (72 subjects were responsible for 405 assaults)</td>
</tr>
<tr>
<td>Data source</td>
<td>Violent incidents register</td>
<td>2) Ethnicity: 16.8% of control group were African-Caribbean 19.8% of those committing severity I offences were African-Caribbean 33.9% of those committing severity I &amp; II offences were African-Caribbean “The tendency for Afro-Caribbeans to commit more serious violence was significant (chi-square = 7.23, p &lt; 0.01)”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3) “There was a tendency for the Afro-Caribbeans to show higher incidences of delusions, hallucinations and schizophrenia, and also more threatening behaviour, and for them to be younger than the Caucasians.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4) Compulsory admission: Violent group 54.3% African-Caribbean 39.3% White Non-violent control group 53.3% African-Caribbean 16.8% White p &lt; 0.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>5) On locked ward: Violent group 37.1% African-Caribbean 15.7% White p &lt; 0.01 Non-violent control group 52.2% African-Caribbean 14% White p &lt; 0.001</td>
</tr>
<tr>
<td>Author (Date)</td>
<td>Sample &amp; Data</td>
<td>Findings</td>
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</tr>
<tr>
<td>Dunn &amp; Fahy, 1990</td>
<td>Sample</td>
<td>1) Previous s.136 referral:</td>
</tr>
<tr>
<td>(London)</td>
<td>All consecutive s. 136 referrals over a 2-year period (n = 268)</td>
<td>40% White men 24% Black men 24% White women 32% Black women</td>
</tr>
<tr>
<td></td>
<td>Data source</td>
<td>2) African-Caribbeans and Africans account for 15% of the population in catchment area, but 33% of s. 136 admissions.</td>
</tr>
<tr>
<td></td>
<td>Case notes</td>
<td>3) Black men were more likely to receive psychotropic medication and become involuntary after s. 136 had lapsed.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4) A violent presentation was more common among White women and Black men.</td>
</tr>
<tr>
<td>Naismith &amp; Coldwell, 1990</td>
<td>Sample</td>
<td>Of all admissions:</td>
</tr>
<tr>
<td>(Special Hospital)</td>
<td>All admissions to a special hospital over a 2-year period (n = 109)</td>
<td>84% White 8% African-Caribbean 7% Other</td>
</tr>
<tr>
<td></td>
<td>Data source</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Case notes</td>
<td></td>
</tr>
<tr>
<td>Chen et al, 1991</td>
<td>Sample</td>
<td>Compulsory detention, including s. 5(2) &amp; 5(4):</td>
</tr>
<tr>
<td>(Nottingham)</td>
<td>Sample drawn from patients recruited to Harrison et al, 1988 -</td>
<td>50% African-Caribbean 22% White</td>
</tr>
<tr>
<td></td>
<td>40 African-Caribbean 40 White (General population)</td>
<td>This is a significant difference</td>
</tr>
<tr>
<td>Author (Date)</td>
<td>Sample &amp; Data</td>
<td>Findings</td>
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</tbody>
</table>
| Dean & Webster, 1991 (Manchester) | Sample: Consecutive compulsory admissions to three hospitals (n = 90 (30 each hospital)). Each patient was matched with the next informal patient who fulfilled criteria for age, diagnosis, and responsible consultant (n = 90) | 1) No ethnic differences in rates of compulsory admission. Numbers were, however, very small – only 16 of non-white ethnicity, and the make-up of this 16 is not known.  
2) Main differences:  
Detained patients were more likely  
To have a conviction involving violence  
To be admitted via emergency services, e.g. police, A&E, etc.  
To be involved in incidents of violence or self harm pre admission  
Detained patients were less likely to think they were ill and in need of treatment and fewer thought they needed to be in hospital |
| McGovern & Cope, 1991 (Birmingham) | Sample: 33 African-Caribbeans and 29 Whites, from a wider study of all first and subsequent admissions over a four year period | 1) No ethnic differences in rates of compulsory admission at first admission or on re-admission.  
2) African-Caribbeans were less likely to contact GPs, and experienced greater levels of police or criminal justice service involvement. |
| Moodley & Perkins, 1991 (London) | Sample: All consecutive hospital admissions (n = 60) | 1) Compulsory admission:  
24% White  
59.1% African-Caribbean  
2) Thought had no problem:  
0% White  
32% African-Caribbean  
3) No ethnic differences in routes to care. |
<table>
<thead>
<tr>
<th>Author (Date)</th>
<th>Sample &amp; Data</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owens et al, 1991</td>
<td>Sample</td>
<td>All consecutive hospital admissions over a 2 year period (n = 2279)</td>
</tr>
</tbody>
</table>
| (Nottingham) | Sample | 1) Admissions:  
Informal - 2000 (88%)  
Compulsory - 279 (12%) |
| | Data source | Case notes and nursing staff |
| | | 2) Compulsory admission:  
46% African-Caribbean  
10% White |
| | | 3) Police involvement:  
62% African-Caribbean  
31% White |
| | | 4) Violent, etc. behaviour:  
Public place:  
53% African-Caribbean, 52% White  
Private place:  
36% African-Caribbean, 30% White |
| | | 5) GP contact:  
38% African-Caribbean  
62% White |
<p>| Perera et al, 1991 | Sample | Drawn from a larger study. From this, all AC's (n = 22) were matched on age and sex with Asians (n = 22) and Whites (n = 22) |
| (London) | Sample | “There was a significant difference between the groups in the history of police contact extracted from the case notes, and there was a significant interaction between police contact and sex: three Asians and six Caucasians had such a history compared with 14 of the Afro-Caribbeans (p&lt;0.0002): while no Caucasian and Asian women had a history of police contact, four Afro-Caribbean women did (p&lt;0.01).” |
| | Data source | Case notes |
| Pipe et al, 1991 | Sample | All patients subject to s.136 during a one-year period (n = 99) |
| (London) | Sample | 1) 21% of the sample was African-Caribbean, but African-Caribbeans comprised only 5.5% of the catchment population. |
| | Data source | Case notes |
| | | 2) African-Caribbeans were younger, more likely to be single and to have been subject previously to s. 136. |
| | | 3) Those African-Caribbeans under 30 were more likely to have been previously subject to s. 136, been perceived as threatening, and more often denied illness. |</p>
<table>
<thead>
<tr>
<th>Author (Date)</th>
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<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birchwood et al, 1992</td>
<td><strong>Sample</strong>&lt;br&gt;All cases admitted during a three-year period were retrospectively studied for baseline data, and then prospectively studied over a one-year follow-up (n = 169)</td>
<td>1) There was no statistical difference across ethnic origin.  &lt;br&gt;2) African-Caribbeans were significantly more likely to come to care via judicial services, though numbers are small:  &lt;br&gt;   5 White  &lt;br&gt;   10 African-Caribbean  &lt;br&gt;   2 Asian  &lt;br&gt;3) African-Caribbeans also tended to have a longer period of untreated illness.</td>
</tr>
<tr>
<td>(Birmingham)</td>
<td><strong>Data source</strong>&lt;br&gt;Case notes and patients</td>
<td></td>
</tr>
<tr>
<td>Turner, T.H. et al, 1992</td>
<td><strong>Sample</strong>&lt;br&gt;2 year retrospective study of 163 referrals and a 3-month prospective study of 28 referrals to psychiatric hospital</td>
<td>1) Ethnicity of police referrals:  &lt;br&gt;   48% (78) African-Caribbean  &lt;br&gt;   45% (73) White European  &lt;br&gt;   35% (57) African-Caribbean Male  &lt;br&gt;2) Most common reason for detention was causing a disturbance (36% (n = 59)).  &lt;br&gt;3) 62% of schizophrenia diagnoses were African-Caribbeans.  &lt;br&gt;4) Males under 39yrs were over-represented.</td>
</tr>
<tr>
<td>(London)</td>
<td><strong>Data source</strong>&lt;br&gt;Variety of case records</td>
<td></td>
</tr>
<tr>
<td>Mokhtar &amp; Hogbin, 1993</td>
<td><strong>Sample</strong>&lt;br&gt;All patients admitted on s.136, 2 &amp; 4 over a one-year period.</td>
<td>1) 68 patients included:  &lt;br&gt;   39 on s. 136  &lt;br&gt;   18 on s. 2  &lt;br&gt;   11 on s. 4  &lt;br&gt;2) No statistically significant differences between the groups.</td>
</tr>
<tr>
<td>(London)</td>
<td><strong>Data source</strong>&lt;br&gt;Patients, staff and case notes</td>
<td></td>
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<tr>
<td>Author (Date)</td>
<td>Sample &amp; Data</td>
<td>Findings</td>
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</tr>
<tr>
<td>Perkins &amp; Moodley,</td>
<td>Sample Consecutive admissions to wards serving an inner city area (n = 60)</td>
<td>1) Ethnicity and perception of problem:</td>
</tr>
<tr>
<td>1993 (London)</td>
<td>Data source Data collected from interviews with patients and case notes</td>
<td>Perceived to be psychiatric</td>
</tr>
<tr>
<td></td>
<td></td>
<td>52% White</td>
</tr>
<tr>
<td></td>
<td></td>
<td>36.4% African-Caribbean</td>
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<tr>
<td></td>
<td></td>
<td>Perceived to be physical / social</td>
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<tr>
<td></td>
<td></td>
<td>48% White</td>
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<tr>
<td></td>
<td></td>
<td>31.8% African-Caribbean</td>
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<tr>
<td></td>
<td></td>
<td>Perceived to be no problem</td>
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<tr>
<td></td>
<td></td>
<td>0% White</td>
</tr>
<tr>
<td></td>
<td></td>
<td>31.8% African-Caribbean</td>
</tr>
<tr>
<td></td>
<td>2) Compulsory admission and perception of problem:</td>
<td>Perceived to be psychiatric</td>
</tr>
<tr>
<td></td>
<td></td>
<td>33.3% Compulsory</td>
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<tr>
<td></td>
<td></td>
<td>51.6% Voluntary</td>
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<td>Perceived to be physical / social</td>
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<td>33.3% Compulsory</td>
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<td>45.2% Voluntary</td>
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<td></td>
<td>Perceived to be no problem</td>
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<tr>
<td></td>
<td></td>
<td>33.3% Compulsory</td>
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<tr>
<td></td>
<td></td>
<td>3.2% Voluntary</td>
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<tr>
<td></td>
<td>3) GP involvement and perception of problem:</td>
<td>Perceived to be psychiatric</td>
</tr>
<tr>
<td></td>
<td></td>
<td>42.1% Yes</td>
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<tr>
<td></td>
<td></td>
<td>45.5% No</td>
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<td></td>
<td></td>
<td>Perceived to be physical / social</td>
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<tr>
<td></td>
<td></td>
<td>57.9% Yes</td>
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<tr>
<td></td>
<td></td>
<td>30.3% No</td>
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<tr>
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<td></td>
<td>Perceived to be no problem</td>
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<tr>
<td></td>
<td></td>
<td>0% Yes</td>
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<td></td>
<td></td>
<td>24.2% No</td>
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<td></td>
<td>4) Police involvement and perception of problem:</td>
<td>Perceived to be psychiatric</td>
</tr>
<tr>
<td></td>
<td></td>
<td>35.7% Yes</td>
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<tr>
<td></td>
<td></td>
<td>47.4% No</td>
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<tr>
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<td></td>
<td>Perceived to be physical / social</td>
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<td>21.4% Yes</td>
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<td>47.4% No</td>
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<tr>
<td></td>
<td></td>
<td>Perceived to be no problem</td>
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<tr>
<td></td>
<td></td>
<td>42.9% Yes</td>
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<tr>
<td></td>
<td></td>
<td>5.2% No</td>
</tr>
<tr>
<td></td>
<td>5) African-Caribbeans significantly more likely to be compulsorily admitted,</td>
<td>6) Ethnic status predicted compulsory admission independent of diagnosis.</td>
</tr>
<tr>
<td></td>
<td>though figures not given.</td>
<td></td>
</tr>
</tbody>
</table>

330
<table>
<thead>
<tr>
<th>Author (Date)</th>
<th>Sample &amp; Data</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Thomas et al,    | Sample: All acute psychiatric admissions over a four-year period (n = 1534) | 1) 26% of the sample were first admissions, 74% were re-admissions.  
2) Rates of compulsory admission at first contact were significantly higher for African-Caribbeans aged 16-29. This finding disappeared when only psychotic patients were considered.  
3) African-Caribbeans were significantly more likely to be compulsorily re-admitted (63% v. 13%).  
4) Second generation African-Caribbeans were significantly more likely to be admitted under s. 37 (35% v. 8%).  
5) Second generation African-Caribbeans used hospital services or GPs significantly less frequently and were more often admitted via the police. |
| 1993 (Manchester) |                                                                                   |                                                                                                                                                                                                          |
| Bebbington et al,| Sample: Audit of hospital in-patients in 2 London boroughs over a 6 month period | 1) Compulsory admission for Black Caribbean men was 13x and 6.7x that for White men in the two boroughs, and for Black Caribbean women it was 2.9x and 5x that for White women in the two boroughs.  
2) Most parsimonious log-linear model of compulsory admission included only diagnosis and challenging behaviour. A second model showed a mild effect of ethnicity. |
<p>| 1994 (London)    |                                                                                   |                                                                                                                                                                                                          |</p>
<table>
<thead>
<tr>
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<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>McGovern et al, 1994</td>
<td>Sample</td>
<td>1) There were significantly more Black admissions under Part III of the MHA 1983, and in readmissions from prison, but not under Part II:</td>
</tr>
<tr>
<td>(Birmingham)</td>
<td>Follow-up of 33 White and 42 Black patients with first-episode of schizophrenia, over 5-10 year period</td>
<td>Part II</td>
</tr>
<tr>
<td></td>
<td></td>
<td>19% (8) White</td>
</tr>
<tr>
<td></td>
<td></td>
<td>33% (33) Black</td>
</tr>
<tr>
<td></td>
<td>Data source</td>
<td>Part III</td>
</tr>
<tr>
<td></td>
<td>Patients, relatives, professionals and from case notes</td>
<td>2% (1) White</td>
</tr>
<tr>
<td></td>
<td></td>
<td>13% (13) Black</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Re-admitted from prison</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2% (1) White</td>
</tr>
<tr>
<td></td>
<td></td>
<td>13% (13) Black</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2) Black patients were more likely to have had convictions and to have been imprisoned:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Convictions</td>
</tr>
<tr>
<td></td>
<td></td>
<td>31% (9) White</td>
</tr>
<tr>
<td></td>
<td></td>
<td>58% (24) Black</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Prison</td>
</tr>
<tr>
<td></td>
<td></td>
<td>9% (3) White</td>
</tr>
<tr>
<td></td>
<td></td>
<td>28% (11) Black</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3) Black patients had significantly more readmissions in the follow-up period:</td>
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<tr>
<td></td>
<td></td>
<td>55% (18) White</td>
</tr>
<tr>
<td></td>
<td></td>
<td>78% (32) Black</td>
</tr>
</tbody>
</table>

| Anderson & Parrott, 1995 | Sample | “The demographic and psychiatric profile of the group was notable for its preponderance – 16(80%) – of Afro-Caribbean ethnicity. This is a greater percentage of Afro-Caribbean ethnicity than the representation thereof in the prison population as a whole. (On a point prevalence estimate in Belmarsh Prison those ratios were: Caucasian 59%; Afro-Caribbean 38%; Asian 3%). These results are likely to be a reflection of the disproportionately high incidence of paranoid psychotic illness amongst this ethnic group.” |
| (Belmarsh Prison) | All patients transferred on s. 48 over a one year period from Belmarsh prison (n = 20) | |
| | Data source | Case records and consultant psychiatrists |

<p>| Banerjee et al, 1995 | Sample | The main result of interest is that Black remand prisoners were much more likely to require transfer: |
| (Belmarsh Prison) | All prisoners first remanded in custody to Belmarsh over a 6-month period (n = 1229) | Black prisoners formed 50.9% of the transfer group, compared to 29.6% of the remaining prisoners. The comparable figures for Whites were 41.5% and 66.5% respectively. |
| | Data source | Patients and case notes |</p>
<table>
<thead>
<tr>
<th>Author (Date)</th>
<th>Sample &amp; Data</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cole et al, 1995</strong> (London)</td>
<td><strong>Sample</strong>&lt;br&gt;All first onset psychosis patients presenting to services over a one-year period (n=106, recruited to study n = 93)</td>
<td>1) No significant ethnic differences in rates of compulsory admission.</td>
</tr>
<tr>
<td></td>
<td><strong>Data source</strong>&lt;br&gt;Patients, a close informant and case notes</td>
<td>2) No ethnic differences in rates of police involvement.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3) Factors significantly associated compulsory admission were:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Living in public housing</td>
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<tr>
<td></td>
<td></td>
<td>Living alone</td>
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<tr>
<td></td>
<td></td>
<td>No GP or family/friend involvement</td>
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<tr>
<td></td>
<td></td>
<td>Living away from family</td>
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<td></td>
<td></td>
<td>4) Variables independently predicting compulsory admission:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No help-seeker involvement</td>
</tr>
<tr>
<td></td>
<td></td>
<td>No GP involvement</td>
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<td></td>
<td></td>
<td>5) There was a non-significant trend for black patients to present later than others. Being single was the only predictor of 'later' presentation (i.e. 1+ month).</td>
</tr>
<tr>
<td><strong>McKenzie et al, 1995</strong> (London)</td>
<td><strong>Sample</strong>&lt;br&gt;Follow-up at four years of a cohort study of consecutive admissions to two South London hospitals (n = 113)</td>
<td>1) 82.3% of African-Caribbeans who were readmitted were admitted under section, compared to 43.2% of Whites.</td>
</tr>
<tr>
<td></td>
<td><strong>Data source</strong>&lt;br&gt;Multiple sources of information were used including the patient and case notes</td>
<td>2) There were no differences in hospital use, but the African-Caribbean group had more involuntary admissions and more imprisonments over the follow-up period.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3) The African-Caribbean group spent more time in a recovered state during the follow-up period, were less likely to have a continuous illness, were less at risk of self-harm and were less likely to have been prescribed anti-depressant treatment.</td>
</tr>
<tr>
<td>Author (Date)</td>
<td>Sample &amp; Data</td>
<td>Findings</td>
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<tr>
<td>Shubsachs et al, 1995</td>
<td><strong>Sample</strong>&lt;br&gt; All African-Caribbeans admitted to Rampton over a 10-year period (n = 62) and a sample of non-African-Caribbeans admitted over the same period (n = 62)</td>
<td>1) Very few differences between the two groups. The major difference was in diagnosis:&lt;br&gt; African-Caribbeans: 87% Mental illness, 6% Psychopathic personality disorder&lt;br&gt; Whites: 52% Mental illness, 36% Psychopathic personality disorder&lt;br&gt; 2) Only other differences:&lt;br&gt; Increased likelihood of the mentally ill African-Caribbeans having a previous adult court appearance&lt;br&gt; Higher doses of anti-psychotics received by African-Caribbeans in first 4 weeks of admission</td>
</tr>
<tr>
<td></td>
<td><strong>Data source</strong>&lt;br&gt; Special hospital register and case notes</td>
<td></td>
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<tr>
<td>Spence &amp; Phillips, 1995</td>
<td><strong>Sample</strong>&lt;br&gt; All s. 136 referrals over a 6-month period (n = 70; of which, there was sufficient data on 65)</td>
<td>57 individuals were assessed in 65 assessments under s. 136:&lt;br&gt; 83% White&lt;br&gt; 15% African-Caribbean</td>
</tr>
<tr>
<td></td>
<td><strong>Data source</strong>&lt;br&gt; Case notes</td>
<td></td>
</tr>
<tr>
<td>Davies et al, 1996</td>
<td><strong>Sample</strong>&lt;br&gt; All cases of psychosis in contact with services during a one-year period (n = 439)</td>
<td>1) Previously compulsorily admitted:&lt;br&gt; 42.5% White&lt;br&gt; 70.4% African-Caribbean&lt;br&gt; 69% African&lt;br&gt; 2) African-Caribbeans &amp; Africans more likely to have been involuntarily detained:&lt;br&gt; African-Caribbean - Adjusted Odds Ratio 3.67&lt;br&gt; African – Adjusted Odds Ratio 2.88&lt;br&gt; 3) Black Caribbeans &amp; Black Africans more likely to have been admitted to a psychiatric intensive care facility.</td>
</tr>
<tr>
<td></td>
<td><strong>Data source</strong>&lt;br&gt; Case notes</td>
<td></td>
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<tr>
<td>Author (Date)</td>
<td>Sample &amp; Data</td>
<td>Findings</td>
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</tbody>
</table>
| Murray, 1996 (England) | **Sample**  
All patients in medium secure facilities in England on a single day (555)  
**Data source**  
Case notes | 1) Total in-patients: 555  
(Male 462 (83%) & Female 93 (17%))  
2) Ethnicity:  
76.4% (424) White British  
17.5% (97) African-Caribbean  
3) In inner-London:  
40% of all in-patients in medium security were African-Caribbean  
50% of remand prison admissions were African-Caribbean  
60% of remand admissions aged 21-30 were African-Caribbean  
75% of population of one unit were African-Caribbean |
| Commander et al, 1997a, 1997b (Birmingham) | **Sample**  
1) Survey of all patients in contact with specialist services on a specified day and over next 6 months  
2) Primary care survey  
3) General population survey  
**Data source**  
Range of sources, including patients and case notes | Paper I  
1) "Black people were over-represented among users of specialist services compared to both Asians and Whites … They were more likely to be detained under mental health act."  
2) Rates of detention per 100,000 of the population:  
48 White  
254 Black  
37 Asian  
3) Nearly all patients in the local Regional Secure Unit were Black.  
Paper II  
Black people were less likely than Whites to have their mental illness recognised by GPs. |
<table>
<thead>
<tr>
<th>Author (Date)</th>
<th>Sample &amp; Data</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Koffman et al, 1997</td>
<td>Sample</td>
<td>1) Sample: 75% (2978) White, 16% (632) Black, 4% (160) Asian</td>
</tr>
<tr>
<td>(2 UK Regions)</td>
<td>All in-patients in all NHS and 7 private hospitals in two regions on 15 June 1994</td>
<td>2) Compulsorily detained: 30.6% (907) White, 63.5% (399) Black, 38.8% (62) Asian</td>
</tr>
<tr>
<td></td>
<td>Total of 3710 acute and 268 low security patients surveyed</td>
<td>3) Compulsory admissions ratio for Blacks was more than 4x that for Whites.</td>
</tr>
<tr>
<td><strong>Data Source</strong></td>
<td>Ward managers completing a data form from case notes</td>
<td>4) These differences remained significant after controlling for diagnosis.</td>
</tr>
<tr>
<td>Singh et al, 1997</td>
<td>Sample</td>
<td>1) Compulsory admission: 43.2% African-Caribbean, 18.8% White</td>
</tr>
<tr>
<td>(Nottingham)</td>
<td>All consecutive hospital admissions over a 6-month period</td>
<td>2) Independent risk factors for compulsory admission: Diagnosis of psychosis, Risk of violence, African-Caribbean ethnicity</td>
</tr>
<tr>
<td><strong>Data source</strong></td>
<td>A questionnaire completed by the admitting medical officer</td>
<td>5) Admitted to low secure beds: 6.1% (182) White, 10.5% (66) Black, 3.1% (5) Asian</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6) Not registered with GP: 6.3% (185) White, 11.3% (70) Black, 5% (8) Asian</td>
</tr>
<tr>
<td>Author (Date)</td>
<td>Sample &amp; Data</td>
<td>Findings</td>
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</table>
| **Bhui et al, 1998 (London)** | Sample Cross-sectional survey during a one-year period of a sample of potentially mentally ill men remanded to Brixton prison (n = 277) | 1) Diagnosis: Significantly more of the Black sub-groups had a diagnosis of schizophrenia compared to the white group  
2) Outcome: Significantly more of the Black sub-groups were placed on Mental Health Act hospital orders compared to the white group  
   - 16% (29) White  
   - 27% (7) Black Caribbean  
   - 38% (6) Black African  
   - 58% (7) Black British  
3) Logistic regression: Adjusting for diagnosis, the relationship between ethnicity and Mental Health Act outcome disappears |
| **Johnson et al, 1998 (London)** | Sample 5 year follow-up of all originally selected for interview in baseline study (320) who were available and eligible. (n = 286) | 1) Detention under the MHA 1983 during the follow-up:  
   - 15% (26) White  
   - 33% (23) African-Caribbean  
   - 27% (4) African  
2) No difference between ethnic groups in terms of number of in-patient admissions, suggesting that it was not need for in-patient care that varied between ethnic groups, but the circumstances of admission.  
3) Logistic regression: Ethnicity not independently related to detention over follow-up period |
<table>
<thead>
<tr>
<th>Author (Date)</th>
<th>Sample &amp; Data</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Takei et al, 1998 (London) | **Sample** Follow-up of cohort of African-Caribbeans and Whites with first episode of psychosis | 1) Compulsory admission at some point over the study period: 
- 65.6% African-Caribbean
- 26.5% White

2) Strong interaction of ethnicity and diagnosis in predicting compulsory admission – “Thus, African-Caribbean patients had a higher rate of involuntary admission than White patients, a tendency especially marked in those diagnosed as schizophrenic”.

3) African-Caribbeans were also more likely to have been compulsorily admitted more than once over the study period: 
- 21.9% African-Caribbean
- 4% White

4) African-Caribbeans were significantly more likely to spend longer in hospital and have more admissions.

| Burnett et al, 1999 (London) | **Sample** All first onset psychosis patients presenting to services over a two-year period (n = 100) | 1) First onset sample: 
Compulsory admission - 28%. No relationship between ethnicity and compulsory admission 

GP referral (non-significant trend): 
- 37% African-Caribbean
- 50% White
- 54% Asian

2) Camberwell Register sample: 
No ethnic differences in rates of compulsory admission at first contact 

Total compulsory admissions 
- 68% African-Caribbean
- 49% White

**Data source** Patients, relatives, and case notes
<table>
<thead>
<tr>
<th>Author (Date)</th>
<th>Sample &amp; Data</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Commander et al, 1999</td>
<td><strong>Sample</strong> All admissions with a non-affective psychosis presenting to psychiatric services over a set period, until 40 from each of the three ethnic groups was identified at both admission and discharge (n = 120 at each point in time)</td>
<td>1) Black patients had more complex and aversive pathways to the hospital. 2) Compared to Whites, black patients were significantly more likely to have: 3+ contacts on pathway - 18 v. 4 Police involvement - 24 v. 4 GP involved - 12 v. 5 Compulsory admission - 27 v. 11 3) And less likely to have: Accompanied by family/friends - 4 v. 15 Self-perceived mental illness 14 v. 23 Agreed need to be in hospital 13 v. 24 3) On discharge and during follow-up, Black patients were significantly less likely to see a GP - 6 v. 17.</td>
</tr>
<tr>
<td>(Birmingham)</td>
<td><strong>Data source</strong> Patients and case notes</td>
<td></td>
</tr>
<tr>
<td>Coid et al, 2000</td>
<td><strong>Sample</strong> All admissions to secure forensic psychiatric services over a 7-year period from 7 of the 14 regional health authorities (n = 3155)</td>
<td>1) Standardised admission rates: Males 85 White 473 Black 181.1 Asian 62.9 Other 5.6 x as many Black as White patients</td>
</tr>
<tr>
<td>Author (Date)</td>
<td>Sample &amp; Data</td>
<td>Findings</td>
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</tr>
<tr>
<td>Lelliott et al, 2001</td>
<td>Sample</td>
<td>1) Characteristics of the sample:</td>
</tr>
<tr>
<td>(London)</td>
<td>All patients in medium secure facilities in a London health authority on a census day in 1997 (n = 183).</td>
<td>87% men 93% unemployed prior to admission 92% single</td>
</tr>
<tr>
<td></td>
<td>2) Ethnicity</td>
<td>35% (65) White 57% (103) Black</td>
</tr>
<tr>
<td></td>
<td>3) The Black group:</td>
<td>78 (43% of total) African-Caribbean 20 (11% of total) Black African</td>
</tr>
<tr>
<td>Audini &amp; Lelliott, 2002</td>
<td>Sample</td>
<td>1) Rates of episodes of detention:</td>
</tr>
<tr>
<td>(England)</td>
<td>Data from 26 areas with a combined population of 9.2 million were combined.</td>
<td>450 per 100 000 population – Black 324 per 100 000 population – Asian 68 per 100 000 population – White</td>
</tr>
<tr>
<td></td>
<td>Produced data on 31,702 episodes of detention under Part II</td>
<td>Detentions are, therefore, over 6x more likely to be of Black people than White.</td>
</tr>
<tr>
<td></td>
<td>2) Detentions of Black men are 8x more frequent than of White men:</td>
<td>553 v. 69 per 100 000</td>
</tr>
<tr>
<td></td>
<td>3) These patterns are present at all ages.</td>
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</table>
APPENDIX 2

INTERVIEW AND DATA COLLECTION INSTRUMENTS

Screening Schedule for Psychosis
MRC Sociodemographic Schedule (Relevant questions)
Culture and Identity Schedule 1 (Relevant questions)
Psychiatric and Personal History Schedule (Relevant questions)
Pathways Recording Sheet, Variables List and Recording Sheet Instructions
Mental Disorder Beliefs Schedule
SCREENING SCHEDULE FOR PSYCHOSIS

A 1. Is this patient’s age below 16 or above 65? No
   2. Does this patient live outside the study catchment area? No

B Is there evidence that this patient has any of the following problems?
   1. Clinically manifest organic cerebral disorder (e.g. infections, parasitic, toxic, cerebrovascular, epilepsy, brain injury, etc.) No
   2. Severe or moderate mental retardation (i.e. IQ less than 50 or clinically manifest as such) No

C Has the patient ever presented any of the following?
   1. Hallucinations or pseudo-hallucinations in any modality No
   2. Delusions No
   3. Marked thought and speech disorder (e.g., incoherence, irrelevance, thought blocking, neologisms, incomprehensibility of speech) other than simple retardation or acceleration No
   4. Marked psychomotor disorder (e.g., negativism, mutism or stupor, catatonic excitement, constrained attitudes or unnatural postures maintained for long periods) other than simple retardation or acceleration No
   5. Emergence or marked exacerbation of bizarre and grossly inappropriate behaviour (e.g., talking or giggling to self, acts incomprehensible to others, loss of social constraints, etc.) No

D A definite change of personality and behaviour manifested in any of the following
   1. Marked reduction or loss of interests, initiative and drive, leading to serious deterioration of the performance of usual activities and tasks No
   2. Emergence of marked exacerbation of social withdrawal (active avoidance of communication with other people) No
   3. Severe excitement, purposeless destructiveness or aggression No
   4. Episodic or persistent states of overwhelming fear or severe anxiety No
   5. Gross and persistent self-neglect No

E Has the patient ever made contact with the psychiatric services for symptoms C or D which could be considered to represent a previous episode? Do not exclude patients with contact for symptoms outside the criteria of C or D (e.g. affective illness). No

Conditions for inclusion in the study: All replies to questions in Sections A, B and E must be “NO” and there should be at least one “YES” in Section C or two in Section D.

Patient does / does not satisfy entry criteria

Name: ........................................
SOCIO-DEMOGRAPHIC SCHEDULE

Starting Time: ____________________  Finishing Time: ____________________

Date of interview:

Interviewer ID No:

Centre No:

Resp. ID No:

1) Sex:
   1. Male  2. Female

3) Age:

11) Indicate total number in household

23) Do you own the house/flat or is it rented accommodation?
   1. Yes: Self/joint owner occupied
   2. No: Family owner occupied
   3. No: Private rented
   4. No: Local Authority rented
   5. No: Housing Association rented
   6. Other (specify)

Note: For coding missing values in each field: -77 = Don't Know  -88 = Refused to answer  -99 = Not applicable

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25) What is your current relationship status?

1. Married/Living with someone
2. Single in steady relationship
3. Single in casual relationship(s)
4. Single – no partner
5. Divorced
6. Widowed
7. Separated

53) What was the highest level of education you reached?

Write qualifications attained below and where attained

1. No qualifications
2. GCSE/CSE
3. O’ levels
4. A’ levels
5. Vocational/college (B. Tees/NVQs etc.)
6. Teaching/HND/nursing
7. University/Professional Qualifications

62) Are you currently employed?

1. Yes
0. No

93) How often do you visit or speak to friend(s)/neighbour(s)/work associates outside of work?

1. Visit/Speak to daily
2. Visit/Speak to weekly
3. Visit/Speak to fortnightly
4. Visit/Speak to monthly
5. < than above
0. Never

Note: For coding missing values in each field: -77 = Don’t Know -88 = Refused to answer -99 = Not applicable
LIST MAIN FRIENDS/PEOPLE SEEN/SPOKEN TO REGULARLY

94) [If applicable] Do your friends live close to you?
   0. No
   1. Yes locally (same area)
   2. Yes (same town)

95) How often do you visit/speak to your close family (including in-laws)?
   1. Visit/Speak to daily
   2. Visit/Speak to weekly
   3. Visit/Speak to fortnightly
   4. Visit/Speak to monthly

96) Do your family live close to you?
   0. No
   1. Yes (same area)
   2. Yes (same town)

97) Do you have any close confidants?
   1. Yes
   0. No

98) If yes, who (check family and friends above)

99) Would it be the same person as a year ago?
   1. Yes
   0. No

100) If no, then who?

101) How often do you visit/speak to confidants?
   1. Visit/Speak to daily
   2. Visit/Speak to weekly
   3. Visit/Speak to fortnightly
   4. Visit/Speak to monthly
   5. < than above

Note: For coding missing values in each field: -77 = Don't Know -88 = Refused to answer -99 = Not applicable
102) If you had a worrying/upsetting problem who would you discuss it with first?
1. Partner
2. Parent
3. Sibling
4. Other relative
5. Friend – female
6. Friend – male
7. No one in particular
8. Don’t share problems

103) Anyone else?
1. Partner
2. Parent
3. Sibling
4. Other relative
5. Friend – female
6. Friend – male
7. No one in particular
8. Don’t share problems

104) How helpful are they when you confide in them?
1. Very helpful
2. Fairly helpful
3. Not very
4. Critical but truthful
5. Too critical

105) What about emotional support and advice/listening?
1. Very helpful
2. Fairly helpful
3. Not very
4. Critical but truthful
5. Too critical

106) How else do they help you?

Note: For coding missing values in each field: -77 = Don’t Know -88 = Refused to answer -99 = Not applicable
INTRODUCTION
Interviewers should introduce themselves and describe the purpose of the interview. The objective is to gain an insight into the extent to which people identify with the British cultural environment or retain, (re)create or adapt their own cultural signifiers. While this schedule is for everyone, interviewers should specifically aim to get some idea about the experiences and the attitudes of people of migrant origin or descent living in the United Kingdom, and the level of comfort they feel in that culture. Researchers must always remember that ethnicity and ethnic status does not only apply to people who are “visibly different” to the majority ethnic group, but also to people who define themselves as of different ethnic and cultural backgrounds to the majority population, even if they are of the same “colour” group.

Legend: ★ = Instructions to interviewer/promt questions

1. How do you identify yourself, that is in terms of ethnicity/nationality what term do you use to describe yourself to others?

   ★

   1 = British
   2 = Black British
   3 = Black other [specify]
   4 = African-Caribbean
   5 = West Indian
   6 = Jamaican
   7 = Barbadian
   8 = Trinidadian
   9 = Other specified Caribbean Country
   10 = African [specify country]
   11 = Asian British
   12 = Indian
   13 = Pakistani
   14 = Bangladeshi
   15 = Asian
   16 = Asian other [specify]
   17 = English
   18 = Scottish
   19 = Welsh
   20 = Irish (incl. Northern Ireland)
   21 = White European
   22 = Turkish/Greek Cypriot

Note: For coding missing values in each field: -77 = Don’t Know -88 = Refused to answer -99 = Not applicable
23 = White other [specify]
24 = Other [specify]

25 = East African Asian

6a. Do you feel British?

Yes = 2
No = 1
Somewhat = 3

Note: For coding missing values in each field: -77 = Don’t Know -88 = Refused to answer -99 = Not applicable
<table>
<thead>
<tr>
<th>Section</th>
<th>Yes = 1</th>
<th>No = 0</th>
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<tbody>
<tr>
<td>Type of Section</td>
<td>2 = 1</td>
<td>3 = 2</td>
</tr>
</tbody>
</table>

Note: For coding missing values in each field: -77 = Don't Know -88 = Refused to answer -99 = Not applicable
PART 1. PSYCHIATRIC HISTORY

“What, if anything, happened to make it necessary for X to come (to be brought to ...)? (Specify the hospital, clinic or other facility) at this particular time?” Cross-examine: “What was that the only reason?” “Which was the most important reason?” “Was there anything else?” Try to obtain a description of behaviour or of an event if such has occurred. (The mode of agency of referral is not rated here but in item 1.6)

1.1 RATE MAIN REASONS FOR CURRENT ADMISSION OR ATTENDANCE ACCORDING TO INFORMANT (rate as many as applicable)

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<tbody>
<tr>
<td>1</td>
<td>Yes</td>
</tr>
<tr>
<td>8</td>
<td>Not applicable or no information</td>
</tr>
<tr>
<td>9</td>
<td>Uncertain</td>
</tr>
</tbody>
</table>

1.1.1 Patient **attempted** suicide or bodily harm

1.1.2 Patient’s behaviour perceived as **potential** danger to himself (e.g., talked of killing or harming himself; refusal of food, etc.).

1.1.3 Patient **committed** an assault, or other violent or hazardous act (e.g., setting fire or destroying property)

1.1.4 Patient’s behaviour perceived by others as **threatening** or grossly annoying.

1.1.5 Onset or exacerbation of odd behaviour, appearance or talk (e.g., excitement or withdrawal, self-neglect, incoherent talk, bizarre ideas, loss of interest or abandoning work, wandering, marked anxiety or fears, etc.)

1.1.6 Patient developed signs of **physical illness** or sustained an **injury**

1.1.7 Recent **change of crisis in family or household** necessitating contact without change of patient’s condition (e.g., illness of a household member, rehousing, birth of a child, death of a household member, somebody getting married, etc.)

1.1.8 Patient was referred for a **routine checkup** by a doctor or other health worker, or by an agency (e.g., school, driving licence authorities, etc.)

1.1.9 Patient himself requested admission or an appointment to see a doctor or other health worker because of complaints about his mental health (other than problems listed above)

Note: For coding missing values in each field: -77 = Don’t Know -88 = Refused to answer -99 = Not applicable

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PSYCHIATRIC AND PERSONAL HISTORY SCHEDULE

1.1.10 Other reason (specify)

1.2 "You have already told me about the reason why X had to come to/ hospital, clinic, etc. - as relevant/ at this point in time, and about the kind of problems he has now. I should like now to ask you about things which happened in the past, mainly in the last year and maybe even earlier. What was it that made you aware for the first time ever that X was not behaving like his usual self? Did other people notice anything unusual about X's behaviour around that time; or maybe even earlier than you did?"

Allow for informant to think and reply, then cross-examine: "Was there nothing of the sort before that? Did that happen before or after ... ? Use as a reference point in time a fact that the informant has already mentioned, or an event which should be locally known? Write down a narrative note, in informant's own words, on first ever abnormality that he recollects, and its approximate timing:

PROBABLE EARLIEST MANIFESTATION OF PATIENT'S ABNORMALITY PERCEIVED BY INFORMANT OR OTHERS

1.5 "You told me about some unusual things that X did or said, which made you think that he was not behaving like his former self. When you think of it, did this change in X develop quite suddenly, say within days, or slowly, over a longer period of time, maybe in weeks or even months? How about ...? Interviewer picks up examples of abnormal behaviour recorded under previous item, did it start suddenly? Has X never before been like this/or said, done, etc.?"

1.5 RATE INFORMANT'S IMPRESSIONS OF MODE OF ONSET OF PATIENT'S DISORDER

1 = Clearly sudden onset, one or more psychotic symptoms appeared within days (up to a week); previous psychiatric symptoms can be safely excluded

2 = Precipitous onset of one or more psychotic symptoms within days, (up to a week) but previous existence of other non-psychotic symptoms likely or certain

3 = Acute onset, psychotic symptoms developed over a period of up to one month; previous psychotic symptoms can be safely excluded

Note: For coding missing values in each field: -77 = Don't Know -88 = Refused to answer -99 = Not applicable

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4 = Acute onset; psychotic symptoms developed over a period of up to one month; previous existence of other, non-psychotic symptoms likely or certain

5 = Insidious, slow incremental development of psychotic symptoms over many months

6 = Informant cannot draw a clear demarcation line between health and mental illness in the patient (no clear-cut psychotic symptoms described)

7 = Informant’s description inadequate for making any judgement about mode of onset

8 = Question not asked

1.6 “Where did X/or informant/first go for help? Then where did X/or informant/next go for help?” Interviewer continues in this manner until informant has enumerated all different sources of lay or professional help outside the household. Help from neighbours or relatives (unless they are professionally qualified) is not rated here. The last entry in the sequence of boxes below should refer to present treatment.!

Note: Rate only first contacts with a particular type of helping agent. For example, a patient who made three visits to two different traditional healers, then saw a general practitioner who referred him to a psychiatrist with whom the patient had two outpatient sessions, and then hospitalisation during which he was treated by another psychiatrist, should be rated 5 2 1. A contact is a transaction between patient and helping agent which leads to some actions related to the management or treatment of a problem that in the rater’s judgement was part of, or associated with the patient’s mental illness.

RECORD CONSECUTIVE CONTACTS WITH DIFFERENT HELPING AGENTS

<table>
<thead>
<tr>
<th>1st</th>
<th>2nd</th>
<th>3rd</th>
<th>4th</th>
<th>5th</th>
<th>6th</th>
<th>7th</th>
</tr>
</thead>
</table>

1 = Psychiatrist or other mental health professional

2 = General practitioner or other medical specialist (non-psychiatric)

3 = Nurse, other health worker, or social worker

4 = Police

Note: For coding missing values in each field: -77 = Don’t Know -88 = Refused to answer -99 = Not applicable

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5 = Traditional healer or no-allopathic practitioner (include here homeopaths, naturopaths, acupuncturists, etc.)
Specify ____________________________

6 = Priest or other religious person

7 = Other specify ____________________________

8 = Unspecified (contact took place but type of agent unknown)

9 = Unknown

1.6.1 (Inserted for purposes of the current study)
Please write a narrative summary of the patient’s pathway to contact with services including all sources of help utilised by or offered to the patient since onset of symptoms and prior to contact with professional psychiatric services (family, friends, alternative therapies/healers, church, etc.). Include details of who initiated help-seeking and what the respondent and patient felt about the help offered.

Note: For coding missing values in each field: -77 = Don’t Know -88 = Refused to answer -99 = Not applicable
<table>
<thead>
<tr>
<th>A. Psych history</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>B. Previous contact</td>
<td>Rating</td>
</tr>
<tr>
<td>C. Date of onset</td>
<td>Rating</td>
</tr>
<tr>
<td>D. Agencies contacted</td>
<td>Type</td>
</tr>
<tr>
<td>1.</td>
<td></td>
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<td>2.</td>
<td></td>
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<tr>
<td>3.</td>
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<tr>
<td>Details</td>
<td>Rating</td>
</tr>
<tr>
<td>E. Total agencies</td>
<td>Rating</td>
</tr>
<tr>
<td>F. Family etc. inv.</td>
<td>Rating</td>
</tr>
<tr>
<td>G. GP inv.</td>
<td>Rating</td>
</tr>
<tr>
<td>H. Police inv.</td>
<td>Rating</td>
</tr>
<tr>
<td>I. Mode of referral</td>
<td>Rating</td>
</tr>
<tr>
<td>J. Mode of contact</td>
<td>Rating</td>
</tr>
<tr>
<td>K. Date of contact</td>
<td>Rating</td>
</tr>
<tr>
<td>L. DUS</td>
<td>Rating</td>
</tr>
</tbody>
</table>
Pathways Recording Sheet Variables List

A. Previous (non-psychotic) psychiatric history
1. Yes
2. No

B. Previous contact with mental health services for a non-psychotic illness
1. Yes
2. No

C. Date of onset

D. Agencies contacted
Type
1. General Practitioner
2. Psychiatric home visit
3. Direct to Emergency Clinic
4. Accident & Emergency Department/General Hospital Ward
5. Police
6. Social Worker
7. Other social care worker, inc. housing officer, drugs worker, etc.
8. Counsellor
9. Church leader
10. Alternative or complementary healer/remedy
11. Prison
12. Other(Specify)

Contact initiated by
1. Self
2. Family
3. Friends/neighbours
4. Police
5. Prison/Court
6. Other

E. Total number of outside agencies contacted prior to referral to mental health services

F. Involvement of family and/or friends in pathway
1. No involvement
2. Limited involvement
3. Full involvement

G. GP involvement
1. Yes
2. No

H. Police/Criminal Justice System involvement
1. Yes
2. No

I. Mode of referral to mental health services
1. Via GP
2. Via Accident and Emergency Department/General Hospital Ward
3. Via Emergency Clinic
   i. Self-presentation
   ii. With family/friend(s)
4. Via Police
5. Via Prison
6. Via Social Services
7. Via Psychiatric Home Visit
8. Other

J. Mode of contact
1. Non-compulsory
2. Compulsory in-patient (specify MHA Section)

K. Date of contact with mental health services

L. Duration of Untreated Symptoms
Pathways Recording Sheet Instructions

A. Previous (non-psychotic) psychiatric history
A positive rating is made if there is a clear account of a previous history of non-psychotic mental illness, i.e. depression, anxiety, etc. A positive rating here does not necessarily mean the patient received treatment.

B. Previous contact with mental health services for a non-psychotic illness
A positive rating is made if there is a clear account of prior contact and it is clear that no treatment was received for a psychotic illness, i.e. an anti-psychotic was not prescribed. Treatment by a GP is not rated. A positive rating here implies a positive rating for previous (non-psychotic) psychiatric history.

C. Date of onset
This is taken directly from the Psychiatric and Personal History Schedule (WHO, 1996).

D. Agencies contacted
Type
Each type of helping agency contacted for help with the patient’s psychosis prior to contact with mental health services is recorded in the order that the patient first saw them. Helping agency includes all external sources of help, but does not include help from family and friends.

A rating of 2, Psychiatric Home Visit, is only made if the patient and/or his/her family have contacted services directly, without a formal referral, and a home visit has been arranged. If the patient has been to the EC then this rating cannot be made and a rating of 3, Direct to EC, should be considered, subject to the conditions below.

A rating of 3, Direct to the EC, is only made if the patient and/or his/her family have contacted the EC in the absence of a formal referral. In cases where a GP or any other professional refers the patient to the EC a rating of 3, Direct to the EC, is not made.

Category 10, Alternative or Complementary Healer/Remedy, is meant in the broadest sense and includes all types of help that are not part of formal medical or social services and which are not available as one of the other categories. A patient who uses herbs of any kind is given a positive rating 10.

If more than three agencies have been contacted prior to contact with services, these should be fully recorded on a separate sheet.

Date
This is the date that the patient first contacted the specified agency. A date, if possible, should be recorded for each agency on the pathway.

Initiated by
This records who took the initiative in prompting the patient to seek help from the specified agency. A positive rating is made when there is a clear account of who initiated help-seeking. Here help-seeking is meant in its broadest sense. So, if police or the courts compel the patient to go to hospital, the police or courts are recorded as the initiators of help-seeking. Obviously, the police or courts will also have been recorded as one of the agency types contacted on the pathway.

Details
A brief narrative account of the pathway to care should be provided.

E. Total Agencies
Record the total number of agencies contacted prior to contact with mental health services. Contact with any mental health service is not counted. So, psychiatric home visits and EC contact are not included in the total number of agencies. If a patient’s first contact with an external helping agency is a psychiatric home visit or direct contact with the EC, then the total number of agencies is 0.

F. Involvement of Family and/or Friends in the Pathway
This is a general rating of family or friend involvement at any point during the pathway to care.
A rating of 1, No Involvement, is made when it is clear that family or friends have not been involved at any point.

A rating of 2, Limited Involvement, is made when family or friends have played some part in supporting the patient and/or in enabling the patient to access services. In this case, the main role in bringing the patient into contact with services will have been played by either the patient themselves or by an external agency, i.e. the police.

A rating of 3, Full Involvement, is made when family or friends have played a central role in supporting or bringing the patient into contact with services.

G. GP Involvement
This is a general rating of whether a GP has been involved in the patient’s pathway to care at any point.

H. Police/Criminal Justice System Involvement
This is a general rating of whether the police or any criminal justice agency, including courts, prison, probation officers, etc., have been involved in the patient’s pathway to care at any point. It should be noted if police used section 136.

I. Mode of Referral to Mental Health Services
This records the source of referral to mental health services. It records the agency that made the referral resulting in patient contact with services.

Many patients will see a GP prior to contact, but for whatever reasons the GP may not provide a formal referral to services. In such cases, the patient may go back to the GP and eventually the GP will refer the patient, or the patient will access services via another route. This may, for example, be by going direct to the EC or through a psychiatric home visit. In the case of a patient accessing services via another route the source of referral is not the GP.

J. Mode of Contact
This records mode of contact with services at the point of contact. If contact was compulsory, the section of the Mental Health Act used should be noted.

K. Date of Contact with Mental Health Services
This is taken directly from the Psychiatric and Personal History Schedule (WHO, 1996) coding sheet.

L. DUS (Duration of Untreated Symptoms)
This is the number of days between first onset of psychosis.
MENTAL DISORDER BELIEFS SCHEDULE

INSTRUCTIONS FOR THE INTERVIEWER:

Please try and reassure the subject that he/she is not on trial. The schedule is not to test whether the subject is mad/mentally ill/nervy or whatever. There are no right or wrong answers. The aim of the schedule is to get an idea about feelings and views concerning mental distress.

Please emphasize that the subject is not being examined/or under duress. We hope that the answers we get will help us to understand what you think causes people to suffer from mental distress.

The first question asks about the word(s) the subject would us to describe someone who is crazy or insane. For subsequent questions use the term that has been supplied by the subject.

*USE SUBJECTS OWN WORDS WHEREVER POSSIBLE

TERMINOLOGY:

1. What word or words do you us to describe someone who “appears to have lost control of their actions or their senses?”

(Keep asking for more terms until the subject runs out. When the subject has produced a list of terms, explore what he/she means by them and choose the term that best fits a psychotic illness. Use that term in all subsequent questions).

2. Is that an illness? If no, do you know of any *mental illnesses? Describe.

3. Are there different types of *these illnesses?
SIGNS:

The following prompts should only be offered if the subject makes no suggestions. The interviewer should try to offer them in as unsuggestive a manner as possible, and all responses should be probed fully.

4. What would be the telltale signs by which you and your friends could identify someone who is *crazy?*
   - Violence? Are *mad* people more or less violent that other people?
   - Extreme anger, fear or worry?
   - Apparent loss of control?
   - Apparent loss of sense? [*i.e. Speaking nonsense*]
   - Insomnia?
   - Withdrawal?

Can you think of other signs?
CAUSES:

The interviewer must become familiar with the probe areas, rather than asking every single probe question. There are seven general groupings of questions:

(I) some which focus on the congenital/hereditary nature of illness;

(II) some which concentrate of physical factors as possible determinants;

(III) some ask about ingestion of foodstuff, drink or medicine;

(IV) others focus upon magico-religious variables such as religion, superstition and the bad influences of others;

(V) others look to the activities of the individual themselves as possible causatory factors; or the pressure put on people by other people, by relationships or by situations;

(VI) some look at psycho-social factors such as family problems and worry;

(VII) and finally others ask about environmental/economic factors and focus upon the pressures of life and society.

As you ask the probe questions on causation, try to keep notes of:

a. which causes were spontaneously provided by the respondent;
b. which were admitted to as a result of prompting by the interview process;
c. which causes appear to be the most important;
d. and which the least likely.

5. What do you think are the possible causes for someone going *crazy*?
MENTAL DISORDER BELIEFS SCHEDULE

PROBES:

6. Is *madness passed down in the family?

7. Is *madness to do with the brain not working properly?

8. If someone is weak and often run down would they tend to go *mad?

9. Who are more prone to become *mad, women or men? Why?

10. Are young or old people more prone to *mental health problems? Why?

11. Do darker skinned people go *mad more so than those with fairer skins? If yes, why?

12. People get what they deserve, they bring it upon themselves. Is this true of *madness?

13. If a person has ideas or tries to rise above their station in life, or tries to outdo their friends and neighbours, can this cause *madness? (as in the saying: "some folk up a basket higher than they can reach").

14. Do higher class people go *mad more so than lower class people? If yes, why?

15. Are people in certain occupations more prone to *mental health problems? Why?

16. There is a saying that "people are like crabs in a barrel scrambling over each other, pulling each other down". Can other peoples' envy of someone's attempts to better themselves (ie. better job, house, car) cause the person to go *mad?

17. Can failure to succeed in life cause *madness?
MENTAL DISORDER BELIEFS SCHEDULE

PROBES:

18. Can a young person or child be driven to a *nervous breakdown by parents who want him/her to be brilliant at school and get a highly paid professional job?

19. Can studying too hard make a person *crazy?

20. Do you think that if a man or woman is unwilling to settle down to a steady job or a steady relationship they might have *mental problems sooner or later? Who would this affect more, men or women?


22. Can drinking too much alcohol send you *crazy?

23. Can smoking marihuana tip someone over the edge and send them *mad? Probe for other drugs.

24. If a person has a problem and keeps turning it over and over in their mind and thinking too hard on it, would that make them *crazy?

25. If your man or woman leaves you for another person could the shame of it bring you down and cause *mental problems?

26. If a woman doesn’t have a man, or a man a woman, for a long time can this send them *mad?

27. Can keeping your own company too much cause you to go *mad?

28. Can losing touch with your faith cause you to go *mad?
MENTAL DISORDER BELIEFS SCHEDULE

PROBES:

29. Can too much religion cause someone to go *mad?*

30. If the house you live in needs a lot of work on it and has serious faults, is too small or in a bad area, can this make your life a misery and cause you to go *crazy?*

31. Can bad neighbours bring you down and make you feel like *going crazy,* especially if you are stuck next to them?

32. Does pressure or stress in life cause *madness?*
   
   **Probe:** What do you understand by stress and pressure? What are they and where do they come from? **Also probe for unemployment and racism as part of pressure.**

33. If a person is not strong enough to bear this pressure, will he/she go *mad?*

34. Do you feel that the deprivations and disadvantages that some people face are causes of *mental distress?*

   **Can you give some examples of these disadvantages?**

35. If a person is not in touch with their community (family/friends/home of origin), will this make them confused about who they are?

   **What effect does this have and can this cause *madness?***

36. Does ethnic mixing cause *madness?*
MENTAL DISORDER BELIEFS SCHEDULE

PROBES:

37. Do you think that “society” makes people *crazy?
   What do you understand by “society”?

38. If you tell your neighbour a secret personal thing about yourself, could they use what you have
told them to bring you bad luck?

39. Are some *mad/crazy people the victims of their enemies getting revenge on them?

40. Could a jealous person cause illness or misfortune by working something on someone?

41. Do you think *madness could be caused by anything spiritual or supernatural? Can
ghosts/duppies send people *crazy?

42. Can black magic/obeah cause *madness? Can a person be made to go *insane by the use of
black magic/obeah/science? Why/How?

43. Who do you feel believes in black magic/obeah?

44. Could there be other causes of people becoming mentally ill?

45. Is it up to the individual whether they let circumstances (poverty, bad relationships, deaths)
drive them to the point of *insanity?

46. Is there are purpose to *these illnesses?
SOCIAL DISTANCE:

47. How would you deal with a *mad person if they:-
    a) Came up to you in the street asking for help or money?
    b) Came to live next door to you?
    c) Wanted to marry a family member?

48. How would you feel if a half-way home/hostel for *mentally distressed/disturbed people was sited near to your home?

49. What would you do if a member of your family became *mentally disturbed?

50. How do you think that a person who is *very far gone mentally should be treated?

51. What about if they are a nuisance to you and your family, but basically harmless?

52. Do you think that people with *mental health problems should remain in the community? [ie. outside of an NHS institution]
MENTAL DISORDER BELIEFS SCHEDULE

TREATMENT:

53. What kind of illnesses can be treated in the community?

54. What or who helps people get better if they are *crazy?*

55. Is there any type of iron, tonic, bush or juice that is good for the nerves?

56. Is there any type of medication that can help?

57. Can smoking marihuana help?

58. Would going to church or religious assembly help?

59. Can someone with *mental problems* be helped to get better just by talking and the experience of sharing their problems with a sympathetic listener? Who do you think would be the best person to talk to? **Probe for family, friends, church, doctor** etc.

60. Who would be the first port of call?

61. If that didn’t work, who would be the next port of call?

62. Would going to the doctor or the hospital help?

63. What can any of these people do to help?
APPENDIX 3

CATEGORIES DEVELOPED IN ANALYSIS OF MENTAL DISORDER BELIEFS
SCHEDULE TRANSCRIPTS

Categories and Criteria
This appendix lists all the categories and sub-categories developed in the analysis of the Mental Disorder Beliefs Schedule transcripts and provides, where appropriate and necessary, the criteria developed to define each category. Following the structure of the Mental Disorder Beliefs Schedule, the categories are grouped according to Terminology, Signs, Causes, Social Distance and Treatment.

**TERMINOLOGY**
This is a simple list of all the terms mentioned by respondents

<table>
<thead>
<tr>
<th>Terminology</th>
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<tbody>
<tr>
<td>Anxious</td>
</tr>
<tr>
<td>Attacked</td>
</tr>
<tr>
<td>Berserk</td>
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<tr>
<td>Bewildered</td>
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<tr>
<td>Confused</td>
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<tr>
<td>Crackpot</td>
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<tr>
<td>Crazy</td>
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<tr>
<td>Deranged</td>
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<tr>
<td>Disordered</td>
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<tr>
<td>Disoriented</td>
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<td>Disturbed</td>
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<td>Eccentric</td>
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<td>Fear</td>
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<td>Hysterical</td>
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<tr>
<td>Insane</td>
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<tr>
<td>Irrational</td>
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<tr>
<td>Lost</td>
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<tr>
<td>Lost it</td>
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<tr>
<td>Lost your mind</td>
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<tr>
<td>Lunatic</td>
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<tr>
<td>Mad</td>
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<tr>
<td>Mental illness / disorder</td>
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<tr>
<td>Mentally unstable</td>
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<tr>
<td>Nervous breakdown</td>
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<tr>
<td>No term</td>
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<tr>
<td>Not all there</td>
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<tr>
<td>Not nice</td>
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<tr>
<td>Not well</td>
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<tr>
<td>Nuts</td>
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<tr>
<td>Out of sync</td>
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<tr>
<td>Out of touch with reality</td>
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<td>Potty</td>
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<tr>
<td>Pushed too far</td>
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<td>Rebellious</td>
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<tr>
<td>Retarded</td>
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<tr>
<td>Sad</td>
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<tr>
<td>Schizophrenic</td>
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<tr>
<td>Sick</td>
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<tr>
<td>Sick in the head</td>
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<tr>
<td>Silly</td>
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<tr>
<td>CATEGORIES</td>
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<td>---------------------</td>
</tr>
<tr>
<td>Appearance</td>
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<tr>
<td>Eyes / face</td>
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<tr>
<td>Speech</td>
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<td>Emotional state</td>
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<td>Disturbed public behaviour</td>
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<tr>
<td>Loud</td>
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<td>Odd / bizarre</td>
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<tr>
<td>Unpredictable</td>
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<tr>
<td>Bad / wrong</td>
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<tr>
<td>Loss of control / sense</td>
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<tr>
<td>Outside norms</td>
</tr>
<tr>
<td>Psychiatric symptoms</td>
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<tr>
<td>Depends …</td>
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</tbody>
</table>
CAUSES

Categories relating to causes are grouped into three overarching categories according to the location of the perceived cause: individual, social and spiritual / supernatural.

INDIVIDUAL

The category "Individual" is derived from Helman's (1994) scheme for classifying illness aetiology (see p. 89, Chapter 4). The key feature of explanations categorised as "Individual" is that severe mental illness is believed to arise from factors intrinsic to the individual. Causal explanations focusing on the individual tend to attribute illness to biological malfunctioning, and this assumed malfunctioning is often viewed as stemming from individual behaviours or individual susceptibility. The sub-categories "Substance abuse" and "Biological" fit with this formulation. The category "Biological" incorporates all sub-categories and data in which aspects of individual biology are identified as possible causal factors. In these types of explanation the individual is not usually believed to be responsible. As Helman (1994) suggests, these types of causes are deemed to arise from within the body and beyond the conscious control of the individual. In relation to severe mental illness, these types of explanation include "imbalance", e.g. chemical imbalance, "dysfunction", e.g. brain dysfunction, "hereditary proneness", e.g. genetics, "vulnerability", e.g. weakness and resistance, "injury", e.g. head injury. This latter example, rather than arising within the body, is about an insult to the body, but it falls under this category as it is injury to the body that disrupts biological functioning. This example is the only one of these explanations that might implicate individual behaviour, e.g. recklessness. To some degree then there may, empirically, be overlap between biological and behavioural explanations in aetiological theories that invoke head or brain injury. "Individual susceptibility" is not included as a further sub-category as such explanations usually already fall under one of the other categories. That is, susceptibility is usually seen in terms of genetic predisposition, constitutional weakness, psychological proneness, etc., all of which are coded under one of the other categories.

<table>
<thead>
<tr>
<th>CATEGORIES</th>
<th>CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substance Abuse</td>
<td>Include any data under the relevant sub-code in which substance abuse is</td>
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<td>identified as a possible cause of severe mental illness.</td>
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<tr>
<td>Alcohol</td>
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<tr>
<td>Drugs</td>
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<tr>
<td>Biological</td>
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</tr>
<tr>
<td>Brain / head injury</td>
<td>Include any data in which brain or head injury is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Brain dysfunction</td>
<td>Include any data in which brain dysfunction (i.e. chemical imbalance and the like) is identified as a possible cause of severe mental illness or in which brain dysfunction is viewed as the ultimate mechanism through which someone becomes mentally ill.</td>
</tr>
<tr>
<td>Constitutional weakness</td>
<td>Include any data in which being weak and run down is identified as a possible cause of severe mental illness. This includes those responses in which the respondent says that being weak increases vulnerability.</td>
</tr>
<tr>
<td>Genetic</td>
<td>Include any data in which genes (or heredity) are identified as possible causes of severe mental illness, either as a direct cause or as a factor increasing vulnerability.</td>
</tr>
</tbody>
</table>
SOCIAL

The category "Social" is derived from Helman's (1994) scheme for classifying illness aetiology. However, there are important differences between this category and that described by Helman. Helman's (1994) description of aetiologies located in the social world emphasises interpersonal interactions and motivations, making his formulation of the category very similar to what Foster (1978; 1976) termed personalistic beliefs. Indeed, this category, as defined by Helman (1994), includes explanations in which the active involvement of others in causing ill health is invoked, such as obeah, evil eye, etc. It is not clear, however, whether it is also intended to incorporate explanations that implicate impersonal socio-economic or structural/situational factors (unemployment, racism, etc.). On the face of it, such factors fit more readily into "social" than any of the other categories, but the utility of grouping these types of explanations with ones invoking obeah, evil eye, etc. is questionable. The solution adopted here, and other modifications, is as follows:

1. Explanations in terms of obeah, etc., i.e. those that invoke aspects of the supernatural world as the ultimate force/agent causing severe mental illness, are NOT included in the social category. While acknowledging that interpersonal disputes are an essential feature of these explanations, the primary causal agent lies in the supernatural sphere and these factors are categorised under "Supernatural/spiritual".

2. The category "Social" is then conceived very broadly, incorporating all beliefs that invoke individual psychological processes and/or interpersonal interactions (excluding obeah) and/or factors external to the individual, i.e. structural/situational (excluding supernatural/spiritual).

3. In order to retain a more fine-grained categorisation, sub-categories have been developed to distinguish psycho-social (i.e. beliefs invoking individual psychological processes and/or interpersonal interactions excluding obeah) and structural/situational (i.e. factors external to the individual) beliefs. The precise definitions for each of these sub-categories is below.

4. The further sub-codes "chronic difficulties" and "life events" have been developed to distinguish the types of explanations further. This is more for the purposes of organising the data than a feature of respondents' accounts.

<table>
<thead>
<tr>
<th>CATEGORIES</th>
<th>CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psycho-social</td>
<td>Include all data in the relevant sub-code in which individual psychological processes and/or interpersonal interactions/problems are identified as possible causes of severe mental illness. Respondents may or may not view these factors as stressors. Where the respondent does view them as stressors or within a stress framework the data should also be coded &quot;examples of stressors&quot;.</td>
</tr>
<tr>
<td>Chronic difficulties</td>
<td>Include any data in the relevant sub-code in which the specified causal factor is a problem or difficulty that is not a time limited, discrete event.</td>
</tr>
<tr>
<td>Childhood learning/experience</td>
<td>Include any data in which childhood experiences or family environment are identified as possible causes of severe mental illness.</td>
</tr>
<tr>
<td>Failure to achieve</td>
<td>Include any data in which failure to achieve is identified as a possible cause of severe mental illness.</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Topic</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt</td>
<td>Include any data in which guilt is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Jealousy / envy</td>
<td>Include any data in which jealousy, envy, or bringing people down is identified as a possible cause of severe mental illness. When such factors are implicated in relation to obeah or other supernatural forces the data SHOULD NOT be coded here.</td>
</tr>
<tr>
<td>Loss of faith</td>
<td>Include any data in which loss of faith is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Religion</td>
<td>Include any data in which &quot;too much religion&quot; is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Self esteem</td>
<td>Include any data in which poor self confidence, self worth, or self esteem is identified as a possible cause of severe mental illness or as the mechanism through which other factors cause severe mental illness, e.g. racism undermining self-confidence and this leading to severe mental illness. Where self-confidence, etc. is implicated as a mechanism, the other factor should also be coded elsewhere, under the relevant sub-code.</td>
</tr>
<tr>
<td>Studying too hard</td>
<td>Include any data in which studying too hard or &quot;studiation&quot; is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Thinking too much</td>
<td>Include any data in which thinking too much, brooding, or worry is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Interpersonal problems</td>
<td>Include any data in the relevant sub-code in which interpersonal problems and difficulties are identified as a possible causal factor.</td>
</tr>
<tr>
<td>Family</td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td></td>
</tr>
<tr>
<td>Neighbours</td>
<td></td>
</tr>
<tr>
<td>Relationships</td>
<td></td>
</tr>
<tr>
<td>Work colleagues</td>
<td></td>
</tr>
<tr>
<td>Not having a relationship</td>
<td>Include any data in which not having a relationship for an extended period is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Parental pressure</td>
<td>Include any data in which parental pressure is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Social pressures / expectations</td>
<td>Include any data in which social pressures or expectations are identified as possible causes of severe mental illness, e.g. advertising, pressure to be a beautiful, slim, etc.</td>
</tr>
<tr>
<td>Striving to outdo others</td>
<td>Include any data in which striving to outdo others is identified as a possible cause of severe mental illness, e.g. keeping up with the Jones', trying to outdo others, &quot;crab antics&quot;, etc.</td>
</tr>
<tr>
<td>Life events</td>
<td>Include any data in the relevant sub-code in which the specified causal factor is a discrete life event. Where the response refers to life events generally, or elaborates on how life events contribute to the genesis of severe mental illness, include this in this main code &quot;Life events&quot;, e.g. where life events are conceptualised as triggers.</td>
</tr>
<tr>
<td>Bereavement / loss</td>
<td>Include any data in which bereavement or loss is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Relationship break-up</td>
<td>Include any data in which relationship break up is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Social network</td>
<td>Include any data in which the absence, loss or type of social network is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Structural-situational</td>
<td>Include all data in the relevant sub-code in which structural/situational factors are identified as possible causes of severe mental illness. Structural factors are those arising from impersonal socio-economic forces, from a person's position in the social structure, etc. (e.g. unemployment, homelessness, etc.). Situational factors are those arising from specific situations in which people might find themselves (e.g. caring for children).</td>
</tr>
<tr>
<td>Chronic difficulties</td>
<td>Include any data in the relevant sub-code in which the specified causal factor is a problem or difficulty that is not a time limited, discrete event.</td>
</tr>
<tr>
<td>Caring for children</td>
<td>Include any data in which the difficulties of caring for children are identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Disadvantage</td>
<td>Include any data providing a positive response to the question: do disadvantages or deprivations or generally socio-economic conditions cause severe mental illness?, but which does not elaborate on what these disadvantages might be. Where the respondent does elaborate on what the disadvantages are, the relevant segments should be coded using more specific codes, e.g. financial difficulties, etc.</td>
</tr>
<tr>
<td>Financial difficulties</td>
<td>Include any data in which financial difficulties are identified as possible causes of severe mental illness.</td>
</tr>
<tr>
<td>Living circumstances / conditions</td>
<td>Include any data in which living circumstances, conditions, or location, is identified as a possible cause of severe mental illness. Homelessness is included in this definition.</td>
</tr>
<tr>
<td>Migration / loss of community</td>
<td>Include any data in which the process of migration or the consequence of being in a strange country is identified as a possible cause of severe mental illness. Also include data in which problems arising from being a member of a minority culture, except racism, are identified as a possible causes of severe mental illness, even if this is referring to people of ethnic minority origin being born in the UK.</td>
</tr>
<tr>
<td>Racism / prejudice</td>
<td>Include any data in which racism is identified as a possible cause of severe mental illness, whether this works through another mechanism (i.e. lowering self-esteem) or not.</td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
</tr>
<tr>
<td>-------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Society</td>
<td>Include any data in which society or &quot;the system&quot; is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Unemployment</td>
<td>Include any data in which unemployment is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Work problems</td>
<td>Include any data in which reference is made to problems at or with work as a possible cause of severe mental illness. If these problems are with work colleagues, then this should NOT be coded here. If the problem is that the job is stressful, then it should NOT be coded here.</td>
</tr>
<tr>
<td>Life events</td>
<td>Include any data in the relevant sub-code in which the specified causal factor is a discrete life event. Where the response refers to life events generally, or elaborates on how life events contribute to the genesis of severe mental illness, include this in the code “Psychosocial: Life events”, e.g. where life events are conceptualised as triggers.</td>
</tr>
<tr>
<td>Abuse / assault</td>
<td>Include any data in which abuse or assault of any kind is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Accident</td>
<td>Include any data in which being involved in and/or witnessing an accident of any kind is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Job loss</td>
<td>Include any data in which job loss is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Loss of home</td>
<td>Include any data in which loss of home is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Trauma</td>
<td>Include any data in which trauma, tragedy, etc. (i.e. any extreme adverse event) is identified as a possible cause of severe mental illness.</td>
</tr>
<tr>
<td>Stress</td>
<td>Include any data in which, in general, stress or pressure is identified as a possible cause of severe mental illness, or in which the concept of stress is discussed.</td>
</tr>
<tr>
<td>Examples of stressors</td>
<td>Include any data in which an identified causal factor is considered to be a stressor or is considered a factor by a respondent who has identified these types of factors as stressors.</td>
</tr>
<tr>
<td>Group exposure to stress</td>
<td></td>
</tr>
<tr>
<td>Ethnic minorities more exposed</td>
<td>Include any data in which the respondent says that ethnic minorities experience more stress and pressure, and consequently are more likely to become mentally ill.</td>
</tr>
<tr>
<td>Lower classes more exposed</td>
<td>Include any data in which the respondent says that lower classes experience more stress and pressure, and consequently are more likely to become mentally ill.</td>
</tr>
<tr>
<td>Men more exposed</td>
<td>Include any data in which the respondent says men experience more stress and pressure, and consequently are more likely to become mentally ill.</td>
</tr>
<tr>
<td>------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Old more exposed</td>
<td>Include any data in which the respondent says older people experience more stress and pressure, and consequently are more likely to become mentally ill.</td>
</tr>
<tr>
<td>Women more exposed</td>
<td>Include any data in which the respondent says women experience more stress and pressure, and consequently are more likely to become mentally ill.</td>
</tr>
<tr>
<td>Young more exposed</td>
<td>Include any data in which the respondent says young people experience more stress and pressure, and consequently are more likely to become mentally ill.</td>
</tr>
<tr>
<td>Occupational stress</td>
<td>Include any data in which the respondent says certain occupations can contribute to the onset of severe mental illness, either directly or indirectly, by causing stress.</td>
</tr>
<tr>
<td>Accumulation of difficulties / events</td>
<td>Include any data in which the respondent identifies a number of psycho-social and/or situational/structural factors as working together to cause severe mental illness. This may be through notions of “accumulation”, “build up of events”, “one after the other”, “all sorts of things”, etc. or simply a listing of events and some notion that together they increase the likelihood of severe mental illness.</td>
</tr>
</tbody>
</table>
SPIRITUAL / SUPERNATURAL
This category is the same as Helman's (1994) "Supernatural" category, except that in addition to including causes ascribed to the direct actions of supernatural entities, such as gods, demons, spirits, ancestral shades, etc., it also includes those explanations in terms of sorcery, obeah, etc. that Helman (1994) originally located in his "Social" category.

<table>
<thead>
<tr>
<th>CATEGORIES</th>
<th>CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ghosts / spirits / demons</td>
<td>Include any data in which ghosts, spirits, demons and the like are identified as possible causes of severe mental illness. This should be interpreted widely.</td>
</tr>
<tr>
<td>Obeah</td>
<td>Include any data in which obeah is identified as a possible causal factor.</td>
</tr>
<tr>
<td>Concept of obeah</td>
<td>Include any data in which the nature of obeah is discussed, i.e. what it is, how it works, etc.</td>
</tr>
<tr>
<td>Obeah practices</td>
<td>Include any data in which the practice of obeah is detailed, i.e. examples of rituals, etc.</td>
</tr>
<tr>
<td>Who believes</td>
<td>Include any data addressing the question of who believes in obeah.</td>
</tr>
</tbody>
</table>

CAUSES DEPEND ON …

<table>
<thead>
<tr>
<th>CATEGORIES</th>
<th>CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depends on …</td>
<td>Include any data in which the respondent says that the causes of severe mental illness are dependent on other factors, such as personality, context, etc. Where a specific causal factor (e.g. impact of unemployment depends on person's strength) is mentioned the text segment should also be coded under the relevant code for this factor.</td>
</tr>
<tr>
<td>CATEGORIES</td>
<td>CRITERIA</td>
</tr>
<tr>
<td>---------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Negative</td>
<td>Include any data in the relevant sub-code in which a negative attitude towards people with a severe mental illness is expressed.</td>
</tr>
<tr>
<td>Antipathy / intolerance</td>
<td>Include any data in which the respondent says he/she would not tolerate certain types of activities, actions, outcomes, etc. for someone who is mentally ill, e.g. a member of their family marrying someone who is mentally ill.</td>
</tr>
<tr>
<td>Apprehensive</td>
<td>Include any data in which the respondent expresses some feeling of apprehension at the prospect of contact with someone who is mentally ill.</td>
</tr>
<tr>
<td>Ignore / avoid / not help</td>
<td>Include any data in which the respondent says he/she would avoid or ignore someone who is mentally ill.</td>
</tr>
<tr>
<td>Positive</td>
<td>Include any data in the relevant sub-code in which a positive attitude towards people with a severe mental illness is expressed.</td>
</tr>
<tr>
<td>Give / get help</td>
<td>Include any data in which the respondent says that he/she would give help to someone who had a severe mental illness.</td>
</tr>
<tr>
<td>Tolerant</td>
<td>Include any data in which the respondent says he/she would not be perturbed by certain situations in which he/she came into contact with someone who was mentally ill.</td>
</tr>
<tr>
<td>Stigma</td>
<td>Include any data in which reference is made to the stigma associated with severe mental illness. This does not necessarily mean that the respondent has a negative attitude towards severe mental illness. It may be that the respondent is merely reporting an awareness or expressing a view about the stigma attached to severe mental illness.</td>
</tr>
<tr>
<td>Depends on ...</td>
<td>Include any data in which the response towards people with severe mental illness is said to be dependent on the context or other factors.</td>
</tr>
</tbody>
</table>
TREATMENT
Beliefs about appropriate treatment have been grouped into four overarching categories: 1) What type of treatment is identified as helpful; 2) When should help be sought from others; 3) Where should treatment be provided; and 4) Who should provide the treatment.

WHAT TYPE OF TREATMENT?

<table>
<thead>
<tr>
<th>CATEGORIES</th>
<th>CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>General care / support</td>
<td>Include any data in the relevant sub-code in which the respondent mentions general, vague approaches that should be adopted in response to severe mental illness.</td>
</tr>
<tr>
<td>Advice</td>
<td>Include any data in which the giving of advice is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Care</td>
<td>Include any data in which &quot;care&quot; is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Change of environment</td>
<td>Include any data in which a change of environment is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Love</td>
<td>Include any data in which giving love to someone is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Patience</td>
<td>Include any data in which patience is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Respect</td>
<td>Include any data in which the respondent says someone who is mentally ill should be treated with respect, or where respect is implicit, e.g. treating them like everyone else.</td>
</tr>
<tr>
<td>Rest</td>
<td>Include any data in which rest is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Support</td>
<td>Include any data in which support of a general kind is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Sympathy</td>
<td>Include any data in which sympathy towards the sufferer is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Time</td>
<td>Include any data in which simply the passage of time is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Talking treatment</td>
<td>Include any data in which talking generally is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Talking</td>
<td>Include any data in which therapy provided by counsellors, psychologists, Drs etc. is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Therapy</td>
<td>Include any data in which therapy provided by counsellors, psychologists, Drs etc. is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Category</td>
<td>Description</td>
</tr>
<tr>
<td>---------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Practical Activities</td>
<td>Include any data in the relevant sub-code in which the doing of practical activities by the sufferer or for the sufferer is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Living circumstances</td>
<td>Include any data in which intervening to improve a person's living circumstances is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Problem solving</td>
<td>Include any data in which the giving of practical help to sufferers, the solving of problems, etc. is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Work</td>
<td>Include any data in which being employed is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Traditional / alternative</td>
<td>Include any data in the relevant sub-code in which any form of traditional, folk, spiritual, alternative, complementary treatments/interventions are believed to be effective in treating/relieving severe mental illness. The scope of this category should be interpreted broadly.</td>
</tr>
<tr>
<td>Cannabis</td>
<td>Include any data in which cannabis is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Church</td>
<td>Include any data in which the &quot;church&quot; is identified as helpful in responding to severe mental illness, e.g. belonging to church, going to church, etc.</td>
</tr>
<tr>
<td>Faith</td>
<td>Include any data in which having a &quot;faith&quot; is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>God</td>
<td>Include any data in which God is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Herbs</td>
<td>Include any data in which herbs, bush, tonic, iron, and the like are identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Homeopathy</td>
<td>Include any data in which homeopathic remedies are identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Laying on of hands</td>
<td>Include any data in which the laying on of hands is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Prayer</td>
<td>Include any data in which prayer is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Medical</td>
<td>Include any data in which the need for an accurate diagnosis as a basis for treatment is identified as helpful in responding to severe mental illness.</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Medication</th>
<th>Include any data in which medication is identified as helpful in responding to severe mental illness.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depends ...</td>
<td>Include any data in which the respondent says the type of treatment/intervention is dependent on certain factors, e.g. nature of illness, type of person, etc.</td>
</tr>
</tbody>
</table>

**WHEN SHOULD TREATMENT BE SOUGHT?**

<table>
<thead>
<tr>
<th>CATEGORIES</th>
<th>CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>When</td>
<td>Include any data relating to the stated order of help-seeking, using the sub-codes to identify where in the hierarchy of resort the data fits.</td>
</tr>
<tr>
<td>First</td>
<td></td>
</tr>
<tr>
<td>Second</td>
<td></td>
</tr>
<tr>
<td>Third</td>
<td></td>
</tr>
</tbody>
</table>

**WHERE SHOULD TREATMENT BE PROVIDED?**

<table>
<thead>
<tr>
<th>CATEGORIES</th>
<th>CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>Include any data in which hospital treatment is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Community</td>
<td>Include any data in which community treatment is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Drop-in centre</td>
<td>Include any data in which drop-in centres are identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Depends on ...</td>
<td>Include any data in which the respondent says that the location of treatment is dependent on certain factors, e.g. risk, severity, etc.</td>
</tr>
</tbody>
</table>

**WHO SHOULD PROVIDE TREATMENT?**

<table>
<thead>
<tr>
<th>CATEGORIES</th>
<th>CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lay</td>
<td></td>
</tr>
<tr>
<td>Close confidants</td>
<td>Include any data in which close confidants are identified as helpful in responding to severe mental illness. Where the type of close confidant is specified, this data should be coded using the relevant sub-code.</td>
</tr>
<tr>
<td>Family</td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td></td>
</tr>
<tr>
<td>Self</td>
<td>Include any data in which the sufferer themselves is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Fellow patients</td>
<td>Include any data in which fellow patients are identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>-----------------</td>
<td>--------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Traditional / alternative</td>
<td>Include any data in the relevant sub-code in which traditional, folk, alternative, spiritual, complementary, etc. healer, doctor, etc. is identified as helpful in responding to severe mental illness.</td>
</tr>
<tr>
<td>Alternative practitioners</td>
<td></td>
</tr>
<tr>
<td>Buddhist monk</td>
<td></td>
</tr>
<tr>
<td>Obeah doctor</td>
<td></td>
</tr>
<tr>
<td>Pastor</td>
<td></td>
</tr>
<tr>
<td>Spiritual healer</td>
<td></td>
</tr>
<tr>
<td>Professional</td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>Include any data in the relevant sub-code in which the person identified as a possible source of help is a medical professional.</td>
</tr>
<tr>
<td>Ambulance</td>
<td></td>
</tr>
<tr>
<td>Doctor</td>
<td></td>
</tr>
<tr>
<td>GP</td>
<td></td>
</tr>
<tr>
<td>Psychiatrist</td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td></td>
</tr>
<tr>
<td>Non-medical</td>
<td>Include any data in the relevant sub-code in which the person identified as a possible source of help is a non-medical professional.</td>
</tr>
<tr>
<td>Counsellor</td>
<td></td>
</tr>
<tr>
<td>Phone help</td>
<td></td>
</tr>
<tr>
<td>Police</td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td></td>
</tr>
<tr>
<td>Social worker</td>
<td></td>
</tr>
<tr>
<td>Support worker</td>
<td></td>
</tr>
<tr>
<td>No cure ...</td>
<td>Include any data in which the respondent says that severe mental illness is not curable or treatable.</td>
</tr>
</tbody>
</table>