TITLE: ASSOCIATION BETWEEN PERCEIVED RACISM AND MEDICATION ADHERENCE IN PATIENTS OF CARIBBEAN ORIGIN WITH PSYCHOSIS

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ABSTRACT

Research shows that UK Caribbean patients with psychosis have more aversive pathways in psychiatric care compared with the white British population. This may indicate "cultural mistrust" of services which is attributed by Caribbean patients to racism, explaining their poorer adherence and engagement with services.

Mistrust may reflect a mismatch in the attribution of illness between patient and psychiatrist: whereby the patient perceives both his predicament and services as racist and oppressive, whilst the psychiatrist over-estimates the "dangerousness" of the patient. No study to-date has examined the association between the perception that society and services are racist and adherence with psychiatric treatment in Caribbean patients with psychosis.

This is a London-based prospective cohort study of 100 Caribbean patients with psychosis. It uses the Perceived Racism Scale (PRS - a multi-dimensional measure of self-reported racism), the Drug Attitudes Inventory (DAI) and the Kemp seven-point scale (a commonly used self-report and multi-sourced measure of adherence, respectively). Perceived racism was measured at baseline using the PRS, with adherence and hospital admission data determined after 12 months, using the DAI and Kemp Scale.

The study found small but independent and significant associations between measures of total perceived racism for the previous year, over

a lifetime, and everyday racism for the previous year, with medication adherence one year later. It also found that feeling ashamed and powerless about any racism that was personally experienced within the health system were associated with increased adherence and fewer hospital bed-days in the subsequent year. Finally, the strongest positive association was between perceived racism within the system and both the number of subsequent hospital bed-days and length of hospital admission over the next year.

This implies that in this group of UK Caribbean patients with psychosis, perceived racism is a determinant of adherence with psychotropic medication over a twelve-month period.

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finally but most importantly, to Boo and to my beloved and most precious wife, Mia, whose endless love, altruism and insight have enabled me to achieve.

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1. INTRODUCTION

1.1 General introduction

There is substantial evidence of differential outcomes for different racial and ethnic groups in many health, social and economic arenas in the United Kingdom today, ranging from disease prevalence and outcome, hiring and promotion in the labour workforce, to loan approvals in mortgage lending, to rate of arrest and detention in the criminal justice system. These disparities – and others – describe social conditions that most Britons believe deserve some measure of attention. To understand such conditions and to fashion appropriate responses, it is important to assess whether and how racial discrimination, along with other factors, may contribute to observed disparities among racial and ethnic groups.

Research in social psychology and psychiatry suggests that categorizing individuals on the basis of salient, observable characteristics such as race, gender, age, and even patterns of dress and speech is inevitable, occurs automatically, and activates biases associated with these characteristics (Allport 1954; Brewer and Brown 1998; Devine 1989, 2001; Fiske 1998). Some researchers postulate that automatic categorization will fail to elicit biased responses among those motivated not to be prejudiced (Devine 1989, 2001), yet people regularly use such categories to make distinctions and sometimes to perpetuate social inequalities among different groups.

Examinations of the uses of race in epidemiology, health services research, and medical sociology have led to the observation that race is included in the majority of empirical studies in those fields. Jones and colleagues found that race was used in 64% of studies in their

sample of articles published in the 'American Journal of Epidemiology' between 1910 and 1990 (Jones et al 1991). In an examination of medical sociology, LaVeist and his colleagues found that 53% of the articles from the 'Journal of Health and Social Behaviour' included race (LaVeist et al 1996). And Williams (1994) found that race was used in 64% of the articles published in 'HSR: Health Services Research'.

That race is so frequently included in health research would suggest there is consensus in the conceptualization and appropriate uses of race. This is not the case. An essayist examined medical and allied health dictionaries and demonstrated that there is substantial inconsistency in the conceptualization of race within health sciences (LaVeist et al 1994). Dictionaries ranged from purely biological definitions (Last 1988) to attempts to incorporate the political aspects of race (Segen 1992).

The lack of conceptual clarity is, perhaps, what accounts for the finding that the two most common uses of race in epidemiology, medical sociology and health services research, are as an exclusion criterion in the selection of samples and as a variable to be adjusted for in regression analysis (Jones et al 1991; LaVeist et al 1996; Williams 1994). These two approaches attempt to avoid the problem of a lack of conceptual clarity by regarding race as a confounding variable and trying to "control" for its effects. These methods to deal with race fail to produce new knowledge about the role that race might play in the study in question. Clearly, excluding a racial group from the analysis does not produce new knowledge. And the "control" approach in regression analysis does not either. The inclusion of a binary race variable in a regression model merely produces an adjusted mean value

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for the dependent variable for each racial group and adjusts the coefficients for the other independent variables. This approach cannot inform the researcher if the other independent variables operate differently among the various groups. This is necessary information if one is to design appropriate policy or program interventions to address race-associated differentials in health status.

In addition to sample selection and binary variables, the third most common methodological use of race is to report findings stratified by race without scientific justification. These practices are commonly taught to graduates in epidemiology, sociology, bio-statistics and health services research. This had the effect of slowing the development of high-quality research literature on race and health as illustrated by Jones and colleagues (1991). Their research found that an increase in the number of epidemiological studies that use race as an exclusion criterion in sample selection since the 1960s. As a group, health researchers have preferred to avoid the challenges posed by the analysis of race, rather than confront the problems caused by this variable.

In spite of the lack of conceptual clarity and specificity in the appropriate uses of race, empirical studies consistently show substantial disparities in morbidity and mortality for groups that we have come to know as racial minorities. Whatever race is measuring, one thing appears to be clear. With few exceptions, people who have been categorized as "white" have a better health profile than people who have not been categorized as "white." The next step is to conceptualise the variable of race in terms of biogenetic, cultural and social factors as it is used in epidemiological research.

1.1.1 General introduction: SUMMARY

a) Different racial and ethnic groups in the UK have different health, social and economic outcomes.

b) Racial categorization on the basis of observable characteristics seems to occur automatically, often activating biases associated with those characteristics.

c) The category of racial group is frequently used in epidemiological research, despite remaining a term that lacks conceptual clarity.

d) Research has more or less consistently found that people categorized as "white" have a better health profile than those not categorized as "white."

e) The next step is to conceptualise the variable race and its use in epidemiological research.

1.1.2 Search method for literature review

As will be seen, the literature review within the introduction is extensive and broad ranging. It examines the following concepts: race; racism; racial discrimination; measurement of perceived racism; racism and health; adherence; then UK African-Caribbeans with psychosis. The following bibliographic databases were searched: ASSIA; CINAHL; Cochrane Trials Register; EMBASE; HealthStar; PubMed; PsycLIT; and Science Citation Index. The search was restricted to articles published in English between January 1960 and August 2008. Titles and abstracts of papers were initially identified that covered the areas of interest. The search terms included: (a) RACISM, RACIAL, DISCRIMINATE, DISCRIMINATION, PREJUDICE, PREJUDICIAL, INEQUITY, HATE; (b) ETHNIC, ETHNICITY, RACE, RACIAL, MIGRANT, MIGRATION, IMMIGRANT, AFRICAN-CARIBBEAN, CARIBBEAN, AFRICAN-AMERICAN; (c) SCHIZOPHRENIA, SCHIZO-AFFECTIVE, PSYCHOSIS, SCHIZOPHRENIC, CHRONIC NON-AFFECTIVE PSYCHOSIS, SEVERE MENTAL ILLNESS; (d) ADHERENCE, MEDICATION, TREATMENT, COMPLIANCE. In databases where MESH terms were available they were exploded and combined. Searches were adapted according to the database in question and reviewed by two additional people within the research team to the main author. These searches were supplemented by personal bibliographies of the team, forward citation tracking using the Science Citation Index as well as Social Science Citation Index Databases and by seeking references in retrieved articles.

1.2 Defining race

The focus on measuring racial discrimination in this study raises and initial question of "what is race?" Defining race is a task far more complex than can be accomplished here. In fact, there is little

consensus on what race actually means (Alba 1992; Anderson & Fienberg 2000; Appiah 1992; Frederickson 2002; Jones 1997; Loury 2002; Omi 2001; Winant 2001).

1.2.1 Biological definition

Biological classifications of race were first developed from the work of eighteenth-century naturalists who studied population groups in what had been relatively isolate geographical areas (Montagu 1972; Zuberi 2001). The term "race" was used to distinguish populations in different areas on the basis of differing physical characteristics that had developed over time, such as the colour of skin, facial features, and other features (van den Burghe 1967; Zuckerman 1990).

Recently, genetics researchers have found evidence of genetic clusters that correspond to geographically similar populations and yield the kind of variations in phenotype that have been used to construct concepts of race. Rosenberg and colleagues (2002) report on a study of 1,056 individuals from 52 different populations. The researchers found that a "soft" classification method using no *a priori* information on population groups identified six genetic clusters, five of which correspond directly to major geographic regions, as well as sub-clusters corresponding to specific populations. However, they concluded that within-population differences accounted for 93-95 percent of genetic variation in these individuals, supporting the theory that there are only small genetic differences among geographically different groups.

Recent developments in the fields of genetics and evolutionary biology have prompted a renewed focus on identifying the biological basis of human behaviour as well as ascertaining the historical relationships among different populations (Graves, 2004; Olson, 2002). With studies of the human genome and discoveries of the role of DNA in disease, it has become possible to speculate on specific genes as sources of human behaviour. Population variations in the genes linked to the making of serotonin, testosterone, and dopamine have already led some race scientists to speculate about race differences in behaviour (Oubre, 2004; Rushton, 1995). Some anticipate that they will eventually be able to actually prove race differences in violence, temperament, sexuality, intelligence, and many other mental characteristics.

More important, developments in the structuring of an International HapMap, which maps clusters of genes, have revealed variations in strings of DNA that correlate with geographic differences in phenotypes among humans around the world (Olson, 2002). Such findings may well be used by race scientists to argue that geographic variations in DNA confirm the existence of biological human races.

The components of the idea of social race fail to find congruence with the reality of culture as sui generis. And those categories of people that constitute social races bear little relationship to the reality of human biological diversity.

New genetic data has enabled scientists to re-examine the relationship between human genetic variation and 'race'. A review of the results of genetic analyses has shown that human genetic variation is geographically structured, in accord with historical patterns of gene

flow and genetic drift (Jorde and Wooding 2004). Analysis of many loci now yields reasonably accurate estimates of genetic similarity among individuals, rather than populations. Clustering of individuals appears to be correlated with geographic origin or ancestry and, although these clusters are also correlated with some traditional concepts of race, these are imperfect, because genetic variation tends to be distributed in a continuous, overlapping fashion among populations. Therefore, ancestry, or even race, may in some cases prove useful in the biomedical setting, but direct assessment of disease-related genetic variation is thought ultimately to yield more accurate and beneficial information.

Data from many sources have shown that humans are genetically homogeneous and that genetic variation tends to be shared widely among populations. Genetic variation is geographically structured, as expected from the partial isolation of populations during much of their history. Because traditional concepts of race are in turn correlated with geography, it is inaccurate to state that race is "biologically meaningless."

On the other hand, because they have been only partially isolated, human populations are seldom demarcated by precise genetic boundaries. Substantial overlap can therefore be seen to occur between populations, invalidating the concept that populations (or races) are discrete types.

When great numbers of gene loci are evaluated, it is possible to infer individual ancestry, at least approximately. If done accurately,

ancestral inference may be useful in genealogical studies, in the forensic arena, and in design of case-control studies. When it finally becomes feasible, individual genetic assessment of relevant genes will probably prove more helpful than race in medical decision-making.

In the meantime, race may in some cases provide useful information in biomedical contexts, just as other categories, such as gender or age, do. But the potential usefulness of race must be balanced against the potential hazards. Ignorance of the shared nature of population variation could lead to diagnostic errors or to inappropriate treatment. The general public, including policy-makers, may be seduced by typological thinking, and so they should be made aware of the genetic data that help to prove it wrong.

Race remains an inflammatory issue, both socially and scientifically. Fortunately, modern human genetics may deliver the salutary message that human populations share most of their genetic variation and that there is no scientific support for the concept that human populations are discrete, non-overlapping entities.

Although not all scientists are in agreement (Crow 2002; Mayr 2002; van den Brugh 1967; Zuckerman 1990), many critics deny that meaningful distinctions among contemporary human groups can be derived from a notion of race based upon biology (Cavalli-Sforza 2000; Mead et al 1968; Omi 2001). To date, science has not identified a set of genes that correspond with social conceptions of race.

It may be argued therefore that race is not a naturally occurring phenomenon. The belief in race as a biological concept struggles to withstand scrutiny on at least two bases. First, genetic differences between population groups may not support the belief that there are genetic differences that justify racial groups (Nei & Roychoudhury 1983). There appear to be genetic differences among groups of people but these population groupings are not the same as racial groupings. The genetic distinctiveness of population groups appears to be a function of geography more than anything else (Lewontin et al 1984). But racial categorization is not and could not be based upon geography. Population groups that "belong" to different racial groups may be very similar genetically, whereas population groups that "belong" to the same racial group may be relatively dissimilar, genetically speaking.

Secondly, physical differences among racial groups do not appear to reflect genetic differences (Nei & Roychoudhury 1983). Genotypic differences are not reliably mirrored by the differences in phenotype upon which racial group membership is largely based. The physical differences that signify race do not correlate with the genetic differences on which the biological claim for racial categorization appears to rest. Even if genetic variation justified a concept of race, our demarcation of racial groupings based on physical features does not seem to correspond to the underlying genetic differences.

In summary, racial categories do not seem to track genetic variation among population groups. Even if there were an underlying genetic justification for the designation of racial, as opposed to population groupings, genetic differences are not reliably reflected in the physical characteristics that are perceived to signify race. As will be

discussed, the existence of commonly recognized racial groups is more a matter of social, political and historical contingency, rather than biological necessity.

Race may be better regarded as a social construction. A century earlier, belief in the biological basis of racial categorization obscured this notion. Now, however, the biological bases of race have been widely questioned (Cavalli-Sforza & Feldman 1973; Lewontin et al 1984; Nei & Roychoudhury 1983). From the standpoint of biology, there appear to be no races. Yet, race continues to be among the most meaningful of social categories. From the standpoint of social psychology and psychiatry, race is among the most interesting and important of social phenomenon.

1.2.2 Social construction of race

In virtually all human societies, people take note of and assign significance to the physical characteristics of others, such as skin colour, hair texture, and other distinctive features. Race becomes socially significant when members of any society routinely divide people into groups based on the possession of these characteristics. These characteristics become socially significant when societal members routinely use them to establish racial categories into which people are classified on the basis of their own or their ancestors' physical characteristics and when, in turn, these categorizations elicit differing social perceptions, behaviours and attitudes toward each group (Hollinger 2000; Loury 2002; Smelser el al 2001).

The notion that race is linked to *embodied social signification* is often referred to as the *social-cognitive approach* to thinking about race (Fiske & Taylor 1991; Loury 2002). It is important to understand that this approach is conceptually distinct from biological-taxonomic notions of the classification of race. No *objective* racial taxonomy needs to be valid in order to warrant the *subjective* use of racial classifications. In the social-cognitive sense, "races" may be identified in a society, acknowledged over generations, and believed to be biologically determined even though such groups may not exist in the biological-taxonomic sense.

Recent behavioural and social research supports the social-cognitive notion that race is a construct that is based upon observable physical characteristics (such as skin colour) that have acquired socially significant meaning (Banton 1983; Loury 2002; Omi & Winant 1986). In addition to physical features, ascribed and other characteristics such as given name, diet and dress may also contribute to categorizations of race (Nagel 1994). Cultural factors, such as language, religion and nationality, have more often been used in reference to ethnicity – that is, groups of people who share a common heritage, such as various European immigrant groups in the United States (Bobo 2001).

The social meaning ascribed to racial classifications activates beliefs and assumptions about individuals in a particular racial category. Consequently, if someone is perceived or identifies him or herself as belonging to the African-Caribbean or other social group – regardless of the person's precise or other physical characteristics – that classification creates a social reality that can have considerable consequences. For instance, racial classification may affect access to

resources (such as education, health care, and employment), the distribution of income and wealth, political power, residential living patterns, and inter-personal relationships. Moreover, the consequences of racial classification over time can create boundaries among racially defined groups that affect people today.

Race may be thought of as a social category that was created historically to serve particular interests: "Racial categories did not emerge simply as the products of energy- and time-saving cognitive devices, but as functional entities constructed in the service of social power and cultural domination" (Eberhardt & Randall 1997). The idea of race did not exist in its present form before the Atlantic slave trade; it only gradually took hold in society as it became necessary to rationalize and account for slavery (Fields 1990). If races did exist, and if one was inferior to the other, then the democratic principles of liberty and equality would not be threatened or undermined by the existence of slavery.

Specific definitions of race were also developed to fulfill particular goals of the slavery system. The general principle that "one drop" of "black blood" made someone black, for example, combined with the principle that a child took his or her mother's race to ensure the maintenance of the population of slaves, in spite of widespread miscegenation between white men and black slave women.

Historically, physical appearance has been the identifiable, surface characteristic on which racial categorization has been based. Physical features such as complexion, hair, lips, nose, and body-type have been central to determining race. Ancestry, although not a "physical"

feature, may be best viewed as a surface characteristic pointing towards the essence of the category more than it constitutes it. Ancestry and appearance are linked through the metaphor of "blood", whose physicality suggests physical features and whose biological character symbolizes the transmission of race through lines of descent.

The "deeper" properties of race are considered to be comprised not only of a biological essence (such as DNA), but also of psychological and status characteristics as well. Beliefs about those deeper properties constitute the essence of racial categorization. The psychological characteristics of race included factors such as racial sentiments, instinct, affinities, proclivities, and moral character. The social status characteristics include the general (e.g., dominant vs. subordinate) and the specific (e.g., master vs. slave) roles that racial groups often occupy in society relative to one another. Biological conceptions of race often, but not always, underpin beliefs in race-based psychological and social status characteristics.

Although both psychological and social status characteristics may be thought of as the deep properties of race (and therefore as part of the essence of the categories), features of social status (i.e., which roles particular racial groups occupy in society) may be believed to naturally follow form psychological characteristics (Hoffman & Hurst 1990; Jost & Banaji 1994; Yzerbyt et al 1997). Black African-Caribbeans' often-low status in contemporary times, for example, may be thought to result from an aversion to hard work.

Disparate physical features including hair, complexion and bone structure become understood, through the lens of racial essence, as

similar. Some characteristics but not others become salient because they are assumed to signify race. Related to this, surface features such as skin colour and hair texture, according to this view, signify internal qualities of an individual. As suggested by Allport (1954), "[dark] skin implies more than pigmentation, it implies social inferiority". Far from merely contributing to appearance, surface features point toward the unseen moral, psychological, or intellectual properties of race.

1.2.3 The ambiguity of race

As a social cognitive construct, the meaning of race in the United Kingdom has changed and is likely to continue to change over time with changing socio-political norms, economic patterns and waves of immigration (e.g., the growing acknowledgement of mixed-race origins in the twenty-first century). Moreover, race has and may continue to have different meanings for different groups, sometimes overlapping and sometimes not (Lieberman 1993).

Shifts in societal views on race, political pressures from different groups, increasing diversity in the country's population, and consequent changes in the standards of data collection and practices add ambiguity to the way data on race is understood and interpreted. Two specific measurement problems are inconsistent reporting for individuals and groups, currently and over time, and different data-collection practices, such as self-reporting in surveys and, frequently, reporting by others in administrative records systems. Some researchers have suggested that multiple indicators are needed to fully understand racial categorization in British society today.

1.2.4 Inconsistent reporting

Population groups and individuals vary in their consistency of reporting race when comparing surveys across time and with each other. For example, because country of birth is recorded on death certificates and in census data, much of the published data in this area has allocated race according to country of birth, a strategy that is clearly inadequate. In addition, many studies have used categories such as Black or South Asian to describe the ethnicity of those studied. Although it has been suggested that this may be a useful starting point (Chatuverdi & McKeigue 1994), it is important to recognise that such categories are heterogeneous, containing racial groups with different cultures, religions, histories of migration, and geographical as well as socio-economic locations (Modood 1994). In fact, rather than being a good starting point, combining racial groups is likely to lead to differences between them being ignored.

If work on race and health is to progress further, assessments of race should be more adequate and the process needs to be clearly defined (Senior & Bhopal 1994). One solution is to accept the dynamic, fluid and contextual nature of concepts such as race and ethnicity, and to research the relationship between race and health with this explicitly in mind (Ahmad 1995). However, such a task is difficult, if not impossible, to undertake in a quantitative study, which inevitably must rely on a relatively crude and one-dimensional measure.

Quantitative strategies require essentially arbitrary choices to be made about the appropriate demarcation of racial categories. An alternative to a truly contextualized assessment of race is to permit

participants to assign themselves into an ethnic group, which was the strategy adopted for the 1991 and 2001 Censuses.

Some people believe self-identification is the only reasonable method to use because it allows people to express their own racial identity (Harris 2002). Other people argue against self-identification because they believe racial data, if used to enforce civil rights, should capture the observer's report of an individual's race - after all, people are most often discriminated against on the basis of the observer's beliefs. However, this method suffers from instability; individuals often move from one group to another when the question is repeated at a later date (Sheldon & Parker 1992), a situation that no doubt reflect the contextual nature of racial identity. For example, with changes to questions and category labels for some groups over time, differences in who reports the race of an individual (the individual, another household member, or an observer), and changing political reasons for identifying with a particular race (e.g., civil rights enforcement, collective identity), responses can be inconsistent and difficult to interpret. However, results from the National Health Interview Study suggest that, if prompted, a majority of people choosing more than one race to describe themselves will select one primary racial category (Sondik et al 2000).

Another alternative is largely to ignore the role of self-perceived ethnicity and to assign racial category according to family origin (Nazroo 2001). This could be done by asking the question: "Do you have family origins which are: Black Caribbean; Indian Caribbean; Pakistani; Bangladeshi; Indian; Chinese; Irish; White British; or did your family come from somewhere else?" Unsurprisingly, perceived racial group and

country of family origin have been found to be highly related (Nazroo 2001).

This approach based on the country of family origin has the advantage of being a relatively straightforward and stable approach, although individuals within particular groups cannot be considered to be homogeneous in respect of many factors that could be related to both self-perceived race, such as religion or country of birth, and health. This method becomes even more sophisticated if specific details are sought on country of origin of particular family-members, such as mother, father or either grand-parent (as performed in this study).

Using different approaches to identify and report race and ethnicity can make it difficult to compare racial categorizations across time and among data sets. Moreover, reporting procedures are not often the same even within a single data set.

1.2.5 Multiple indicators of racial identification

Harris (2002) argues that the classification of race is a social process that varies across contexts and observers. To determine an individual's race, people may use one or more ancestry or biological bases, phenotypic or physical characteristics, and cultural bases, such as ideology and language. Furthermore, racial classifications for an individual may differ according to the perspective of the person making the classification: internal (self-assigned classification based on how an individual's beliefs about his or her own race); expressed (self-classification based on how the individual presents his or her race to others – e.g., choosing not to identify as a member of a non-white

group to avoid stigmatisation); and external (classification by observers based on their views of an individual's race). These are not mutually exclusive dimensions; they all interact within a social context. Thus, a mixed-race individual may identify himself or herself as multi-racial in private settings but express a dominant race in public and be classified in different categories by different observers.

Obtaining multiple indicators of racial identification would likely provide helpful data to inform racial classification and analysis. As noted by Harris, however, indicators for race along these lines are not available in most current data sets. To collect these data, it would be necessary to add specific additional categories and observations, still further complicating the measurement and analysis of race data.

1.2.6 Towards a definition of race

Race is a structurally complex variable that is related to a number of social variables and that reflects cultural and status heterogeneity. The impulse to use race as one of the variables that measures class and status is often strong. In epidemiological studies, appearance tends to form the primary indicator of race. Individuals characterized by similar skin colour are assumed to belong to the same racial group. Group identity is presumed to be associated with varying degrees of health risk. This risk is based on empirical evidence and has a distinct circularity in reasoning. The health risks of African-Caribbeans (as defined by their physical appearance) are compared to the health risks of white British people (as defined by appearance).

These differences are interpreted as being due to the risk of belonging to the defined group.

Because of these problems, some authors have moved away from measuring race as a categorical variable toward measuring it as a continuous variable. These authors literally measure skin colour (Keith & Herring 1991; Klag et al 1991). Some authors use skin colour as a measure of the variations in social status within the black population (Keith & Herring 1991).

A biological measure of race leads to some philosophical problems. If one starts with the premise that race is not a biological but a social variable, then a more-refined measure of a biological indicator would, on the face of it, seem to be a move in the wrong direction. The conundrum is made more complex since the first indicator of group identity is physical. Racial boundary formation between African Americans and others may be argued to be primarily based on skin colour. Some have argued that racial boundary formation within the black population is equally important and leads to economic benefits for those African Americans who are more "mulatto" (Cabral et al 1990).

However, what must be considered as the logical starting point is that the health effects of race are not due to race classification, but are due to the notions of supremacy inherent in racism. The ontological, psychological, psychosocial and sociological effects of racism are fundamental to the understanding of racial differences in health and disease, and that accurate skin colour measurements do not, on their own, allow for the explanation of the differences.

Race should be part of a multi-dimensional construct of social status. Ideally, the construct should include: a) some measure of self-identification; b) a measure of group identity; c) a measure of social distance between the group that the individual belongs to and other groups; d) measures of social mobility; e) socio-economic status; and f) contextual variables of family and community.

1.2.7 Race and ethnicity as a variable in research

Ethnicity has been used increasingly as a key variable to describe health data, further stimulated by ethnic monitoring in the NHS. Senior and Bhopal identified four fundamental problems with ethnicity in epidemiological research - the difficulties of its measurement; the heterogeneity of the populations under study; the lack of clarity about the purpose of the research; and ethnocentricity affecting the interpretation and usage of the data (1994). They argue that ethnicity should not be confused with nationality or with migrant status, and that ethnicity should be differentiated from race, which in the biological sciences refers to differentiation according to physical characteristics.

They go on to argue that ethnicity may not be a sound epidemiological variable for a number of reasons (1994). Firstly, as ethnicity is not easily measured, several methods are in use. Skin colour, which is genetically determined, is clearly based on race, and observers have

classified subjects' ethnicity by means of skin colour, which is subjective, and therefore imprecise and unreliable. Secondly, the problems of population heterogeneity mean that populations identified by current methods of measuring ethnicity are often too diverse to provide useful information. Next they discuss the problem of testing etiological hypotheses and research for health-service planning. Tit is argued that studies emphasizing ethnic differences have drawn attention to the potential for etiological inquiry but failed to adequately test hypotheses nor extend the knowledge of disease causation because of the problems above and because of superficial inquiry. Etiological research requires detailed information and focuses on relative risks, whereas research for the planning of health services requires a broad view and simple data and focuses on absolute risks. Finally, the authors highlight the problem of ethnocentricity including how the impact of the researcher's values may influence the development and interpretation of hypotheses on the causes of variations in the prevalence of diseases.

Senior and Bhopal have suggested how the value of ethnicity as an epidemiological variable may be improved (1994): ethnicity should be differentiated from race; ethnicity's complexity and fluidity should be acknowledged; ethnic classifications should be more explicit and their current limitations set out; investigators should recognize the potential influence of their personal values and ethnocentricity upon research an policy-development; socio-economic differences should not be ignored; and the relative importance of environmental, cultural, lifestyle and genetic influences should be factored in to the analyses of difference.

Bhopal and Donaldson widen their argument in reference to the term "White" in a separate paper (1998). They point out that the request for scientifically appropriate terminology in research on race, ethnicity, and health has apparently bypassed the term White. This and other words, such as Caucasian, are embedded in clinical and epidemiological discourse, yet they are rarely defined, which would make scientific comparison all the more difficult. By suggesting that by using broad labels for heterogeneous groups comparisons would be misleading; others have read this as a call for abandoning terms such as race in race research (Buehler 1998; Rabin 1998). This, the responders argue would not remove racism bur serve to perpetuate its effects by ignoring ethnic differences in this way. The rebuttal to this may read that what is needed is not a doing away with such terms but a greater clarity in the definition of labels of different groups before sound and scientific comparison to test hypotheses, may be possible (McKenzie and Crowcroft 1994).

1.2.7 Defining race: SUMMARY

a)   "Race" remains both a complex and controversial term to define by biologists and sociologists.

b)   The biological basis for race is undermined by the observation that categorization according to physical features does not seem to correspond to underlying genetic differences.

c)   However, race is a construct often based upon observable physical characteristics that have acquired socially significant meanings in relation to cultural factors such as diet, dress, language and religion.

d)   Race in the UK is a fluid concept in the sense that societal views seem to shift according to the prevailing political landscape, as well as attitudes toward immigration and ethnic diversity.

e)   Survey-measures of race are undermined by both inconsistent reporting and different data-collection practices.

f)   Two methods commonly used to categorize race are self-identification and by family of origin, although some prefer multiple indicators than a "reductionist" approach.

g)   A common approach is to use skin colour to categorize race, which may be perceived as straightforward but is fraught with problems.

h)   The next section examines the concept of racism.

1.3 Racism

Race has been described earlier as a social-cognitive construct that evolves over time and in which racial categories reflect the person's ancestors' physical features and associated characteristics that have acquired social meaning. Racism may be defined as a belief or doctrine that inherent biological differences among the various human races determine cultural or individual achievement, with a corollary that one's own race is superior and has the right to rule others.

The term racism is sometimes used interchangeably to refer to preference for one's own ethnic group (ethnocentrism), fear of foreigners (xenophobia), views against mating between the races (miscegenation), and/or a generalization of a specific group of people (stereotype); regardless of any explicit belief in superiority or inferiority embedded within such views or preferences. Racism therefore has been used in attempts to justify social discrimination, racial segregation and violence, including genocide.

When racism, the belief, is applied in practice, it takes forms such as prejudice, discrimination, segregation or subordination. Racism can more narrowly refer to a system of oppression, such as institutional racism. Organizations and institutions that put racism into action discriminate against, and marginalize, a class of people who share a common racial designation. The term racism is usually applied to the dominant group in a society, because it is that group that has the

means to oppress others. The term can also apply to any individual or group, regardless of social status or dominance.

Racism can be both overt and covert. Individual racism sometimes consists of overt acts by individuals, which can result in violence or the destruction of property. Institutional racism is often more covert and subtle. It often appears within the operation of established and respected forces in the society, and frequently receives less public condemnation than the overt type.

1.3.1 Racial attitudes

Covert, less obvious aspects of racism are often contained within people's beliefs and attitudes about different races. Although attitudes are more difficult to evidence, it is important to register their presence and attempt to measure them because attitudes may influence behavioural inequity towards different racial groups, and attituds to racaism are often cosidered no less important than overt acts of racism by the recipients of racial discrimination.

There is evidence that negative stereotypes about minority groups are declining. For example, in 1933, 75% of white US respondents described blacks as lazy; in 1993, that figure declined to just 5% (Dovidio et al 1996). White America is also becoming more accepting of black leaders. In 1958, the majority of whites reported that they would not be willing

to vote for a well-qualified black presidential candidate; in 1994, over 90% said that they would (Davis & Smih 1994). In addition, this apparent increased tolerance extends beyond blacks to other racial and ethnic minority groups as well (American National Election Survey 1995).

Despite these trends in the inter-group attitudes of the white majority in the west, there are still reasons for concern. One reason is that a proportion of people are still expressing the old-fashioned, overt form of bigotry. Those respondents consistently describe blacks as less intelligent than whites and oppose programmes designed to ensure full integration and equality of opportunity. Another reason for concern is that people may espouse racial tolerance but not true openness to or enthusiasm for full racial equality. A third reasaon is that there is also evidence that up to 85%-90% of the white US popualtion may believe they are not prejudiced but may nonetheless be practising a modern, subtle form of bias. This bias is believed by some researchers to account, at least in part, for the persistence of racism in our society (Dovidio & Gaertner 1998).

In a 1988 national American poll, 25% of the black respondents said that they believed that white people "want to hold" black people down; 44% of all respondents said that they believed that society is holding blacks down (Gelman 1988). In a more recent survey, 32% of blacks reported that discrimination is the primary obstacle to achieving equality in the United States (Anderson 1996). Furthermore, despite

dramatic improvements in the expressed racial attitudes of whites over time, racial disparities persist. US data shows that gaps between blacks and white Americans in infant mortality, life expectancy, employment, income and poverty have continued to exist; and, in many cases, these disparities have actually increased over the past few decades (Hacker, 1995).

1.3.1.1 Aversive racism

Aversive racism represents a prevalent type of modern racial bias which researchers feel is important but ofen hard to identify (Dovidio & Gaertner 1991; Gaertner & Dovidio 1986; Gaertner et al 1997). In contrast to "old-fashioned" racism, which is expressed directly and openly, aversive racism is a subtle, often unintentional form of bias that characterizes those who possess strong egalitarian values and who believe that they are not prejudiced. Aversive racists are also felt to possess negative racial feelings and beliefs of which they are unaware or that they try to dissociate from their non-prejudiced self-images. The negative feelings that aversive racists have for blacks do not reflect open hostility or hate. Instead, thir reactions are found to involve discomfort, uneasiness, disgust, and sometimes fear. That is they are found to regard blacks as "aversive", while, at the same time, they find any suggestion that they might be prejudiced aversive as well.

This aversive racism framework incorporates ambivalent feelings; the positive and negative feelings that aversive racists experience creates

psychological tension that may lead to behavioural instability. Thus, unlike the consistent and overt pattern of discrimination that might be expected from old-fashioned racists, aversive racists discriminate (manifesting their negative feelings) and sometimes do not (reflecting their egalitarian beliefs of justice and fairness).

Consistent support has been found for the aversive racism framework across a broad range of situations (Gaertner & Dovidio 1986). In brief, there are four implications of this framework: the bias of aversive racists is expressed in more subtle ways than that of old-fashioned racists; despite their conscious rejection by aversive racists, unconscious negative feelings linger; aversive racists express more bias toward higher-status than towards lower-status minorities; and relatedly, aversive racists often oppose programmes designed to improve the status of blacks, but ostensibly on the basis of factors other than race (such as in the interests of equity).

1.3.1.2 Racial microaggressions

An equally subtle yet significant form of racism developed by the US psychiatrist Chester Pierce is the concept of microaggressions (1974). Microaggressions are subtle insults (verbal, nonverbal, and/or visual) directed toward people of colour, often automatically or unconsciously: "... one must not look for the gross and obvious. The subtle, cumulative miniassault is the substance of today's racism..." (Pierce, 1974, p. 516)

In and of itself a microaggression may seem harmless, but the cumulative burden of a lifetime of microaggressions can theoretically contribute to raised morbidity and flattened confidence. (Pierce, 1995, p. 281) Little is known about microaggressions, and yet this subtle form of racism is reported as having a dramatic impact on the lives of African Americans. Pierce and his colleagues have defined racial microaggressions as "subtle, stunning, often automatic, and nonverbal exchanges which are 'put downs' of blacks by offenders" (Pierce et al 1978, p. 66). They further maintain that these "offensive mechanisms used against blacks often are innocuous" and that the "cumulative weight of their never-ending burden is the major ingredient in black-white interactions" (p. 66).

Racial microaggressions, though pervasive, are rarely investigated (Delgado & Stefancic, 1992; Solorzano, 1998) and may be related to the concept of aversive racism. Davis (1989) has suggested that Whites are capable of such utterances because "cognitive habit, history, and culture [have made them] unable to hear the range of relevant voices and grapple with what reasonably might be said in the voice of discrimination's victims" (p. 1576).

1.3.2 Racial discrimination

A social science definition of racial discrimination may be best used for the purposes of this study. This includes two components: (1) differential treatment on the basis of race that disadvantages a racial group and (2) treatment on the basis of inadequtely justified factors other than race that disadvantages a specific racial group (differential effect). Each of these components is based on behaviour or treatment that disadvantages one racial group over another, yet the

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parts differ on whether the treatment is based on an individual's race or some other factor that results in a different racial coutcome.

The first component of the definition of racial discrimination occurs when a member of one racial group is treated less favourably than a similarly situated member of another racial group, and suffers adverse consequences. This definition of discrimination is used in many academic fields to refer to unequal treatment because of race. The second component of the definition of racial dsicrimination includes instances in which treatment based on inadequately justified factors other than race results in negative racial conseequences, such as promotional practice that generates differential racial effects. A process with adverse racial consequences may be considered discrimination under the law, depending on whether there is a sufficiently compelling reason for its use and whether there are alternative processes that would not produce a racial disparity. In areas in which this type of discrimination is unlawful, the reason is to limit the use of unintentional practices that may harm racial minorities, as well as to sanction intentional discrimination that may not be identified because of the inherent difficulty in establishing intent in the legal setting.

The two components of the definition - differential treatment and differential effect discrimination - are related to, but broader than, the standards usually applied in legal settings - disparate treatment and disparate impact discrimination. The legal definition of disparate

treatment racial discrimination is when an individual is treated less favourably (for example, when they are not employed for a job) because of their race. Disparate impact racial discrimination occurs when a behaviour or practice that does not directly involve race has an adverse impact on a racially disadvantaged group, without sufficiently compelling reason. An example is an employment policy against employing job applicants with a criminal arrest record when such a policy results in proportionately fewer people employed from disadvantaged racial groups whilst not significantly advancing any legitimate employer interests. These kinds of practices – whether intentionally or unintentionally harmful – are deemed unlawful unless a sufficiently compelling business reason can be supplied to justify them.

It is important that research into racial discrimination encompasses categories that include behaviours and processes which are either not explicitly unlawful or not effectively prohibited because of difficulties in measurement or proof. This is in order to capture as true a picture of the experience of racial discrimination for the individual as possible. For example, subtle forms of discrimination which might not be susceptible to legal challenge but fall within this definition include when interviewers of job applicants more frequently adopt behaviours (e.g., interrupting, asking fewer questions, or using a hectoring tone) that result in poor communication and consequently poorer performance by disadvantaged minority ethnic applicants as compared with other applicants. Even though it may be more difficult to prove legally, such subtle discrimination in theory constitutes actionable disparate treatment discrimination.

This definition of racial discrimination is based on behaviours and practices, and as such it differs from a definition that also includes prejudiced attitudes and stereotypical beliefs. Discriminatory behaviours and practices may arise from prejudice and stereotyping, but prejudice need not result in either differential treatment or effect. Similarly, whereas discriminatory behaviour in many domains is unlawful, prejudiced attitudes and stereotypical beliefs are not.

1.3.3 Race, racism and racial discrimination

Throughout this thesis, therefore, the terms race, racism and racial discrimination shall have very specific meanings and they are as follows:

Race is defined as a human population considered distinct based on physical characteristics.

Racism is defined as a belief or doctrine that inherent biological differences among the various human races determine cultural or individual achievement, with a corollary that one's own race is superior and has the right to rule others.

Finally, racial discrimination is defined as differential behaviour or treatment on the basis of race that disadvantages a racial group.

1.3.4 Racism: SUMMARY

a)   Racism is the belief that biological differences between races determine achievement with the corollary that one's own race is supperior to others.

b)   Racism includes overt, easily-recognisable acts and covert, more subtle behaviour; it may be enacted by either individuals or institutions through their policies and systems.

c)   Negative beliefs about other races held by the dominant racial group are reported as declining in prevalence; but this may reflect increasing concealment of those attitudes.

d)   Aversive racism is a subtle bias, marked by ambivalence, often consciously denied by the individual but evidenced by their actions and beliefs.

e)   Racial microaggressions are subtle insults, either verbal or non-verbal in nature directed toward people of colour and often occur automatically or unconsciously.

f) Racial discrimination is both differential treatment on the basis of race that disadvantages a racial group, and treatment on the basis of inadequtely justified factors other than race that disadvantages a specific racial group.

g) The next section focusses on the phenomenon of racial discrimination in Britain.

1.4 Racial discrimination in Britain

Evidence of large and persistent differentials in social, economic, and political outcomes among racial and ethnic groups in the United Kingdom charcterises virtually every social domain.

Immigration from the New Commonwealth and Pakistan since the Second World War has resulted in the formation of distinct minority ethnic communities within British society making it more ethnically diverse. While there is general agreement that the reception extended to these communities has been generally unwelcoming, two different reasons have been offered as explanations. One emphasises that minority ethnic groups are relatively new to British society, typically being either immigrants or now more commonly children of immigrants; the other emphasises that minority groups are different in outward appearance from the native white population. The first answer sees the newness of ethnic minorities as central to an understanding of their negative reception, while the second answer sees the colour of ethnic minorities as central to the understanding of this reception.

1.4.1 The immigrant-host framework

The first position is described by Patterson (1965) but hints of it can be found in early post-war writing on race and ethnicity in Britain. It is argued that immigrants have to go through two processes before they can be assimilated into the society they have entered: they have to adapt themselves to and at the sasme time be accepted by the host

society. Neither of these two processes usually occurs within the life span of one generation, resulting in at least a temporarily negative reception. Some immigrants may find the transition fom one culture to another difficult, in terms of language, religion, and family structure. The host society on the other hand, may find it difficult to come to terms with people who do not seem to show an understanding of the implicit norms governing local behaviour and ttherefore seem strangers.

Although most writers who expound the 'immigrant-host' framework recognise a degree of cultural antipathy towards minority ethnic communities in Britain making 'absorption' difficult, the overriding mood is one of optimism. Supporting this position, are the experiencecs of immigrant groups generally in the United States. Across the Atlantic, although later generations still tend to retain traces of their roots (Glazer & Moynihan 1970), immigrant adaptation and host acceptance have been to a large extent completed, and the earlier hostility and discrimination overcome.

The immigrant-host framework derives from the theoretical perspective of functionalism from the writings of Durkheim. This sees society as held together by common values - the shared customs and traditions of 'community' and 'nation' - such that immigration constitutes a potential threat to social order. Assimilation is therefore considered crucial. According to this framework, Britain is characterised as having been culturally homogeneous prior to the Second World War.

The assumptions within the immigrant-host framework are problematic and have been challenged. Has Britain ever been a culturally homogeneous society? Has it not been characterised in the last two centuries by social classes with different customs and traditions and has there not been significant conflict between them? What about the significant national and regional differences which have persisted over a considerable period? Is assimilation into a uniform culture desirable? Does the coexistence of many cutures not make a society vibrant and allow its members more options? Is not the demand that ethnic minorities assimilate "asking for conflict and destabilization and the fragmentation of communities that are currently the sources of stability, group pride and self-esteem?" (Modood 1992: 5). While some immigrant groups have indeed been assimilated, this may have been related to being white in skin colour, so that later generations are not easily distinguishable from the indigenous white population. The children of immigrants from the "New Commonwealth" for example, do not share this physical attribute with the host population which may make them liable to experience more lasting patterns of hosility. This leads into the second account of how immigrants from the New Commonwealth and Pakistan have been received into this country.

1.4.2 The imperialism-racism framework

This account stresses the high status attached to being white in British society and is the view found in much recent writing on the subject. Attention is drawn to imperialism, involving the domination of people with a different skin colour by whites from European counties. In the 'New World', colonialism involved the transfer of people from

Africa to work as slaves on the plantations. In order to reconcile this treatment of slaves with their dimly recognised humanity, beliefs emerged which classsified such people as inferior. These beliefs spread from situations of slavery to other aspects of colonialism, with the image of the 'inferior slave' stamped on all who were colonised. In the process, white domination could then be justified. It is argued that these beliefs are still endemic in British culture, so that the arrival of people with a different skin colour from countries formerly a part of the British Empire, was met with a degree of hostility not triggered by the entry of white immigrants.

For those who point to the prevalence of such beliefs, the passsing of time and a new generation will not necessarily entail a dramatic lessening in racial discrimination. The African American position is often quoted in support of this position; black people in the USA have found that, over one hundred years after the abolition of slavery, completely equitable treatment is still difficult to achieve.

1.4.3 Evaluating the two perspectives: newness or racism?

In consideration of the two accounts described, both agree on picking out discrimination as significant in the reception met by the first generation of migrants. However, they differ in their choice of what constitutes the basis for this discrimination. In the first case, the immigrant's status as a newcomer is highlighted and in the other case, their status as a non-white person is highlighted. Examination of the empirical data is needed to assess the support for either account.

1.4.4 Direct racial discrimination

Three PSI studies provide good evidence over a 20-year period on the extent of discrimination in the UK (Daniel 1968; Smith 1977; Brown & Gay 1985). To ascertain the level of discrimination and whether it was based on newness or colour, Daniel conducted a series of situation tests in which actors applied for jobs, housing and commercial services in carefully controlled circumstances. A non-white immigrant (Caribbean or Asian), a white immigrant (Hungarian) and a white native, age-matched and claiming equivalent occupational qualifications or housing requirements, applied for a job, a house, or a commercial service on offer for the public. Discrimination was defined as a case in which one tester was made an offer or a better offer, and the other(s) none or a worse offer. Daniel found that the non-white immigrant met by far the most discrimination. The subsequent studies revealed significant discrimination based predominantly on colour, despite the introduction of anti-racist legislation in the interim. While Smith detected a fall in the level of discrimination between 1967 and 1973, Brown and Gay, utilising both actor testing and a form of situation test, pioneered by Smith, known as "correspondence testing", in which matched written applications were sent in reply to advertised vacancies, found little evidence to suggest that the level of discrimination in 1984-5 had decreased since 1973. At least a third of employers still discriminated against non-white applicants for jobs.

The 1994 PSI survey instead of measuring comparable discrimination, chose to examine people's beliefs and attitudes. It reports that "the belief that employers discriminate is much more widespread than the

experience of discrimination" (Modood et al 1997: 132). Only 20% of minority ethnic respondents reported direct experience of discrimination, while 90% of white respondents and 75& of minority ethnic respondents believed in its existence. The discrepancy may be due to the existence of both overt and covert (and often unacknowledged) discrimination. Both the belief in discrimination and its reported experience had risen since the 1982 report. This may be due to an increased salience of discrimination as an issue and its victims feeling more able to openly discuss it.

In contrast to previous PSI studies, the most recent PSI survey suggests a "religious component of racial discrimination" (Modood et al 1997: 352). Two arguments for this are proffered. Firstly, a significant proportion of ethnic minorities, especially south Asians, who report experiencing discrimination believe it to be a result of both race and religion. Secondly, "there is now a consensus across all groups that prejudice against Asians is much the highest of any ethnic, racial or religious group; and it is believed by Asian people themselves that the prejudice against Asians is primarily a prejudice against Muslims" (Modood et al 1997: 133). These arguments however do not negate the argument that discrimination is colour-based. A greater proportion of those that reported discrimination saw it as based primarily on race and, although there is evidence of greater prejudice especially among younger white people, against Asians and in particular Muslims, prejudicial attitudes are not necessarily equivalent to discriminatory behaviour (Pilkington 1984).

The most recent tests of local-level discrimination continue to point to racial discrimination (CRE 1996; Simpson & Stevenson 1994). A Nottingham study in 1992 repeated the format of an earlier study conducted between 1977 and 1979, which used application letters from three fictional applicants (white; Asian; and Caribbean), matched in terms of age and qualifications to prospective employers, the authors found that "much as in 1979", a white applicant's chances of being interviewed were twice as high as either the Asian or African-Caribbean applicants (Simpson & Stevenson 1994: 15). The latter two groups have been described as facing an "ethnic penalty" (Heath & McMahon 1997). This is defined as a broader concept than discrimination, referring to all sources of disadvantage that might lead an ethnic group to fare less well in the labour market than similarly qualified whites.

Analysis of the 1983-89 Labour Force Survey revealed the absence of ethnic penalties for the Irish and Chinese and their presence among first-generation Indian, Pakistani and Caribbean men, strongly suggesting that discrimination occurred along the line of skin colour (Cheng & Heath 1993). More recently, Heath and McMahon drew from the 1991 Census to compare the situation of this generation with that of a matched second generation-immigrant group, born and raised in Britain, with British qualifications and fluent in English (1997). They reported that this second-generation group experienced ethnic penalties of the same pattern and magnitude in the British labour market as their parental generation, suggesting even more strongly that racial discrimination is occurring.

Both the local evidence and the national analyses point to continuity rather than change and suggest that the extent of discrimination has not changed significantly since 1984-85. Furthermore, the Nottingham study indicates that Caribbeans and Asians face the same level of discrimination, and analyses of ethnic penalties reveal a complex pattern, in which Asian groups, including Muslims, do not stand out as in a worse position than other minority groups. The main conclusion of this research therefore should be that the basis for the discrimination met by minority ethnic groups is primarily colour, rather than newness or a mixture of religion and colour. Following the events of September 11th however, some would argue this may be changing with an apparent rise in Islamophobia; however research into religious discrimination is still in its infancy (Sheridan 2006).

1.4.4.1 Race-related crime, racial attacks and harassment

The main UK sources of recorded information on racial incidents are the British Crime Survey (BCS), which estimates crime levels and trends in persons aged 16 years or over in England and Wales. This includes offences such as vandalism, burglary, wounding, robbery, common assault, as well as threats of crime. The police also is required to record incidents in which it appears that an element of racial motivation is involved. Neither police records nor the BCS however, document non-criminal expressions of racial prejudice and hostility which are believed to account for the majority of racial harassment experienced in the UK.

In 1996, the BCS estimated that over 2% (382,000) of all reported criminal offences in their survey were considered by the victims as motivated by racism; 69% of racially motivated threats were also associated with the use of racist language by perpetrators (Fitzgerald & Hale 1996). In 1996/7, 38% of recorded racial incidents in Britain involved verbal harassment, and 20% criminal property damage. Assaults made up 21% of incidents and 2% were serious crimes against the person, with eight racially motivated homicides identified in 1997/8 (Fitzgerald & Hale 1996).

Between 1989 and 1996, the number of race-related incidents reported to the police increased nearly three-fold, with a 6% increase between 1996/7 and 1997/8. It should be noted that this may not reflect a real rise in racist events but rather an increase in its awareness.

The BCS estimates that only between 15 and 45% of racially-motivated incidents are actually reported by minority ethnic residents of the UK. However, Chahal and Julienne (1999) observed that between 43 and 62% of incidents go unreported in the UK. Proffered explanations for this lack of reporting are distrust of the police and unresolved immigration-related issues of the victim, causing them to avoid law enforcement agencies.

1.4.5 Indirect racial discrimination

The term indirect racial discrimination is often used inter-changeably with the term institutional discrimination. This refers to institutional practices which, albeit unintentionally, have the consequence of systematically operating to the disadvantage of groups which are seen as racially different. Examples of this are: restrictions on the size of council houses, a policy which may affect particular groups that wish to live together as an extended family; recruitment to a workforce via old universities which still have a disproportionate numbers of white graduates, or through informal networks to which minority groups may have less access; a school policy which has the consequence of prohibiting the wearing of turbans.

These are only examples from the research literature, but they indicate that indirect discrimination is pervasive (Braham et al 1992). Inevitably however, on examination of specific cases, the distinction between direct and indirect discrimination is less clear-cut. Nevertheless, the distinction is still thought to be a useful one by researchers and writers alike (Collier 1999; King 1993).

1.4.6 Racial discrimination in Britain: SUMMARY

a) Minority ethnic groups in the UK seem to fare worse in social, economic and health outcomes than the white British majority.

b) This observation has been linked to a less-than welcoming reception attributed to either beliefs about "newness" (immigrant-host framework) or racism (imperialism-racism framework) of the incoming population.

c) Research supports the position that discrimination experienced in the UK by immigrant groups is based upon racism, skin-colour and, increasingly religion, rather than upon newness.

d) Overt race-related incidents reported to the police are on the increase, although the majority of racial harassments in the UK are non-criminal acts which go unrecorded.

e) Indirect racial discrimination (such as access to council-housing and employment) is thought to be equally pervasive in the UK, but may pass unnoticed.

f) The next section examines approaches to the measurement of racial discrimination and attendant problems.

1.5 Measuring racial discrimination and its effect upon health

Because discriminatory behaviour can rarely be directly observed, researchers face the challenge of establishing when racial discrimination has actually occurred and whether it explains some portion of a racially disparate outcome. Those who attempt to identify the presence or absence of discrimination typically observe an individual's race (e.g., black) and a particular outcome (e.g., health status) and try to determine whether that outcome would have been different if the person had a different racial origin (e.g., white).

Establishing that racial discrimination did or did not occur requires causal inference. Identifying a racial disparity and determining that an association between race and an outcome remains after adjusting for plausible confounding factors is relatively straightforward. The real difficulty lies in going beyond the identification of an association to the attribution of cause. Ultimately, researchers must rely upon the evaluation of evidence from multiple studies - whilst considering the strength of association, consistency, and plausibility of each study's design and findings - to draw conclusions about causality.

Experimental designs facilitate causal inference but may be ethically questionable and of limited generalisability. Experimental researchers frequently manipulate racial cues (e.g., racial designations or photographs on a CV) or train black and white confederates to respond in standard ways. In both approaches, an attempt is made to manipulate apparent race while holding all other variables constant, and to elicit

a response from participants. This method has focused more on measuring subtle forms of bias and non-verbal forms of discriminatory behaviour and less on examining overt behaviours (Word et al 1974; Dovidio et al 2002). This has in effect limited the generalizability and external validity of their effects.

Observational designs facilitate generalisation as there is minimal experimental intervention or manipulation, but they limit causal inference, unless they are of a prospective nature. Properly designed and executed field audit studies can provide an important and useful means of measuring discrimination in various domains and is another avenue to explore.

1.5.1 The challenge of direct measurement of racial discrimination

Legislation passed in the twentieth century both in the UK and the US have made open discrimination on the basis of race or ethnicity illegal, and perpetrators can be prosecuted under both criminal and civil law. Although readily observable acts of discrimination have declined, the persistence of high levels of residential segregation along racial lines and large racial gaps with respect to income, wealth, and other societal outcomes indicate the continued existence of racial discrimination albeit in new forms, that are not as easily identifiable but may be damaging nonetheless (Krieger 2000).

Surveys provide valuable evidence for understanding the extent of discrimination, but they cannot directly measure its occurrence. They tend to measure self-reported attitudes, perceptions or experiences of discrimination which may be unreliable for two main reasons. First, if a discriminatory occurrence is ambiguous, a minority ethnic respondent may misreport its incidence with more subtle forms of discrimination not as easily detected. Secondly, white respondents are often not willing to admit to practising or supporting discriminatory actions, which leads to inaccurate reporting of their true beliefs or attitudes.

Despite this, results to date suggest that valid and reliable data on racially discriminatory attitudes and experiences can be gathered from social surveys. Repeated cross-sectional surveys provide time-series information such as the General Social Survey (Smith 2002).

There is increasing support for a life-course approach to measuring the effects of discrimination on the individual's outcome (Sampson & Laub 1997) with development of theories of cumulative disadvantage over time (Jacobsen et al 2001; Phillips et al 1998). Longitudinal studies lend themselves to this approach; they analyse the incidence, causes and consequences of changes in attitudes about race and experiences of racial discrimination at the level of the individual. Their approach is very valuable, although there is a dearth of such work primarily owing to its difficult and costly methods.

Reports of discrimination in administrative records systems, such as governmental agencies, private organisations and non-profit groups can also provide useful information for analysis that is usually available at low cost to the researcher. However, this information may be restricted in availability, and biased with variable information on co-variate data captured, restricting its overall validity.

The next group of sections examines more closely three approaches used by epidemiologists to determine the association between racial discrimination and health.

1.5.2 Indirect measurement of health effects of racial discrimination

This approach acknowledges that discrimination may be difficult to measure and thus compares health outcomes of "dominant" and discriminated-against racial groups. An example of this approach is the EMPIRIC (Ethnic Minority Psychiatric Illness Rates) study, which examined common mental disorders and ethnicity in England (Weich et al 2004). This large-scale survey was carried out by the Joint Health Surveys Unit of the National Centre for Social Research (NatCen) and University College, London among ethnic minority adults aged 16-74 living in England to make comparisons with the prevalence of psychiatric morbidity in the general population. The survey took place in 2000 and was conducted at the same time as the Office for National Statistics (ONS) survey of the adult population of Great Britain. It had a focus on some of the main ethnic minority groups in England.

If any obtained differences in outcome cannot be wholly explained by known risk factors (i.e., by statistical adjustment), it may be inferred that the residual difference could be explained by racial discrimination (Krieger et al 1993). It is usually postulated that socio-economic status is the main confounder for such health outcome differences. If a residual difference remains after adjusting for socio-economic status, four alternative explanations may be put forward.

Firstly, socio-economic position has been inadequately measured, which accounts for the residual confounding. Secondly, an intermediary, economically-unrelated variable such as psychological distress has led to the disparity in health outcomes. A third explanation is that unexplained differences are explained by unmeasured factors associated with race and the outcomes have not been accounted for, i.e. unknown confounders (such as culturally-shaped dietary patterns). The final possibility is that of genetic differences between races explaining the residual difference in outcome.

Existing research relying upon indirect strategies to measure the health effects of racial discrimination are able to address both the health effects of types of discrimination not readily perceived by the individual (such as the treatment decisions of clinicians), and whether economic disparities can explain the health differences that may occur between racial groups. These methods are not able to measure direct experiences of racial discrimination, nor can they investigate effects

related to intensity, duration, or period of exposure to any
discrimination.

1.5.3 The measurement of perceived racism versus objective racism

Research investigating the untoward effects of racism is on the rise.
As the empirical literature exploring the associations between racism
and health emerges, the development of an equally strong theoretical
literature is needed to explain the pathways thorugh which racism may
influence health outcomes. Equally, attention should be given to
assessments of racism that are reliable and valid.

Although research suggests that perceptions of events as stressful are
more predictive of psychological and physiological fucntioning than
objective demands, comparative research exploring the relationship
between a person's perceptions an objective demands may provide
additional concurrent validity. Further research is also needed to more
clearly interpret observed findings with respect to perceived racism.
For example, for some people who perceive stimuli as involving racism
probably do so because it is less anxiety-provoking than attributing
the failure of being say, promoted at work, to personal deficits.
Furthermore, some people who do not report perceiving racism probably
fail to do so because of denial or as an attempt to avoid the expected
psychological distress that would be associated with negotiating an
uncontrollable stressor. Accordingly, in addition to assessing the
perceptions of racism, the simultaneous measurement of other
contributory factors such as attributional style, impression

management, self-deception, and affective state would help to delineate the possible mitigating effects of these variables.

According to Krieger (1999), of the 20 published studies that have assessed the effects of unfair treatment (including racism), more than half used measures with questionable or unreported psychometric properties. When psychometric data were presented, minimal attention was given to the generalisability of these data for the gender and/or ethnic groups being studied. Additionally, almost without exception, each author used different measures or response formats to assess racism. As a result of these methodological caveats, comparisons of findings across studies remain somewhat limited.

Measures used to assess racism should: be reliable and valid for the target groups and subgroups as well as ethnic-gender groups and subgroups being studied; be specific enough to capture the reported multidimensional nature of racism; and be developed with equivalent shorter and longer versions to facilitate use with different study designs.

Notwithstanding this, it is important to note that perceived racism need not be any less significant than objective racism, or an observer-related account of the same racist event. The individual's subjective experience of a putatively racist event is more significant to that individual than some third party account of the same occurrence.

Therefore, one might argue, that little may be gained by measuring objective racism rather than perceived racism if it is the latter that holds greater significance and possible predictive ability in terms of prognosis or health outcome.

Systematic efforts by national agencies to "unpack" the broad ethnic groupings are also needed. In addition to unpacking such broad ethnic grouping as Asians and Hispanics, ethnic groups who are presumed to be more or less homogeneous (e.g., blacks and whites) should also be unpacked to provide a greater and more detailed understanding of the cumulative perceptions of racism by ethnic subgroups. For example, although viewing whites as a homogeneous group probably has been convenient, the health profiles of white ethnic groups (e.g., Irish, Turks, and Cypriots) probably are influenced by differences in the amount of discrimination to which these ethnic groups are exposed and perceived (Aspinall, 1998).

1.5.4 Measuring self-reported experiences of racial discrimination and its health effects

A relatively new approach in determining the health effects of racial discrimination is by determining people's direct experiences of discrimination and their relation to health status. The most common outcomes of these studies have been mental health (e.g., depression, psychological distress) and hypertension or blood pressure. The main

problem with this approach is a lack of standardisation in measuring
self-reported experiences in terms of: length, intensity and frequency
of exposure; domain of exposure (e.g., global or specific sitautions);
and the targets of discrimination (e.g., individual family members or
the family unit as a whole); reactions to racial discrimination.

Empirical studies adopting this approach have tended to focus on the
racial attitudes of those who discriminate and used qualitative, in-
depth techniques rather than methods that are easily interpretable by
epidemiological methods (Schuman et al 1985; Jackman 1994).

There are a number of techniques that should enable useful
interpretation of self-report studies. The epidemiological issue of
intensity and frequency of exposure to self-reported racial
discrimination could be addressed by using direct questions, addressing
multiple facets of discrimination each in different situations rather
than asking vague or global questions about discrimination. Single as
well as cumulative exposures need to be measured, with attention paid
to the daily wear-and-tear of everyday discrimination and "micro-
aggressions" which are thought to pose health hazards distinct from
major episodes of discrimination (Williams et al 1997). Measurement of
the individual's perceptions and fears about discrimination against
themselves as compared with discrimination against their family would
draw attention to the "personal/group discrimination discrepancy": the
observation that people typically report perceiving greater

discrimination directed toward their group than to themselves personally (Mays & Cochran 1997; Ruggerio & Taylor 1995).

There are three factors which may mean people experiencing the same discriminatory "exposure" would report them differently. The notion of "internalised oppression" adopted by some oppressed group-members and a sense of their subordinate status being in some way "deserved", may lead to an under-statement of an actual discriminatory act (Meyer 1995). Secondly, the notion of "social deirability" leads to people shaping their responses according to the percecived status of the interviewer (Cohen et al 1995). Finally, individuals may exaggerate discriminatory experiences (system-blame) to avoid blaming themselves for failure (Neighbours et al 1996).

Researchers have attempted to circumvent the issue of self-presentational biases impairing the self-report of racial discrimination by the use of implicit rather than explicit measures of discrimination. The Implicit Attitudes Test is a computer-measured task which measures response speeds to racially-charged imagery to compute unconscious racism measures rather than through explicit questioning (Greenwald et al 1998). A related approach to avoid such biases would be to incorporate questions to assess identity formation, political consciousness, stigma and internalized oppression (Meyer 1995; Waters & Eschbach 1995).

1.5.5 Measuring population-level experiences of racial discrimination and their health effects

Racial discrimination measured at a population-level is being increasingly measured in research to see if it relates more closely to population health than individual-level measures of discrimination (Kennedy et al 1997; Polednak 1997). Although this work is in its infancy, promising measures of population-level indicators of discrimination are: economic segregation of neighbourhoods (Jargowsky 1996); occupational segregation of jobs by race/ethnicity and gender (Rothenberg 1988); voting rates and registration of different dominant and subordinate groups; and socio-demographic composition of subsidiary branches of Government, such as the judiciary.

Concerns related to this particular approach to research are that of the aetiological period and the ecological fallacy. With regards to the aetiological period, the issue is making appropriate distinction between the effects of acute and cumulative exposures, and between outcomes with short and longer latency periods. It is harder to infer causality from a potentially aetiological agent when the latency period is longer, the agent far-removed in time, from the outcome.

The ecological fallacy centres on whether causal inferences at the population level are valid at the individual level. This fallacy results from confounding introduced through the grouping variable (e.g., city, nation) used to define the group-level dependent and independent variables (Alker 1969). It has been suggested that the

ecological fallacy could be minimised by population-level measures of

discrimination meaningfully combined with individual-level measures

through techniques of multi-level analyses (Blalock 1984; Williams

1997).

1.5.6 Measuring racial discrimination and its effect upon health: SUMMARY

a)   Measuring racial discrimination requires both the observation of such an act as well as the demonstration of causal inference between racism and the outcome.

b)   Surveys provide an indirect measure of racial discrimination as they focus on self-reported attitudes rather than verifiable events.

c)   Longitudinal studies provide life-course evidence of cumulative racism and its impact upon health, although these studies are rare.

d)   An indirect approach compares health outcomes between majority and minority ethnic groups, and then calculates the contribution of racial discrimination to any difference in outcome.

e)   A newer approach is to measure people's direct experiences of discrimination in relation to their health status, although this lacks the standardization of self-reported experiences.

f) Self-reported events could be quantified by direct and systematized questioning and subdividing although people's own beliefs are likely to colour their perceptions of both the event and its perceived cause.

g)   The next section examines research instruments currently used to measure racial discrimination.

1.6 Instruments and measures of perceived racism

As has been discussed, racism is a multi-dimensional phenomenon with dimensions related to the type of racism and to the context of racial events.

In order to select an appropriate measure of perceived racism for this study, a literature search for potential measures was performed. The following bibliographic databases were searched: ASSIA; CINAHL; EMBASE; HealthStar; PubMed; PsycLIT; and Science Citation Index. The search was restricted to articles published in English between January 1960 and August 2008. Titles and abstracts of papers were initially identified that covered the areas of interest. The search terms included were: (a) RACISM, RACIAL, DISCRIMINATE, DISCRIMINATION, PREJUDICE, PREJUDICIAL, INEQUITY, HATE; (b) MEASURE, SCALE, INSTRUMENT, VALUE, QUANTIFY, ESTIMATE, TOOL. In databases where MESH terms were available they were exploded and combined. Searches were adapted according to the database in question and reviewed by two additional people to the main author. These searches were supplemented by personal bibliographies of the team, forward citation tracking using the Science Citation Index as well as Social Science Citation Index Databases and by seeking references in retrieved articles. This revealed the most relevant instruments, which are briefly reviewed below.

The Cultural Mistrust Inventory is a psychometric instrument that measures four domains of cultural mistrust: education, interpersonal relations, business and work, and politics and law (Terrell & Terrell

1981). It has a test-retest reliability of 0.86 over two weeks and takes approximately twenty minutes to complete.

The Difference Indicators Scale is a quantitative index of institutional racism (Fiman 1981).

The Index of Race-Related Stress is a measure of the stress experienced by African Americans as a result of daily encounters with racism and discrimination (Utsey & Ponterotto 1996). It consists of 46 items with four sub-scales (cultural, institutional, individual, and collective racism) and a global weighted racism measure, determined using a five-point Likert scale. The scale has adequate indices of internal consistency (Cronbach's alpha for the above four dimensions are 0.87, 0.85, 0.84 and 0.79 respectively) and fair-to-adequate estimates of test-retest stability (test-retest reliabilities of the four dimensions are: 0.77, 0.69, 0.61, and 0.79 over two to three weeks). Several other factors also indicated the measure's reliability and it takes around thirty minutes to complete.

The Institutional Racism Scale was developed to assess how individuals regard racism, engage in activities to reduce racism, and view organizational commitment to the reduction of institutional racism (Barbarin & Gilbert 1981). The scale consists of 72 items grouped into six subscales, including (1) indices of racism (2) strategies for reducing racism, (3) strategies for reducing racism effectiveness, (4)

personal efforts to reduce racism, (5) agency climate for racism, and (6) management efforts to reduce racism. Administration of the scale to different groups provided additional information on the influence of race (minority versus non-minority) and reference group (white college students, government personnel, and participants in a conference on institutional racism) on individual perceptions of racism.

The Modern Racism Scale has been extensively used in the US since the mid-1970s (McConahy 1986). It is an outgrowth of work on symbolic politics (Kinder & Sanders 1996). It is generally split into three parts and encompasses modern (subtle) racism, old-fashioned (overt) racism, and filler items on irrelevant current events to disguise the measure. Items on modern racism included believing that discrimination is no longer a problem, and that blacks are too demanding. In contrast, items on old-fashioned racism ask about open opposition to fair housing laws, integration and inter-marriage.

A variant of the Modern Racism Scale distinguishes explicit and subtle prejudice against immigrant minorities in Europe (Pettigrew & Meertens 1995). It measures blatant or explicit prejudice, defined as resentment of racial and ethnic minority groups (their alleged stealing of in-group jobs but also relying on welfare), as well as rejection of ties to minorities. High scores predict generalized ethnocentrism and overall rejection of out-groups not one's own, as well as approval of racist political movements and hate crimes (Green et al 1999).

The Perceived Racism Scale is a multi-dimensional measure of racism (contextual, attitudinal, behavioural and cultural) in African Americans (McNeilly et al 1996). It is discussed in further detail ahead.

The Perceptions of Racism Scale is an affective, behavioural and cognitive measure of perceived racism in African American women (Green 1995).

The Personal Discrimination and Racial Climate Scale measures individual discriminatory experiences and racism in the organizational context (Allan-Clairborne & Taylor 1981).

The Racial Life Events Scale is a multi-dimensional measure of racial life events and chronic difficulties in minority ethnic and immigrant populations (Bhugra et al 1994). It has subscales examining pre-immigration, accommodation, employment, education, racial incidents, attitudes and beliefs regarding discrimination. It has five domains and 24 yes/no questions, which are completed by an interviewer over fifteen minutes.

The Racial Reactions Scale is an instrument designed to assess reactions related to race in African American students (Thompson et al 1990). It consists of 19 statements with responses required upon a

seven-point Likert scale. It has a concurrent validity with a Pearson's correlation coefficient of 0.343 with the Cultural Mistrust Inventory, and a significant and positive correlation with the Perceived Racism Scale. It has Cronbach alpha scores for whites = 0.69; for blacks = 0.59; and total = 0.68, although it has been determined to have a low internal consistency.

The Racism and Life Experience Scale – Brief Version, or RaLES-B (Harrell 1997) is a self-completed scale, which measures the impact of racism upon minorities' lives. It comes in two parts with 32 items, determined by four-point Likert scales. Part one has Cronbach alpha scores of 0.88 and 0.90 and part two has scores of 0.83 and 0.90. It has a correlation coefficient of 0.24 - 0.46 ($p < 0.01$) with the Index of Race Related Stress.

The Schedule of Racist Events (Landrine and Klonoff 1996) is a self-completed, uni-dimensional scale, which measures the frequency of racist events over the individual's lifetime and within the last year, and stressfulness is also appraised. It consists of 18 items with three sub-scales (frequency of events in the preceding year; event-frequency in a lifetime; and cognitive appraisal of those events). The Cronbach alpha scores of the three respective parts are as follows: 0.95, 0.95, and 0.94 respectively. Limited validity and reliability evidence exists to-date.

Difficulties associated with such self-report instruments are that of social desirability and bias created by the subject's perception of the researcher's ethnicity (Jackson et al 1996). Another potential problem is that of the biased recall and overemphasis of adverse or memorable events. Related to this is the period effect when the predominant racial climate of the respondent's nation influences, either positively or negatively, the recall of racially related events. However, the perceptions of the individual are thought to be a major factor in determining the adherence and outcome of the individual (as discussed later) and thus underscore the importance of recording the individual's experiences and responses to racial discrimination.

A more explicit model of which forces determine expressed attitudes could improve survey research: expectations, experiences, social pressure and so on. The analysis of relationships between past experiences, expressed attitudes, and future behaviour seem remarkably under-developed. Embedding attitude reports within a lifetime of reported behaviours would permit this area of research to develop in new ways.

1.6.1 Instruments and measures of perceived racism: SUMMARY

a) Several self-report instruments measure racism, including:

b) The Cultural Mistrust Inventory measures cultural mistrust.

c) The Difference Indicators Scale measures institutional racism.

d) The Index of Race-Related Stress measures stress resultant from daily encounters with racism and discrimination.

e) The Institutional Racism Scale measures both the individual's and organisation's commitment to the reduction of institutional racism.

f) The US Modern Racism Scale has been modified for use in Europe.

g) The Perceived Racism Scale is a multi-dimensional measure of self-reported racism which is discussed in detail ahead.

h) The Perceptions of Racism Scale measures perceived racism in African American women.

i) The Personal Discrimination and Racial Climate Scale measures both individual and organisational racism.

j) The Racial Life Events Scale is a multi-dimensional measure of racial life events and chronic difficulties.

k) The Racial Reactions Scale assesses race-related reactions

l) Most of these instruments rely upon self-report: self-report problems are that of social desirability and recall bias; however this perception may be crucially related to adherence.

1.7 Racism and health

The relationship between racism and both physical and mental health is a complex one. In Figure One, a framework is provided to understand the relationship between racism and health; the arrows indicate associations. It can be seen that racism is a major societal force that affects health status. At the societal level, racism within medical institutions could affect minority health status through the organisation of medical services. There are large differences in access to medical care and receipt of medical procedures between racial groups in the US (Blendon et al 1989, 1995; Franks et al 1993; Giles et al 1995; Peterson et al 1994), which is likely to affect prognosis and outcome. If racism is so embedded in social and cultural institutions, race-related risk factors and resources such as racial beliefs and racial bias are likely to be important influences upon health.

Literature suggests that internalisation of society's negative cultural stereotypes about a racial group by members of that group can lead to worsened health status. African Americans that do so have been shown to have elevated rates of substance misuse and physical and mental illness (Taylor & Jackson 1990; Taylor et al 1991; Williams & Chung 1995).

Economic institutions are thought to play a powerful role in affecting health status along racial lines. Moore and colleagues have argued that there is disproportionate targeting of minority ethnic consumers by the tobacco and alcohol industries leading to over-consumption and worse health (Bryant & Mohai 1992).

Residential segregation is an important potential mechanism perpetuating health differences between races. Racism enacted at an institutional level through financial institutions (banks, mortgage lenders) may create and sustain a social status that results in differential housing. And once in place, such segregation restricts employment opportunities, thus socio-economic mobility and the individual's situation worsens. When considering this notion, it is striking that there has been little report of any decline in the level of racial segregation in African Americans over time (Farley & Frye 1994).

Figure one: A framework for understanding the relationship between race and health (Williams 1996).

Experiences of racial bias at the individual level may have deleterious consequences by acting as a negative stressor (Thoits 1983). The stress literature suggests that the persistence of a difficult situation and its resolution, or lack of it, are important determinants of its adverse impact. To elucidate more clearly the effects of racism as a stressor, there needs to be a greater understanding of the way in which racism combines with other sources and types of stress, as well as the identification of intervening variables that may moderate or mediate the effects of stress on health (coping factors, personality types etc). For example, Lazarus and Folkman (1984) have researched stress in relation to coping and noted that both the subjective evaluation of the seriousness of an event as well as coping responses determine whether a psychological stress response will follow. This may be useful in the development of a model including racism as an environmental stressor.

The next few sections review the literature of studies that have specifically examined the association between racism and health.

1.7.1 Racism and physical health

A recent excellent systematic review of self-reported racism and health is the main source for the information in this section (Paradies 2006). That source reviewed 138 empirical quantitative population-based studies of self-reported racism and health, each study often determining several outcomes and associations. The study designs included were cross-sectional, cohort, experimental and case-control in nature, with the majority (73%) of significant associations determined in cross-sectional studies; this of course limits the inference of causality. However, 12% of the reported significant associations between racism and health

outcome were found in longitudinal studies. A variety of ethnic groups were included: African American (most frequent); Asian; Latino; Whites and refugee groups.

The most consistent association found was that self-reported racism had an association with negative mental health outcomes on 72% of occasions (Paradies 2006). The association was found to be far weaker for physical health outcomes: the association between self-reported racism and worse physical health was only found 36% of the time, with no association found in 63% and a positive association (i.e., with better physical health) in 1% of the research. It is hypothesised that this weaker effect may be due to racism exert a lagged effect upon physical health, mediated by negative mental health outcomes.

The majority of physical health outcome studies examined the relationship between racism and blood pressure (Paradies 2006). 19 out of 79 occasions found self-reported racism was associated with elevated blood pressure, with no association found on 59 occasions, and with a negative association on one occasion. Furthermore, self-reported racism was associated with increased heart rate on five out of ten occasions. A possible pathway through which perceived racism may affect blood pressure is anger (Steffen et al 2003). Perceived racism has been related to higher levels of anger and hostility (Bullock & Houston 1987) and large studies have found that African Americans tend to score higher on anger and hostility measures than whites (Barefoot et al 1991; Scherwitz et al 1991). Paradies' review found a positive association between low infant birth-weight/decreased gestational age and self-reported racism on 15 out of 27 occasions, which may be speculated to be

associated with deprivation and poorer access to ante-natal services (2006).

General self-reported health status was identified by Paradies (2006) as a common outcome when measured either as a global measure or through use of the instruments Short Form-12/36 (Jenkinson et al 1997). A negative association between health status and self-reported racism was found on 19 out of 45 occasions.

In terms of health-related behaviours, Paradies identified a positive association between racism and increased cigarette smoking on four occasions, increased alcohol misuse on eight out of 14 occasions and increased drug misuse on five out of six occasions (2006). Possibly related to this, results from a national sample found that discrimination was related to an elevated mortality risks over a 13-year follow-up period among African Americans who had self-blaming as opposed to external attributional orientations (LaVeist et al 2001).

1.7.2 Racism and mental health

Mental health outcomes are the most frequently measured in relation to racism. An alternative theoretical framework to that outlined in Figure One, linking racism to mental health has multiple, inter-related connections (Turner & Kramer 1995). These connections were divided into the following areas where racism may potentially exert an effect: the definitions of mental health and illness; aetiological theories of mental illness; the evaluation process (assessment and diagnosis); the provision of direct services; the organisation and structure of mental

health institutions; and the training of mental health professionals and care providers.

The definitions and aetiological theories of various mental illnesses may be influenced by a belief that there may be underlying, fundamental or genetic differences between different racial groups which constitute a vulnerability to certain illnesses more frequently in those groups when compared to others. Although differences do occur, the weight of the evidence does not support the notion of a genetic basis for racial and ethnic differences in rates of mental illness.

Social class is often cited as a confounder of both ethnicity and poor health status: the inverse relationship between social class and mental illness is consistently reported. This association may be mediated by an increased exposure to, and vulnerability to, social stressors. Some have also argued that minority status in itself is a source of stress, independent of social class (Moritsugu and Sue 1982). A related phenomenon is the "ethnic-density" effect: this is the observation that the incidence of schizophrenia in non-white ethnic minorities is greater when they comprise a smaller proportion of the local population (Boydell et al 2001). Those authors attributed this to a greater vulnerability to social stressors when an individual is a member of a small minority group rather than a larger minority group.

It has been argued that the psychiatric assessment process is undermined by racial biases and ethnocentricity. The argument is that owing to the development of most assessment and measurement tools within Western cultures, this limits their use in different ethnic or cultural groups, leading to a possibility that culturally-acceptable behaviour may be

labelled as psychopathology. Cross-cultural clinical assessment is therefore increasingly favoured and researchers have developed a number of approaches to facilitate a more culturally informed assessment (Jones & Thorne 1987) and tested these in medical students with success (Chakraborty et al 2004a).

With regards to minority ethnic access to psychiatric services, there is a problem of an inequity of service provision. This will be covered in relation to the UK Caribbean population in a later section but, in brief, the service-related inequities thought to be linked to racism are: minority groups being less likely to receive psychotherapy or counselling than their white counter-parts; and the former being more likely to receive oral or depot-injection pharmaco-therapy and inpatient treatment; more likely to present to psychiatric services via an emergency pathway (the police or Accident and Emergency Departments) rather than through primary care or their families; more likely to be detained under the Mental Health Act; less likely to comply with management plans and remain linked with services (Chakraborty et al 2001).

Research and training issues are also thought to connect racism to mental ill health in a number of ways. If researchers were to bring racist attitudes, perspectives or values to their scientific enterprise the result could be attribution of inter-ethnic differences to "cultural deficiencies." Secondly, racist research is poorly-conducted research; examples of this kind of poor research are: ignoring the cross-cultural validity of research instruments, neglecting to think about the impact of the ethnicity of the interviewer upon engagement with minority ethnic respondents, under-studying of phenomena in minority ethnic groups with

transposition of findings from the dominant ethnic groups, labouring under the assumption that the findings are universally applicable. Similarly, training issues which could be relevant to the service-related inequities between ethnic groups may be the lack of experience acquired by mental health trainees in ethnically-diverse areas, and the relative scarcity of both clinical and academic senior mental health professionals from minority ethnic backgrounds (Turner & Kramer 1995).

Given the ever-expanding presence of minority ethnic groups in the west, the benefits of increasing the minority ethnic mental health workforce would be several: those minority patients whom were thought could benefit from an ethnically-matched therapist would be more likely to access one. Secondly, the increased presence of minority health professionals may be regarded by service-recipients as a clear sign that those services are, in reality, available to them, in turn making help-seeking seem less threatening and more acceptable. Finally, their presence may lead more majority health providers to think of cultural factors as important considerations, with cross-cultural work becoming more mainstream and routine, and less for the sake of "political correctness".

A major and substantial study was a 13-year national panel study from 1979 to 1992, which revealed complex relationships between the experiences and perceptions of racism and the physical and mental health status of a sample of 623 African Americans (Jackson et al 1996). It found that reports of negative racial encounters over the 13-year period were weakly predictive of poor subjective well-being in 1992. A more general measure of racial beliefs – perceiving that whites want to keep blacks down – was found to be related to poorer physical health in 1979-

80, better physical health in 1992, and predicted increased psychological distress, as well as lower subjective well-being in 1992. The authors concluded that cumulative perceptions of racism resulted in poorer mental health but, surprisingly better physical health. The latter finding could have been due to those respondents who perceive whites as wanting to keep them down being more vigilant when it comes to their own physical health; hence the better outcome.

Returning to Paradies' review of the extant empirical evidence for associations between mental ill health outcomes and self-reported racism (2006), improved mental health was almost never found to be associated with increased racism. On 40 out of 62 occasions a positive association was found between self-reported racism and psychological/emotional distress, with no association on 21 occasions.

Depressive symptoms or frank depressive disorder were positively associated with racism on 39 from 52 occasions (Paradies 2006). Several models have explained this phenomenon, with the common pathway often identifying racial stress as both a vulnerability factor and a stressful life event (Bhugra & Ayonrinde 2001). Several community-based studies have found a higher prevalence of depression in minority ethnic groups than in the dominant population (Lloyd 1998; Nazroo 1998; Shaw et al 1999). Goldberg and Hodes have proposed that the higher rates of over-dosing among their sample of young Asian women might be associated with the racial attacks they had experienced (1992).

Obsessional and compulsive symptoms were found to be associated with self-reported racism on five out of five occasions in different studies (Paradies 2006); however, it could be that this positive finding is

artefactual and in fact due to improved recall of racist (as well as other) events in those with an obsessive tendency.

Somatisation was found to have a positive association with self-reported racism on five out of five occasions (Paradies 2006). Anxiety symptoms were found to be positively associated with racism on 15 out of 22 occasions. Several stress models describe a relationship between threatening events and the onset of anxiety symptoms. Racial discrimination was found to be the crucial factor associated with high levels of anxiety in non-white immigrants to New Zealand (Pernice & Brook 1996).

Stress was found by Paradies to be associated positively with self-reported racism on 13 out of 22 occasions (2006). Psychiatric symptomatology following a racist threat or attack has been conceptualised by some researchers as a form of post-traumatic stress disorder – PTSD (Dassori & Silva 1998; Kim-Goh et al 1995). Loo has described PTSD following race-related verbal and physical assaults, racial stigmatisation and the cumulative effect of racism as a trauma in an Asian group (1994). Other symptoms common to PTSD such as poor concentration, hyper-vigilance, avoidance and autonomic arousal have also been described following experiences of racism (Thompson 1996; Goldberg & Hodes 1992; Armstead et al 1989).

There is a dearth of empirical evidence considering the association between racism and psychosis. No studies were found by Paradies (2006), although a recent cross-sectional survey found an increased risk of psychosis in UK minority groups after adjusting for gender, age and socio-economic status (Karlsen et al 2005). This study (EMPIRIC)

consisted of a multi-variate analysis of quantitative, cross-sectional data from a nationally-representative community sample of people aged between 16 and 74 years from the largest minority ethnic groups in England: those of Caribbean, Indian, Pakistani, Bangladeshi, an Irish origin. The researchers found that the experience of interpersonal racism and perceiving racism in the wider society each have independent effects on the risk of common mental disorder and psychosis, even after adjustment.

From the same dataset, authors examined perceived discrimination and its association with common mental disorders among workers in the United Kingdom (Bhui et al 2005). Discrimination was measured as reports of insults; unfair treatment at work; or job denial stemming from race, religion or language. The risk of mental disorders was found to be highest among ethnic minority individuals reporting unfair treatment and racism insults. The overall greatest risks were observed among Black Caribbeans exposed to unfair treatment at work and Indian, Bangladeshi, and Irish individuals reporting insults.

Furthermore, the EMPIRIC dataset permitted the examination of the examination between racism and mental illness in minority ethnic groups, using social support as a moderating factor (Chakraborty et al 2004b). Social support was quantified as both the number of relatives as well as their geographical proximity to the individual. When quantified in either way, social support did not moderate the size of the association between perceived discrimination and mental illness. The finding that this association was not reduced by the supposedly "buffering" effect of familial social support, suggests that racism has a strong and pronounced effect (Chakraborty et al 2004b).

A population-based incidence and case-control study of first-episode psychosis (Aetiology and Ethnicity in Schizophrenia and Other Psychoses (ÆSOP)) examined the cross-sectional association between ethnicity and psychosis and whether this was mediated by perceptions of disadvantage (Cooper et al 2008). The Black ethnic groups were found to have a higher incidence of psychosis (OR 4.7, 95% CI 3.1,7.2). After controlling for unemployment, the association of ethnicity with psychosis was attenuated by perceptions of disadvantage (OR 3.0 95% CI 1.6,5.4). This suggests that perceived disadvantage is at least partly associated with the excess of psychosis among Black people living in the UK.

A second group has carried out a series of studies in the Netherlands, looking at the association between discrimination and the incidence of psychotic disorders. The first paper reports upon the incidence of psychotic disorders over seven years in The Hague, a city with a large and diverse minority ethnic population (Veling et al 2007). They found a dose-response relationship between discrimination and age- and gender-adjusted incidence rate ratios of both schizophrenic and all psychotic disorders in ethnic minority groups, suggesting that perceived discrimination might contribute to the increased risk of schizophrenia.

In their second paper, the group describes a case-control study of first-episode schizophrenia investigating whether perceived discrimination at the individual level is a risk factor for schizophrenia (Veling et al 2008). Cases included all non-western immigrants who made first contact with a physician for a psychotic disorder in The Hague, the Netherlands, between October 2000 and July 2005, and received a diagnosis of a schizophrenia spectrum disorder (N = 100). Two matched control groups were recruited, one among immigrants

who made contact with non-psychiatric secondary health care services (N = 100), and one among siblings of the cases (N = 63). Perceived discrimination in the year before illness onset was measured with structured interviews, assessing experiences of prejudice, racist insults or attacks, and perception of discrimination against one's ethnic group. Cases reported somewhat higher rates of perceived discrimination in the year prior to illness onset than their siblings and the general-hospital controls, but these differences were not statistically significant. Therefore they concluded that perceived discrimination at the individual level was not a risk factor for schizophrenia in these data, although they concede that the relationship between racial discrimination and psychosis may vary with the aspect of discrimination that is studied, and may also depend upon the social context in which discrimination takes place.

An earlier UK study reported raised incidences of schizophrenia in all minority ethnic groups presenting to psychiatric services within a deprived, inner-city setting (King et al 1994). Racism has been attributed as a cause of illness by psychotic patients but the study was cross-sectional in nature, limiting an assumption about causality (Chakraborty et al 2001).

Another study found that black and minority ethnic patients with psychotic illnesses reported no more life events than their white British counterparts, but they were more likely to attribute them to racism, potentially disinclining the minority patients from using services they perceive to be racist (Gilvarry et al 1999). Societal racism has been mooted as a cause of increased risk of schizophrenia in Black populations in the UK (Littlewood & Lipsedge 1998); and

institutional racism, life events and chronic stress may also be associated with an increased risk of developing psychosis (Perera et al 1991).

The analysis conducted in this thesis, namely the prospective association between perceived racism and mental health outcomes is, to date, underreported in the literature. However, there are certain relevant studies that merit initial mention here, with further comparison to the findings made in the "Discussion" section.

Perceived racism (measured by the Perceived Racism Scale - McNeilly et al 1996) has been examined for its predictive effects upon paranoia among African Americans (Combs et al 2006). In a population of African American college students, Combs and colleagues found that perceived racism was highly significantly correlated with both cultural mistrust and with non-clinical paranoia, even following adjustment.

A prospective study from the Netherlands examined people with no history of psychosis at baseline and at three-year follow-up (Janssen et al 2003). It found that baseline perceived discrimination was associated in a dose-response fashion, with delusional ideation at follow-up, irrespective of ethnicity and after adjustment.

Both this and the Combs et al study suggest that perceived racism/ discrimination are correlated with both sub-clinical paranoia and frank delusional ideation.

Race appears to play a significant role as a determinant of health in the UK and US. The study of racism and health is in relative infancy

(Chakraborty & McKenzie 2002). The persistence of racial inequalities in health need to be understood in light of the persistence of racialised social structures that appear to affect health status in multiple ways. It may be suggested that the self-reported racism is a neglected determinant of health in research and this, in itself, may contribute to the racial disparities in health outcome.

1.7.3 Racism and health: SUMMARY

a)   There is a complex relationship between racism and both physical and mental health with interaction at individual (genetic and psychological), societal, economic and cultural levels.

b)   A recent review of evidence found the effect racism has upon physical health is less-often measured, deemed to be weaker and more delayed than upon mental health.

c)   Racism has been linked to elevated blood pressure, increased heart rate, and low infant birth-weight/decreased gestational age, poorer health status, cigarette smoking, alcohol misuse and elevated mortality.

d)   Racism has been found to predict poor subjective well-being, increased psychological distress, paranoia and delusional ideation; it has also been linked to psychosis, depression, obsessive-compulsive symptoms, somatisation, stress, and life events in psychotic patients.

e)   Racism may also exert an effect upon mental health status through the diagnostic process, access to treatment and inequity of service-provision, as well as biases in research and training.

f)   The link between racism and services may be mediated through treatment adherence, which is discussed in the next section.

1.8 Adherence to treatment in psychosis

Psychotic illnesses such as schizophrenia and schizo-affective disorder are severe mental illnesses that can have devastating consequences to the individual and to those who care about them, including family and friends. It is also a chronic illness and in most cases requires life-long treatment.

As will be discussed in more detail later, people of Caribbean origin with psychosis residing in the UK have different service-related outcomes to their white counterparts. This is reflected in the following findings: those of Caribbean origin are more likely to be compulsorily admitted under the Mental Health Act (Davies et al 1996; Harrison et al 1989; Littlewood 1986; McGovern & Cope 1987; McKenzie et al 1995; Owens et al 1991; Perkins & Moodley 1993); a disproportionate number of people of Caribbean origin are brought to hospital by the police (Dunn & Fahy 1990; Pipe et al 1991; Rogers & Faulkner 1987; Turner et al 1992) and they are twice as likely as whites to be admitted from prison (Littlewood & Lipsedge 1997); those of Caribbean origin remain in hospital for longer (Dunn & Fahy 1990); are more often treated in secure facilities (Cope 1989); are given higher doses of psychotropic medication and larger amounts of depot injections (Chen et al 1991); and receive less psychotherapy than whites (Campling 1989; Yamamoto et al 1968). The reasons for the difference in outcome measured in this way are unknown.

Routes to care and rates of involuntary admission may be the same for people of Caribbean origin and British whites at first presentation (Cole et al 1995) but diverge thereafter, with people of Caribbean origin more likely to be admitted against their will (Goater et al

1999). People of Caribbean origin leave hospital with more untreated symptoms and are less likely to stay engaged with services (Bhugra et al 1997). Younger patients of Caribbean origin describe low satisfaction with the services with each hospital admission (Parkman et al 1997).

Service-related outcomes, such as poor satisfaction and poor subsequent engagement, reflect an interaction between the individual and the system of care. Outcomes such as the rate of involuntary hospitalization and the administration of depot medication indicate poor patient adherence.

Scientifically, adherence can be expressed as the ratio between observed treatment behaviour and given treatment standards (Fleischhacker et al 1994). This definition explains a problem with adherence research. First, there is no truly objective measure for observed treatment behaviour and, second, although there are numerous clinical guidelines and recommendations for the treatment of psychotic illnesses, there are still no definitive treatment standards for these disorders. That there is still a lack of adequate methodology to study adherence and still a reliance on indirect evidence, such as subjective reporting by patients or staff, pill counting and measurement of plasma drug levels, may explain why there has been only modest success in improving adherence.

If adherence and outcome are inextricably linked, and service-related adherence is poorer in UK Caribbeans with psychosis, it is important that the concept of adherence with psychiatric treatment should be examined.

1.8.1 Factors influencing adherence

Although the factors that influence adherence often overlap or influence each other, they may be differentiated into factors that are related to the patient, the patient's environment, the treating clinician, and the treatment itself. Although this is a somewhat artificial differentiation, it may help us to assess non-adherence in a systematic way.

1.8.1.1 Patient-related factors

Certain demographic factors have been linked to adherence behaviour. Age is a controversial issue: it seems that patients at the extreme ends of age distribution are less adherent. Both young, especially male, patients have been found to be poor adherers (Di Matteo & Di Nicola 1982) and the elderly as well. Increased age is an independent predictor of poor adherence, possibly secondary to cognitive impairment, compounded by the increased likelihood of poly-pharmacy that comes with age.

The nature of a person's illness also impacts on their adherence. Those with paranoid or persecutory beliefs may feel they are being poisoned and hence comply less well. On the other hand, someone with prominent grandiose symptoms may be hard to persuade that they need any treatment. The presence of negative symptoms has been linked with both good (Miner et al 1997) and poor adherence (Tattan & Creed 2001). This apparent paradox could be explained in the poor adherers as being due to a motivational deficit which impairs the individual from taking their treatment; and in the good compliers it may indicate a level of anergia and wanting to avoid an active confrontation with the treatment-provider

leading to a non-reflective, automated continuation of drug treatment. Comorbid alcohol or substance-misuse is also a strong predictor of non-adherence (Drake et al 1989; Kashner et al 1991; Owen et al 1996).

Another issue is the individual health belief model, which reflects patients' thoughts about both the causes and the severity of their illness. A cross-sectional study examined this by quantifying patients' personal beliefs about the necessity of their prescribed medication and their concerns about taking it and assessed relations between beliefs and reported adherence among 324 patients from four chronic illness groups: asthma, renal, cardiac, and oncology (Horne and Weinman 1999). It found that medication beliefs were more powerful predictors of reported adherence than the clinical and socio-demographic factors, accounting for 19% of the explained variance in adherence.

With regards to mental illness, patients have been found to rate their schizophrenia as a less serious disorder than diabetes, epilepsy or cancer (Rettenbacher et al 2004); which is bound to impair adherence. The social perception of an illness and its aetiology may be of importance (Hummer & Fleischhacker 1999). If this is at odds with their physician, it may explain poorer adherence (Chakraborty et al 2001).

It is important to note that adherence may vary with age. Hofer and colleagues found that a negative attitude toward treatment was related to positive symptoms and certain sided effects; this may be a transient phenomenon within the life course of the illness (Hofer et al 2002).

1.8.1.2 Environment-related factors

Support and assistance are important variables in adherence with medication. Patients who live alone are less compliant than those in supportive environments with carers present (Irwin et al 1971). Alternatively, stressful social interactions such as from family-members who are either over-demanding or do not agree with treatment plans can also impede adherence (Tamminga & Schulz 1991).

The media may also shape attitudes through mis-reporting, which raises people's expectations about "miracle cures" or by under-playing side effects which often leads to disappointment when those hopes are not realized and hence worse adherence (Hummer & Fleischhacker 1999). A patient feeling that a drug has a positive effect on their illness has been found to be an important factor in adherence (Hofer et al 2002).

A positive therapeutic environment is also important: an inpatient setting where a fellow patient has only had bad experiences of taking a particular drug will shape the attitude of the patient treated with the same medicine. Finally, attitudes about treatment within a multi-disciplinary team need to be consolidated when people from different training backgrounds are supervising individual patient care; medical professionals tend to advocate the provision of anti-psychotic medication when treating schizophrenia to a greater extent than their social worker colleagues, which is likely to shape the patient's adherence (Rettenbacher et al 2004).

1.8.1.3 Physician-related factors

It has been reported that the most important factor influencing adherence is the patient's perception of the doctor's interest in them, which is reinforced by the amount of time that physicians spend with their patients (Nelson et al 1975). Such a relationship is crucial in generating an effective, working therapeutic alliance and the provision of reliable information within that context. Psycho-education improves adherence and reduces relapse (Kemp et al 1998) helping to allay fears about side effects.

Structured and regular appointments and therapy may improve adherence, as they give the patient a clear signal about the importance of the therapeutic measures employed and adherence to them. Marder demonstrated the importance of providing adequate information to patients by showing greater consent to neuroleptic treatment and more satisfaction with ward staff and physicians expressed by such patients (Marder 1998).

1.8.1.4 Treatment-related factors

Side effects experienced early in treatment have been shown to lead to a substantial impairment in adherence later on (Van Putten et al 1984). Side effects are just one of the facets of the complex issue of adherence: some patients with substantial side effects display good adherence and others who tolerate antipsychotics perfectly, may show poor adherence behaviour (Fleischhacker et al 1994; Hummer et al 1999).

An additional problem is the delayed action of onset of drugs, so patients do not experience immediate positive effects, but the side effects appear almost straight away (Van Putten et al 1984). In

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addition, people with schizophrenia in remission do not usually have a relapse immediately upon stopping treatment. Conversely some patients in full remission have problems realizing that this remission is related to the drug they are taking. These relationships require regular reinforcing to improve adherence.

Patients with complicated treatment regimens – who must take drugs at different times in the day or take two or more different medications – have more problems adhering to their prescriptions than those receiving a once-daily drug treatment (Eisen et al 1990). Route of administration has been found to influence adherence. A review has reported improved adherence with depot neuroleptic versus oral medication (Young et al 1986), whereas others have reported that the switch from oral to depot medication for non-compliant patients has not been effective (Buchanan 1992; Weiden et al 1995).

1.8.2 Measurement of adherence

There are three main methods of measuring adherence. These include patient and clinical self-report, pill counts, and biological measures. Self-report methods represent the most efficient and cost-effective method of measuring adherence (O'Shea 1995; Gaebel 1997), although such methods have been thought to over-estimate adherence by up to 30% (Piatkowska & Farnhill 1992; Wright 1993).

In comparison, pill counts have the disadvantage of undermining trust within the therapeutic relationship and are also unreliable as there is no guarantee that the tablets removed from the container or dose-set box were actually consumed (Fenton et al 1997). Biological measures are less

frequently used due to cost and availability limitations (Piatkowska &

Farnhill 1992; Kane 1983). The accuracy of biological measurement is

compromised by individual variation in metabolism, and is also dependent

on the period of time between ingestion of the last tablet and testing

(Cochran & Gitlin 1988), as well as on the pharmaco-dynamic profile of

the drug. In addition, serum assays are considered unpleasant and

invasive by some patients, and are of limited value in assessing partial

adherence.

No single measurement of adherence can be completely accurate (O'Shea

1995) and the concordance rate across these different measures is

reported to be low (Fenton et al 1997). Nevertheless, self-report

measures are perhaps the easiest to administer, the least expensive,

whereas biological methods are considered to be more objective though

not necessarily more accurate and are more expensive.

For the purposes of this study, measures of adherence were selected by

performing an initial literature review of existing scales and their

screening for suitability. The task was to find both a self-report and

an observer-rated measure of adherence, to offer two complementary

perspectives upon that individual's adherence to their treatment. The

following bibliographic databases were searched: ASSIA; CINAHL; Cochrane

Trials Register; EMBASE; HealthStar; PubMed; PsycLIT; and Science

Citation Index. The search was restricted to articles published in

English between January 1960 and August 2008. Titles and abstracts of

papers were initially identified that covered the areas of interest. The

search terms included: (a) SCHIZOPHRENIA, SCHIZO-AFFECTIVE, PSYCHOSIS,

SCHIZOPHRENIC, CHRONIC NON-AFFECTIVE PSYCHOSIS, SEVERE MENTAL ILLNESS;

(b) ADHERENCE, MEDICATION, TREATMENT, COMPLIANCE. In databases where MESH terms were available they were exploded and combined. Searches were adapted according to the database in question and reviewed by two additional people to the main author. These searches were supplemented by personal bibliographies of the team, forward citation tracking using the Science Citation Index as well as Social Science Citation Index Databases and by seeking references in retrieved articles.

One of the most commonly used self-report measures of adherence is the Drug Attitudes Inventory (DAI) originally devised by Hogan and colleagues (1983). They devised a 30-item questionnaire tested on a sample of 162 people with schizophrenia and found the scale had an internal consistency of 0.93 and test-test reliability of 0.82. A factor analysis highlighted seven factors, which accounted for 60% of the total variance in adherence. Those factors may be labeled as: subjective positive attitudes, subjective negative attitudes, health/illness, physician, control, prevention, and harm. The questionnaire was then validated by grouping subjects as compliers and non-compliers based on ratings made by therapists on these subjects' medication-taking behaviour. Ten items were selected as having maximal group discrimination and on this basis; Hogan and colleagues concluded that 68% of the sample was correctly classified as either compliant or non-compliant using questionnaire responses (1983).

The DAI's validity has been questioned on a number of grounds, despite its widespread use. The scale's validity was based solely on the therapists' judgment which may have over-estimated adherence (Fenton et al 1997). Secondly, the arbitrary classification of participants as compliers and non-compliers reduces the complex nature of adherence to a

dichotomy, which may be an over-simplification (Hughes et al 1997). Finally, the DAI measures attitudes toward medication, rather than adherence behaviour (e.g., in relation to therapy, appointment attendance etc.) which may undermine the construct validity of the measure.

A short but robust scale was developed by Kemp and colleagues (1996). As previous members of the author's department, there was familiarity with the working and the nature of Kemp's scale, which favoured its inclusion. They developed a seven-point scale, which used as many sources as possible including relatives, the psychiatrist at the outpatient clinic, the community psychiatric nurse, and the general practitioner. This informant-based scale if used in addition to the DAI would provide a more comprehensive measure of patient adherence with treatment.

Adherence is rarely compromised by a single cause; usually an array of inter-related factors impeding adherence is found. Self-report measures of adherence whilst not perfect, offer an effective and efficient way of determining a patient's concordance with a treatment plan.

1.8.3 Adherence with treatment in psychosis: SUMMARY

a) Adherence is the ratio between observed treatment behavior and given treatment standards.

b) Poorer adherence is seen in: the young, paranoid, grandiose, the elderly, male patients, those isolated or with over-involved families, and with co-morbid alcohol and substance-misuse problems.

c) Individual illness beliefs, media coverage, the therapeutic environment and the patient's perception of the doctor's interest in them also affect treatment adherence.

d) Delayed-onset of medication, excessive side effects and complex treatment regimes may impair adherence.

e) Three methods to measure adherence are: patient self-report, pill counts and biological measures (serum assay and urine testing); no one measure can be completely accurate.

f) The Drug Attitudes Inventory (DAI) and the Kemp seven-point scale are a commonly used self-report and multi-sourced measure of adherence, respectively.

The next section examines service interactions of UK African Caribbeans with psychosis and relates this to treatment adherence.

1.9 The recognition of ethnic inequalities in UK mental health care

Inequitable variation in the use of British health care services between ethnic groups has been a matter of concern for British policy-makers and the Government alike (Acheson 1998; Department of Health 2000). It has been reviewed that mental health services are unappealing to some ethnic groups, who complain of more coercive treatment as and adverse experiences (Cochrane and Sahshidharan 1996) and these experiences have been recently more systematically reviewed, and outlined below (Bhui et al 2003).

The UK Government's Department of Health has recognized that there is a problem of race inequality regarding the provision, management and outcome of mental health services and addressed the issue of race and mental health care in the National Health Service in two documents: "Inside Outside: Improving mental health services for black and minority ethnic communities in England" (DoH 2003) and "Delivering race equality in mental health care" (DoH 2005). The "Inside Outside" document sets out a framework within which ethnic inequalities may be addressed, in particular, detailing that specific and coordinated action is required in certain areas: that ethnic inequalities in mental health experience and outcome should be reduced and eliminated; that the capabilities of the mental health workforce should be developed to provide appropriate and effective mental health services for a multi-cultural population; and that there should be investment in community development of minority ethnic groups aimed at achieving greater community participation and ownership around mental health.

The second document "Delivering race equality in mental health care" is an action plan for achieving equality and tackling discrimination in

mental health services in England for all minority ethnic groups, in
response to the death of a 38-year-old African-Caribbean patient in a
medium secure psychiatric unit after being restrained by staff. The
response was a programme based on three "building blocks", as follows:
more appropriate and responsive services to be achieved through action
to develop organizations and the workforce, to improve clinical
services; community engagement delivered though healthier communities by
action to engage communities in planning services, supported by 500 new
Community Development Workers; and finally, the provision of better
information in terms of improved monitoring of ethnicity, better
dissemination of information and good practice, and improved knowledge
about effective services, including a new regular census of mental
health problems.

These programmes have arisen from considerable evidence of inequity in
minority ethnic mental health care, as shall be discussed in the next
section.

1.9.1 Ethnic differences in experience, adherence and pathways to care

Bhui and colleagues recently conducted a thorough systematic review of
UK studies published between 1983 and 2000, which compared access and
use of mental health services by different ethnic groups (2003). Bhui
examined all quantitative studies comparing use of mental health
services by more than one ethnic group in the UK; narrative analysis was
supplemented by meta-analysis, where it was deemed appropriate. Thirty-
eight papers were eventually selected for review and the following
findings were revealed.

Black patients had more complex pathways to specialist services, seeing at least three carers before contact with specialist services (Commander et al 1999). Also, the police were more likely to be involved in admissions or readmissions of Black people (Thomas et al 1993; Burnett et al 1999; Commander et al 1999), which may have been associated with a lack of GP involvement rather than due to ethnic origin of the patients (Cole et al 1995). Black people were most likely to present in a crisis, often seeing the duty psychiatrist in an accident and emergency department as a first point of contact with services (Turner et al 1992; Cole et al 1995). Of all ethnic groups with a mental disorder, south Asians were the least likely to be referred to specialist care (Commander et al 1997a; Odell et al 1997).

Next, Bhui examined whether contact between specialist services and Black and South Asian people was maintained (2003). Compared with white patients, services were less likely to maintain contact with non-whites in one part of south London but not in another neighbouring area; however, this suggested that variation in local service configuration and practice were influential and that ethnicity alone does not account for variations in patient contact (McCreadie et al 1997).

Bhui and colleagues went on to review the use of in-patient services and found consistent greater use of those services by Black people (2003). Compared with Black patients, South Asians were less likely to be admitted for in-patient care, had the lowest admission rates to secure wards (Commander et al 1997b; Koffman et al 1997), had shorter admissions than other ethnic groups (Gupta 1991) and were least likely to be readmitted (Birchwood et al 1992). However, compared with White

patients, South Asians were more likely to be admitted to in-patient care (Commander et al 1997a; Koffman et al 1997).

The majority of papers showed a higher rate of compulsory admissions for Black compared with White patients, with it remaining unclear as to whether this was confounded by social isolation in the Black group. The findings on Asian patients were deemed inconclusive. A summary odds ratio obtained from the 12 papers that reported the exact proportions of compulsorily admitted Black and White in-patients and sample sizes, produced a pooled value of 4.31 (95% CI 3.33,5.58) for Blacks compared with Whites.

In summary, this comprehensive review article (Bhui et al 2003) suggested that Black people are over-represented among in-patients and that Asian patients use in-patient facilities less often than White patients. Also, there is some evidence for variations in pathways to specialist mental health care, with Black people traversing more complex routes. Variation in primary care assessments or primary care involvement could explain some of those ethnic pathway-differences to specialist services but the primary care literature was found to be limited. The authors end by deeming a future priority as the measurement of discrimination as a potential explanatory factor for some of these differences.

More recently, the Aetiology and Ethnicity in Schizophrenia and Other Psychoses (ÆSOP) study sought to investigate the relationship between ethnicity and pathways to mental health services in two UK centres in a large cohort of patients with a first episode of psychosis (Morgan et al 2005a). African-Caribbean patients were significantly more likely to be

compulsorily admitted than White British patients, as were Black African patients. African-Caribbean men were the most likely to be compulsorily admitted and, even when adjusted for potential confounders such as criminal justice referral, the odds of compulsory admission was 3.52 times greater than for White British men. Similarly, when other factors were controlled for, the odds of compulsory admission for Black African patients were 4.27 times greater than those for White British patients. Therefore, diagnosis, socio-demographic characteristics and how patients came into contact with services do not explain the high levels of compulsory admission among African-Caribbean and Black African patients.

In a companion study, the ÆSOP group investigated the pathways to mental health care and ethnicity in a sample of patients with a first episode of psychosis drawn from two UK centres (Morgan et al 2005b). They found that compared with White British patients, general practitioner referral was less frequent for both African-Caribbean and Black African patients and referral by a criminal justice agency was more common. With the exception of criminal justice referrals for Black African patients, these findings remained significant after adjusting for potential confounders. This suggested to the authors that factors operate during a first episode of psychosis to increase the risk that the pathway to care for Black patients will involve non-health professionals.

Linked to pathways to mental health care, the patient's experience of treatment within services is significant. It has been reported that Black patients receive higher doses of anti-psychotic medication and with a greater likelihood of depot medication and less psychotherapy than their White British counterparts (see section 1.9.3.3); however more recent work challenges these findings (Connolly and Taylor 2008).

This survey of the prescribing of antipsychotic medication for in-patients in three south London mental health trusts, included 255 patients (152 White, 103 Black). The median dose of antipsychotic (% of licensed dose) was similar for both groups as was the proportion of delivered high-dose antipsychotics. However antipsychotic polypharmacy was greater in the Black group (adjusted OR 3.05; 95% CI 1.44,6.46).

There is limited research-work examining the effects of ethnicity upon adherence with psychotropic medication. One US study compared psychotropic adherence rates in monolingual-Hispanics (mostly Puerto Ricans), bilingual-Hispanics, and African-Americans as compared with Caucasians in 122 subjects recruited from a community mental health center (Diaz et al 2005). After controlling for possible confounding factors monolingual-Hispanics and African-Americans had lower medication adherence rates (77% and 68%, respectively) than Caucasians (90%). Older age was a significant predictor of higher adherence among monolingual-Hispanics. Depressive symptoms were associated with lower adherence and more years of past treatment with higher adherence among Caucasians.

A second US study of Texan Medicaid claims (n = 3583) retrieved for patients diagnosed with either schizophrenia or schizoaffective disorder assessed the association between ethnicity (African-American, Mexican-American, White) or medication and days' use of the medication in the year following initiation, using multi-variate linear regression (Opolka et al 2003). It found that African-American and Mexican-American patients were significantly less adherent than White patients (19d less, $p<0.001$ for African-Americans; 18d less, $p = 0.003$ for Mexican-Americans), even after controlling for potential confounding factors.

The net result for Black patients of more aversive pathways to care, greater compulsory admissions and poorer medication adherence, unsurprisingly, seems to lead both to increased mutual distrust from both patients and care-providers, as well as a more costly experience for Black patients through mental health services. The finding that Black people are often reluctant to engage with mainstream mental health services with delays in seeking help, seems to create new risks, such as police involvement or use of the Mental Health Act, which leads to disproportionately high rtes of hospital inpatient admission, compulsory admission, admission to intensive care and secure services and use of seclusion and restraint in all types of hospital. Such patterns of service-use are negatively experienced and associated with poor outcomes, as measured by relapse and readmission. In turn, these adverse consequences reinforce mistrust of mainstream services that is the initial cause of delayed engagement.

The report "Breaking the Circles of Fear" (Sainsbury Centre for Mental Health 2002) looked into the relationship between African and Caribbean people and mental health services. It confirmed previous quantitative findings in relation to the over-representation of African and Caribbean people in services. It also highlighted: high concentrations of African and Caribbean people within inpatient, acute and secure treatment settings; limited involvement of primary care and a lack of community-based crisis care; people coming into contact with services via the criminal justice system; poor levels of engagement and satisfaction; questionable attributions of risk to Black service users; high levels of fear among Black service users of both mental health professionals and of statutory services; a related high level of fear among mental health

professionals in relation to the risks posed by Black service users; and alienation and lack of involvement of Black carers.

A notable feature of the above patterns of service use is that they entail the over-representation of Black people in high-cost services, particularly hospital inpatient care, raising the possibility that a shift towards a more representative pattern of care among this group might not only improve outcomes but also save expenditure, by reducing the demand for high-cost services.

A further paper by the Sainsbury Centre for Mental Health analyzed the cost implications of this over-representation in the Black group of patients in four London Mental Health Trusts (SCMH Policy Paper 6, 2006). Overall, it found that the total average annual cost per Black service user was £6,539, compared with £4,132 per White service user. It also reported that total spending on inpatient care for Black people was 2.4 times higher than would be predicted purely on the basis of relative population numbers, with the scale of relative overspending being particularly pronounced in the case of medium secure, intensive care and low secure services, but even for care in acute wards spending on Black people was nearly twice the expected level. Therefore, if this overspending could be eliminated so that expenditure on inpatient care per head of population was the same for Black adults as the London average, the total reduction in spending would amount to £76.2 million. This figure would be £85.7 million if levels of service use were the same as for White people.

Furthermore, the estimated scope for savings on community services in London as a whole was estimated at £198.4 million. Per head of

population, the paper reports that combined spending on inpatient and community services as just described was about 170% higher in the Black population than in the White population (SCMH Policy Paper 6, 2006). About a third of this difference can be attributed directly to higher spending per service user, with the remainder to be attributed to differences in the relative numbers of people in the Black and White populations who use mental health services.

The overspend is even more marked in the primary author's own Trust, standing at £120,000 per 100,000 Black community-residents, compared with £40,000 per 100,000 White British people (Camden & Islington Mental Health & Social Care NHS Trust 2005). This report highlights the considerable scope for spending money differently, but also notes that new, more appropriate services need to be developed before funds can be released from those in which Black people are over-represented, if the overspend is to be avoided.

1.9.2 Institutional racism and mental health

Institutional racism may be defined as "the collective failure of an organization to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. This can be seen or detected in processes, attitudes, and behaviour that amount to discrimination through unwitting prejudice, ignorance, thoughtlessness, and racist stereotyping which disadvantages people in ethnic minority groups" (MacPherson 1999). The concept has been applied to psychiatry (McKenzie and Bhui 2007) and will be discussed later but prior to this and related to it, has been the debate of the provision and delivery of

services to minority ethnic groups and to best suit their mental health needs.

The fairly consistent findings reported in the previous section have suggested certain themes of mental health care in relation to the Black British population: that of increased coercion, more aversive pathways to care, leading to greater mistrust, sooner disengagement from services with poorer service-related outcome and greater rates of readmission. These themes have prompted the charge of either a prejudicial or discriminatory mental health system when it comes to care provision for minority ethnic groups, and the need for a suitable solution if the is indeed the case.

One solution to the charge of institutional discrimination within the NHS has been whether or not there should be separate psychiatric services for ethnic minority groups (Bhui & Sashidharan 2003). These authors looked at whether the mental health problems faced by minority ethnic groups in the UK are better addressed by the development of culturally specific (or "culturally competent") services within the UK, or through the funding of voluntary sector services that target specific ethnic minority groups.

As an aside, cultural competence has been proposed as a general approach for improving services, which requires changes at both institutional and clinical levels (Qureshi & Francisco 2005). The key constructs of culture, ethnicity and race underlie important philosophical perspectives in cultural competency models. How these constructs, particularly race, are understood to relate to health and healthcare is of considerable importance in both the development of the competency

models and their application and acceptability, which are not always the same, in a given context. Clinical cultural competence consists of specific knowledge skills and attitudes that function together to provide an individualized, culturally sensitive and appropriate treatment. Knowledge about cultural specifics is considered less important than an awareness of the different ways in which culture, race, and the migratory process can affect psychosocial functioning and mental health treatment.

The main argument for culturally separate services has been that neither the consistent findings of greater coercion and growing dissatisfaction for Black people has led to systematic changes in the delivery of mental health services in multicultural societies (Bhui & Sashidharan 2003). A growing body of experiential evidence and individual service-user testimony favouring culturally-separate services ahs been ignored in favour of an economic argument that such services are too expensive. It goes on that professionals are not sufficiently skilled to be able to offer equity in assessment and management of mental distress in distinct cultural groups. As a consequence, specialist services have flourished in the voluntary sector whilst there has been neglect of such issues by mainstream Governmental health policy. The need for such services is argued for due to the apparent neglect of cultural, spiritual and religious beliefs by both the caring professionals and in the care plans they develop. Existing statutory services have difficulty attracting and retaining minority ethnic staff which further undermines the incorporation of culturally competent working into mainstream practice, with a focus being on the management of risk rather than building relationships, trust and engagement.

The argument proffered against culturally separate services goes that their advocacy further supports the nation of minority ethnic groups as being "the other" and "separate" which, is not only divisive but also alienating and harmful to such groups (Bhui & Sashidharan 2003). It is argued that there is little evidence to support that the mental health needs of minority ethnic groups are somehow different from those of others, rather the inequity in service delivery is a product of institutional factors embedded in the cultural history of Western psychiatry. This would argue for the need for mainstream change in practice rather than marginal initiatives, which might imply marginal importance of the mental health needs of minority ethnic groups.

A second argument against separate services is that cultural competence is important to all cultural groups, not just in relation to the minority ethnic population which, otherwise might suggest that culture is a problem foe minority groups rather than for the wider population. The creation of specialized services is argued to give credit to the "colonial" discourse of trans-cultural psychiatry, allowing mainstream psychiatry to turn a blind eye to the needs of the wider multi-cultural society. If the central issue of institutional racism within psychiatry were to be addressed, then the needs of minority ethnic groups would be automatically met; with the focus on delivering equity and tackling discrimination, rather than focusing on special needs which is perceived as a "flirtation with outdated ideas from our colonial past" (Bhui & Sashidharan 2003).

The charge of whether or not UK psychiatric services are institutionally racist has also been recently hotly debated in the literature (Singh and Burns 2006; McKenzie and Bhui 2007). A focus of the debate has been the

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Healthcare Commission's report of the findings of the "Count me in" one-day census of NHS hospitals, private mental health hospitals and learning disability units (Healthcare Commission 2006). The survey of 32,023 inpatients reported that 21% of patients were from black and minority ethnic groups, although they represent only 7% of the population. Rates of admission were lower than average in the white British, Indian, and Chinese groups, but three or more times higher than average in black African, black Caribbean, and white and black Caribbean mixed groups. Not only were people in these three groups more likely to be admitted to hospital, but also those in hospital were 19-39% more likely to be admitted involuntarily. Once in hospital, people who defined themselves as black Caribbean had the longest stay.

Singh and Burns state that these findings do not necessarily prove institutional racism, and that the scientific evidence to support this charge is inconclusive (2006). They argue that the increased rate of psychotic disorder in UK second-generation African-Caribbeans is not a specific phenomenon, rather a common experience of migrants in a new country. They argue that the more aversive care pathways of African-Caribbeans through the mental health system may be better explained by: greater stigma of mental illness within this minority community, and less social support from the immediate family, rather than by psychiatric racism. The racist argument is further undermined, they suggest, by the lower aversive pathways for the south Asian community (which, presumably would also be subject to racism from the system) where the familial support might be stronger. They write that the accusation of racism against the health system can be pernicious, as it sets up distrust in the minority community which may present to services

with an expectation of inequitable services leading to their delayed help-seeking further and impeding recovery. It may also undermine staff morale, whom may feel undervalued and blamed as a result of charges of racism.

In response to this, academics have suggested that the above position represents a set of stereotyped responses to charges of racism rather than sound scientific arguments (McKenzie and Bhui 2007). Those inappropriate responses consist of either blaming the individual making the charge of racism; misunderstanding institutional racism as the fault of the individual rather than a systemic failure; requiring proof of intent within a racist action if it is to be truly racist; and finally, ignoring the urgency of the problem by calling for more research rather than suggesting remedial action.

McKenzie and Bhui argue for effective leadership to improve services in a strategic way, encompassing action in the criminal justice, social services, and educational systems as well as within the NHS. They argue that this could be monitored if a body such as the National Institute for Health and Clinical Excellence were to develop a formal impact assessment for race equality (2007).

1.9.3 Epidemiological issues around hospital admission data

The use of psychiatric hospital in-patient admissions statistics to examine ethnic variations in the pattern of mental illness offers both advantages and disadvantages. These statistics present both general challenges (Weich 1997) as well as those specific to interpreting trends within ethnic groups.

On the one hand these data have been available on a national scale and are not likely to be influenced by the research process itself. On the other hand these data suffer from several problems, which means that findings based on them exclusively can be considered only as a starting point in the research process rather than necessarily as a basis for drawing conclusions.

The main methodological problems inherent is the way NHS statistics relating to ethnicity have been gathered are: 1) only data based on 'Country of Birth', not ethnicity, have until recently been available; while this was not a significant problem in the past when most members of ethnic minorities in Britain were born abroad, now that even the majority, of these groups are born in Britain the data become increasingly confounded; 2) Record keeping and statistical returns in the NHS have been of low standard although with modern census practices this is now improving; 3) There is still no standardized scheme for recording diagnosis - each clinician who has to make a return operationalises the diagnosis employed in their own way. Not only can this give rise to regional variations in case definition but also make the interpretation of trends over time difficult as diagnostic criteria change; 4) as long as there are differences in care pathways taken by different ethnic groups, and there is a delay in help-seeking from the community to services, any attempted extrapolation of hospital admission data to the wider community will be met by charges of inaccuracy. It could be argued that excess diagnostic rates in minority groups are partially artefactual and secondary to numerator or denominator errors. Also the excess rates may be misattributed to an individual's ethnicity when the confounding influence may, instead, be social deprivation.

With the recent improvement in quality of hospital data, some of these

challenges should be met; however, while people seek out care and a

solution to their mental health problems via alternatives to hospital

such data will always be of limited value.

Sashidharan raises problems with epidemiological research in examining

the issue of increased diagnosis of schizophrenia in African-Caribbeans

in his elegant review, which is still relevant today (1993). He begins

by discussing the invoking of a commonality of culture to heterogeneous

peoples as misleading: that the categorization of African-Caribbeans as

a single cultural group is inappropriately simplistic. He goes on to

state that the tradition of epidemiological approaches to cross-cultural

comparisons of rates of schizophrenia is often problematic because of

vastly different methods used across studies including differing case

finding methods, lack of diagnostic criteria and the failure to control

for confounding variables such as socio-demographic factors.

Sashidharan delineates the epidemiological issues by examining

separately the inherent biases that are introduced by the choice of

numerators and denominators (1993). He sees the most significant bias

that can be introduced in the calculation of any disease rate stems from

the choice and definition of the numerator, which is especially so when

its magnitude is small. There are inherent problems in both case

identification and case definition. The sampling frames are frequently

not the same, although they have tended to rely upon hospital

admissions. This would rely on the assumption that both African-

Caribbeans and Whites with schizophrenia have equal chances of being

admitted to hospital. This is dependent upon variations in professional

practice, the availability of alternative provision and the perceptions

of illness and satisfaction with the services available. It has been shown not to be the case, with African-Caribbeans having a more aversive pathway to care (see previous section). The net effect of this is that there will be significant differences in the proportions of Black and White patients in sampling frames based on hospital utilization due to the differing probabilities that ethnic groups have of being recognized, referred and admitted to hospital.

Problems with case definition could also undermine the actual magnitude of the risk ratios derived from research (Sashidharan 1993). He argues that the diagnosis of schizophrenia may not be reliable and is perhaps over-inclusive in the case of Black patients, which may account, at least partially, for the increased rates. He then describes the broader issue of the cultural critique of the taxonomy of psychiatric disorders based on culture-specific notions about symptomatology, and how this may lead to an over-pathologising of people from other than the White, Western majority culture.

Sashidharan next discusses denominator problems, which may arise in cross-cultural epidemiological research; this refers to the size of the at-risk population (1993). The previous lack of ethnicity data in Census information which could have led to an under-count is not likely to be as much of an issue today as this information is now collected and available for incorporation into research. The second source of denominator bias is related to the catchment population used in studies. He argues that most studies are conducted in the inner city where populations are transient and highly mobile which could be argued to lead to both qualitative and quantitative changes in the estimation and characterization of the at-risk population. If there is an ethnic bias

in such population shift into and out of cities, these are bound to have a differential effect on local hospital utilization thus affecting the comparability of disease rates calculated on the basis of ethnicity. He finally argues that a source of error in case-control methods used ignore demographic differences which are likely to impact on hospital utilization and illness onset such as soil class and economic activity.

1.9.4 Alternative explanations

There may be other factors than perceived racism, which are predictive of therapeutic engagement in those with schizophrenia and psychosis. These include the following and will be further discussed in the Discussion section: remission of paranoia; impaired insight; involvement with the criminal justice system; recovery style; physical abuse as a child; lack of knowledge regarding consumer rights; difficulties in building an alliance; low neuroticism and high agreeableness (Tait et al 2003; Lecomte et al 2008; Compton 2005). It is possible that these factors act alongside that of perceived racism or are in fact either confounders or proxy measures of the relationship between racism and outcome.

1.10 African Caribbean people in the United Kingdom and psychosis

Migration from the Caribbean to the United Kingdom began in the early 1950s. Psychiatric research in Britain over the past three decades has consistently shown elevated rates of schizophrenia among African Caribbean people compared with the indigenous white British population, with Caribbeans typically reported to be three to five times more likely than whites to be admitted to hospital with a first diagnosis of

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schizophrenia (Kiev 1965; Bagley 1971; Bebbington et al 1981; Dean et al 1981; McGovern & Cope 1987; Harrison et al 1988; Littlewood & Lipsedge 1988; Cochran & Bal 1989; van Os et al 1996a; Kirkbride et al 2006). These findings have been repeated in studies that have looked at first contact with all forms of treatment, rather than just hospital services (King et al 1994; van Os et al 1996a); and the rates of schizophrenia were found to be even higher in the UK-born children of the immigrants (McGovern & Cope 1987; Harrison et al 1988).

Some commentators have not accepted the validity of these data and continue to suggest that a higher incidence remains unproven owing to methodological flaws with the research (see Sashidharan 1993). Epidemiological issues are as follows: until the 1991 Census, where a question on ethnic background was asked for the first time, the data on the size of the African Caribbean population in the UK was limited and unreliable, resulting in its possible underestimation and consequent overestimation of morbidity rates. However some have shown that even if the Caribbean population was much larger than initially estimated, the psychosis rate still remains significantly greater than in the white population (Harrison et al 1988; King et al 1994; van Os et al 1996a; Bhugra et al 1997). The incidence rates reported for Caribbeans in their countries of origin however, seem much lower and closer to the rates seen in the white British population in the UK (Mahy et al 1999; Hickling & Rodgers-Johnson 1995), although this may only be inferred from certain work where ethnicity was not reported (Bhugra et al 1996).

Therefore, people have sought to explain why there is an elevated rate of psychosis in African Caribbeans in the UK compared with the

indigenous population and compared with their counterparts in the Caribbean.

1.10.1 The issue of misdiagnosis

The anthropological argument against applying the Western concept of schizophrenia to people from other cultures has been raised (Fernando 1988). Fernando argues that explanations for differences in rates of schizophrenia are invariably concerned with biological differences between racial groups, whilst failing to consider the socio-political (often racist) context in which the diagnoses are made. He continues that schizophrenia is "over-diagnosed" and this hinges on the nature of a psychiatric diagnosis and the nature of racial bias. Fernando views diagnosis as a hypothesis: no more, no less, but in a psychiatric culture where he perceives racial bias to be active, a correct diagnosis in the psychiatric tradition could still be viewed as a racist one, and therefore inappropriate.

Furthermore, the practice of studying single diagnostic categories of questionable validity may introduce selection bias (Robins & Guze 1970). It has been suggested that unfamiliarity with Caribbean beliefs and culture in UK psychiatrists as well as stereotypical beliefs held by diagnosticians about dangerousness may lead to them over-diagnosing psychosis in African-Caribbeans (Littlewood & Lipsedge 1981; Sashidharan 1993; Adebimpe 1994). Lewis and colleagues however found no difference between the diagnostic attitudes of foreign and British-trained graduates (1990).

Hickling and colleagues compared the diagnoses made by British psychiatrists with a Jamaican psychiatrist and found no significant difference; however, interestingly, the two groups agreed in only 55% of cases, suggesting that the diagnosis of schizophrenia is inherently unreliable, irrespective of ethnicity (1999). Some researchers have questioned the methodology of this study.

Many non-Western cultures do not regard hallucinations as pathological as they are in the West (al-Issa 1995). This could mean an increased readiness to volunteer hallucinatory experiences by non-Western groups. Indeed, increased hallucinatory behaviour and paranoid experiences have been described by Blacks compared with Whites in both the UK and the US general populations (Adebimpe et al 1981, 1982; Mukherjee et al 1983; Lawson et al 1984; Ndetei & Vaadher 1985; Johns et al 1998; Sharpley & Peters 1999).

It has been argued that African-Caribbeans are more likely to experience affective symptoms within a psychotic illness, but these may be difficult to identify without specific enquiry (Hutchinson et al 1999). Indeed it has been reported that UK Caribbeans are at greater risk of mania (Hunt et al 1993; Leff et al 1976), and schizo-mania (van Os et al 1996b), which has been conceptualised as a form of reactive mania or stress reaction (Tyrer 1982). Kirov and Murray found that African-Caribbean patients with bipolar disorder were more likely to express schizophrenic symptoms (1999), which could result in a mis-diagnosis of schizophrenia.

There is a belief that African-Caribbeans diagnosed with schizophrenia experience a more relapsing and remitting illness, with more affective

symptoms and social disturbance, but fewer negative symptoms than their white counterparts (McKenzie & Murray 1999; Takei et al 1998). McGovern and Cope found greater incidence of atypical psychoses and acute-onset illnesses in UK Caribbean patients, usually associated with a good outcome (1991). They also found greater diagnostic variability and fewer first-rank symptoms in their group, but a greater frequency of admissions and a stronger family history (the latter two phenomena more suggestive of schizophrenia). However, others have found little difference in symptomatology, social functioning and course of illness between white and African-Caribbean patients (Goater et al 1999; Harvey et al 1990; Sugarman 1992).

McKenzie and colleagues conduced a four-year follow-up study of patients with recent-onset psychosis and found the Caribbean patients spent more time in a recovered state, were less likely to have a continuous illness, although they suffered more compulsory admissions and imprisonments; this may suggest at least an illness with a different outcome if not a different illness entity (1995).

1.10.2 Biological hypotheses

1.10.2.1 Genetics

There is a large genetic component to the risk of developing schizophrenia and other psychoses among White populations; up to 60-80% of the liability variance may be genetic in origin (Walls-Bass et al 2006; Pacheco and Raventos 2004; Kendler & Diehl 1993); the more genes that an individual shares with an affected person, the higher the risk of schizophrenia.

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It has been argued that the increased risk of schizophrenia for Caribbeans in the UK may simply be due to an increased genetic risk. This runs counter to the evidence that there is no increased incidence rate of schizophrenia in Jamaica compared to the UK white population (Hickling & Rodgers-Johnson 1995). In addition, the African centre in the World Health Organization's International Pilot Study of Schizophrenia (Sartorius et al 1986) did not find an increased incidence rate of schizophrenia.

Sugarman and Craufurd found that the morbid risk for schizophrenia was similar for parents and siblings of white and first-generation UK Caribbeans with schizophrenia, and for the parents of second-generation Caribbean probands (1994). However, the siblings of second-generation probands had a markedly higher risk for schizophrenia than their white counterparts. This suggests that environmental factors are acting upon second-generation Caribbeans with individuals from certain families being especially vulnerable (Hutchinson et al 1996).

1.10.2.2 Perinatal factors

Obstetric complications and viral infections leading to brain injury have been hypothesized as early environmental hazards (Geddes & Lawrie 1995; McGrath & Murray 1995; Murray et al 1992; Sham et al 1992; Gupta 1993). Several studies suggested an increased incidence of schizophrenia in people who were in mid-gestation during the 1957 influenza epidemic (Sham et al 1992), but sample sizes were too small to suggest that influenza in gestation led to an increase in psychosis in African-Caribbean individuals.

There was an epidemic of congenital rubella in the African-Caribbean

population of the UK in the 1950s and 1960s, as rubella was not endemic

in the Caribbean at that time, and so many of the migrating women did

not have immunological resistance to rubella (Glover 1989). However, it

is unlikely that the increased psychosis rate in the UK can be

attributed to rubella-induced brain damage during pregnancy, as the

increased rate of psychosis is also reported in UK Africans, whose

mothers were not exposed to rubella (Wessely et al 1991).

Hutchinson and colleagues (1997) measured the frequency of obstetric

complications in a series of psychotic patients in London; they found

they were twice as common in white as Caribbean patients, lending no

support for an obstetric aetiology for schizophrenia in UK Caribbeans.

1.10.2.3 Childhood risk factors

Children who develop schizophrenia in adult life are more likely to have

lower mean IQs, more personality problems, an excess of conduct disorder

and lower educational achievement than their unaffected peers (Jones et

al 1994; Davies et al 1998). African-Caribbean children are more likely

to under-achieve academically and to be diagnosed with a learning

disability compared with the general population, which may be relevant

(Wing 1979). The former group is also more likely to be exposed to

social factors (such as parental separation, foster care etc.)

associated with mental disorder than their white counterparts (Maughan

1989). The significance of these points to aetiology has yet to be

established.

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1.10.2.4 Cannabis use

Cannabis use has been proposed as a risk factor for psychosis in general and the excess risk of psychosis in UK African-Caribbeans, however controversy surrounds both claims (Boydell et al 2007; McGuire et al 1994; Thornicroft 1990). A review of prospective studies of cannabis use and adult psychosis (Arsenault et al 2004) concluded that cannabis use appears to be neither a sufficient nor a necessary cause for psychosis; it is a component cause, part of a complex constellation of factors leading to psychosis.

The most convincing work was a 15-year prospective study on the risk of schizophrenia in cannabis users compared with non-users (Andreasson et al 1987). This found it to be an independent risk factor for schizophrenia; other work has found it to trigger relapse in particularly prone patients (Turner & Tsuang 1990).

Cannabis use is often attributed as a cause of psychosis by the relatives of black rather than white patients (Callan and Littlewood 1998). Other research has found that cannabis consumption amongst Caribbean immigrants to the Netherlands was lower than the native population, but their incidence rate of schizophrenia was higher (Selten et al 1997; Selten & Sibjen 1994). Thus the evidence to date for cannabis as an aetiological agent seems somewhat contradictory.

1.10.2.5 Migration

It has been suggested that those who are genetically predisposed to schizophrenia are more likely to migrate (Odegaard 1932). However, a comprehensive review of the migration literature (Canadian Taskforce on

Mental Health Issues, 1988) concluded that there is just as much evidence for no difference in occurrence of mental disorders in those that migrate, as there is for a greater occurrence in migrants.

There is little evidence for an increased risk of schizophrenia in the UK Asian population (Sashidharan 1993), suggesting that it is not migration in itself but some factor within the UK affecting the Caribbean population that leads to an increased incidence of schizophrenia.

1.10.3 Social hypotheses

1.10.3.1 Urbanicity

There is a clear association between inner-city deprivation and high rates of psychiatric admission in general (Giggs & Cooper 1987) and schizophrenia in particular. It has been suggested that being born or brought up in the city increases the risk of schizophrenia (Marcellis et al 1998; Lewis et al 1992) rather than simply a consequence of social drift or social residue (Freeman 1994). This increased risk has been linked to stressful life events (Brown & Prudo 1981), isolation (Burnett et al 1999), overcrowding (Magaziner 1988), higher crime (Dekker et al 1997), and lower socio-economic status (Castle et al 1993). The association may be confounded by the observation that physical risk factors occur more commonly in the city, such as low birthweight and perinatal infections (Takei et al 1992; Torrey & Bowler 1991).

Harrison and colleagues did not find that area of residence alone was capable of explaining the elevated risk of schizophrenia in Caribbeans in UK cities (1988). It could be that African-Caribbean people are

exposed to adverse social factors more frequently than their white counterparts, such ass stressful life events, lower socio-economic class and unemployment levels (Bhugra et al 1997).

1.10.3.2 Social disadvantage

Social support systems influence health (Lomas 1988). The physical structure of communities and social cohesion could either encourage or discourage mutual support, self-esteem, a sense of belonging and enriched social relationships. The level of mutual dependency and positive support that can arise from a community, which has high reciprocity and structured caring, (known as "social capital" [Putnam 1995]) may protect against mental illness.

Researchers have argued that Caribbean community structure is compromised relative to other groups, in terms of more single-parent families, more parental separation and more children raised in foster care or children's homes (Maughan 1989; Littlewood & Lipsedge 1982; Cox 1977). More people live alone and are imprisoned (Bhugra et al 1997; Burnett et al 1999), leading to a form of social exclusion which may increase a susceptibility to poor health. Indeed, it has been found that the incidence of schizophrenia in non-white ethnic minorities in London is greater when they comprise a smaller proportion of the local population, supporting the "ethnic density" effect (essentially, safety in numbers) as a buffer against psychosis (Boydell et al 2001).

1.10.3.3 Pathways to care and within the system

As described earlier, it has been found that African-Caribbean patients with schizophrenia in the UK have more aversive pathways into care, i.e. greater police involvement, less general practitioner involvement and a greater occurrence of compulsory hospital admissions (Davies et al 1996; Cole et al 1995; Harrison et al 1989; Rwegellera 1980). This appears to be unrelated to the duration of untreated psychosis, occurring in early-onset and more chronic cases alike (Morgan et al 2004).

It has been thought that African-Caribbean patients may not seek general practitioner help early on in their illness due to embarrassment and shame about stigma (Rack 1982), leading to a deterioration in health and the need for more dramatic intervention later on (Owens et al 1991; Harrison et al 1989). Young black men are more often perceived as dangerous and threatening, and this too may contribute to increased rates of compulsory admission (Pipe et al 1991).

Once within care, black Caribbean patients are more likely to remain in hospital for longer (Dunn & Fahy 1990) with more frequent admissions (McKenzie et al 1995); are more often treated in secure facilities (Cope 1989); are given higher doses of psychotropic medication and larger amounts of depot injections (Chen et al 1991); and receive less psychotherapy than white patients (Campling 1989; Yamamoto et al 1968). People of Caribbean origin leave hospital with more untreated symptoms and are less likely to stay engaged with services (Bhugra et al 1997). Possibly linked to this is the finding that younger black patients of Caribbean origin describe progressively lower satisfaction with the services with each subsequent hospital admission (Parkman et al 1997). However, McGovern and Hemmings found no significant difference between

the perspectives of the relatives of black and white psychotic patients that had been sectioned; the majority of whom agreed with the diagnosis and with the decision that a compulsory admission was required (1994).

1.10.3.4 The effect of racism

Racism is a plausible explanation for the increased rates of psychosis in UK Caribbeans. As already discussed, racism is multi-faceted concept and has multiple effects at different levels: at the individual, familial, institutional and societal levels (Williams 1996). Racism compounds the effects of gender and social deprivation (Lillie-Blanton & LaVeist 1996). In addition, thwarted aspirations have been linked to psychological stress (Parker & Kleiner 1966) and the persistent, prolonged struggle and failure to overcome difficulties of denied opportunities has been linked to a decrease in psychological well-being and hypertension (James 1994).

Discrimination has been prospectively linked to delusional ideation (Janssen et al 2003) but prospective work examining the association between racism and psychosis is still sparse. It is conceivable that there is an association between racism and lack of adherence as Caribbean psychotic patients are more likely to attribute their problems to racism then mental ill health (Chakraborty et al 2001).

A lack of adherence with treatment is typically associated with a mismatch of explanatory models between doctor and patient (Callan & Littlewood 1998); if the patient is more likely to frame their problems within a framework of racism rather than mental illness, they are less likely to comply with a treatment plan that fails to acknowledge their

framework. The perception that services and treatment are discriminatory deters African-Caribbeans from accessing these services (Campling 1989; Mclean et al 2003).

Kleinman first championed the notion that patients' explanatory models of illness elicited using an ethnographic approach could assist the clinician in gaining a better understanding of the subjective experience of illness and so promote collaboration, improve clinical outcomes and patient satisfaction (1988). Despite the initial appeal of this theory, it has not been extensively investigated or influential upon routine clinical practice. It has been argued that this is due to the lack of social sciences training in health professionals as well as the difficulty in the task for the clinician (Bhugra and Bhui 2002). Latterly, the premise being that the delineation of explanatory models requires an open-ended anthropological investigation which the relatively closed, hierarchical nature of the traditional psychiatric assessment process cannot allow for; with reductionism undermining the garnering of sufficiently rich information to flesh out the patients' individual model. Those authors argue for the usage of the term explanatory "map" rather than model implying that a much broader contextualizing perspective of the condition is required to reflect the complexity of beliefs encompassed by the illness experience.

One could argue that the perception of the African-Caribbean patient's illness experience of the phenomenon known as schizophrenia represents an explanatory map that overlaps with that of a schizophrenic patient from a different culture with both common and distinct elements, with differing emphasis placed on those elements by the illness-sufferer. If greater regard is paced upon the racial elements by the patient and

correspondingly less attention is paid to them by the clinician, it becomes understandable why therapeutic alliances fail to form, treatment programmes break down and prognosis and service-related outcomes suffer.

As a result, service-related outcomes, such as poor satisfaction, poor subsequent engagement, compulsory hospitalization and depot medication use, reflect an impaired interaction between the individual and the system of care, which may at least in part be due to the individual perceiving services as racist. A recent US study found that African American men with mild paranoia were less likely to be hospitalized than their white counterparts, suggesting a state of "cultural mistrust" of services by the former group, leading to them delaying help-seeking (Whaley 2004).

1.10.4 Psychological hypotheses

1.10.4.1 Attributional style

An excess of life events has been found to precede psychotic relapse, irrespective of ethnicity (Bebbington et al 1993). However, Gilvarry and colleagues did not find a difference in the number of life events preceding relapse of psychotic illness between black Caribbean and white British patients (1999), but they did find that the black group was more likely to attribute adverse life events to racism.

A small study within the general population found that proto-delusional paranoid and grandiose ideas (those ideas determined to be precursors to delusional beliefs) were more common amongst African-Caribbean than white participants (Sharpley & Peters 1999).

Smaller-scale life-events or daily hassles ("micro-aggressions" - Pierce 1995) that are said to be experienced by minority ethnic groups have been thought to be significantly related to mental ill health (see section 1.3.2.2) but the association with psychosis has yet to be examined.

Investigation of the role of social factors, in particular racism, and how they interact with biological and/or with other social and psychological risk factors in the UK Caribbean community is essential if causal mechanisms and effective preventive strategies for psychosis are to be identified.

1.10.5 African Caribbean people in the United Kingdom with psychosis: SUMMARY

a)   Research has shown elevated rates of schizophrenia among UK African Caribbeans compared with the white British population.

b)   This has been attributed to over-diagnosis due to racism, stereotypical beliefs about dangerousness and a greater readiness to volunteer hallucinatory experiences.

c)   The increased risk of schizophrenia has also been attributed to an underlying genetic susceptibility, obstetric injury, maternal congenital rubella, migration, and cannabis misuse but these theories remain either largely unsubstantiated by the epidemiological evidence or the findings themselves are contradictory.

d)   In terms of social explanations, social deprivation, compromised "social capital" and "ethnic density" have both been associated with the increased risk.

e)   African-Caribbean patients with schizophrenia in the UK have more aversive pathways into care as well as interactions therein, which may indicate their "cultural mistrust" of psychiatric services.

f)   It may be that this mistrust is attributed by African-Caribbean patients to racism, either from the environment or from within the various institutions they encounter, and this may explain the poorer adherence and engagement with services.

1.11 Rationale for this study

People of Caribbean origin with a psychotic illness residing in the UK have worse service-related outcomes than their white counterparts. Routes to care and rates of involuntary admission diverge, with those of Caribbean origin more likely to be admitted against their will, less likely to stay engaged with services and less likely to comply with medication. In addition, younger patients of Caribbean origin describe lower satisfaction with services with each hospital admission.

Poor satisfaction and engagement reflect the interaction between the individual and the system of care. The poorer service-related outcomes described indicate poor patient adherence with management plans. Patient satisfaction and adherence have been shown to be greatest when there is a concordance between the patient's and their psychiatrist's explanatory models.

A qualitative study undertaken by the author was the first to demonstrate a difference in the attribution of illness between psychotic patients of Caribbean and British white origin. Those of Caribbean origin were more likely to claim that their illness was caused by racism and that the services were racist. A review of the literature indicates that both the excess risk of psychosis as well as the poorer service-related outcome in UK African-Caribbeans with psychosis may at least in part be explained by racism.

The perception that difficulties are due to racism rather than mental illness produces different problems for clinicians for acceptance and adherence with treatment. One can understand how it may be more difficult to persuade a patient to accept treatment for a problem that

they consider to be caused and perpetuated by society. Offering an individual treatment for something that they see as someone else's problem could be seen as a bitter pill to swallow. Moreover, the lack of acknowledgement of this perspective puts psychiatrists in the position of being perceived as part of the problem rather than part of the solution. There is some evidence for the association between the experience of discrimination and mental health problems. This appears to be clearer to patients than their clinicians. Moreover, it is clear that being black and having a mental health problem is likely to be a "double jeopardy" with regards to discrimination. Again this was clear to patients in the author's study but is not an issue that has been taken up by UK psychiatry.

In the UK the poor satisfaction figures for African-Caribbean patients, the poor adherence rates, the high rates of re-admission and the progression to more coercive and higher security treatment modalities could be a reflection of the fact that some patients believe they have to continue their fight against racism in the psychiatric setting.

Psychiatrists in the UK are trying to offer the best care they can for a diverse population and individually are trying to offer equitable care. Institutionally, however, there has not been user-led research from the African-Caribbean perspective. The community is rarely consulted about what they see as mental illness and has not been canvassed about what solutions they would like to use. When it is asked, the community has demanded radical change, through the establishment of ethnically specific services and ethnically matched staff. At the time of the author's pilot study, mental health workers were not trained in cross-cultural psychiatry and there was little training in cultural

competence, despite the fact that 40% of in patients in London are from ethnic minority groups.

Cultural and institutional exclusion and racism has been reported to characterise the African-Caribbean community's experience of mental health services, discouraging African-Caribbean people from approaching such services. Similarly, the high levels of socio-economic disadvantage among African-Caribbeans are felt to increase the likelihood of poor mental health and to decrease the likelihood off accessing services.

Not surprisingly therefore, there seems to be no equity in provision of treatment for Caribbean patients, and the differences that those patients in the qualitative study commented on reflect actual differences in service-related outcome. It should be noted however, that when research has been conducted on non-service related outcomes, such as whether people are actually suffering from symptoms at follow-up or whether they have episodic or continuous disease, people of Caribbean origin have been shown to have a relatively good prognosis.

How can this be - good prognosis and worse service-related outcomes? The model proposed is that people of Caribbean origin in the UK have psychotic illness that is precipitated by social factors - such as racism. Psychosis that occurs in the context of previously good personal development retains a good prognosis and is more "affective" in nature. The chronicity with regards to service-related outcomes such as re-admission or more coercive treatment may occur because people of Caribbean origin are reluctant to see services early in their illness; when they do present to services they are more likely to be diagnosed as suffering from schizophrenia. They recognise their affective symptoms

though these are more likely to be missed by psychiatrists. They also believe that the problem is due, at least in part, to discrimination and their social circumstances. Because they do not think that the problem is internal and do not trust services they regard as misunderstanding them, they are less willing to take treatment.

Psychiatric services in the UK are particularly concerned about dangerousness. Because of this and the prevalent stereotypes of people of Caribbean origin (hooks 1993) they are more likely to use their powers to detain people of Caribbean origin who refuse treatment. Disparities in the use of coercion have become widely reported in the media and so psychiatry is seen as part of a racist and oppressive system likened to the prison justice system. The doctor-patient alliance is undermined and adherence becomes less and less likely as the cycle continues.

Insight is linked to better adherence. Measurements of insight often measure agreement between the psychiatrist's and patient's Attribution of illness. The differing perception of illness-causes by psychiatrists and patients of Caribbean origin may impair the therapeutic alliance between patient and doctor and, hence, worsen outcome.

Notwithstanding the unsatisfactory experience and emotional costs to patients and their families of having a poorer outcome, excessive psychiatric hospital bed days are also expensive. The cost of hospital in-patient treatment for inappropriately placed patients has been shown to greatly exceed the costs of community-based care (Knapp et al 1997). If this cost could be avoided through improved adherence all the parties involved are bound to benefit.

It is possible that factors other than perceived racism are linked to poor adherence or service-related outcome. A multiplicity of factors have been identified in previous work, and these include: involvement with the criminal justice system; recovery style; physical abuse as a child; lack of knowledge regarding consumer rights; difficulties in building an alliance; low neuroticism and high agreeableness (Tait et al 2003; Lecomte et al 2008; Compton 2005). However it is equally possible that racism is a significant, independent predictor of poor outcome and worthy of examination given its relative paucity of examination in the extant literature.

The readiness with which patients would discuss and explore discrimination may demonstrate that it is an issue that they want to talk about. Such issues could be dealt with in the consultation or in therapy depending on whether it is seen as a live issue in the individual's context. Sensitive exploration of these issues could be used to forge links between patients and their clinicians, perhaps improving the therapeutic alliance and outcome.

To date, no reported study has investigated possible associations between the perception that society and services are racist and adherence with psychiatric treatment. If such associations could be demonstrated, novel management approaches that take into account patients' beliefs could be devised, so that both adherence and outcome could be improved.

1.11.1 Rationale for this study: SUMMARY

a) A mismatch of the attribution of illness between a patient and their psychiatrist is often associated with poorer adherence, hence outcome.

b) People of Caribbean origin with a psychotic illness in the UK have worse service-related outcomes (more compulsory admissions, greater disengagement and worse medication-adherence), requiring greater coercion to adhere with treatment than their white counterparts.

c) This greater coercion may reflect a mismatch in the attribution of illness between patient and psychiatrist: whereby the patient perceives both his predicament and services as racist and oppressive, whilst the psychiatrist over-estimates the "dangerousness" of the patient.

d) This attribution-mismatch has yet to be studied in detail; no study to date has examined the association between the perception that society and services are racist and adherence with psychiatric treatment in Caribbean patients with psychosis.

e) The examination of racism and treatment adherence has been welcomed by the Caribbean community, and if it enables a more open interaction during the psychiatric consultation, this could improve therapeutic alliances, engagement and hopefully the outcome for those suffering from illness.

2. METHOD

2.1 Hypotheses and study design

The primary hypothesis is that there will be an inverse association between perceived racism as measured by the Perceived Racism Scale in patients of Caribbean origin with psychosis and adherence with treatment as measured by Kemp et al's seven-point scale and the Drug Attitudes Inventory.

The secondary hypothesis is that in Caribbean people with psychosis, perceived racism will be associated with higher rates of admission to hospital over 12 months.

The hypotheses are explored by performing a prospective cohort study of patients with psychosis of Caribbean origin over 12 months. Perceived racism will be measured at baseline in all patients using a suitable instrument, with adherence and hospital admission data determined at the end of the follow-up period, again using suitable measures.

2.2 Measuring perceived racism

The first step to determining perceived racism at baseline is to ensure that an appropriate instrument is available to measure it. The Perceived Racism Scale (PRS) is one of the instruments used in the clinical assessment of research participants for this study at the baseline interview (McNeilly et al 1996). The PRS is an American, self-completed instrument that measures the frequency of exposure to perceived racism, emotions, coping behaviours, and cognitive appraisals related to the racist encounter. It explores four domains: at work, in academic settings, in the public realm (or everyday racism), and responses to racist statements.

Its value is derived from its measurement of both perceived racist events as well as emotional and behavioural reactions to such events. This it gives a measure of coping strategies as well. It scores highly in terms of reliability with Cronbach alpha scores of the (i) four domains, (ii) emotional reaction domains and (iii) coping domains being 0.89-0.93, 0.85-0.95, and 0.64-0.91, respectively. The test-retest reliability score over a two-week period was 0.50-0.78, which is acceptable. Its validity has been tested by principal components factor analysis with parts (i-iii) scoring 0.51-0.83, 0.60-0.84, and 0.52-0.9, respectively.

Two modifications were made to the PRS to make it more appropriate for this sample of research participants. Firstly, any "Americanisms" were modified to make the PRS more readable by a UK audience. Secondly, as most of the participants were predicted to be both unemployed and to not have been in employment for any significant period of time, the work domain statements were replaced by domain statements pertaining to racism from mental health services.

It may be justified that the work items of the PRS were omitted from the study as it was anticipated that a large proportion of the sample group would not have had a recent experience of employment. This is not to say that those with schizophrenia are invariably unemployed, but that the employment history has a greater likelihood of being sparse or erratic and therefore recollections of events pertaining to employment may be subject to a greater level of recall bias.

There is evidence that those with psychosis are far less likely to be in employment. A study from the 1990s in the inner London Borough of Wandsworth examined data collected over 10 years on 1 April each year as part of an annual census of adults with longer-term mental health problems using community mental health and rehabilitation teams (Perkins and Rinaldi 2002). They found that unemployment among people with long-term mental health problems increased from 80% in 1990 to 92% in 1999, and the unemployment rates among those with a diagnosis of schizophrenia increased from 88% in 1990 to 96% in 1999.

The causes for the association between unemployment and long-term mental ill health were postulated to be related to the nature of jobs available in the economic climate were such that they were inappropriate for this population; Second, during this period there has been increasing pressure to reduce bed usage and ensure that as many people as possible are supported in living outside a hospital setting. This may result in mental health workers devoting most of their time and energy to maintaining people in their accommodation, with relatively little time devoted to other issues such as employment. Third, at the same time as there has been a focus on the role of employment in promoting social inclusion, there has been an increasing focus on stress in the workplace and the detrimental impact of some employment on mental health. If it is assumed that work is stressful, and that people who experience serious mental health problems are not able to cope with stress, then there may be a reluctance on the part of clinicians to encourage clients to work, and on the part of clients to undertake an activity that they believe may worsen their difficulties. Fourth, the 'benefits trap', which makes

it difficult for people with mental health problems to take low paid jobs, especially on a part-time basis, without risking loss of income, is undoubtedly a disincentive to entering employment. And finally, during the 1990s there has been a major increase in the popular association between violence and mental health: it seems unlikely that employers are immune to such popular representations and they may have become increasingly fearful of employing people who they assume to be dangerous.

The literature on employment, ethnicity and psychosis is sparse but it is likely that the same trends as seen in the 1990s are likely to be seen today, irrespective of ethnic group. Thus, by removing the "work" domain from the PRS, this made its length more manageable than if it were left in alongside the new mental health services domain and would therefore increase the likelihood of the instrument's completion by respondents.

The domain statements that explored racism from mental health services were developed using a number of sources. The first source was the author's qualitative pilot study (Chakraborty et al 2001), which examined experiences of racial discrimination described by black African and African-Caribbean patients with psychosis in north London. The second source was a focus group facilitated by the author, with staff members working in an early intervention service for black African and African-Caribbean patients with psychosis aged 16 to 25 years and resident in Haringey.

The group critically and candidly explored the experiences and perceptions of racism within mental health services as described by their patients. The final source was from the author's principal supervisor and secondary supervisor, who are both established and prominent academic figures in the field of psychiatry and mental health service-provision for ethnic minorities in the UK. It is with this final source that the author arrived at a consensus about the exact wording of the mental health service-domain statements. As can be seen in comparison of the work domain and mental health service domain, the subject content of the statements is of course different, but the wording and style of each statement remains relatively preserved. This was in order to maintain the integrity of the original PRS instrument as much as possible.

The new mental health services-domain was then piloted on a small group of patients to test its acceptability and readability. The domain was found to be both appropriate and "user-friendly" and thus was incorporated into the PRS. Both the original PRS and the modified PRS are provided in the Appendix.

2.3 Research participants

The inclusion criteria for research participants in this study were as follows: being aged between 18 and 65 years; having an ethnicity of "Caribbean origin" – this refers to people with a self-assigned ethnicity of "Black other" or "Black Caribbean" (according to the O.P.C.S criteria), with either or both parents or grand-parents born on a Caribbean island; having a Research Diagnostic Criteria-defined psychotic illness (either schizophrenia or schizo-affective disorder);

being in receipt of psychiatric services from either Barnet, Enfield and Haringey Mental Health NHS Trust or from Camden and Islington Mental Health and Social Care NHS Trust. Those patients with a primary diagnosis of either an organic disorder or a substance-misuse disorder were excluded from the study.

2.4 Power calculation to determine sample size

It was initially determined by power calculation that a sample of at least eighty (80) patients would be required for this study. This power calculation was based upon the work of Kemp and colleagues (1996). They found that insight was positively associated with adherence, Pearson's correlation coefficient being 0.95 (p=0.001 using a two-tailed test). For the purposes of this study, it was hypothesized that perceived racism should be regarded as an ethnically specific factor with a similar effect to insight, but one that varies inversely with adherence. Therefore, using a sample-size calculator and a study sample size of 80, with 80% power and a significance level of 0.05, this study would be able to detect a correlation in the primary analysis of -0.3, and to detect a correlation of -0.45 with 99% power.

2.5 Ethical approval

Formal ethical approval for the study was obtained from the Local Research and Ethics Committees for Barnet, Enfield and Haringey Mental Health NHS Trust and Camden and Islington Mental Health and Social Care NHS Trust.

2.6 Recruitment

Research participants for the study were contacted in the following manner. In the first instance, all of the Community Mental Health Teams (CMHTs) in Haringey and North Camden, London were contacted via their team managers and provided with information about the study and given a request for suitable participants. At the same time, each of the Medical Consultants attached to the CMHTs were also contacted and given similar information. For the next step, the author attended each CMHT's weekly team meeting to give a short address about the study, with information and again a request for participants. Next, the author contacted by telephone each individual CMHT member on at least three separate occasions to seek out suitable participants. CMHT members consisted of community psychiatric nurses, social workers, clinical psychologists, occupational therapists and support workers.

The author's specific request was that consultants and CMHT members should try and identify appropriate participants, and then they should approach each individual and seek their verbal consent to both participate in the study and be contacted by the author. Once verbal consent was obtained, the author contacted the participant by telephone to set up the research interview. At least three attempts were made to set up the interview with each prospective participant, before they were deemed unsuitable for the study. The participant was told that the research interview would take about one hour to conduct, was private and confidential, consisted of self-completed instruments as well as observer-rated instruments, and could take place at a time and location convenient to the participant. The participant was told that they would be invited to an interview at baseline as well as a fairly similar

interview at one-year follow-up and that for each interview they would receive £10 cash to cover their time and expenses.

2.7 Actual sample sizes

From a purposive sample of one hundred and fifty (150) patients that was initially approached to take part in the study, one hundred and ten (110) patients agreed to take part in the baseline assessment of this study. Of those 110 patients, one hundred (100) agreed to the follow-up assessment, one year later. Neither the initial purposive sample, nor the baseline sample, nor the follow-up sample differed from one another in diagnostic or socio-demographic characteristics. The final followed-up sample comprised 100 patients (57 men and 43 women).

2.8 Baseline assessment

The baseline assessment consisted of the following: a socio-demographic assessment (to measure putative confounders); the World Health Organisation Life-Chart (confounders), the Structured Clinical Interview - Positive and Negative Syndrome Scale (current mental state), the Drugs Attitudes Inventory (primary outcome), the modified Perceived Racism Scale (primary exposure), the Kemp et al Adherence Scale (primary outcome), and the Operational criteria checklist for psychotic and affective illness (to confirm diagnosis).

The research interviews were all conducted by the primary author: a psychiatrist with ten years' clinical and research experience. The interviews occurred variously at the participant's residence, the CMHT centre, the general in-patient unit, the regional secure unit, the day

hospital, or the drop-in day centre. Prior to beginning the interview, each participant had the opportunity to ask further questions about the study and then formal written consent to participate was obtained from them.

The baseline assessment required spending about one hour, face-to-face with each participant, as well as time consulting patient records and individual caseworkers. The various instruments are described in detail below.

2.8.1 Socio-demographic assessment

This was observer-rated and collected information about: the participant's age; gender; residential status and accommodation; their family and relationships; their education; their employment history; parents' occupations; confidant and support networks; ethnicity information of grand-parents and great-grand-parents (if known).

2.8.2 World Health Organisation (WHO) Life-Chart

This is an observer-completed instrument that records clinical and health service-usage information for the participant over the preceding year. It assesses longitudinally employment, independent living and hospitalisation, self-harm, and treatments received. It also assesses severity of course of illness by using clear definitions for all ratings. Course was rated as continuous (no remission longer than six months), neither episodic nor continuous, episodic (no episode longer than six months), and not psychotic in this period. A "usual severity of symptoms" rating indicates the symptomatic level of the patient during

most of the follow up period. Ratings were severe, moderate, mild, or recovered. Self-harm included all attempts at self-harm regardless of the outcome (that is, both parasuicide and completed suicide were included). It is completed on the basis of case-records examination and verbal information from participants, corroborated by their individual caseworker. It compiles information about their residence, their work history, illness course and symptoms, suicide attempts and assaults, physical and psychological treatments, and family-involvement in the treatment process.

2.8.3 Structured Clinical Interview – Positive and Negative Syndrome Scale (SCI-PANSS or PANSS)

The PANSS is an observer-rated instrument developed and standardised for typological and dimensional assessment of schizophrenic phenomena. This thirty-three item, seven-point rating instrument is an operationalised method that evaluates positive, negative, and other symptom dimensions on the basis of a formal semi-structured clinical interview and other informational sources. The instrument includes items that are scored on a: positive scale, negative scale, composite scale (positive scale minus negative scale), general psychopathology scale, and supplemental aggression risk profile. Additional scores are available for clusters of symptoms including: anergia, thought disturbance, activation, paranoid/belligerence, and depression.

The authors of the instrument reported that in the initial reliability assessments of the PANSS, each item correlated strongly with the appropriate scale total (Kay et al 1987). The mean total correlations of 0.62 (positive) and 0.70 (negative) far exceeded cross correlations of

0.17 (positive items with negative scale) and 0.18 (negative items with the positive scale). Alpha coefficients of single items ranged from 0.64 to 0.84. Removing any items could make no gains in the alpha coefficients. Test-retest Pearson correlations were all significant in the positive direction ranging from 0.60 for general psychopathology to 0.80 for the positive scale. Additional assessments of inter-rater reliability demonstrated consistently strong correlations between 0.89 and 0.94 (Kay et al 1988; von Knorring and Lindstrom 1995).

The SCI-PANSS has also demonstrated to be well correlated to other measures of schizophrenia symptoms (Norman et al 1996) such as the Scale for the Assessment of Positive Symptoms (Andreasen 1984) and the Scale for the Assessment of Negative Symptoms (Andreasen 1983). Additionally, the SCI-PANSS correlates well with its predecessor (Bell et al 1992), the Brief Psychiatric Rating Scale (Singh and Kay 1974). There have been many studies that demonstrate the instrument's validity in assessing the dimensional nature of schizophrenia. These assessments of validity include discriminate and convergent validity (Kay et al 1988; Opler and Kay 1985; Opler et al 1984; Kay and Opler 1987), criterion related validity (Kay et al 1988; Lindenmayer et al 1984), predictive validity (Kay and Opler 1985; Kay and Lindenmayer 1987; Lindenmayer et al 1986) and concurrent validity (Peralta and Cuesta 1994).

Several studies report a five-factor model of the SCI-PANSS items that are similar to each other (Lepine 1991; Lindstrom et al 1994; Lindenmayer et al 1994; Bell et al 1992). The five-factor solutions have explained between 57 to 70 percent of the total variance. This model includes a positive, a negative, an excited, an anxious/depressive, and a cognitive factor.

2.8.4 Drugs Attitudes Inventory (DAI)

The DAI is a ten-item scale developed to assess how the attitude of schizophrenic patients toward their medications may affect adherence. Respondents indicate 'true' or 'false' for each item. Based on the analysis of responses of 150 patients, the DAI was indicated to be an assessment tool with high consistency and high validity (Hogan et al 1983). This assessment tool has the ability to distinguish between patients who are compliant with treatment and those patients who are non-compliant. Items on the DAI were selected specifically based on comments made by patients regarding their treatment adding to the relevance of this assessment tool.

The reliability of the DAI was assessed in one study of 150 outpatients with schizophrenia (Hogan et al 1983). The internal consistency was good (Cronbach alpha = 0.81). In addition, the test-retest reliability in a random sample of 27 of the original 150 study subjects was also good (ICC = 0.82). The reliability of the instrument has also been established in Spanish (Robles-Garcia et al 2004) and French (Droulout et al 2003) versions.

Correlations between the DAI and the older Neuroleptic Dysphoria Scale (NDS) a four-item, interview-based scale that also assesses dysphoric response, were also good: 0.76 at 24 hours after beginning antipsychotic treatment and 0.74 at 48 hours after beginning antipsychotic medication (Hogan and Awad 1992). There are preliminary data that the DAI may predict a past history of antipsychotic medication adherence (96%

accuracy) and non-adherence (83% accuracy). Similar results were found in a second group of 19 hospitalized inpatients. Here, eight of eleven (73%) patients with a history of medication adherence and five of eight (63%) patients with a history of non-adherence were correctly categorized by the DAI. Interestingly, in both studies a positive score on the DAI proved better predicting adherence than a negative score did at predicting non-adherence. The concurrent validity of the DAI has also been demonstrated in the Spanish and French versions (Droulout et al 2003; Robles Garcia et al 2004).

There is some evidence that higher scores on the DAI are associated with better medication adherence (n=2657) although the relationship between DAI and adherence was not directly assessed in this study (Garcia-Cabeza et al 2001). In one study (Hogan and Awad 1992), the DAI score after 24 hours of treatment was significantly associated with the total BPRS score (partial r = -0.75) and Global Assessment of Functioning score (partial r = 0.68).

The DAI is a brief, easy-to-use, self-report instrument. Most outpatients and many inpatients can independently complete the form. It provides a reliable and valid assessment of dysphoric response to antipsychotic medication. The DAI is potentially useful in identifying patients at high risk for non-adherence. In addition, the DAI may be useful in predicting the likelihood of short-term improvement in psychosis with antipsychotic treatment.

2.8.5 Modified Perceived Racism Scale (PRS)

The PRS is a self-completed instrument, constructed to assess the experience of racism in African Americans in a multidimensional manner. The scale not only provides a measure of the frequency of exposure to many manifestations of racism (including individual and institutional, overt and covert, attitudinal, behavioral, and cultural), but takes a step forward in more comprehensively measuring the experience of racism by assessing emotional and behavioral coping responses to racism. These responses are measured with respect to exposure to racism in three situational domains: on the job, in academic settings, and in the public realm. Measurement of responses to a fourth domain, that of exposure to racist statements is also included.

The PRS was modified in order to pertain to the present sample of research participants, by performing two steps. The Americanisms were removed to make it more readable for a UK audience and the job domain was replaced by a mental health services domain as described earlier in the Methods section.

2.8.6 Kemp et al Adherence Scale

The Kemp et al Adherence Scale is a seven point observer-rated rating scale, which produces a continuous score of adherence. The scale is completed by the participant's individual caseworker. Complete refusal is scored as one; partial refusal--for example, refusing depot drugs or

accepting only the minimum dose--is scored as two; reluctant acceptance-
-accepting only because treatment is compulsory or questioning the need
for treatment often (every two days)--is scored as three; occasional
reluctance about treatment--questioning the need for treatment once a
week--is scored as four; passive acceptance is scored as five; moderate
participation--some knowledge of and interest in treatment and no
prompting needed to take the drugs--is scored as six; and active
participation, ready acceptance, and taking some responsibility for
treatment is scored seven.

2.8.7 Operational criteria (OPCRIT) checklist for psychotic and affective illness

The OPCRIT is a suite of computer programs that allow data entry and
generate diagnoses according to twelve operational diagnostic systems,
including the Research Diagnostic Criteria of the International
Classification of Diseases (ICD-10) and is used in a wide range of
psychiatric research. The OPCRIT was designed to facilitate a poly-
diagnostic approach to mental illness. It provides a convenient,
reliable, rapid and valid approach to poly-diagnostic assessment that
can be used as an adjunct to conventional best-estimate consensus
diagnostic procedures. Sources of information that are used to produce
an OPCRIT-generated diagnosis are the WHO Life-chart and the PANSS.

The OPCRIT checklist consists of 90 different items of psychopathology, pre-morbid functioning, personal-, and family history information. A computer program produces diagnoses of main affective and psychotic disorders associated with 12 major classificatory systems, including the ICD-10 and DSM-IV. OPCRIT can be rated on a lifetime- or episode basis, and was, in this study, rated on the lifetime basis. OPCRIT was originally designed to facilitate a polydiagnostic approach to the diagnosis of psychotic and affective disorders for molecular genetic research and has been adopted as part of the minimum dataset for the European Foundation Programme on the Molecular Neurobiology of Mental Illness (Leboyer and McGuffin 1991) and the National Institute of Mental Health initiative on linkage studies in Schizophrenia and Bipolar Disorder (Berg et al 1994). OPCRIT has been, and is being, used in a wide variety of clinical, epidemiological and biological research applications (e.g. Castle et al 1991; Kendell et al 1993; Williams et al 1993).

OPCRIT has been shown to have good reliability when used by different raters rating lifetime diagnoses on case vignettes. The original (74 item) version of OPCRIT was shown to have good reliability between three rates who rated 54 case vignettes (McGuffin et al 1991). An international study including 30 clinicians from both sides of the Atlantic who rated 30 case vignettes demonstrated good reliability within all classification systems for the current 90-item version of OPCRIT (e.g. DSM-III-R, K = 0.73, RDC, K = 0.71, ICD-10, K = 0.70; Williams et al 1996). On comparison between diagnoses generated by OPCRIT from data rated by two trained clinicians with diagnoses made

according to consensus, best-estimate, lifetime procedures by the same two raters according to DSM-III-R and RDC classifications, good to excellent agreement was achieved (P = 0.98 and K = 0.97 for DSM-III-R and P = 0.95 and K = 0.93 for RDC).

2.9 Follow-up assessment

The follow-up assessment occurred one year after the initial assessment. It required spending about one hour, face-to-face with each participant, as well as time consulting patient records and individual case-workers. It consisted of the following assessments.

2.9.1 Socio-demographic assessment

This was observer-rated and collected current residence information; current general practitioner and monitoring CMHT; and next-of-kin details.

2.9.2 World Health Organisation (WHO) Life-Chart

Clinical and health service-usage information for the participant over the preceding year (i.e. since initial assessment) was recorded.

2.9.3 Structured Clinical Interview - Positive and Negative Syndrome Scale (SCI-PANSS or PANSS)

This was completed and scored by the author in the same way as at initial assessment.

2.9.4 Drugs Attitudes Inventory (DAI)

This was completed by the participant in the same way as at initial assessment. The participant was in effect blinded to their exposure status, as they would not be aware of their scores on the Perceived Racism Scale.

2.9.5 Experience of Discrimination

Perceived racism was measured for events during the year since initial assessment using three questions taken from the Fourth National Survey (Modood et al, 1997). The questions measured whether or not (and if so, how much) respondents had experienced in the last twelve months: physical attack due to racism; property damage due to racism; and verbal insult due to racism. Two further questions were devised through consensus by the author and supervising team (see Appendix 6.5). They asked firstly, whether the participant had received a good standard of care from mental health services and if not, whether they attributed this to racism amongst other things. Secondly, the participant was asked if they had received a poor standard of care, whether or not they had complained to anyone. If they had not complained they were asked to give reasons why not.

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2.9.6 Kemp et al Adherence Scale

This was scored by the participant's caseworker in the same way as at initial assessment. The caseworker was also masked to their client's exposure status, as they would not have known their scores on the PRS.

2.10 Statistical analysis

Data were entered into the statistical computer package SPSS Version nine, and were then cleaned by a co-worker for subsequent analysis.

2.10.1 Descriptive statistics

Basic descriptive statistics of the socio-demographic and clinical data were calculated for the baseline sample (n=110), for the follow-up sample (n=100), and for the group that was lost to follow-up (n=10). The t-test and chi-squared statistics were used appropriately to determine if there were significant differences between the baseline sample and the follow-up sample in socio-demographic or clinical data.

2.10.2 Primary exposures

The primary exposure at baseline was perceived racism, and was measured by the PRS. The PRS produces a number of continuous scores for exposure to perceived racism, which were normally distributed. These are as follows: total perceived racism for the previous year; total perceived racism over the lifetime; from mental health services for the previous year; from mental health services over the lifetime; at school or college for the previous year; at school or college over the lifetime;

everyday racism for the previous year; everyday racism over the lifetime; racist statements over the previous year; racist statements over the lifetime.

The PRS also produces scores for emotional responses to perceived racism in different settings. These are as follows: feeling angry when experiencing racism from mental health services; feeling hurt; feeling frustrated; feeling sad; feeling powerless; feeling hopeless; feeling ashamed; and feeling strengthened when experiencing racism from mental health services. Individual emotional response scores are similarly produced from perceived racism experienced in the other settings, namely: in school or college, everyday racism and exposure to racist statements. Finally, a total emotional response score is produced for by summing each emotional response across the four different domains.

2.10.3 Primary and secondary outcomes

The primary outcome was adherence with treatment at one-year follow-up and this was measured by the DAI score and the Kemp et al score. They both produce a continuous measure of adherence. The reason for obtaining two measures of adherence was that they measure different people's perspectives: the DAI score is a well-tested but self-report measure, whereas the Kemp et al score also provides a multi-disciplinary measure of adherence.

The secondary outcomes were as follows: the number of days spent in hospital for psychiatric problems in the year following baseline assessment; the number of hospital admissions in the year following baseline assessment; and the length in hospital bed-days of the longest

psychiatric admission in the year following baseline assessment (these were specifically determined by the WHO Life-Chart and would provide a more detailed description of hospital stay than total bed-days over a year).

2.10.4 Univariate analysis

Univariate analysis was performed to determine the associations between the primary exposure, perceived racism at baseline, and the primary outcome, adherence with treatment at one-year follow-up. This was calculated using correlation between each of the perceived racism scores and each of the adherence scores. Univariate analysis was also performed to determine the correlation between each primary exposure and each secondary outcome, in the same way.

2.10.5 Confounders

Univariate analysis was also performed between each variable from an *a priori* list of potential confounders and each primary exposure, followed by each putative confounder and each primary and secondary outcome, separately. The list of potential confounders included the following variables: DAI adherence score at baseline; gender; age; PANSS paranoia score at baseline; PANSS paranoia score at follow-up; number of months prescribed anti-psychotic medication in the two years prior to initial assessment; number of months prescribed anti-psychotic medication in the year between assessment and follow-up; number of months prescribed anti-depressant medication in the two years prior to initial assessment; number of months prescribed anti-depressant medication in the year between assessment and follow-up; in receipt of depot anti-psychotic at

baseline; in receipt of depot anti-psychotic at follow-up; and whether or not the participant consults their general practitioner for stress.

Potential confounders that were continuous variables were considered significant (and therefore worthy of inclusion in the subsequent analysis) if the correlation r>0.20. This is based on statistical theory, below.

If the true correlation between X and Y within the general population is **rho**=0, and if the size of the sample, **N**, on which an observed value of **r** is based is equal to or greater than 6, then the quantity is distributed approximately as **t** with **d. of f.**=**N**—2. Application of the formula below to any particular observed sample value of **r** will accordingly test the null hypothesis that the observed value comes from a population in which **rho**=0:

$$t = \frac{r}{\textbf{sqrt}[(1-r^2)/(N-2)]}$$

2.10.6 Primary regression analysis

For the primary analysis, linear regression was performed to determine the association between perceived racism score at baseline and adherence with treatment at follow-up. Prior to analysis, dependent and independent variables were checked for normality of distribution. If

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they were not normally distributed, they were collapsed into categories to make maximal use of the information.

Those confounders which were found to be significantly correlated with either a primary exposure or primary outcome could then be entered into each regression analysis. Baseline adherence as measured by the DAI score or the Kemp et al score, gender, and baseline PANSS paranoia score were always entered into each regression model; these were determined by the research committee (with expertise in this area) to be factors that would be significantly associated with the outcome (males, with poor baseline adherence and with paranoid symptoms are historically poorer adherers to treatment) and would therefore require adjustment.

2.10.7 Secondary regression analysis

For the secondary analysis, linear regression was performed to determine the association between perceived racism score and each of the secondary outcomes identified above. Significant confounders as well as age, gender, and baseline PANSS paranoia score were entered into each regression analysis (for reasons outlined in the section above).

2.10.8 Imputation of missing values

For both the primary and secondary regression analyses, the missing data (i.e. from those ten participants that were lost to follow-up) were multiply imputed using STATA's "ICE" program, and were used in the main analysis. The one hundred participants that were successfully followed-up had complete datasets. This is an increasingly popular technique of managing the inadequacy of "complete-case" analysis of datasets with

missing observations (Royston 2004). Prior to imputation, the pattern of missing data was examined against the main variables to confirm that they were missing completely at random (an assumption of the ICE program).

The technique of multiple imputation (MI) is a three-step process. The first step is to create m complete data sets (in STATA's case, m=5) by substituting the missing values m times using m independent draws from an imputation model. The imputation model is constructed to reasonably approximate the true distributional relationship between the missing values and the observed values. In the second step, the m imputed complete data sets are analysed by treating each imputed complete data set as a "real" complete data set. Standard complete data procedures and software can be utilized directly. In the third step, the analysis results based on the m complete data sets are combined by a simple, appropriate way to obtain the so-called repeated imputation inferences (Rubin 1987). The variances of combined estimates consist of within-imputation and between-imputation variances, so the uncertainty in the imputed data is being properly incorporated into the final inference. This method overcomes the drawback of single imputation, which underestimates the standard error of estimate.

Specifically, the "uvis" command was used, which performed each imputation of a single variable on a set of predictors. This allowed the use of all 110 participants rather than the 100 that were followed-up. Secondly, in both the primary and secondary regressions, clustered analyses were performed using out-patient / in-patient / day-patients status as strata and geographic CMHT as the primary sampling unit.

3. RESULTS

Descriptive statistics will firstly be provided for the baseline sample (n=110). Socio-demographic and clinical information was collected and will be presented.

3.1 Socio-demographic information

3.1.1 Gender, age, religion and place of birth

55% of the sample (n=61) were male and 45% (n=49) were female. The average age of the sample was 43 years, ranging from 18 to 79 years. 30% (n=33) of the sample described themselves as Church of England, 15% (n=17) were Catholic and 26% (n=29) reported having no religious belief. 53% of the sample (n=58) were born in the United Kingdom, followed by 39% (n=43) born in the Caribbean. The rest (n=9) were born either in Africa, Europe or the rest of the world. Of those born outside the UK, 29% (n=15) had moved to the UK by the age of ten years and 69% (n=36) had done so by the age of 20 years.

3.1.2 Ethnicity of parents and grand-parents

Table one shows birthplace information of the study participants' parents and grand-parents. Participants' fathers born in the Caribbean formed the largest group (86.4%) and the largest UK-born group consisted of the participants' mothers (13.6%).

Table one. Ethnicity information on parents and grand-parents of participants

Variable	Frequency	Percentage
Maternal birth country		
UK	15	13.6
Caribbean	83	75.5
Africa	7	6.4
Other	5	4.5
Paternal birth country		
UK	5	4.6
Caribbean	95	86.4
Africa	4	3.6
Other	6	5.5
Grand-maternal birth country		
UK	4	3.6
Caribbean	91	82.7
Africa	2	1.8
Other/not known	13	11.8
Grand-paternal birth country		
UK	3	2.7
Caribbean	91	82.7
Africa	2	1.8
Other/not known	14	12.7

3.1.3 Place of residence

Information on whom participants live with, the number of people living in their household, the number of addresses held in the last three years, and the number of rooms in their accommodation is shown in table two. The largest group within the sample lived alone (36.4%) with 49.1%, occupying no more than a single room and most (53.6%) had not moved in the last three years. However, a significant proportion (23.7%) had had three or more addresses in that time period.

Table two.   Residential information of the study sample

Variable	Frequency	Percentage
Whom they live with		
Mother	12	10.9
Sibling(s)	4	3.6
Spouse/partner	7	6.4
Children	13	11.8
Alone	40	36.4
Group home/hostel	34	30.9
Household number		
One	40	36.4
Two	23	20.9
Three	15	13.6
Four	9	8.2
Five or more	22	20.0
Number of addresses in last three years		
One	59	53.6
Two	25	22.7
Three	14	12.7
Four	5	4.6
Five	1	0.9
Six	6	5.5
Number of rooms		
Shared single	1	0.9
One	54	49.1
Two	23	20.9
Three	17	15.5
Four	13	11.8
Five	1	0.9
Six	1	0.9

3.1.4 Relationships

Relationship and family information is shown in table three. As can be seen, the majority of participants (61.8%) were single with no partner; only 6.4% were either married or living with someone. Most had no children (45.5%), although a significant proportion had one or two children (35.4%). The largest proportion of the sample was raised by at least one natural parent (70.0%), and a small proportion (8.2%) had no siblings. 40.0% of the sample was the eldest child and over half of the sample shared the same parents with all their siblings (53%).

Table three. Relationship information of the study sample

Variable	Frequency	Percentage
Relationship status		
Married/living with someone	7	6.4
Single, steady relationship	5	4.6
Single, casual relationship	10	9.1
Single - no partner	68	61.8
Divorced	3	2.7
Widowed	6	5.5
Separated	11	10.0
Number of children		
None	50	45.5
One	25	22.7
Two	14	12.7
Three	9	8.2
Four	4	3.6
Five	5	4.6
Six or more	3	2.7
Main childhood caregiver		
Natural parent(s)	77	70.0
Grandparents	15	13.6
Aunts/uncles	8	7.3
Foster parents/social services	6	5.5
Other	4	3.6
Number of siblings		
None	9	8.2
One	8	7.3
Two	15	13.6
Three	23	20.9
Four	14	12.7
Five	15	13.6
Six or more	26	23.6
Number of dead siblings		
None	81	73.6
One	20	18.2
Two	6	5.5
Three	2	1.8
Four	1	0.9
Position in sibship		
Eldest	44	40.0
Middle	33	30.0
Youngest	27	24.6
Only child	6	5.5
Same parents shared with all siblings?		
Yes	53	48.2
No	57	51.8

3.1.5 Education

Education and employment information is given in table four below. The largest proportion of the sample went to secondary school in the UK (70.9%), followed by the Caribbean (22.7%). Most had not received remedial education at school (80.0%) and 53.7% had at least some form of qualification, mostly GSCE or CSE level (30.9%). 85.5% had not studied in the past year, but 53.6% had received additional vocational skills training or formal education since leaving school.

Table four. Education information of the study sample

Variable	Frequency	Percentage
Secondary school location		
UK	78	70.9
Caribbean	25	22.7
Africa	4	3.6
Other	3	2.7
Highest educational level		
No qualifications	51	46.4
GCSE/CSE	34	30.9
O' levels	7	6.4
A' levels	4	3.6
Vocational/college	11	10.0
University/professional	3	2.7
Received remedial education		
Yes	22	20.0
No	88	80.0
Studied in the past year?		
No	94	85.5
Yes, full-time student	1	0.9
Yes, part-time student	13	11.8
Yes, but discontinued	2	1.8
Any skills training/formal education since school?		
Yes	59	53.6
No	51	46.4

3.1.6 Employment

Table five below shows employment information for the study sample. The vast majority of the sample was unemployed (97.3%), although 96% had been previously employed and 32.7% had been employed for more than ten

years. Most were in receipt of income support (83.6%) or disability

living allowance (62.7%); a smaller proportion had done voluntary work

or odd jobs for friends in the last two years (14.6%).

Table five. Employment information for the sample

Variable	Frequency	Percentage
Currently employed?		
Yes	3	2.7
No	107	97.3
Total Years in employment		
Less than one year	24	21.8
One-three years	8	7.3
Three-five years	17	15.5
Five-ten years	21	19.1
More than ten years	36	32.7
Not known	4	3.6
In receipt of benefit		
Housing benefit	77	70.0
Family benefit	11	10.0
Income support	92	83.6
Disability living allowance	69	62.7
Performed voluntary work in the last two years?	16	14.6
Yes	94	85.6
No		

3.1.7 Family and friends

Information gathered about the friends and family of study participants

is given in table six. Most people spoke to a friend at least weekly, if

not daily (64.6%), although a large proportion never spoke to friends

(24.6%). Participants' friends tended to live in the same area as them

(74.1%), as did family members (42.7%); however 20.0% of patients had no

family members in the same city. Nevertheless, participants tended to

speak to at least one family member weekly, if not daily (65.5%).

Table six. Information about participants' family and friends

Variable	Frequency	Percentage
How often do they visit or speak with friends?		
Daily	42	38.2
Weekly	29	26.4
Fortnightly	2	1.8
Monthly	2	1.8
Less	8	7.3
Never	27	24.6
Do friends live close by?		
No	3	3.5
Yes, same area	63	74.1
Yes, same town	19	22.4
How often do they visit or speak with family?		
Daily	43	39.1
Weekly	29	26.4
Fortnightly	1	0.9
Monthly	27	24.5
Less or never	10	9.1
Does family live close by?		
No	22	20.0
Yes, same area	47	42.7
Yes, same town	41	37.3

3.1.8 Confidants/support network

Table seven shows confidant/support network information for the sample. Approximately half of the sample had a close confidant (47.3%) with whom they spoke at least weekly or daily (80.8%). The greatest proportion reported not sharing an upsetting problem with anyone (35.5%), followed by discussing it with a parent (17.3%). 91.8% of the group was registered with a general practitioner, and only 45.8% would approach them with a stressful problem.

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Table seven. Information about confidants/support network of the sample

Variable	Frequency	Percentage
Close confidant(s)?		
Yes	52	47.3
No	58	52.7
How often do they visit or speak with confidants?		
Daily	21	40.4
Weekly	21	40.4
Fortnightly	1	1.9
Monthly	6	11.5
Less than above	3	5.8
With whom would they first discuss a worrying or upsetting problem?		
Partner	5	4.6
Parent	19	17.3
Sibling	7	6.4
Other relative	7	6.4
Male friend	11	10.0
Female friend	12	10.9
No one in particular	10	9.1
Doesn't share problems	39	35.5
How helpful are they for emotional support and advice/listening?		
Very helpful	26	46.7
Fairly helpful	22	29.3
Not very helpful	9	12.0
Critical but truthful	16	21.3
Too critical	2	2.7
Registered with a GP?		
Yes	101	91.8
No	9	8.2
Would they go to GP with a stressful problem?		
Yes	49	45.8
No	58	54.2

3.2 Clinical information from case-notes

Data on participants' clinical status will be presented next, gathered from the baseline WHO Life-chart. It should be remembered that this schedule charts information for the preceding two years, compiled from the participants' clinical case-notes.

3.2.1 Clinical status of the baseline sample

Table eight shows the patients' status and distribution across geographical Community Mental Health Teams (CMHTs) at baseline. Most participants were hospital in-patients (49.1%), and participants were fairly evenly spread across the various CMHTs.

Table eight. Clinical status information at baseline

Variable	Frequency	Percentage
Status		
Outpatient	45	40.9
Inpatient	54	49.1
Day-hospital patient	10	9.1
Regional Secure Unit patient	1	0.9
CMHT		
One	12	10.9
Two	1	0.9
Three	18	16.4
Four	15	13.6
Five	9	8.2
Six	9	8.2
Seven	13	11.8
Eight	21	19.1
Nine	12	10.9

3.2.2 Additional residential information for the preceding two years

Table nine displays information about participants' residence for the previous 24 months. The largest proportion of participants had spent at least one month in a supervised residence (including hospital) for those with mental illness (34.5%). 90.9% of participants reported spending no time vagrant and 70.9% no time in jail.

Table nine. Additional residential information at baseline for the preceding two years

Variable	Frequency	Percentage
Months in a supervised residence for mental illness		
None	20	18.2
1-6	38	34.5
7-12	14	12.7
13-18	12	10.9
19-24	26	23.6
Days vagrant		
0	100	90.9
1-7	7	6.4
8-14	3	2.7
Days in jail		
0	78	70.9
1-7	27	24.5
8-14	2	1.8
15-60	1	0.9
61-120	1	0.9
121-270	1	0.9

3.2.3 Diagnostic and psychiatric symptomatology and risky behaviour recorded at baseline for the preceding two years

Table ten shows psychiatric symptoms and risk behaviour of participants as described by their clinicians. Most participants had an OPCRIT-generated ICD-10 diagnosis of schizophrenia (72.7%). The greatest proportion of participants had moderately severe symptoms (51.8%) and most had a continuous-type illness (48.2%), with 42.7% having an episodic-type illness. Nearly half the sample had at least two hospital admissions in the previous two years, with as many as six admissions recorded. Suicidal thoughts had occurred in 25.5% of participants with actual attempts in 9.1%. Assualtative behaviour was not recorded for the largest proportion of participants (50%).

Table ten. Information on diagnosis, psychiatric symptomatology and risky behaviour of the baseline sample for the preceding two years

Variable	Frequency	Percentage
OPCRIT diagnosis		
Schizophrenia	80	72.7
Schizo-affective disorder	30	27.3
Usual symptom severity		
Severe	32	29.1
Moderate	57	51.8
Mild	21	19.1
recovered	0	0.0
Course type		
Episodic	47	42.7
Continuous	53	48.2
Neither episodic nor continuous	5	4.5
Never psychotic in this period	5	4.5
Depot medication	45	40.9
Thoughts about suicide		
Not at all	82	74.5
Occasionally	22	20.0
Often	6	5.5
Suicide attempt(s)		
Yes	10	9.1
No	100	90.9
Number of assaults		
0	55	50.0
1	27	24.5
2	20	18.2
>3	8	7.3

3.2.4 Hospital and physical treatment information recorded for the two years before recruitment

17.3% of participants had spent no time in hospital for that time period, with 14.5% having spent one to two years in hospital (table 11). Approximately one-third of participants had had at least one hospital admission (36.4%). All had been prescribed anti-psychotic medication, 79.1% prescribed an anti-cholinergic and 72.7% had received an anti-depressant. None had received electro-convulsive therapy during this time period.

Table 11. Hospital and physical treatment information recorded for the two years before recruitment

Variable	Frequency	Percentage
Days in hospital		
0	19	17.3
1-30	6	5.5
31-60	10	9.1
61-90	9	8.2
91-120	12	10.9
121-150	10	9.1
151-180	12	10.9
181-365	16	14.5
366-730	16	14.5
Number of admissions		
0	19	17.3
1	40	36.4
2	30	27.3
3	15	13.6
4	4	3.6
6	2	1.8
Prescribed anti-psychotic medication?		
Yes	110	100.0
No	0	0.0
Prescribed anti-depressant medication?		
Yes	80	72.7
No	30	27.3
Prescribed lithium?		
Yes	7	6.4
No	103	93.6
Prescribed anti-cholinergic medication?		
Yes	87	79.1
No	13	11.8
Received ECT?		
Yes	0	0.0
No	110	100.0

3.2.5 Psycho-social treatments received by the baseline sample in the preceding two years

Table 12 shows the psycho-social treatments received by the sample in the two years preceding initial assessment. Over half the sample had received day hospital treatment (51.8%). Most had not received counselling (66.4%) and only one participant was recorded as having received "traditional" or "alternative" healing. Most had not received

treatment for either a drug or an alcohol problem (88.2%). The family
tended not to be involved in treatment with 61.8% never providing a
substitute for institutional care and 63.6% never monitoring their sick
relative's medication usage.

**Table 12. Psycho-social treatments received over the two years before
recruitment**

Variable	Frequency	Percentage
Day hospital treatment		
Yes	57	51.8
no	53	48.2
Counselling		
Yes	15	13.6
No	95	66.4
Family meetings		
Yes	50	45.5
No	60	55.5
"Traditional" or "alternative" healing		
Yes	1	0.9
No	109	91.1
Treatment for drug problem		
Yes	13	11.8
No	97	88.2
Treatment for alcohol problem		
Yes	13	11.8
No	97	88.2
Family provided substitute for institutional care		
Never	68	61.8
Sometimes	29	26.4
Most of the time	13	11.8
Family monitored medication		
Never	70	63.6
Sometimes	26	23.6
Most of the time	14	12.8

3.3 Baseline PANSS, DAI & "Kemp et al", and PRS scores for the sample

3.3.1 Baseline PANSS scores

Table 13 shows the symptom profile scores at baseline as measured by the
Positive and Negative Syndrome Schedule (PANSS) instrument. A greater

score means a worse symptom profile. The mean positive symptom score (S.E.) for the sample was 19.3(0.47). This corresponds to the 46th percentile provided by the authors, approximately an average result when compared to the authors' normative sample of 240 medicated schizophrenics. The mean paranoia score (S.E.) was 7.8(0.24); this corresponds to the authors' 54th percentile, again an average result when compared to the normative sample. The mean negative symptom score (S.E.) was 22.7(0.62), corresponding to the 58th percentile – again, an average result.

Table 13 Baseline PANSS scores for the sample

PANSS score	Range	Mean(S.E.)	95% C.I.
Total	(30-210)	84.3(1.54)	81.3-87.4
Positive	(6-42)	19.3(0.47)	18.4-20.2
Negative	(6-42)	22.7(0.62)	21.5-24.0
Composite	(-36-36)	-3.4(0.59)	-4.6--2.3
Paranoia	(3-21)	7.8(0.24)	7.3-8.3
Depression	(4-28)	8.7(0.31)	8.1-9.4

3.3.2 Baseline DAI and Kemp et al scores

Table 14 shows the baseline adherence scores for the sample, as measured by the Drug Attitudes Inventory (DAI) and the Kemp et al scale. A greater score means better adherence with treatment. Both the mean DAI and Kemp et al scores fell approximately in the middle of the normal range, indicating an average level of adherence in the sample at the baseline.

Table 14 Baseline DAI and Kemp et al adherence scores for the sample

Instrument	Range	Mean(S.E.)	95% C.I.
DAI score	(0-10)	4.7(0.27)	4.3-5.3
Kemp et al score	(1-7)	4.2(0.11)	4.0-4.4

3.3.3 Baseline PRS scores

Table 15 shows the baseline sample scores for perceived racism as determined by the Perceived Racism Scale (PRS). Total mean perceived racism score was 54.2(1.84) for the previous year and 71.3(2.10) for the lifetime. The mean scores per question (last column) allow for comparison. These equate to an average level of perceived racist events between "almost never" and "several times a year". The highest mean domain score was for the exposure to racist statements (both in the past year, and over the lifetime). The low mean score for perceived racism at school/college in the past year may be confounded by the low exposure to education in the previous year. Overall, these scores were moderately low.

With regards to the emotional response scores, these appeared relatively higher. Universally, anger and hurt were rated as the greatest strength of emotional responses to perceived racism in each domain. Feeling ashamed was rated as the least strong emotional response to racism again, irrespective of domain.

Table 15 Baseline Perceived Racism Scale (PRS) scores for the sample

PRS domain score	Range	Mean(S.E.)	95% C.I.	Mean/quest.
Total racism, past year	0-210	54.2(1.84)	50.6,57.9	1.29
Total racism, lifetime	0-230	71.3(2.10)	67.1,75.4	1.55
Racism from mental health services, past year	0-50	16.2(0.71)	14.8,17.6	1.62
Racism from mental health services, lifetime	0-50	16.7(0.64)	15.4,17.9	1.67
Racism at school/college, past year	0-50	2.9(0.60)	1.75,4.14	0.29
Racism at school/college, lifetime	0-50	14.2(0.77)	12.7,15.8	1.42
Everyday racism, past year	0-75	23.3(0.80)	21.7,24.9	1.55
Everyday racism, lifetime	0-95	27.8(0.88)	26.0,29.5	1.46
Racist statements, past year	0-35	11.7(0.43)	10.9,12.6	1.67
Racist statements, lifetime	0-35	12.6(0.40)	11.8,13.4	1.80

PRS domain score	Range	Mean(S.E.)	95% C.I.
Total anger at racism	0-20	14.5(0.49)	13.5,15.5
Total hurt at racism	0-20	13.8(0.55)	12.7,14.9
Total frustration at racism	0-20	13.0(0.55)	11.9,14.1
Total sadness at racism	0-20	13.0(0.55)	11.9,14.1
Total powerlessness at racism	0-20	11.6(0.59)	10.4,12.7
Total hopelessness with racism	0-20	10.1(0.58)	8.9,11.2
Total shame at racism	0-20	9.6(0.66)	8.4,10.7
Total strengthened feeling at racism	0-20	12.1(0.58)	10.9,13.3
Anger at mental health service racism	0-5	3.5(0.18)	3.1,3.8
Hurt at mental health service racism	0-5	3.6(0.16)	3.3,4.0
Frustration at mental health service racism	0-5	3.3(0.17)	3.0,3.6
Sadness at mental health service racism	0-5	3.4(0.18)	3.1,3.8
Powerless at mental health service racism	0-5	3.2(0.18)	2.8,3.5
Hopeless with mental health service racism	0-5	2.7(0.18)	2.3,3.1
Ashamed at mental health service racism	0-5	2.4(0.17)	2.1,2.8
Strengthened at mental health service racism	0-5	2.6(0.17)	2.3,2.9
Anger at everyday racism	0-5	3.7(0.18)	3.4,4.1
Hurt at everyday racism	0-5	3.5(0.18)	3.1,3.9
Frustration at everyday racism	0-5	3.2(0.18)	2.9,3.6
Sadness at everyday racism	0-5	3.2(0.18)	2.8,3.6
Powerless at everyday racism	0-5	2.7(0.19)	2.4,3.1
Hopeless with everyday racism	0-5	2.3(0.17)	2.0,2.7
Ashamed at everyday racism	0-5	2.2(0.17)	1.9,2.6
Strengthened at everyday racism	0-5	3.2(0.18)	2.8,3.5
Anger at racist statements	0-5	3.7(0.18)	3.4,4.1
Hurt at racist statements	0-5	3.2(0.18)	2.8,3.5
Frustration at racist statements	0-5	3.0(0.19)	2.7,3.4
Sadness at racist statements	0-5	2.9(0.19)	2.6,3.3
Powerless at racist statements	0-5	2.7(0.18)	2.3,3.0
Hopeless with racist statements	0-5	2.3(0.18)	2.0,2.7
Ashamed at racist statements	0-5	2.3(0.17)	1.9,2.6
Strengthened at racist statements	0-5	3.2(0.18)	2.8,3.5

3.4 Exploration of primary outcomes by linear regression

The primary hypotheses involved examining the association between baseline perceived racism as measured by the PRS and adherence at one-year follow-up as determined by the DAI and Kemp et al scores, after adjusting for a priori confounders.

The baseline group that was lost to follow-up (n=10) did not differ significantly from the group that was followed-up (n=100), as can be

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seen in Table 16. Therefore the missing data could be imputed without the need for additional adjustment in the final linear regression. Those members of the baseline sample that were lost to follow-up were included in the analysis by using the "uvis" command in STATA (univariate imputation sampling) which imputes missing values of a variable based on multiple regression. This permitted use of all of 'the baseline data obtained (n=110).

Table 16. Distribution of baseline, follow-up and missing data

Variable	Sample seen at baseline and follow-up (n=100)	Sample lost to follow-up (n=10)	p-value
age years, x (SD)	43 (14.5)	45.3 (15.3)	0.73
male, n (%)	61 (55.5)	4 (40)	0.50
employed (%)	3 (2.7)	0 (0)	0.58
single, no partner (%)	68 (61.8)	4 (40)	0.13
mother: Caribbean (%) white British (%)	83 (75.5) 15 (13.6)	6 (60) 2 (20)	0.24
lives alone (%)	40 (36.4)	4 (40)	0.92
status (%): outpatient inpatient day-hospital forensic I/P	45 (42.1) 54 (50.5) 7 (6.5) 1 (0.9)	3 (30) 6 (60) 1 (10) 0 (0)	0.68
depot (%)	45 (40.9)	6 (60)	0.17
OPCRIT: scz (%) sczaff (%)	80 (72.7) 30 (27.3)	7 (70) 3 (30)	0.20
PANNS score, x (SD): positive negative baseline paranoia	19.3 (4.9) 22.8 (6.5) 7.8 (2.4)	20.5 (5.7) 21.2 (6.9) 8.5 (3.7)	0.25 0.59 0.60
Baseline DAI score, x (SD)	4.9 (2.7)	3.3 (2.8)	0.07
Baseline Kemp et al score, x (SD)	4.3 (1.1)	3.8 (1.0)	0.06

Information was compared between those who could be followed up (n=100) and those who could not (n=10). The two groups did not differ significantly on either of the two baseline adherence scores (see Table 16), nor did their PRS scores differ significantly (see Table 17 below).

Table 17. Comparison of baseline perceived racism scores determined by the PRS according to follow-up status.

Baseline variable	Sample seen at baseline and follow-up (n=100)	Sample lost to follow-up (n=10)	p-value
Total one-year PRS score (SE)	54.4 (1.8)	56.2 (4.3)	0.81
Total lifetime PRS score (SE)	71.1 (2.0)	74.0 (7.0)	0.81
Racism from mental health services, past year (SE)	16.5 (0.7)	18.3 (1.7)	0.34
Racism from mental health services, lifetime (SE)	16.8 (0.6)	18.7 (1.7)	0.32
Racism at school/college, past year (SE)	2.8 (0.6)	0.1 (0.1)	0.10
Racism at school/college, lifetime (SE)	14.2 (0.7)	12.5 (2.7)	0.67
Everyday racism, past year (SE)	23.3 (0.8)	25.7 (2.2)	0.44
Everyday racism, lifetime (SE)	27.6 (0.9)	30.2 (2.9)	0.57
Racist statements, past year (SE)	11.9 (0.4)	12.1 (1.1)	0.83
Racist statements, lifetime (SE)	12.7 (0.4)	12.6 (1.2)	0.99

3.4.1 Univariate analysis of association between primary exposures and primary outcomes

The first step in this process involved determining which baseline PRS scores were associated with follow-up adherence scores. As PRS, DAI and Kemp et al scores are all continuous and normally distributed; this association is best explored by Pearson's correlation. The correlations are shown in Tables 18a and 18b below. Almost all the results show a negative correlation, as expected. In other words, more perceived racism at baseline was correlated with poorer adherence with treatment at one-year follow-up. Those absolute correlation values that were greater or equal to 0.15 were then selected for further analysis (see Table 18b ahead).

Table 18a. Pearson's correlation between baseline PRS score and follow-up Kemp et al/DAI score

PRS domain	Kemp et al r	DAI r
Total racism, past year	**-0.23**	**-0.23**
Total racism, lifetime	**-0.25**	**-0.18**
Racism from mental health services, past year	**-0.19**	**-0.27**
Racism from mental health services, lifetime	-0.15	**-0.21**
Racism at school/college, past year	-0.12	-0.05
Racism at school/college, lifetime	**-0.20**	-0.09
Everyday racism, past year	**-0.16**	**-0.20**
Everyday racism, lifetime	**-0.22**	**-0.20**
Racist statements, past year	**-0.20**	-0.07
Racist statements, lifetime	-0.13	0.01

Figures in bold, where $|r| > 0.15$

Table 18b (below) shows emotional response scores measured by the PRS in response to perceived racism across all the domains (mental health services, education, everyday racism and racist statements) and for mental health services alone. Again, correlations of equal or greater magnitude than 0.15 were highlighted. Shame at racism perceived in all domains (r=0.15) as well as that perceived in mental health services (r=0.22) was correlated with greater adherence measured by the Kemp et al score. Feeling strengthened as a result of perceived racism in mental health services was correlated with poorer adherence measured by both the Kemp et al and DAI scores (r=-0.21).

Table 18b. Pearson's correlation between baseline PRS emotional response scores and follow-up Kemp et al/DAI score

PRS emotional response	Kemp et al r	DAI r
Total anger at racism	0.14	0.13
Total hurt at racism	0.02	0.08
Total frustration at racism	0.05	0.00
Total sadness at racism	-0.06	0.01
Total powerlessness at racism	0.04	-0.05
Total hopelessness with racism	-0.01	-0.02
Total shame at racism	**0.15**	0.10
Total strengthened feeling at racism	-0.14	-0.11
Anger at mental health service racism	-0.02	0.05
Hurt at mental health service racism	-0.01	-0.01
Frustration at mental health service racism	0.01	-0.08
Sadness at mental health service racism	-0.06	-0.05
Powerless at mental health service racism	0.10	-0.03
Hopeless with mental health service racism	-0.01	-0.05
Ashamed at mental health service racism	**0.22**	0.12
Strengthened at mental health service racism	**-0.21**	**-0.21**

Figures in bold, where $|r| > 0.15$

3.4.2 Univariate analysis of association between confounders and primary outcomes

The next step was to determine which variables if any confound the relationship between primary exposure (baseline perceived racism) and primary outcome (adherence at follow-up). This was done by determining which of the a priori list of confounders (see section 2.6.5) was significantly associated with both the primary outcome and exposure (i.e. Pearson's correlation of a magnitude greater than 0.15 or a p-value of less than 0.05). Those confounders are shown in Tables 19a and 19b, below. Table 19a shows those confounders that are significantly associated with any of the primary outcome measures.

It is worth noting that social factors, which may be considered potentially important confounding factors such as employment status and whether or not GP aid was sought for stress, were not associated with the outcome. This may be because there was insufficient variability in these two. Indeed, 97% of the sample population was unemployed, which supports this; however seeing the GP about stress was split 46/54, which is far less skewed, although a simple "yes/no" response may have been too coarse and masked any subtle variability in response and hence potential correlation with primary outcome.

In addition, examination for an association between other putative confounding social variables and the outcome was not fruitful. There was no significant association between adherence and each of the following: marital/relationship status; geographical proximity of friends/family; presence of a close contact; and the frequency of contacts with friends/family/close contact. Owing to the absence of this association, these variables were not carried forward to the next stage of analysis.

Table 19a. The associations between potential confounders and the primary outcome measures (DAI and Kemp et al scores). Only significant results ($|r| > 0.15$) are shown.

Primary outcome: Potential confounder	Follow-up DAI score	Follow-up Kemp et al score
Gender		
Age		
Baseline DAI score	r=0.56	r=0.33
Baseline Kemp et al score	r=0.35	r=0.41
Depot at baseline		
Depot at follow-up		

Months' antipsychotic medication prior to initial assessment	r=0.31	r=0.31
Months' antipsychotic medication between baseline and follow-up	r=0.27	r=0.41
Months' antidepressant medication prior to initial assessment		
Months' antidepressant medication between baseline and follow-up	r=0.20	
Baseline PANSS paranoia score		
Follow-up PANSS paranoia score	r=-0.39	r=-0.40
GP seen for stress?		

As expected, baseline adherence was correlated with follow-up adherence on both the DAI and Kemp et al scales. The number of prescribed months' anti-psychotic medication for the two years prior to baseline assessment and for the year between baseline and follow-up assessment, was positively correlated with better adherence on both scales. However, prescribed months' anti-depressant medication prior to initial assessment was only positively correlated with follow-up adherence on the DAI scale. PANSS paranoia score at follow-up was negatively correlated with both follow-up adherence scores. These confounders were derived for further analysis (see Table 19b below).

3.4.3 Univariate analysis of association between confounders and primary exposures

Table 19b shows which of those confounders selected from Table 19a were significantly associated with the primary exposures derived from Tables 18a and b.

Table 19b. The associations between potential confounders and primary exposures derived from earlier analysis. Only significant results are shown (i.e. $|r| > 0.15$).

Selected confounders:	Baseline DAI score	Baseline Kemp et al score	Months' antipsychotic medication prior to initial assessment	Months' antipsychotic medication between baseline and follow-up	Months' antidepressant medication between baseline and follow-up	Follow-up PANSS paranoia score
Selected primary exposures:						
Total racism, past year		r=-0.20			r=-0.22	r=0.24
Total racism, lifetime		r=-0.23				r=0.24
Racism from mental health services, past year	r=-0.32	r=-0.26			r=-0.33	r=0.37
Racism from mental health services, lifetime	r=-0.19	r=-0.22			r=-0.22	r=0.21
Racism at school/college, lifetime		r=-0.21				r=0.32
Everyday racism, past year		r=-0.20			r=-0.18	
Everyday racism, lifetime		r=-0.24			r=-0.17	
Racist statements, past year						r=0.19
Total shame at racism						
Ashamed at mental health service racism					r=0.19	
Strengthened at mental health service racism			r=-0.21			

3.4.4 Final list of confounders for multivariate analysis of primary outcomes

This information may now be used to generate Table 20, which lists the various putative models for multi-variate analysis:

Table 20. Putative models for multi-variate analysis, with confounders and exposures identified by univariate analysis.

Primary exposure	Primary outcome	Derived confounders
Total racism, past year	Follow-up DAI score:	b, d, e
	Follow-up Kemp et al score:	b, e
Total racism, lifetime	Follow-up DAI score:	b, e
	Follow-up Kemp et al score:	b, e
Racism from mental health services, past year	Follow-up DAI score:	a, d, e
	Follow-up Kemp et al score:	b, e
Racism from mental health services, lifetime	Follow-up DAI score:	a, d, e
	Follow-up Kemp et al score:	b, e
Racism at school/college, lifetime	Follow-up DAI score:	b, e
	Follow-up Kemp et al score:	b, e
Everyday racism, past year	Follow-up DAI score:	b, d
	Follow-up Kemp et al score:	b
Everyday racism, lifetime	Follow-up DAI score:	b, d
	Follow-up Kemp et al score:	b
Racist statements, past year	Follow-up DAI score:	e
	Follow-up Kemp et al score:	e
Total shame at racism	Follow-up DAI score:	

	Follow-up Kemp et al score:	
Ashamed at mental health service racism	Follow-up DAI score:	d
	Follow-up Kemp et al score:	
Strengthened at mental health service racism	Follow-up DAI score:	c
	Follow-up Kemp et al score:	c

KEY TO CONFOUNDERS:

a = baseline DAI score

b = baseline Kemp et al score

c = months' antipsychotic medication prior to initial assessment

d = months' antidepressant medication between baseline and follow-up

e = follow-up PANSS paranoia score

It can be seen in Table 20 that the most confounders were derived for models related to perceived racism from mental health services. The most frequently-occurring confounder was the months' of prescribed anti-depressant medication between baseline and follow-up - d. Baseline adherence score was only included once as a confounder in any model, to avoid duplication. It is worth noting that there are no social factors as potential confounders at this stage, such as employment status.

3.4.5 Multivariate analysis of primary outcomes by linear regression

The final step was to perform multiple linear regressions, with either Follow-up DAI score or follow-up Kemp et al score as primary outcome, using the appropriate confounders as identified previously. A clustered analysis was performed using patient-status as strata and CMHT as primary sampling unit. The significant models are shown in table 21, below.

Table 21. Significant models from the multiple regression analysis of the primary outcome measures (Kemp et al score and DAI score at follow-up).

mary outcome: low-up Kemp et al score	coefficient	S.E.	t	P>|t|	95% C.I.
osure variables: al racism, past year, unadj. EL ONE	-0.017 (-0.016)	0.0070	-2.37	0.020	-0.030,-0.0027
al racism, past year	-0.0074(-0.0067)	0.0026	-2.79	0.013	-0.013,-0.0018
eline Kemp et al score	0.37	0.13	2.72	0.015	0.082, 0.65
low-up PANSS paranoia score	-0.16	0.044	-3.54	0.003	-0.25, -0.063
stant	4.17	0.75	5.54	0.00	2.58, 5.75
al racism, lifetime, unadj. EL TWO	-0.019 (-0.016)	0.0060	-3.23	0.002	-0.031,-0.0075
al racism, lifetime	-0.0068 (-0.0070)	0.0030	-2.24	0.038	-0.013,-0.00041
eline Kemp et al score	0.37	0.13	2.86	0.011	0.097, 0.65
low-up PANSS paranoia score	-0.15	0.043	-3.59	0.002	-0.24, -0.064
stant	4.21	0.70	6.00	0.00	2.74, 5.70
EL THREE amed at mental health service ism	0.20 (0.17)	0.075	2.71	0.015	0.045, 0.36
stant	3.60	0.22	16.27	0.00	3.13, 4.06
mary outcome: low-up DAI score					
ryday racism, past year, dj. EL FOUR	-0.080 (-0.069)	0.033	-2.44	0.017	-0.15,-0.015
ryday racism, past year	-0.051 (-0.045)	0.024	-2.16	0.046	-0.10,-0.0011
eline Kemp et al score	0.70	0.11	6.27	0.00	0.47, 0.94
ths' antidepressant medication ween baseline and follow-up	0.062	0.063	0.99	0.34	-0.071, 0.20
stant	12.96	0.73	17.69	0.00	11.42, 14.51

Significant primary exposure variables in bold

Bracketed point estimates are for non-imputed dataset (n=100)

The bracketed point estimates show the results for the dataset for which there were no missing values (n=100) and show they are not dissimilar to the imputed dataset (n=110).

Model one shows that total perceived racism for the previous year at baseline is negatively associated with adherence at one-year follow-up as measured by the Kemp et al scale, after adjusting for baseline Kemp et al score and follow-up PANSS paranoia score (b=-0.0074, p=0.013). This translates to a 135-point increase in the total perceived racism for the previous year score being associated with a one-point reduction in Kemp et al adherence score.

Model two shows that total perceived racism over a lifetime at baseline is negatively associated with follow-up adherence measured by the Kemp et al scale, after adjusting for baseline Kemp et al score and follow-up PANSS paranoia score (b=-0.0068, p=0.038). This translates to a 147-point increase in the total perceived racism over a lifetime score being associated with a one-point reduction in Kemp et al adherence score.

Model three shows that feeling ashamed about racism perceived in mental health services at baseline is positively associated with follow-up adherence as measured by the Kemp et al scale (b=0.20, p=0.015). This translates to a five-point increase in the shame about mental health service racism score being associated with a one-point increase in Kemp et al adherence score.

Model four shows that perceived everyday racism for the previous year at baseline is negatively associated with follow-up adherence on the DAI, after adjusting for baseline Kemp et al score and the number of prescribed months' antidepressant medication between baseline and follow-up (b=-0.051, p=0.0046). This translates to a 20-point increase in the perceived everyday racism for the previous year score being associated with a one-point reduction in the DAI score.

3.5 Exploration of secondary outcomes by linear regression

The secondary hypotheses involved examining the association between baseline perceived racism as measured by the PRS and hospital admission data for the year between baseline and follow-up assessments, recorded in the WHO Life chart, after adjusting for a priori confounders.

3.5.1 Univariate analysis of association between primary exposures and secondary outcomes

The association between baseline PRS scores and hospital admission data was explored by determining Pearson's correlation. The correlations are shown in Tables 22a and 22b below. In Table 22a it can be seen that perceived racism at mental health services for the previous year was associated with more days spent admitted to a psychiatric hospital in the following year (r=0.22) as well as a longer single psychiatric admission (r=0.22). Secondly, racism perceived during the previous year at school or college was associated with a greater number of psychiatric hospital admissions (r=0.19).

Table 22a. Pearson's correlation between baseline PRS score and hospital admission data from baseline to follow-up assessment

Secondary outcome: PRS domain	Number of admissions	Psychiatric hospital bed-days	Longest psychiatric admission in days
Total racism, past year	0.12	0.08	0.05
Total racism, lifetime	0.05	0.03	0.03
Racism from mental health services, past year	0.07	**0.22**	**0.22**
Racism from mental health services, lifetime	-0.03	0.07	0.07
Racism at school/college, past year	**0.19**	-0.01	-0.07
Racism at school/college, lifetime	0.11	0.004	-0.01
Everyday racism, past year	0.06	0.05	0.05
Everyday racism, lifetime	0.04	0.07	0.08
Racist statements, past year	0.03	-0.10	-0.11
Racist statements, lifetime	-0.02	-0.10	-0.11

Figures in bold, where |r|>0.15

Table 22b shows that feeling angry at racism in general was associated with fewer days spent in a psychiatric hospital (r=-0.16) and a shorter admission (r=-0.15) in the following year. Feeling angry at mental health service racism specifically was also correlated with fewer psychiatric hospital bed-days (r=-0.20) and with a shorter admission (r=-0.19). Interestingly, feeling hopeless about mental health service racism was associated with fewer hospital bed-days (r=-0.23), fewer admissions (r=-0.22) and a shorter subsequent stay (r=-0.19). Finally, feeling hopeless about mental health service racism was associated with fewer psychiatric hospital admissions (r=-0.21).

Table 22b. Pearson's correlation between baseline PRS emotional response

scores and hospital admission data from baseline to follow-up assessment

Secondary outcome: PRS emotional response	Number of admissions	Psychiatric hospital bed-days	Longest psychiatric admission in days
Total anger at racism	0.02	**-0.16**	**-0.15**
Total hurt at racism	-0.05	-0.002	0.02
Total frustration at racism	0.02	-0.03	-0.01
Total sadness at racism	0.08	-0.04	-0.02
Total powerlessness at racism	-0.08	-0.03	-0.01
Total hopelessness with racism	-0.10	0.09	0.13
Total shame at racism	-0.07	0.13	**0.16**
Total strengthened feeling at racism	-0.14	-0.10	-0.12
Anger at mental health service racism	0.006	**-0.20**	**-0.19**
Hurt at mental health service racism	-0.07	-0.07	-0.04
Frustration at mental health service racism	-0.05	-0.13	-0.11
Sadness at mental health service racism	0.02	-0.12	-0.09
Powerless at mental health service racism	**-0.22**	**-0.23**	**-0.19**
Hopeless at mental health service racism	**-0.21**	-0.04	0.0009
Ashamed at mental health service racism	-0.14	-0.0006	0.03
Strengthened at mental health service racism	-0.07	-0.08	-0.09

Figures in bold, where $|r| > 0.15$

3.5.2 Univariate analysis of association between potential confounders and secondary outcomes

The next step was to determine which variables confound the relationship between primary exposure (baseline perceived racism) and secondary outcome (hospital admission data). This was done by determining which of the a priori list of confounders (section 2.6.5) was significantly associated with both the secondary outcome and primary exposure (i.e. Pearson's correlation of a magnitude greater than 0.15 or a p-value of less than 0.05). Those confounders are shown in Tables 23a and 23b.

Table 23a. The associations between confounders and the primary outcome measures (hospital admission data). Only significant results (p<0.05 or |r|>0.15) are shown.

Secondary outcome: Potential confounder	Number of admissions	Psychiatric hospital bed-days	Longest psychiatric admission in days
Gender	p= 0.027		
Age	r=-0.20		
Baseline DAI score			
Baseline Kemp et al score			
Depot at baseline	p= 0.010	p= 0.008	p= 0.009
Depot at follow-up	p= 0.045	p= 0.030	p= 0.025
Months' antipsychotic medication prior to initial assessment	r=-0.25		
Months' antipsychotic medication between baseline and follow-up			
Months' antidepressant medication prior to initial assessment			
Months' antidepressant medication between baseline and follow-up	r= 0.15		
Baseline PANSS paranoia score			
Follow-up PANSS paranoia score			
GP seen for stress?			

Table 23a shows those confounders that are significantly associated with any of the primary outcome measures. It was found that women had a greater number of psychiatric admissions in the subsequent year than men (p=0.027), and that being younger was associated with more admissions (r=-0.20). Taking depot medication at baseline was associated with fewer admissions (p=0.010), fewer days in hospital (p=0.079), and shorter stays (p=0.085). The same was true of taking depot medication at follow-up. Months' prescribed antipsychotic medication prior to baseline assessment was associated with fewer subsequent admissions (r=-0.25) and

interestingly, months' antidepressant medication between baseline and follow-up assessment was positively correlated with the number of admissions for that same time period (r=0.15). It is worth noting that social factors, which may be considered potentially important confounding factors such as employment status and whether or not GP aid was sought for stress, were not associated with the outcome. Those confounders were selected for further analysis (see Table 23b below).

3.5.3 Univariate analysis of association between confounders and primary exposures

Table 23b shows which of those confounders derived from Table 23a were significantly associated with the primary exposures derived from Tables 22a and b.

Table 23b. The associations between confounders and primary exposures derived from earlier analysis. Only significant results are shown (i.e. |r|>0.15).

Derived confounders: Derived primary exposures:	Gender	Age	Depot at baseline	Depot at follow-up	Months' antipsychotic medication prior to initial assessment	Months' antidepressant medication between baseline and follow-up
Racism from mental health services, past year						r=-0.29
Racism at school/college, past year	p=0.0043	r=-0.23	p=0.0016	p=0.046	r=-0.26	
Total anger at racism						r= 0.23
Total shame at racism		r= 0.20				r= 0.16
Anger at mental health service racism						r= 0.24
Powerless at mental health service racism		r= 0.17				
Hopeless with mental health service racism		r= 0.30				

3.5.4 Final list of confounders for multivariate analysis of secondary outcomes

This information was then used to generate Table 24, which lists the various putative models for multi-variate analysis:

Table 24. Putative models for multi-variate analysis, with confounders and exposures identified by univariate analysis.

Primary exposure	Secondary outcome	Derived confounders
Racism from mental health services, past year	Number of admissions: Psychiatric hospital bed-days: Longest admission in days:	f
Racism at school/college, past year	Number of admissions: Psychiatric hospital bed-days: Longest admission in days:	a, b, c, d, e c, d c, d
Total anger at racism	Number of admissions: Psychiatric hospital bed-days: Longest admission in days:	f
Total shame at racism	Number of admissions: Psychiatric hospital bed-days: Longest admission in days:	b, f
Anger at mental health service racism	Number of admissions: Psychiatric hospital bed-days: Longest admission in days:	f
Powerless mental health service racism	Number of admissions: Psychiatric hospital bed-days: Longest admission in days:	b
Hopeless with mental health service racism	Number of admissions: Psychiatric hospital bed-days: Longest admission in days:	b

KEY TO CONFOUNDERS:

a = gender

b = age

c = depot prescribed at baseline

d = depot prescribed at follow-up

e = months' antipsychotic medication prior to initial assessment

f = months' antidepressant medication between baseline and follow-up

It can be seen in Table 24 that the most confounders were derived for models related to perceived racism at school/college for the previous year. The most frequently occurring confounders were age and the

numerical value for the months' prescribed anti-depressant medication between baseline and follow-up. Again, potential confounders measuring socio-economic status, such as employment status do not appear significant at this stage of the analysis.

3.5.5 Multivariate analysis of secondary outcomes by linear regression

The final step was to perform multiple linear regressions, with either the number of psychiatric hospital admissions, psychiatric hospital bed-days, or the longest psychiatric admission, all for the year between baseline and follow-up assessment as the secondary outcome measures, using the appropriate confounders as identified previously. Again, a clustered analysis was performed using patient-status as strata and CMHT as primary sampling unit. The significant models are shown in table 25 on the next page.

Table 25. Significant models from the multiple regression analysis of the secondary outcome measures (hospital admission data for the year between baseline and follow-up assessments).

Secondary outcome: Psychiatric hospital bed-days	coefficient	S.E.	t	P>|t|	95% C.I.
Exposure variables: MODEL FIVE Racism from mental health services, past year	**5.54 (5.14)**	1.91	2.90	0.010	1.50, 9.58
Constant	52.25	29.30	1.78	0.092	-9.57, 114.08
MODEL SIX Powerless at mental health service racism	**-14.49 (-14.55)**	5.90	-2.46	0.025	-26.94, -2.05
Constant	189.87	27.74	6.84	0.000	131.34,248.40
Secondary outcome: Longest psychiatric admission in days					
MODEL SEVEN Racism from mental health services, past year	**4.92 (5.40)**	1.93	2.55	0.021	0.85, 9.00
Constant	44.14	26.33	1.68	0.112	-11.41, 99.70

Significant primary exposure variables in bold

Bracketed point estimates are for non-imputed dataset (n=100)

The bracketed point estimates show the results for the dataset for which there were no missing values (n=100) and again, show they are not dissimilar to the imputed dataset (n=110).

Model five shows that perceived racism from mental health services over the previous year was positively associated with the number of psychiatric hospital bed-days over the following year (b=5.54, p=0.010). This translates to a one-point increase in the perceived mental health service racism score being associated with approximately five extra psychiatric hospital bed-days.

Model six shows that feeling powerless about mental health service racism is strongly associated with fewer psychiatric hospital bed-days for the following year (b=-14.49, p=0.025). This translates to a one-point increase in the powerlessness about mental health service racism score being associated with approximately fourteen less psychiatric hospital bed-days.

Model seven shows that perceived racism from mental health services over the previous year was positively associated with a longer psychiatric hospital admission in the subsequent year (b=4.92, p=0.021).

3.5.6 Post hoc analyses to elucidate the mechanism

In an attempt to elucidate a possible underlying mechanism, post hoc analyses (available from the author) have been carried out, with the hypothesis being that perceived racism could impact upon medication adherence which, in turn, could have an effect upon hospital outcome (in terms of admissions).

Firstly, further analyses were performed upon the secondary outcome data. If it may be assumed that adherence is an intermediary variable between perceived racism (exposure) and hospital admissions (outcome), adherence scores at six-month follow-up were averaged from the baseline and one-year follow-up scores respectively. This was done for both DAI and Kemp adherence scores, but the DAI scores produced more consistent results. Given that this instrument is more tried and tested than the Kemp score, and to avoid confusion, the Kemp results will be omitted

from this part of the discussion. When looking with greater detail at model five, where psychiatric hospital bed-days was the outcome, and perceived racism from mental health services in the previous year was the exposure, the coefficient was initially found to be 5.54. When the sample was stratified according to high or low six-month DAI scores, this coefficient was attenuated (5.31, $p=0.148$) in the high DAI group (good adherers) and amplified (6.34, $p=0.017$) in the low DAI group (poor adherers).

Next, on further examination of model seven where longest psychiatric admission was the outcome and previous-year perceived mental health service racism was the exposure, the main coefficient was 4.92. If we again divide the sample by averaged six-month adherence score, it is found that the coefficient is reduced (4.92, $p=0.19$) in the high-DAI group and raised (6.5, $p=0.01$) in the low-DAI group.

If model six is subject to the same examination, powerlessness at mental health service racism was the exposure and psychiatric hospital bed-days the outcome, with a coefficient of -14.49. Here, the poor adherence group attenuated this effect (low DAI: -12.7, $p=0.22$; low Kemp: -4.8, $p=0.72$) and the good adherence group amplified the effect (high DAI: -15.3, $p=0.23$; high Kemp -17.2, $p=0.078$). This time, however, the effect was consistent when the sample was divided according to six-month adherence scores averaged from both DAI and Kemp scores. Even though the results were trends only, this level of consistency supports more powerfully the suggested mechanism.

Further analyses for potential interaction have yielded interesting results. Interaction tests were run using perceived racism as the predictor variable, hospital bed-days as the dependent variable and grouping the sample according to tertiles of medication adherence scores at baseline. Using baseline adherence might reduce error as there were actual values obtained rather than calculated ones. Again, the model is that hospital bed-days secondary to perceived racism vary according to medication adherence.

With number of hospital bed days at follow-up regressed onto baseline one year-mental health service racism score, there was a clear trend in results when grouped according to baseline adherence measured by the DAI. A greater PRS score was associated with a greater number of hospital bed days at follow-up, and within that, poorer adherers (b=56.40) had more bed-days than moderate adherers (b=54.21) who had more days, in turn, than good adherers (b=51.11). There was no evidence that the slope of the three regression lines was different (p=0.65); therefore assuming the three slopes were parallel but with different y-intercepts, this model tended to significance (p=0.058).

Next, this analysis was repeated but with the sample participants grouped according to baseline Kemp score, into tertiles. The model again showed a positive association with three parallel slopes, and was "even more" significant (p=0.019) as the gap between poor adherers (b=62.34) and good adherers (b=-12.03) was even greater, but this time the

moderate adherers (b=62.47) had very slightly more bed-days than the poor adherers; both were well above the good adherer group.

Finally, with powerlessness about mental-health service racism as a predictor and hospital bed-days at follow-up as dependent variable, there was a negative regression coefficient (i.e. powerlessness predicted a shorted admission) and, within that, better baseline DAI adherence (b=179.69) predicted less hospital-time than for moderate adherers (b=190.12) and poor adherers (b=224.02). There was no statistical evidence for non-parallel slopes, but the overall model was not significant (p=0.18).

When this analysis was repeated for baseline Kemp adherence, the same trend was seen with poor adherers (b=205.07) spending more time admitted to hospital than moderate adherers (b=188.87) who in turn spent longer admitted than good adherers (113.19), and the model approached significance (*p*=0.088).

4. DISCUSSION

The layout of the discussion will begin with a brief summary of the main results, followed by a more detailed discussion of the results namely, socio-demographic information; clinical information; adherence to treatment; perceived racism; primary and secondary outcomes of regression analysis; ending with an evaluation of the implications and future direction of research.

4.1 Summary of main findings

The main findings of the study are summarised below:

Perceived racism and medication adherence

(i) There was a negative association between total perceived racism for the previous year measured at baseline by the Perceived Racism Scale (PRS) and adherence measured one year later by the Kemp et al score, after adjusting for confounders [b=-0.0074, p=0.013].

(ii) There was a negative association between the baseline total perceived racism-lifetime score and Kemp et al adherence score one year later, after adjustment [b=-0.0068, p=0.038].

(iii) There was a negative association between everyday perceived racism one year-score and adherence one year later measured by the Drug Attitudes Inventory score (DAI), after adjustment [b=-0.051, p=0.0046]

Shame about health service-racism and adherence

(iv) There was a positive association between feeling shame about perceived racism from mental health services on the PRS at baseline and Kemp et al score one year later, after adjustment [b=0.20, p=0.015].

Perceived racism and days in hospital

(v) There was a positive association between the baseline perceived racism from mental health services one-year PRS score and the number of psychiatric hospital bed-days over the following year [b=5.54, p=0.010].

Powerlessness about health service-racism and days in hospital

(vi) There was a positive association between the baseline perceived racism from mental health services one-year PRS score and the length of any psychiatric hospital admission in the following year [b=4.92, p=0.021].

(vii) There was a negative association between feeling powerless about perceived racism from mental health services on the PRS at baseline and the number of psychiatric hospital bed-days over the following year [b=-14.49, p=0.025].

4.2 Socio-demographic information

4.2.1 Age

This sample was fairly representative of chronic patients from black and minority ethnic groups. The average age of the sample was forty-three years; this figure is expected, given that the cumulative lifetime risk of schizophrenia for men and women is similar and greatest around the age of forty years, worldwide (The WHO World Health Report: new understanding, new hope, 2001. Geneva). According to this report, schizophrenia causes a high degree of disability, listed as the 8th leading cause of disability-adjusted life years worldwide in the age group 15-44 years. Therefore it is unsurprising that patients most likely to be encountered were around forty years of age.

4.2.2 Religion

74% of this sample described some form of religious affiliation or belief. It is known that religious beliefs are common in psychotic patients, with figures varying from 30-65% in study populations from Europe (Kirov et al 1998; Neeleman & Lewis 1994) and North America (Brewerton 1994; Kroll & Sheehan 1989). This may be understandable given the degree of meaning afforded by religious beliefs to those with distressing and alienating symptoms: one study found that 71% of those with psychosis reported that religion instilled hope, purpose and meaning in their lives (Mohr et al 2006).

Indeed, it has been reported that having a religious belief is associated with protection against suicidality in both psychotic and non-psychotic patients (Huquelet et al 2006). And a further study found a negative relationship between negative symptom scores or general psychopathology with spiritual well-being measured in hospitalized African American patients with first-onset schizophrenia-spectrum disorders (Compton & Furman 2005).

4.2.3 Place of birth

Approximately half of the sample population was born in the United Kingdom (in fact 53%): this group may be referred to as second- (or indeed third- or now, fourth-) generation migrants. First-generation migrants are people in the first wave of migration into a country: this formed 47% of this study population. A recent meta-analysis sought to quantify the effect size for migration as a risk factor for the development of schizophrenia, by searching for population-based incidence studies concerning migrants in English-language publications

appearing between the years 1977 and 2003 (Cantor-Graee & Selten 2005). The authors found that the mean weighted relative risk for developing schizophrenia among first-generation migrants was 2.7 and among second-generation migrants was 4.5. The overall risk was even greater when the migrants came from areas where the majority of the population was black (relative risk = 4.8).

The relative non-participation in the study of the second-generation group may reflect their more general dissatisfaction with mental health services in comparison to first-generation patients (Parkman et al 1997).

4.2.4 Parentage and acculturation

Entry criteria to the study required that each participant had at least one parent or grandparent from the Caribbean. It is interesting that of those participants whose parents were not African-Caribbean, a greater proportion had white British mothers (13.6%) than white British fathers (4.6%); although, indeed the difference may be attributed to sampling error. There is no literature to directly explain this difference if it is significant, although it may be explained by a relationship with acculturation and identity, and the observation that African-Caribbean children in the UK are more likely to be raised by their mothers than by their fathers.

Societal acculturation may be defined as the "phenomena which result when groups of individuals having different cultures come into continuous first-hand contact, with subsequent changes in the original culture patterns of either or both groups" (Redfield et al 1936).

Landrine and Klonoff (1994, 1995, 1996) articulate a tri-partite, inter-
personal definition of acculturation suggesting that ethnic and cultural
minorities interface with the dominant culture at three levels: (a)
acculturated - having adopted the cultural traditions, values,
assumptions, beliefs, and practices of the dominant culture; (b)
bicultural - straddling the traditions of their own culture as well as
the dominant culture; and (c) *traditional* - remaining immersed in the
culture of origin.

Acculturation and racial identity have been shown to significantly
contribute to the variance in mental health seen in African Americans
(Pillay 2005; Landrine and Klonoff 1996) with those adhering to cultural
norms and values of their culture of origin more likely to experience
distress than those who become more assimilated into the host culture.
There is evidence that maternal child-rearing is influenced by maternal
acculturation (Bornstein M & Cote L 2001; Cruz-Garcia 2006). Therefore,
a white British solo mother raising a mixed-race child may mean that the
child experiences a degree of identity confusion arising from receiving
white-British cultural values alongside experiences of racism and
discrimination incumbent with having darker skin. This (albeit
tenuously) may link with psychological distress and increased contact
with psychiatric services.

4.2.5 Place of residence
With regards to residential information, the largest group of the sample
(36.4%) lived alone and tended to occupy a single room. A substantial
proportion lived in either a group home or hostel setting (28.2%).
Following the closure of the large psychiatric hospitals and the growth

of "community care", it appears that patients did not show a decline in functioning or worsening in symptoms (Thornicroft et al 2005), and most wished to stay in their community-based group homes (Leff et al 1996).

However, with a reduction in the number of people with severe mental illness spending extended periods in long-stay hospitals, more patients are receiving specialist outreach support care from district health authorities, local authorities and housing associations (Chilvers et al 2006). These supported housing projects often prolong exclusion from the community and perpetuate feelings of loneliness and isolation (Lambri et al 2005). It is notable that a significant proportion of this sample had three or more addresses in the last three years (23.7%). Researchers have found that housing instability in schizophrenia was associated with non-adherence with medication, negative symptomatology and greater re-hospitalization (Drake et al 1991), and this was more often than not seen in younger, male patients (Drake et al 1989).

4.2.6 Relationships and birth order

The vast majority of the sample had been raised by at least one natural parent and in adulthood, was single with no partner. It is well documented that those with schizophrenia tend to live outside of a stable relationship (Agerbo et al 2004; Thara & Srinavasan 1997), and this tends to the case more for men than women (Salokangas et al 2001).

An interesting finding was that 40% of the sample was the eldest child. Being the first-born rather than the second-born predicted an elevated risk (odds ratio=1.62) of schizophrenia in patients hospitalized between 1969 and 1996 identified from the Finnish Hospital Discharge Register

(Haukka et al 2004). Over-representation of eldest siblings with schizophrenia has also been reported by a Pakistani study (Bender et al 2000) as well as by a Brazilian study (Terzis 1986). This increased risk has been linked to the stressors incumbent upon the first child in a family, leading to illness in those that are genetically predisposed. However it should be borne in mind that this was not an epidemiological sample and therefore strong inferences about this should not be made.

4.2.7 Education

The sample on the whole was poorly qualified in terms of educational achievement. This is unsurprising since schizophrenia is a condition that manifests itself in late adolescence but is often preceded by social and functional impairment from prodromal symptoms that leads to under-performance in the educational setting. Nevertheless, the majority (53.6%) had received either additional vocational skills training or formal education since they had left school. Indeed, there is some support in the literature for vocational rehabilitation of people with schizophrenia, in particular when it is combined with cognitive training (Burns et al 2007; Fiszdon & Bell 2004).

4.2.8 Employment

An alarming proportion of the sample was unemployed (97.3%). A case-control study which compared social measures between people diagnosed with schizophrenia of African-Caribbean, Asian and white British extraction found that three variables differentiated the African-Caribbean cases from their peers and their normal controls: unemployment, living alone and a long period of separation from either

or both parents as a minor (Mallett et al 2002). These three features appeared prominent for this study; although the final point remained unclear in that 70.9% was raised by either one or both natural parents.

4.2.9 Interaction with family members

65.5% of the sample reported that they lived in fairly close proximity to at least one family member and would speak to them at least weekly, if not daily. Almost the same proportion of patients would speak to a nearby friend daily or at least once a week. It has been widely thought that although the quantity of contact between schizophrenics and their family members may not be deficient it may be the quality and nature of that interaction which may be harmful and potentially contributory to their ill health.

In relation to this, much has been written on the concept of "expressed emotion" in the forms of over-involvement and criticism from family members leading to schizophrenic relapse (Vaughn & Leff 1981). Whether this factor is perceived to be as important in patients of African-Caribbean origin has been debated: a study found no concordance between expressed criticism by family members and perceived criticism by the schizophrenic relative when both parties were of black origin (Weisman et al 2006).

This is supported by the additional finding that family cohesion has been reported as being a protective factor against emotional distress in Latino American and African American families with schizophrenic members, but not in their Anglo-American counterparts (Weisman et al 2005).

In addition, an American study found that for African American patients, high levels of relatives' critical and intrusive behavior were associated with better outcome; whereas for White patients, low levels of both relatives' critical and intrusive behavior and patients' odd or unusual thinking with relatives were associated with better outcome (Rosenfarb et al 2006).

4.2.10 Pathways to care

The overwhelming majority of the sample was registered with a general practitioner (91.8%), but only 45.8% said they would approach their family doctor with a stress-related problem. Either a psychotic relapse was not associated with this kind of problem or, more likely, this reflects the more general finding that African-Caribbeans access mental health care for psychosis by more aversive pathways than GP referral (such as via the police or other emergency services). This has been confirmed in the UK (Morgan et al 2005) but the converse has been found to be true in the US, where general medical care and non-specialist treatment serves as a more efficient safety-net for African Americans with psychosis (Merritt-Davis & Keshavan 2006; Cooper-Patrick et al 1999).

4.3 Clinical information

4.3.1 Patient status and illness-course

Clinical information on the sample at baseline was determined for the preceding two years. The largest subgroup (34.5%) had spent between one and six months in a supervised residence for those with mental illness,

i.e. a supervised hostel or hospital setting and the largest sub-group of patients at interview were hospital in-patients (49.1%).

In addition, the largest group of patients had a continuous-type illness (48.2%), closely followed by those with an episodic-type illness. Nearly half the sample had at least two hospital admissions in the previous two years, with as many as six admissions recorded. This fits with the finding that African-Caribbeans with psychosis may have shorter individual episodes of illness (McKenzie et al 2001; McKenzie et al 1995). Only 17.3% of the sample population had been hospital-free in the previous two years.

4.3.2 Homelessness

The overwhelming majority spent no days as homeless (90.9%). This is in stark contrast to the well-documented finding that severe mental illness is highly prevalent among the homeless, with male gender and being African American reported as specific risk factors (Folsom et al 2005). Consequently, their engagement and follow-up care is both poor and difficult to organise, leading to their under-representation in studies such as this (Cougnard et al 2006; Culhane et al 2002).

4.3.3 Diagnosis

The largest group within the sample had a diagnosis of schizophrenia (72.7%) compared with schizo-affective disorder (27.3%). It has been reported that schizophrenia rather than affective psychosis is more likely to be diagnosed in African American patients than in similar Caucasian patients (Strakowski et al 1996; Strakowski et al 1993).

However this may not be extrapolated to this study as there was no comparison group, nor was the sample randomly selected. Although the prevalence of affective psychoses has not been confirmed to be any less in African-Caribbeans, the apparent mis-diagnosis of schizophrenia in those actually with an affective psychosis has been attributed to the perception that psychotic symptoms are more chronic or persistent than affective symptoms in these patients (Strakowski et al 2003).

4.3.4 Suicidality

20% of the study's patients described suicidal thoughts in the two years prior to interview, with 9.1% having documented attempts at suicide. This is an interesting given two findings. Firstly, that in the general UK population, lifetime suicidal ideation is lower in ethnic minority groups but higher among those born in the UK than those who migrated to England as adults (Crawford et al 2005). Secondly, that the previously reported lower relative risk of suicidal behaviour in people of Caribbean origin in the UK with psychosis is restricted to those over 35 years, suggesting that the protective effect of Caribbean origin is disappearing in younger generations (McKenzie et al 2003).

4.3.5 Risk to others

50% were recorded in their notes as having made between one and three assaults over the two years before the study. Whether this is related to prescribing practices for the sample is unclear. Increased severity of community violence has been linked to medication non-adherence in patients with psychosis, which may suggest an indirect relationship with the perceived necessity of depot medication (Alia-Klein et al 2007).

It has been shown that the perceived risk of violent acting-out in an acute in-patient hospital setting was associated with being African-Caribbean and both were independently associated with being compulsorily detained (Singh et al 1998).

4.3.6 Medication

All 110 patients recruited to this study were prescribed oral anti-psychotic medication, with 40.9% of them receiving this in depot-injection form. The high proportion of depot prescriptions may be in-keeping with previous studies which have suggested that African American patients with psychotic disorders receive higher doses of antipsychotic medication than white patients, are more likely to receive depot antipsychotics, and are less likely to be prescribed second-generation antipsychotics (Arnold et al 2004; Kreyenbuhl et al 2003) Similar findings have been reported in a UK African-Caribbean population (Chen et al 1991). It must however be borne in mind that there was no white British comparison group to confirm this.

4.3.7 Psychological therapy

In contrast to this, 13.6% of the sample received any form of counseling treatment. This seems like a low proportion and may be reflected in other research findings where UK Caribbeans with psychosis were less likely to receive psychotherapy than their white British counterparts (McKenzie et al 2001). This is despite the well-documented efficacy of psychological treatments as an adjunct to medication in the treatment of psychosis (Klingberg et al 2006). Traditional or alternative healing models were rarely reported: this is surprising given the high

prevalence of religiosity reported by the group. This could mean either there is a lack of rigorous recording in case-notes of, (or the instruments used failed to detect) treatment in modalities other than the conventional biomedical ones by the instruments used, or that recipients were genuinely embarrassed about reporting their engagement with such therapy.

4.3.8 Family-substituted health care

Family members usually did not provide a substitute for institutional care (61.8% did not), nor did they monitor medication (63.6% did not). This may explain some of the link with the greater frequency of relapse and illness episodes seen in African-Caribbeans with psychosis when compared with other ethnic groups.

In a first-episode psychosis study in African American patients, it was reported that early psychotic symptoms were often attributed to depression, lack of motivation or relational stressors (Compton et al 2004). Family members' decisions to seek help often were solidified only after the emergence of unbearable psychotic symptoms or socially disruptive behaviors. Low concordance among family members' reports of the duration of untreated psychosis and perceived barriers to accessing psychiatric services were unexpected findings. This finding although potentially extrapolable, has yet to be replicated in those patients with chronic psychosis.

4.3.9 PANSS scores at baseline

The mean baseline total score on the Positive and Negative Syndrome Scale (PANSS) for schizophrenia in the sample was 84.3. To facilitate a clinical interpretation of this, PANSS scores have been simultaneously compared to ratings of Clinical Global Impressions - CGI (Leucht et al 2005). Using this method, 84.3 on the PANSS is equivalent to being "moderately" to "markedly ill" according to the CGI. With regards to inter-ethnic differences in PANSS, one previous study has found that patients of African or mixed-race origin have higher baseline PANSS scores (Emsley et al 2002); whereas another US study found no inter-ethnic differences in PANSS scores (Barrio et al 2003).

4.4 Adherence scores at baseline

The mean baseline adherence scores for the sample measured by the Drug Attitudes Inventory (DAI) and by the Kemp et al score both fell in the middle of their respective normal ranges - 4.2 for Kemp et al and 4.7 for the DAI - indicating an average level of adherence.

4.4.1 Drug Attitudes Inventory

The DAI is a well-tested and validated subjective measure of attitudes toward medication and highly predictive of adherence (Misdrahi et al 2002). The mean DAI score in this study was 4.7. One recent study reported DAI scores in a group of US patients with schizophrenia that was prescribed an injectable long-acting atypical neuroleptic for a fifty-week period (Lindenmayer et al 2005). Mean DAI ratings were 7.3-7.7 and felt to indicate "high patient satisfaction."

A second US study examining the insight of patients recently admitted to acute care state psychiatric facilities obtained a mean DAI score range of 6.4-7.4 (Sajatovic et al 2002). That sample population was 69% male, 73% had a diagnosis of schizophrenia, 27% had schizoaffective disorder but no ethnicity data is reported.

A third study conducted in Spain designed to assess the safety of olanzapine when compared with other antipsychotic drugs in the treatment of outpatients with schizophrenia, reported baseline DAI scores between 5.24-5.38 (Garcia-Cabeza et al 2001). The sample was 64% male, with an average age of 35 years and 65% had a diagnosis of paranoid schizophrenia. All three studies therefore reported higher DAI scores than in this study and, given that ethnicity data was not reported in them, they are unlikely to have consisted of ethnically homogeneous groups, which suggests that the poorer adherence here may be an ethnic effect.

4.4.2 Kemp et al score

The mean baseline and follow-up Kemp et al adherence score was 3.7, which indicates a lower level of adherence than reported by Kemp and colleagues in their original study (1996). That particular study, where they first described the Kemp adherence score, was a randomized control trial of adherence therapy in patients with psychosis (Kemp et al 1996). Their study population was drawn from consecutive patients aged 18-65 who were admitted with acute psychosis over eight months to a ward of an inner London psychiatric hospital. Their mean age was 36.9 years, with 61.2% described as from non-white ethnic groups, and 51.1% had a DSM-

III-R diagnosis of schizophrenia. In these aspects, Kemp's sample is not that dissimilar from the sample in this study.

The sample in this study seemed to score lower at baseline on the DAI than these three populations, which may reflect a more general finding of poorer adherence with medication in African-Caribbeans with severe mental illness (Fleck et al 2005). That this was not reflected when comparing the baseline Kemp et al scores, could mean a greater congruence between the study populations or it could indicate a relative lack of sensitivity in detecting differences between populations, perhaps limiting the scale's generalisability.

4.5 Perceived racism scores at baseline

This is the first known report of the use of the modified-Perceived Racism Scale in a UK study population, which limits the ability to perform direct comparisons. However the original Perceived Racism Scale (PRS) has been used in US studies. The mean total scores obtained in this study were 54.2 for racism over the preceding year, and 71.3 for racism over a lifetime, with a higher score indicating more perceived racist events.

In a study that examined the relationship between perceived racism and paranoia in African American college students recruited from three university settings, representing private, historically African American and state-funded institutions of higher learning, the mean total PRS one-year score was found to be 49.9 (Combs et al 2006). This sample was 75% female, with a mean age of 20.5 years, and 65.6% placed in the middle-class range of measured socio-economic status. This is a markedly

different age and social profile to this study's participants; however the PRS score is remarkably similar. This may in part be due to the fact that the instrument used was largely the same.

A second study sought to determine the association between perceived racism and ambulatory blood pressure measured during daily life (Steffen et al 2003). The participants consisted of employed African American men and women, aged between 25 to 44 years, who participated in the Duke Biobehavioral Investigation of Hypertension study. The exclusion criteria were: elevated systolic blood pressure, cardiovascular medication use, and tobacco product use. The mean total PRS-lifetime score was found to be 50.75, considerably lower than the lifetime figure for this study.

A third study examined the relationship between perceived inter-ethnic group racism and blood pressure responses in a group of African American college women (Clark 2000). The mean total PRS one-year score was found to be 75.25, significantly higher than the figure obtained in this study.

It can be seen that the figures obtained are somewhat different than other studies, but this is hardly surprising given the different profiles of the sample populations in terms of geography, the presence of severe mental illness, socio-economic status, educational level, medication and tobacco use and so on. What is perhaps more interesting is the degree of similarity that appears to exist between the scores, with the greatest difference being no more than 10%. This perhaps supports a universality of the reporting of racism (and its measurement by the PRS) by those of African-Caribbean origin, irrespective of their

backgrounds, cultural experiences and personal histories and this also speaks to the construct validity of the PRS.

4.6 Examination of primary outcomes

4.6.1 Models one, two and four

The primary hypothesis was one of a negative association between baseline PRS score and medication adherence as measured by the DAI and Kemp et al score, one year later in patients of African-Caribbean origin with psychosis. This was found to be the case, but the correlations although statistically significant, and of similar magnitude were both small in terms of absolute value.

To repeat, the results of the multi-variate analysis were as follows: the correlation between baseline total PRS one-year score and follow-up Kemp et al score was found to be b=-0.0074 (p=0.013), after adjusting for relevant confounders (baseline Kemp et al score, and follow-up PANSS paranoia score). The correlation between baseline total PRS lifetime score and follow-up Kemp et al score was determined as b=-0.0068 (p=0.038), after adjusting for baseline Kemp et al score and follow-up PANSS paranoia score. Finally, the correlation between baseline everyday racism PRS one-year score and follow-up DAI score was found to be b=-0.051 (p=0.0046), after adjusting for baseline Kemp et al score, and months' prescribed ant-depressant medication between baseline and follow-up.

These three results suggest that the total racism perceived and reported by the UK-Caribbean patient with psychosis is associated with marginally poorer adherence with psychiatric treatment one year later, even after

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adjusting for other possible explanatory factors. The association increases by a magnitude of ten for the association between specifically everyday racism and adherence, however it still remains small.

The relative importance of the "everyday racism" domain of the PRS as a predictor of poor adherence, may relate to the importance of "micro-aggressions" on outcome, as described by Pierce (1970, 1974). He described the atmosphere for African Americans as a "mundane extreme environment": an environment in which racism and subtle oppression are ubiquitous, constant, continuing and mundane and one in which they suffer daily the annoyance of micro-aggressions. Examples of micro-aggressions given are: being ignored for commercial service; assumed to be guilty of things negative; treated as inferior; singled out because of differences, and so on. These micro-aggressions are measured by the everyday racism domain of the PRS and have been also labeled mundane extreme environmental stress [M.E.E.S] because the perceived impact upon African Americans is considered stressful, distracting and energy consuming (Carroll 1998).

This type of analysis is unreported elsewhere in the literature, but there are certain relevant studies. There exists a body of research that perceived racism is associated with significant personal and psychological costs (see introduction). Clark's paper (1999) described a bio-psychosocial model for perceived racism, its study and how it may exerts its deleterious effects upon health and well-being.

Perceived racism (measured by the PRS) has been examined for its predictive effects upon paranoia among African Americans (Combs et al 2006). By taking a continuum-based approach to the concept of paranoia –

which has received support in the psychological literature (Bentall et al 1988; van Os et al 2000; Whaley 2001a) - cultural mistrust was regarded as similar to the concept of non-clinical paranoia, with both falling at the lower or mild end of the paranoia continuum. In a population of African American college students, Combs and colleagues found that perceived racism was highly significantly correlated with both cultural mistrust (r=0.45) and with non-clinical paranoia (r=0.40), even after adjusting for other theoretically related variables. In contrast, they did not find perceived racism to be predictive of clinical paranoia.

In a New York-based study of hospital patients led by one of the advocates of the continuum-based approach to paranoia, it was found that Black African American men with high levels of mild or non-clinical paranoia were less likely to be hospitalized than their White American counterparts (Whaley 2004). This was attributed to Black men with high levels of distrust or mild paranoia being less likely to seek help for mental health problems, which has been echoed in other literature (Whaley 2001b).

The finding that perceived racism is associated with sub-clinical paranoia, which, in turn, is associated with reduced hospitalization, lends support for the reported finding that perceived racism is associated with poor medication adherence (with the assumption that cultural mistrust may cause a turning away from both a hospital admission and the taking of medicine).

A study examined the relationship of discrimination and delusional ideation in people with no history of psychosis in the Netherlands

(Janssen et al 2003). It was found during a three-year prospective study that perceived discrimination at baseline was associated, in a dose-response fashion, with delusional ideation at follow-up, irrespective of ethnicity and after adjusting for confounders. Although psychotic disorder was not a measured outcome, it was felt both that perceived discrimination might contribute to the higher observed rates of psychotic disorder in exposed minority populations, and that reports of excess risk of psychosis among ethnic minorities may be confounded by experience of discrimination.

Both this and the Combs et al study suggest that perceived racism or discrimination is correlated with both sub-clinical paranoia and frank delusional ideation. Indeed, we found that paranoia as determined by the PANSS subscale at follow-up was positively correlated with perceived racism at baseline; but this association was not complete. Follow-up paranoia did not completely confound baseline perceived racism, as its adjustment in the multi-variate analysis failed to remove all of the effect that perceived racism may have on follow-up adherence. Therefore, paranoia cannot be considered as a proxy measure for perceived racism. There is a small nevertheless significant effect of total perceived racism, independent of clinical paranoia, upon adherence with medication.

This highlights a central issue that perceived discrimination (be it racial in origin or otherwise) reported by patients with psychosis could be attributed to paranoid thinking and represents symptoms of psychosis rather than actual events. The fact that in our quantitative analysis, paranoia did not completely confound perceived racism is less important if this issue represents a firm underlying belief in the mind of the

ethnic majority that minority ethnic groups are misattributing mental distress to racism. If this is the case, this may be much more difficult to shift as it may characterize a defensive reaction to pathologise protest rather than use it as an opportunity to acknowledge the distress in the person on the receiving end of the discrimination (Bhui 2002). Responding to an individual's perceived trauma is being sensitive to that individual and perhaps more important than corroborating whether or not it occurred, as well as a move towards gaining their trust, and hopefully, improving engagement.

4.6.2 Model three

It was found that feeling ashamed about perceived racism from mental heath services (as measured by the modified health services domain of the PRS) was more strongly and positively associated with follow-up adherence on the Kemp et al scale, b=0.20, p=0.015. This concept refers to the emotional response of shame following a personal experience of racism.

This finding has yet to be reported elsewhere in the psychiatric literature, although interestingly a large prospective study of Italian dermatology out-patients reported that high levels of shame and embarrassment as measured by the Skindex-29 emotions scale at baseline was associated with medication adherence at follow-up, probably mediated by high motivation for treatment (Renzi et al 2002).

This may relate to a more general finding of dissatisfaction, disempowerment and disenchantment that has been reported by the users of psychiatric services, both in the general UK population (Rogers et al

1993) and in the African and African-Caribbean community (Wilson & Francis 1997).

Goffman drew a significant comparison in his seminal book "Stigma: notes on the management of spoiled identity" wherein he described persons who are unable to conform to standards that society calls normal (1963). Disqualified from full social acceptance, he regarded both those bearing physical scars as well as psychiatric patients as stigmatized individuals. He saw them as ostracized by society (therefore feeling shame) and having to constantly strive to adjust to their precarious social identities. Their image of themselves must daily confront and be affronted by the image, which others reflect back to them. This constant striving may be the motivation behind the high levels of adherence seen in these superficially disparate groups of patents.

4.7 Examination of secondary outcomes

4.7.1 Models five and seven

These two models demonstrate the link between psychiatric hospital admissions and racism perceived from health services. Model five found a strong positive association between one-year perceived racism from mental health services (as measured by the modified health services domain of the PRS) and the number of psychiatric hospital bed-days in the following year (b=5.54, p=0.010). Model seven found a similarly strong association between one-year perceived racism from mental health services and the length of any psychiatric hospital admission in the following year (b=4.92, p=0.021).

A possible explanation for is that a greater previous experience of racism within mental health services may lead to mistrust of psychiatric services, poorer subsequent interactions with services and poorer adherence with treatment, which results in a greater likelihood of psychotic relapse and more psychiatric hospital bed-days in the subsequent twelve months.

It is notable that paranoia as measured by the PANSS subscale did not confound either of the relationships in models five and seven. This appears to support the "cultural-bias" hypothesis expounded by Whaley in two recent papers, and discussed below.

In the first of this series of Whaley's papers (2001c), the idea of "cultural mistrust" of white society is discussed. It is formulated as a strategy developed by African Americans and regarded by some clinicians and researchers as a normative, healthy and adaptive response to racism (Grier & Cobbs 1968; Ridley 1984; Terrell & Terrell 1981). It is speculated that cultural mistrust may be misinterpreted as pathology, resulting in an over-diagnosis of schizophrenia in African-Americans. However, the study of African American psychotic patients failed to support this hypothesis. The negative finding was attributed to the sample having chronic rather than acute psychosis, leading to "discrete" cultural mistrust merging with their pathology rather than remaining as a distinct, easily recognisable entity.

In Whaley's second related study (2002), the problem was circumvented by examining early-onset cases of psychosis in African Americans and found a strong, negative association between their cultural mistrust score and age at first hospitalization (AFH). It is known that a younger AFH

reflects an earlier onset of psychotic illness, greater severity of subsequent illness, and more psychiatric admissions following on from that (Burack & Zigler 1989; Lewine 1980; Sharma et al 1996).

It has been shown that Black individuals high in cultural mistrust tend to have more negative attitudes toward mental heath services (Nickerson et al 1994), terminate treatment prematurely (Terrell & Terrell 1984) and engage less well with services (Thompson et al 1994). This may indicate that those individuals are more likely to perceive and report specific racist events in their treatment. A failure in effective engagement with treatment is more likely to lead to non-adherence and relapse. If "cultural mistrust" is seen as at least a partial-proxy measure for perceived racism, this may explain the strong association between perceived racism in mental health services and subsequent length of psychiatric hospital admission found in this study.

4.7.2 Model six

This model demonstrated a strong negative association between feeling powerless about perceived racism from mental health services and the number of psychiatric hospital bed-days in the following year (b=-14.49, p=0.025).

This indicates that a feeling of powerlessness experienced about any racism was strongly associated with either shorter or fewer hospital admissions (or both). This may indicate a general sense of disempowerment which could lead to greater trust relinquished to those providing health-care and hence to improved adherence and thus fewer hospital bed-days. That this may occur at the expense of a sense of

self-determination and autonomy may be deemed by some as too high a cost to pay. This also fits with model three's finding of an association between any shame about racism experienced in mental health services and improved medication adherence: shame and powerlessness are arguably two related concepts. Indeed in this study their correlation was strong (r=0.381).

The concept of explanatory illness models may shed some light upon this finding. Callan and Littlewood interviewed white British and minority ethnic patients about their opinions on psychiatric in-patient care, their treatment preferences and their explanatory models of illness (1998). They found that the most significant association with patients' satisfaction was concordance between the patient's and psychiatrist's explanatory model.

McCabe and Priebe compared explanatory illness models among people with schizophrenia from four cultural backgrounds (2004). They found that explanatory models differed reliably according to cultural background and were associated with treatment preferences and satisfaction but not with adherence. Although Whites were more likely to have a biological explanatory model, African-Caribbeans, West Africans and Bangladeshis were more likely to have a social or supernatural model and, having a biological explanatory model, especially compared with a social explanatory model, was linked with greater treatment satisfaction and better therapeutic relationships. It is conceivable that a discordance in illness models between patient and doctor could lead to feelings of powerlessness and shame which, although not impinging adversely upon adherence, (quite the opposite in this study), could be linked with the patient not feeling heard.

4.8 Limitations of the study

4.8.1 Selection bias

Prospective cohort designs are capable of producing powerful evidence; however they are sensitive to selection bias and confounding.

The CONSORT definition of selection bias is a systematic error in creating intervention groups, causing them to differ with respect to prognosis (Altman et al 1999). The groups differ in measured or unmeasured baseline characteristics because of the way in which participants were selected for the study or assigned to their study groups. The inference is that an intervention is being tested; this study is an observational study where no such intervention has been tested. However selection bias can still be examined in terms of the people who decided to take part in the study and those who agreed to follow-up.

Sampling bias, or systematic sampling error, occurs if the selected sample is unrepresentative of the population of interest, which means that sampled individuals differ systematically from those not sampled. For valid inferences to be made about a population effect from an estimate of that effect in a sample, the sample must be representative of that population. The likelihood of obtaining a representative sample is high if some form of random sampling is used. It is therefore important that the researcher specifies clearly in the protocol what target population he/she has in mind, whether a sample will be used and how such a sample will be drawn. In addition, the researcher should indicate how the representativeness of the sample can be validated, e.g. against census information.

The sample obtained was purposive, i.e. those who agreed to take part were recruited to the study. It is unclear whether the group that agreed differed consistently to those who did not agree; the only information collected on those who did not participate indicated that they were more likely to be male and younger in age than participants. This may reflect the more general level of dissatisfaction with mental health services that has been reported in second- and third-generation African-Caribbeans when compared with their older counterparts (Parkman et al 1997).

If there was a sampling error in terms of a systematic exclusion of patients that were younger and male, it could be that this led to a skew in the results against the direction hypothesized. If as the literature suggests, younger male patients are more likely to be disaffected, alienated therefore seeking alternative external explanations for their mental illness such as racism; their exclusion would lead to a reduction in the size of the correlation between primary explanatory and dependent variables. However, this may have been offset by the possibility that people who participate in research may be more likely to be amenable, compliant, facilitative, wanting to help, and therefore happy with their treatment and services.

One indicator that bias in selection may have been introduced is the overwhelming majority of participants that was unemployed. In fact, 97.3% of the sample was unemployed at interview. This lack of variability in employment may perhaps have been related to a restricted variability in socio-economic status. It is known that socio-demographic factors often confounding variables in psychiatric epidemiological research and it is plausible how social deprivation ay be associated

with both perceived racism (people in more deprived situations may be exposed to more racism) and adherence (a strong therapeutic alliance may be less important to a person who is socio-economically deprived and therefore with greater perceived worries than perhaps their mental illness). If perhaps there was greater variability in socio-economic status, the latter may have possessed more predictive ability in the final modeling and analysis.

It is noteworthy that what might be thought of as typical social predictors of adherence were found not be related to adherence, and therefore could not be included as confounders of the final regression model. These were: marital status; geographical proximity of friends/family; frequency of contact with friends/family; presence of a close contact; and frequency of contact with a close contact. There is limited reported data on the relationship between social support, adherence and psychosis. Psychiatric management of antipsychotic non-adherence among schizophrenia outpatients with high and low levels of family contact has been compared and reported (Wilks et al 2008). A national survey was conducted among a random sample of psychiatrists treating schizophrenia, providing data on 310 patients. Patients were stratified by level of family contact. Psychiatrists were more likely to use family interventions to manage non-adherence among patients with high family contact. Psychiatrists were significantly more likely to change antipsychotic dosing in patients with high family contact, though less likely to start depot antipsychotic medications.

Family interventions appear to be commonly used in the psychiatric management of medication non-adherence in schizophrenia. Another identified baseline factors which could predict non-adherence to prescribed treatment (Montero et al 1999). The authors examined 87 schizophrenic patients in a catchment area of Valencia (Spain), which were randomly assigned to two family strategies. The characteristics associated with lack of adherence to the programmes were analysed in both the patients and their families. Living in small households was associated with a higher risk of dropping out of the interventions, which may suggest that poverty of social network predicts non-adherence. Although a small household implies geographical closeness and one that is tightly knit, which seems counter-intuitive to the family supporting the patient's adherence.

A further study acknowledges that little attention has been paid to the role of families in the examination of compliance with medication in schizophrenia, and evaluated the relevance between carers' knowledge or expressed emotion to compliance (Sellwood et al 2003). The authors examined a sample of patient-carer pairs (n=79) involved in a family intervention for schizophrenia trial. Carers' expressed emotion was independently related to non-compliance with medication, although carers' knowledge about schizophrenia was not related to compliance. This suggests that the quality of the relationship rather than the number or physical proximity of people is more important to adherence.

Indeed, we used the EMPIRIC dataset to investigate whether social support from friends or relatives reduces the cross-sectional

association between perceived racism and the risk of mental illness (measured either as common mental disorder or psychotic symptoms) in an ethnic minority group (Chakraborty et al 2004b). We conducted secondary analyses of nationally representative community samples of five UK ethnic minority groups (EMPIRIC dataset; n = 4,281) using multiple regression techniques. We found that the associations between perceived racism, common mental disorder and potentially psychotic symptoms were mainly independent of social support as measured by the number of close persons and their proximity to the individual. We thus concluded that differences in risk of mental illness of an ethnic minority population in an area might not reflect the effects of differing amounts of social support buffering the impacts of racism.

The sampling error of this thesis' study may be estimated from a simple online tool, which allows you to calculate the sampling error for any sample. The DSS tool calculates the finite population correction factor when appropriate to adjust the sampling error upward to account for measuring a significant portion of the population universe (http://www.dssresearch.com/toolkit/secalc/error.asp). Upon entering a sample size of 110; a sample proportion of 50% [this represents the proportion of people in the population being surveyed it is expected to answer a certain way on the key measure in the survey; if uncertain about this, using 50% produces the maximum possible variation]; a total population of approximately 5020 (estimated from the 2001 London census figure for African-Caribbeans of 343,567 [http://www.statistics.gov.uk/census2001/profiles/h.asp], and from the average rate for schizophrenia in African-Caribbeans of 14.61/1,000 from a comprehensive review of the literature (Bhugra and Bhui 2001)]; and a confidence interval to base the sampling error upon; this provides a

sampling error of 9.2%. This means, therefore, that based on a sample of 110 we can be 95% sure that the true measure among the whole population from which the sample was drawn will be within +/-9.2% of 50% i.e. between 40.8% and 59.2%.

Information was compared between those who could be followed up (n=100) and those who could not (n=10). The two groups did not differ significantly on either of the two baseline adherence scores (see Table 16), nor did their PRS scores differ significantly (see Table 17, in 'Results' section). Therefore, the experiences of racism did not appear to differ significantly between those followed up and those who did not agree to follow-up. However of course, the two groups may have differed on unknown confounders.

The comparison of baseline adherence scores almost reached significance, with a trend toward poorer baseline adherence in those who did not agree to follow-up. Following this trend to its natural conclusion, this may indicate that those who did not wish to take part in the study at all may have had poorer adherence with their treatment overall. If it can be assumed that (a) those that did not take part in the study had similar perceived racism to the baseline group; and (b) adherence status remains fairly static over the time-period of a year; their inclusion would increase the magnitude of the negative correlation between baseline perceived racism and follow-up adherence. This however is rather speculative and relies on several assumptions, but is an idea worth testing in the future.

4.8.2 The power calculation

The power calculation to obtain the sample size that was carried out prior to conducting the study may be considered as somewhat rudimentary. It started from the premise of Kemp and colleagues' work (1996), which determined that insight was positively correlated with adherence. It moved on to hypothesise that perceived racism is a factor that acts similarly to insight but that varies inversely with adherence. From there, a sample size was computed on the basis of an inverse correlation of a certain magnitude between perceived racism and adherence.

This process may be considered problematic for a number of reasons: firstly, by using correlation to examine the association between the variables the assumption is that they are both normally distributed. This, in fact, was shown to be the case in the results, but may be considered a premature assumption to have been made prior to data collection. Secondly, the hypothesis that perceived racism is a variable of similar magnitude to insight but of exactly opposite polarity may be considered somewhat simplistic. Firstly, it is unlikely that either insight or racism are discrete, unidimensional phenomena which may be characterised in entirety by single values; and secondly, it is also unlikely that all individuals with a high insight score will have a low perceived racism score; by the arguments laid down here it is likely that the two are negatively associated, but the relationship is unlikely to be that straightforward.

Finally, the power calculation rested on a single correlation calculation: the association between perceived racism and adherence. It does not take into account the effect of other variables. These would likely lead to an increased sample size. The figure arrived at from the

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calculation was eighty. In fact, 110 were included in the analysis and all of the final regression models contained no more than a few significant variables (i.e. most of the confounders dropped out of significance at earlier stage of the analysis). Thus, it may be argued that the power calculation was adequate for the purposes of this study.

4.8.3 Imputation of missing data

Follow-up data was missing on ten cases, as they refused to be followed-up. There was no systematic difference between this group and the group that agreed to follow-up. In order to maximise the use of baseline data, it is possible to impute the missing outcome data using the information gathered at baseline. One such technique is called "multiple imputation" and is an algorithm, which the "STATA" statistical software package can perform.

The concept of multiple imputation (MI) was first proposed by Rubin in the early 1970s as a possible solution to the problem of survey non-response (Rubin 1996). He emphasized that missing data should be handled based on some principled methods rather than ad hoc methods. MI is such a method, consisting of a three-step process, as described in the "Methods" section.

This study used STATA to perform multiple imputation using the "ice" command. This uses a different estimation method for each variable depending on whether the variable is continuous (regression), binary (logistic regression), ordinal (logistic regression), or categorical with three or more categories (multinomial regression); this is an

attractive feature, also with the capability of incorporating a weight variable into the analysis (Acock 2005).

This strategy was used to determine DAI and Kemp et al scores at one-year follow-up in those cases that refused the follow-up interview. The dataset was complete for the 100 cases that were successfully followed-up (this was ensured by the researcher following each and every interview); therefore none of these cases required any imputation. There is controversy over whether an imputed dataset should be used. However, statisticians have become increasingly aware of the inadequacy of "complete-case" analysis of datasets with missing observations (Royston 2004). Therefore to make maximal use of this dataset, MI was performed. It can be seen in Tables 21 and 25 that the point estimates for the final models were not of dissimilar magnitude for the "imputed-value" dataset (n=110) compared with "complete" dataset (n=100), this therefore lends support for MI.

4.8.4 Confounding

For a characteristic to be a confounder in a study, it must be related independently to both the outcome and the exposure. Cohort studies are felt to be exquisitely sensitive to confounding effects in that during the time between initial interview and follow-up, the cohort may have come under the influence of certain effects, which create differences in outcome other than those exposures that are being assessed.

The list of confounders utilized in this study was felt to be comprehensive (see Section 2.9.5). It is known that age and gender are both related independently to psychiatric treatment adherence, but in an

inconsistent fashion (Buchanan 1996). Baekeland and Lundwall reviewed the literature, looking at 51 studies, of which 35 (68.6%) found age to be unrelated to dropping out of treatment (1975). Where a difference between ages has been identified, the conclusion has usually been that older patients comply better (Myers 1975; Davies et al 1977).

Gender of a patient has been found more consistently to affect the likelihood of adherence with psychiatric treatment. Craig and colleagues looked at a relatively deprived inner-city population in Baltimore and found that males were less likely to progress successfully from referral by the emergency service to regular out-patient attendance and reported the finding that when African American males do enter treatment they do so under less favourable circumstances (Brody et al 1967). Despite the surprising lack of research in this area, it seems likely that the directionality of the effect is similar with patients with schizophrenia.

One of the most commonly reported findings in adherence research is that past behaviour predicts future behaviour. This was replicated by Buchanan's study where it was found that previous poor adherence with treatment was associated with subsequent poor adherence at one year follow-up, when measured in terms of non-adherence with medication and failure of out-patient attendance (1996).

Low socio-economic status has been associated with poor adherence with neuroleptic medication (Winkelman 1964); however, there was insufficient variation in this study's population for socio-economic status to act as a confounder: almost all of the study participants had a low socio-economic status.

Confounders were methodically tested individually for their association between both exposure and outcome prior to its inclusion in the multivariate analysis. Often the variables were continuous in nature and rather than performing a comparison of groups by significance testing of means, an association was only considered significant (and therefore to be worthy of inclusion in the final analysis) if the correlation, $r>0.20$. This was so as to make maximal use of the information collected to improve the precision of findings, and also by the use of the statistical theory (see "Methods" section 2.10.5).

If we enter the value N=100 (for cases for which no values were imputed) and r=0.20, this gives a two-sided p-value of 0.05, the usual accepted level of significance. However, one could also argue that perhaps one could use a more relaxed criterion than 0.05 as confounding can also hide associations.

There will always be residual confounding (i.e. confounding that has not been accounted for in the study); however, it is unlikely to have had a major impact on the final results in this case as the unadjusted and adjusted coefficients (b-values) in Table 21 are not that dissimilar from each other.

4.8.5 Measurement of adherence

Both the DAI and the Kemp et al scores are indirect measures of adherence. The DAI is a well-validated, reliable and highly-used instrument in the research literature (see section 4.4.1); the Kemp et al score is less-widely tested but benefits from being a composite measure based on information from a number of sources. There are problems associated with more direct measures such as urine tests since these may overestimate adherence when drugs have a long half life (Churchill 1985). Serum assays, when available, are invasive and are usually of limited value in assessing partial adherence (Babiker 1986). Pill counts are widely considered to be a useful measure, despite the potential for dissimulation and inaccuracy (Kane 1983). In the original work, the Kemp et al score correlated strongly at each time point with self reported measures of attitudes to drug treatment (r>0.68), lending it some concurrent validity.

It is also important to bear in mind that DAI and Kemp et al ratings were performed by case-worker and patient, respectively. Both parties were effectively masked to exposure status (the primary exposure being perceived racism), as neither would have been aware of the PRS scores and how they might be related to adherence. The patient self-completed the PRS, but given its structure and length, would have been hard pressed to sum up their replies and hence unlikely to compute an overall score themselves.

4.8.6 Measurement of racism

The Perceived Racism Scale is a well-tested and validated instrument in the US research literature (see section 4.5); however this is the first time, as far as it can be ascertained, that its use has been reported in both a UK population and in those with psychosis. Secondly, its modification to accommodate a UK readership and a substitution of a domain (Mental health services for Employment) may be considered by some a step too far. However, the domain substitution was carried out subsequent to pilot-work and consensus of the pilot results by national leading experts in the field of cross-cultural psychiatric research in the UK.

The areas covered by the mental health services domain were of course different to those tested by the employment domain. However, the construct and semantics of each question were essentially preserved, only content was altered, in a bid to preserve the integrity of the original instrument as much as possible. The reader may compare for themselves by examining sections 6.1a and 6.1b of the "Appendix" section.

The fact that the experience of racism is a complex, multi-dimensional phenomenon, the PRS is a good response to the charge that there are few instruments that capture the experience of racism in all of its complexity, both in terms of perceived experiences and emotional responses to those experiences. That the PRS is a subjective pencil-and-paper instrument rather than a more objective, corroborated measure of

racist experiences does not necessarily limit its validity. The subjective reality of individual patients is bound to influence their adherence on an individual level, which is why so many researchers call for researchers and service-providers to take on board what the patient is saying (Rogers et al 1993).

Racism is difficult to measure. Researchers rarely observe discriminatory behaviour directly. Instead, they attempt to infer from disparate outcomes whether racial discrimination has occurred. Establishing that racial discrimination did or did not occur requires causal inference. Identifying a racial disparity and determining that an association between race and outcome remains after accounting for plausible confounding factors is a relatively straightforward task. The real difficulty lies in going beyond the identification of an association to the attribution of the cause. In general, observational designs (such as this one) facilitate generalisation while limiting causal inference. The super-position of a prospective cohort offsets this causal inferential problem.

4.8.7 Measurement of secondary outcomes

The measurement of secondary outcomes, i.e. the hospital admission data, was gathered using the Who Life Chart. This information was triangulated using the respective hospital's computer admission data systems; this permitted independent validation. As described in Section 2.8.2, the WHO

Life Chart is an observer-rated instrument; however all its data is objective and quantifiable and was obtained from the psychiatric case-notes of each participant. The information was collected after the baseline data was collected and immediately prior to collection of the follow-up adherence data. As the baseline exposure (that of perceived racism) was a self-report instrument, at the time of collection of WHO Life Chart data, the researcher was blind to each participant's exposure status as the data had yet to be entered. Secondly, the primary outcome data had not yet been collected; therefore the researcher was also blinded to that information. These would both reduce the bias that may be potentially introduced when a data-collector has prior knowledge of a participant's exposure status.

4.9 Conclusion, implications and a putative mechanism

This is the first reported study of African-Caribbean patients with psychosis that has prospectively examined the association between perceived racism at baseline and medication adherence as well as other health service-related outcomes at one-year follow up. The study found small but independent and significant associations between measures of total perceived racism for the previous year, over a lifetime, and everyday racism for the previous year with medication adherence one year later. It also found that feeling ashamed and powerless about any racism that was personally experienced within the health system were associated with increased adherence and fewer hospital bed-days in the subsequent year. Finally, the strongest positive association was between perceived

racism within the system and both the number of subsequent hospital bed-days and length of hospital admission over the next year.

This implies that perceived racism is a determinant of adherence with psychotropic medication determined by both the care-coordinator and the patient, over at least a twelve-month period. Additionally, perceived racism exerts a much stronger effect on more objective, hospital-related outcomes such as the length of psychiatric inpatient admission.

It is not that surprising that racism measured in this way did not have a comprehensively profound effect on adherence. Firstly, the Perceived Racism Scale scores into the hundreds whereas the adherence scales scored no more than ten; the mapping of the former onto the latter is unlikely to produce a coefficient of large magnitude. Secondly, society is racially stratified with groups defined as 'races' often differing in power, status and access to societal rewards. Racism is not the only social factor that affects health and it is not independent of other social influences. In societies stratified by race, racism transforms and structures other societal institutions so that the entire social system may be regarded as racialized.

The differences in magnitude of associations obtained between the primary and secondary analysis might suggest that greater emphasis should be given to the secondary outcomes within the thesis, including its title. However, the primary hypothesis was that of perceived racism

and medication adherence and the study was initially developed around that hypothesis. Therefore the authors thought it appropriate that the style and composition of the writing should in turn reflect this.

The stark difference in the magnitudes of the effects could be for two possible reasons. Firstly, adherence could be a rather crude measure allowing for minimal variation, whereas the variation in hospital bed-days allows for more subtle differences to be determined and hence for a more profound effect to emerge, when the precision of the analyzable data is limited. Secondly, adherence could be an interim variable along the causal pathway between perceived racism and hospital admissions, with racism exerting a smaller effect upon it than the final outcome.

The post hoc analyses, outlined at the end of the Results section (and available from the primary author), are of particular interest in elucidating a hypothetical mechanism. The hypothesis is that perceived racism impacts upon medication adherence as an intermediary variable, with hospital admissions as the final outcome.

The preliminary analyses found that when six-month adherence on the DAI score was estimated and the cohort was divided into two groups based upon this adherence value (good adherers versus poor adherers), with previous-year mental health service racism as the primary exposure and hospital admission, the outcome; good adherence attenuated the admission length while poor adherence amplified it.

The results may be explained by a model whereby the deleterious effects of perceived racism from mental health services as a baseline exposure leading to more time spent admitted to a psychiatric hospital, may be reduced if adherence to medication is improved at six months, or increased if adherence is worsened. It can be seen that the results were often not significant which may be an indication of the sample size being too small or that other explanatory factors need to be taken into account other than perceived racism.

With further analyses, powerlessness about mental health service racism at baseline led to shorter hospital admission length as outcome, suggesting that a resignation to such perceived racism led to less time spent in hospital. With the cohort again grouped according to averaged six-month adherence, the poor adherers attenuated the coefficient and the good adherers amplified it. This time a consistent (although, again, not always significant) result was seen with both Kemp and DAI adherence scores adding further support to the postulated mechanism.

Yet further analyses found that when the cohort was grouped into tertiles according this time to baseline adherence scores (good, moderate and poor adherers), and using the same baseline exposures as above [i.e. previous-year mental health service racism, followed by powerlessness about mental health service racism] as well as outcomes [i.e. length of hospital admission], the same overall trends were seen. Again, the results were not always significant, but it certainly lends support to further investigating this mechanism perhaps with a larger

sample size. By using baseline adherence as the intermediary variable rather than an averaged six-month adherence score, this should have added precision to the model, which justified splitting a cohort of this size into tertiles.

Overall, these results using baseline (measured) adherence rather than six-month (estimated) adherence appear more powerful and supportive of a theory of racism→adherence→outcome, with the lack of significance indicating a lack of power as well as the presence of other explanatory factors unaccounted for by this model.

An idea that should be kept in mind is that this study is essentially a measure of engagement, determined either by the primary outcome - that of medication adherence; or the secondary outcome - hospital admissions. It could be argued that these are both indirect measures of engagement and there is no single engagement measure that has been employed. There do exist measures of engagement, such as the STAR-P which is a measure of the therapeutic relationship in community care with both patient and clinician dimensions (McGuire et al 2007). There does exist a body of research that has examined factors that are associated with engagement in psychosis.

Compton carried out a descriptive case series of facilitators and barriers to engagement in initial outpatient care early in the treatment of schizophrenia (2005). This case series included six single, African-

American first-episode patients. Narratives describing the initial hospitalization and the first outpatient appointments in an urban community mental health setting were presented. Several barriers to outpatient treatment engagement emerged from this relatively homogenous series of first-episode patients. Apparent barriers included inadequate remission of paranoia, impaired insight, and involvement with the criminal justice system between hospital discharge and the first outpatient appointment. Good family support appeared to be an important facilitator of treatment engagement during the first several months of outpatient treatment.

Another study found that recovery style rather than insight seemed to better predict engagements (Tait et al 2003). The authors begin by evidencing that recovery style (i.e. psychological adjustment) may underlie service engagement. They examined fifty patients with schizophrenia during acute psychosis and at 3-month and 6-month follow-ups. Measures included recovery style, psychosis symptoms, insight and service engagement. They found that sealing-over at 3 months following onset of an episode of psychosis predicted low service engagement at 6 months; neither insight nor symptoms predicted engagement; the clear shift from integration to sealing-over within the first 3 months was independent of changes in symptoms or insight; and sealing-over between 3 and 6 months was associated with improvement in psychosis symptoms. They therefore concluded that recovery style contributes more to engagement than did insight; it appears to be dynamic in the short term and is orthogonal to insight. This appears to highlight the importance of addressing psychological adjustment to psychosis as well as illness status when investigating treatment engagement in people with psychosis.

A detailed examination of the predictors of engagement with treatment in psychosis was recently carried out in Canada (Lecomte et al 2008). Treatment adherence in early psychosis individuals is considered problematic. The authors conducted a cross-sectional study with 118 early psychosis individuals, assessing multiple constructs (symptoms, insight, personality traits, alliance, childhood trauma, substance abuse, social functioning and sociodemographics) suggested in the literature as potentially linked to medication adherence or engagement in services. They performed Forward Wald logistic regression which suggested that more positive symptoms, having witnessed violence as a child and high agreeableness as a personality trait predicted poor medication adherence. Forward linear regression also revealed that physical abuse as a child, lack of knowledge regarding consumer rights, difficulties in building an alliance, low neuroticism and high agreeableness predicted poor service engagement. Profiles of non-adherers or low service engagement were strongly linked to childhood trauma, and high agreeableness, as well as more severe symptoms and poor alliance. Males with histories of legal problems were also more prevalent in both groups. No significant differences were found for insight or substance abuse. Overall, individuals with early psychosis who adhered less to treatment in general were inferred to have issues with trusting authority and place more importance on peer acceptance.

These results suggest a number of factors other than perceived racism may account for the association with engagement. These factors appear to include: remission of paranoia; impaired insight; involvement with the criminal justice system; recovery style; physical abuse as a child; lack of knowledge regarding consumer rights; difficulties in building an

alliance; low neuroticism and high agreeableness. However, it is notable in our analysis that perceived racism remained as a significant, independent predictor in several regression models. It is plausible that perceived racism may be a proxy variable for several of these other factors. For example an individual perceiving racism and identifying it as an historical factor may also be more likely to have been exposed to the criminal justice system, they may have been more alienated and thus possess less knowledge of their "rights as a psychiatric consumer"; find it more difficult to building an alliance, and so forth.

These findings may be further explored by measuring these factors in addition to, and alongside, perceived racism and determining their predictive ability of medication adherence and hospital admission data. An interesting slant would be to carry out the same follow-up study with a comparison of two cohorts: one from an ethnic minority with psychosis and the other being White British, to see the amount of variation in outcome that is explained by perceived racism in the minority ethnic group. In addition, the further outcome of therapeutic engagement could be measured, although it could be argued that adherence and service-related outcomes are indirect measures of engagement.

Overall, this thesis' findings allow for racism, adherence and health outcome to be conceptualised within a biopsychosocial model with perceived racism as an environmental stressor placed into context of other moderator variables. The biopsychosocial model for perceived racism is consistent with the conceptualisations of other researchers

(Jorgensen et al 1996; Anderson et al 1994) and builds upon the more general stress-coping model proposed by Lazarus and Folkman (1984).

The principal belief of this model is that the perception of an environmental stimulus as racist results in psychological and physiological stress responses which are influenced by constitutional, socio-demographic, psychological and behavioural factors, and coping responses. Also, there is a complex interplay of these factors in the resultant coping response. These responses are thought to affect health outcomes. Although it is possible that psychological, behavioural, constitutional and socio-demographic factors could influence coping responses directly, for simplicity's sake, these influences are not indicated in Figure One.

It is known that Caribbeans are exposed to environmental stimuli that may be sources of chronic and acute stress; a myriad of these stimuli (especially interpersonal) could be perceived as involving racism. Constitutional factors (such as skin tone) are hypothesized to influence the relationship between exposure to environmental stimuli and health outcomes, as are socio-demographic factors such as socio-economic status.

Depending on individual factors, an event could be perceived as stressful and involving racism. Psychological and behavioural factors may contribute to the presentation or treatment of "almost every general

medical condition" (American Psychiatric Association 1994, p.676). For example, Type A behaviour, cynical hostility, neuroticism, hardiness, anger expression-suppression are among those factors that have been postulated to influence the stress process, health outcomes and immune functioning (Miller et al 1999; Everson et al 1998).

Perceived racism in the model refers to the subjective experiences of discrimination or prejudice. Therefore, perceived racism is not limited to those experiences that may be "objectively" viewed as representing racism. For example, subtler forms of racism include belief systems and symbolic behaviours and micro-aggressions.

The stress literature highlights the importance of the appraisal process to the described model. Lazarus and Folkman (1984) observed that it is both the individual's evaluation of the seriousness of an event and their coping response that determine whether a psychological stress response will occur. That is, the *perception* of demands as stressful is more important in initiating stress responses than *objective* demands that may or may not be perceived as stressful. Thus, the initiation of psychological stress responses as a result of perceiving environmental stimuli as involving racism would qualify these stimuli as stressors.

Among Caribbean patients with psychosis that perceive certain stimuli as stressful, there are likely to be wide individual differences in psychological and physiological stress responses, irrespective of

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ethnicity. The extent of these stress responses will depend on the availability and use of coping responses. Coping responses that do not attenuate stress responses are considered maladaptive and may negatively affect health. That is, when maladaptive coping responses are utilised, the perception of an environmental event as racist will trigger psychological and physiological stress responses. If an individual fails to replace these maladaptive coping responses with ones that are more adaptive, the model further predicts a continued state of heightened psychological and physiological activity.

On the other hand, adaptive coping responses are thought to mitigate enduring psychological and physiological stress responses, thereby reducing the potentially untoward effects of racism on health. As such, it might be possible to identify coping responses that moderate the relationship between perceived racism and stress responses. Measuring social desirability and repression could be used to help to identify individuals who do not report perceiving any stressor or may inhibit the expression of psychological responses yet show exaggerated physiological responses to stimuli.

The usefulness of various coping strategies in reducing the chronic and acute psychological and physiological effects of racist stimuli may depend, in part, on the frequency of the perceived stressor and the context or setting in which racism is perceived. For example, although coping responses like projection or denial may be adaptive with acute stressors, they may be considered maladaptive if used to negotiate

chronic stressors. Equally, expressing emotional reactions to peers might be adaptive in some contexts and maladaptive in others.

Numerous psychological stress responses nay follow perceived racism. These responses include anger, paranoia, anxiety, powerlessness, shame, frustration, resentment and fear. Psychological stress responses may, subsequently influence the use of coping responses, such as anger leading to hostility, aggression, alcohol misuse or medication adherence or non-adherence.

Psychological and physiological responses to perceptions of racism may, over time, be related to health outcome, with adherence to treatment being the inter-mediary variable. There is a growing body of research in the more general stress literature that documents the relationship between stress and health.

The focus of this model has been on the role of racism as a perceived stressor and its implications for health. It is also possible however, that racism may affect health even when it is not perceived as a stressor via, for example, institutional racism. Therefore, perceived racism may be one of several possible pathways by which racism may affect health.

Figure two. The "racism as stress" model

Acute or Chronic Environmental Stimulus

Constitutional Factors

Socio-demographic Factors

Psychological and Behavioural Factors

Perception and Cognitive Appraisal

Perception of Racism

Perception of Different Stressor

No Perception of Racism or Other Stressor

Coping Responses (Adaptive or Maladaptive)

Blunted or No Psychological and Physiological Stress Responses

Psychological and Physiological Stress Responses

Treatment (non/)-adherence

Health Outcomes

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4.10 Future research

Further studies could further elucidate the effect of racism as a "toxic" environmental exposure upon other objective outcome data such as: dose of medication, rates of compulsory detention and frequency of other aversive pathways into hospital (i.e. police involvement). Studies could be extended into the forensic setting where the proportion of African-Caribbean or African American patients is even higher than in a general adult setting (Pinals et al 2004; Coid et al 2000). Serial completions of the PRS could be obtained in a cohort setting to elucidate any "dose-response" effect of racism, providing further support for its aetiological influence. Further still, if such research could take a life-course perspective it could help to identify how these processes unfold over time.

Building upon the post hoc analyses discussed in the previous section, as well as the other findings, it would be important to repeat this study to see if the findings are reliable and valid if carried out in another setting. This would be important to do, seeing as it is the first time such results have been reported. Secondly, it would be important to elucidate whether or not socio-economic factors do not feature as significant in any subsequent studies as there lack of significance is an important and new negative finding in this study. It may be that the population group is such that there is insufficient variability in socio-economic deprivation: the "double whammy" of psychosis and racism may be too much for most to overcome to enable this variability to be seen. Thirdly, a larger sample size may reduce the potential for lack of significance in the post hoc interaction and

stratification analyses. The use of a more subtle adherence instrument with finer gradations may be more illuminating but may be at the expense of taking longer to complete and least to non-response necessitating further imputation. Finally, if an interim adherence score could actually be obtained rather than computed and the follow-up was longer, more useful information may be obtained.

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Until the findings are corroborated or strengthened by their repetition in other studies it is important to regard them with interest and curiosity but as well with a degree of caution and reservation as their positive implications could foster potentially a whole new avenue of research. Until then these findings should be regarded as valid findings that warrant further study or replication.

Research on the impact of racism on adherence and health should pay further attention to the ways in which victims respond to and attempt to manage these negative experiences. More generally, future research should try and identify the health-enhancing resources and cultural strengths that provide protection from at least some of the pathogenic risk factors that may be faced by this group.

Feelings of shame and powerlessness induced by racism from mental health services were found to improve both adherence and reduce hospital admissions; this is a double-edged sword. Those individuals concerned showed improved adherence and outcome, but at what personal detriment to

their psyches and feelings of self-worth? It would be interesting to determine the association between such feelings of powerlessness and shame related to health services and the longer-term psychological and social functioning of individuals.

If the experiences of racism are viewed as a significant stressor they, like other stressful life events, could be inquired into and recorded within the psychiatric history-taking process. Indeed, increasing patient-centeredness in African-Americans has been raised as an important strategy to address racial/ethnic disparities in health care (Johnson 2004); which builds on previous research where patient activation has been linked to improved health outcome (Stewart 1995). Through sensitive and genuine acknowledgement, this could be a way of relieving the sense of disempowerment and shame the patient might have felt about their experiences. Perhaps such a clinical encounter could strengthen the therapeutic relationship through a sense of mutual trust, and hopefully improve the outcome of people in the UK suffering from the effects of both racism and psychosis.

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6. APPENDIX

6.1a Modified Perceived Racism Scale

Date_____   **Patient ID**_____

SECTION I: Please circle the number which corresponds to how often you experience each event. Please **circle only one number for question "A" and one number for question "B" for each item.** For example, if you felt over the past year that you were you have been called insulting names related to your skin colour, on average, "several times a month," you would circle number "3" next to item 21A. If you felt, over your lifetime you have been called insulting names related to your skin colour, on average "several times a year," you would circle number "'2" next to item 21B.

A. RACISM FROM MENTAL HEALTH SERVICES: (If you have never had psychiatric treatment from mental health services, please skip this section and go to page 2, question 11, section B).

	Because I am Black, I get psychiatric treatment no-one else wants	Not Applicable	Almost Never	Several Times A Year	Several Times A Month	Several Times A Week	Several Times A Day
1	a. How often has this happened in the past year?	0	1	2	3	4	5
2	b. How often has this happened during my life?	0	1	2	3	4	5
	In the mental health system, when different opinions would be helpful, my opinion is not asked for because of my race.						
3	a. How often has this happened in the past year?	0	1	2	3	4	5
4	b. How often has this happened during my life?	0	1	2	3	4	5
	I am treated with less dignity and respect than I would be if I were white.						
5	a. How often has this happened in the past year?	0	1	2	3	4	5
6	b. How often has this happened during my life?	0	1	2	3	4	5
	I am watched more closely than other patients because of my race.						
7	a. How often has this happened in the past year?	0	1	2	3	4	5
8	b. How often has this happened during my life?	0	1	2	3	4	5
	Racial jokes or harassment are directed at me when I am using mental health services.						
9	a. How often has this happened in the past year?	0	1	2	3	4	5
10	b. How often has this happened during my life?	0	1	2	3	4	5
	Because I am Black, I feel as if I am expected to be more balanced than whites (psychologically).						
11	a. How often has this happened in the past year?	0	1	2	3	4	5
12	b. How often has this happened during my life?	0	1	2	3	4	5

Treatment that requires intelligence (such as counselling or psychotherapy) is usually given to Whites, while Blacks get medication.

		Not Applicable	Almost Never	Several Times A Year	Several Times A Month	Several Times A Week	Several Times A Day
13	a. How often has this happened in the past year?	0	1	2	3	4	5
14	b. How often has this happened during my life?	0	1	2	3	4	5

I am often ignored or not taken seriously by my mental health staff because of my race.

15	a. How often has this happened in the past year?	0	1	2	3	4	5
16	b. How often has this happened during my life?	0	1	2	3	4	5

White medical and nursing staff often assume I am more unwell than I am, and treat me as such.

17	a. How often has this happened in the past year?	0	1	2	3	4	5
18	b. How often has this happened during my life?	0	1	2	3	4	5

A white patient who was more unwell than me got discharged before me.

19	a. How often has this happened in the past year?	0	1	2	3	4	5
20	b. How often has this happened during my life?	0	1	2	3	4	5

B. RACISM AT SCHOOL, COLLEGE, COURSES OR STUDY: (How often has this happened to you or have you thought this?)

I have been made to feel uncomfortable in a classroom of White students.

		Not Applicable	Almost Never	Several Times A Year	Several Times A Month	Several Times A Week	Several Times A Day
21	a. How often has this happened in the past year?	0	1	2	3	4	5
22	b. How often has this happened during my life?	0	1	2	3	4	5

Teachers and students have assumed I'm less intelligent because of my race.

23	a. How often has this happened in the past year?	0	1	2	3	4	5
24	b. How often has this happened during my life?	0	1	2	3	4	5

Whites assume I did OK at school only because of positive discrimination- not based on my abilities or intelligence.

25	a. How often has this happened in the past year?	0	1	2	3	4	5
26	b. How often has this happened during my life?	0	1	2	3	4	5

	My work has been judged more critically because I am Black.	Not Applicable	Almost Never	Several Times A Year	Several Times A Month	Several Times A Week	Several Times A Day
27	a. How often has this happened in the past year?	0	1	2	3	4	5
28	b. How often has this happened during my life?	0	1	2	3	4	5

Although I'm equally prepared and responsive, I have been asked for my opinion less than Whites in the class.

29	a. How often has this happened in the past year?	0	1	2	3	4	5
30	b. How often has this happened during my life?	0	1	2	3	4	5

When I have done well academically, I am looked upon as an exception to my race.

31	a. How often has this happened in the past year?	0	1	2	3	4	5
32	b. How often has this happened during my life?	0	1	2	3	4	5

I have found it difficult to trust White teachers and/or students.

33	a. How often has this happened in the past year?	0	1	2	3	4	5
34	b. How often has this happened during my life?	0	1	2	3	4	5

My academic progress has suffered because of my race.

35	a. How often has this happened in the past year?	0	1	2	3	4	5
36	b. How often has this happened during my life?	0	1	2	3	4	5

Although I am equally intelligent, Whites often haven't included me in study groups because I am Black.

37	a. How often has this happened in the past year?	0	1	2	3	4	5
38	b. How often has this happened during my life?	0	1	2	3	4	5

I have been taught in school that Europeans are civilized and Africans are primitive.

39	a. How often has this happened in the past year?	0	1	2	3	4	5
40	b. How often has this happened during my life?	0	1	2	3	4	5

C. EVERYDAY RACISM : (How often has this happened to you or have you thought this?)

		Not Applicable	Almost Never	Several Times A Year	Several Times A Month	Several Times A Week	Several Times A Day
	I have been called insulting names related to my skin colour.						
41	a. How often has this happened in the past year?	0	1	2	3	4	5
42	b. How often has this happened during my life?	0	1	2	3	4	5
	When I go shopping, I am often followed by security guards or watched by White shop assistants.						
43	a. How often has this happened in the past year?	0	1	2	3	4	5
44	b. How often has this happened during my life?	0	1	2	3	4	5
	I hear comments from Whites expressing surprise at my or other "minority" individuals' intelligence or hard work.						
45	a. How often has this happened in the past year?	0	1	2	3	4	5
46	b. How often has this happened during my life?	0	1	2	3	4	5
	People "talk down" to me because I am Black.						
47	a. How often has this happened in the past year?	0	1	2	3	4	5
48	b. How often has this happened during my life?	0	1	2	3	4	5
	I have been refused rental housing which was then later rented to Whites of similar standing (e.g. comparable family income).						
49	a. How often has this happened in the past year?	0	1	2	3	4	5
50	b. How often has this happened during my life?	0	1	2	3	4	5
	I know of people who have been hurt, beaten up, shot by Whites (individuals, gangs, police, BNP or National Front).						
51	a. How often has this happened in the past year?	0	1	2	3	4	5
52	b. How often has this happened during my life?	0	1	2	3	4	5
	I have difficulty getting a loan because I am Black.						
53	a. How often has this happened in the past year?	0	1	2	3	4	5
54	b. How often has this happened during my life?	0	1	2	3	4	5
	I am followed, stopped or arrested by White police more than others because of my race.						
55	a. How often has this happened in the past year?	0	1	2	3	4	5
56	b. How often has this happened during my life?	0	1	2	3	4	5

I have had to make sure that my speech and the way I carry myself do not appear aggressive when dealing with Whites.

		Not Applicable	Almost Never	Several Times A Year	Several Times A Month	Several Times A Week	Several Times A Day
57	a. How often has this happened in the past year?	0	1	2	3	4	5
58	b. How often has this happened during my life?	0	1	2	3	4	5

Waiters and waitresses ignore me and serve Whites first.

59	a. How often has this happened in the past year?	0	1	2	3	4	5
60	b. How often has this happened during my life?	0	1	2	3	4	5

White males talk about not desiring Black women for "serious" relationships but do talk about serious relationships with White women.

61	a. How often has this happened in the past year?	0	1	2	3	4	5
62	b. How often has this happened during my life?	0	1	2	3	4	5

My house has been vandalized because of my race.

63	a. How often has this happened in the past year?	0	1	2	3	4	5
64	b. How often has this happened during my life?	0	1	2	3	4	5

I have had to allow Whites to obtain the best seats in public places.

65	a. How often has this happened in the past year?	0	1	2	3	4	5
66	b. How often has this happened during my life?	0	1	2	3	4	5

I have been denied hospitalization or medical care because of my race.

67	a. How often has this happened in the past year?	0	1	2	3	4	5
68	b. How often has this happened during my life?	0	1	2	3	4	5

I have known Black men who have been hurt or killed for talking to White women

69	a. How often has this happened in the past year?	0	1	2	3	4	5
70	b. How often has this happened during my life?	0	1	2	3	4	5

71   I have encountered rules that restrict my access to: housing, marriage, jobs, use of public facilities because of my race (Please circle each one that applies.

72	b. How often has this happened during my life?	0	1	2	3	4	5

D. RESPONSES TO RACIST STATEMENTS: (How often have you heard this said?)

"Over the past few years, Blacks have had more economic and educational breaks than they deserve."

		Not Applicable	Almost Never	Several Times A Year	Several Times A Month	Several Times A Week	Several Times A Day
73	a. How often has this happened in the past year?	0	1	2	3	4	5
74	b. How often has this happened during my life?	0	1	2	3	4	5

"Blacks should not push themselves into places where they are not wanted."

75	a. How often has this happened in the past year?	0	1	2	3	4	5
76	b. How often has this happened during my life?	0	1	2	3	4	5

"Most Blacks are on benefits because they are too lazy to get a job."

77	a. How often has this happened in the past year?	0	1	2	3	4	5
78	b. How often has this happened during my life?	0	1	2	3	4	5

"If a Black family moved in next door to me, I would seriously think about moving."

79	a. How often has this happened in the past year?	0	1	2	3	4	5
80	b. How often has this happened during my life?	0	1	2	3	4	5

"Black people are generally not as smart as Whites."

81	a. How often has this happened in the past year?	0	1	2	3	4	5
82	b. How often has this happened during my life?	0	1	2	3	4	5

"Black men have an 'animal-like' passion in bed."

83	a. How often has this happened in the past year?	0	1	2	3	4	5
84	b. How often has this happened during my life?	0	1	2	3	4	5

"Some Blacks are so touchy about their rights that it is difficult to get along, with them."

85	a. How often has this happened in the past year?	0	1	2	3	4	5
86	b. How often has this happened during my life?	0	1	2	3	4	5

SECTION 11: In answering the questions in this section, PLEASE CIRCLE A RESPONSE NEXT TO EACH EMOTION THAT BEST DESCRIBES HOW YOU FEEL:

When I experience RACISM FROM MENTAL HEALTH SERVICES,

		Not at All		Moderately		Extremely
I generally feel: 87	Angry	1	2	3	4	5
88	Hurt					
89	Frustrated					
90	Sad					
91	Powerless					
92	Hopeless					
93	Ashamed					
94	Strengthened					

When I have experienced RACISM AT SCHOOL, COLLEGE, COURSES OR STUDY,

		Not at All		Moderately		Extremely
I generally feel: 95	Angry	1	2	3	4	5
96	Hurt					
97	Frustrated					
98	Sad					
99	Powerless					
100	Hopeless					
101	Ashamed					
102	Strengthened					

When I experience EVERYDAY RACISM,

		Not at All		Moderately		Extremely
I generally feel: 103	Angry	1	2	3	4	5
104	Hurt					
105	Frustrated					
106	Sad					
107	Powerless					
108	Hopeless					
109	Ashamed					
110	Strengthened					

When I hear RACIST STATEMENTS,

		Not at All		Moderately		Extremely
I generally feel:	Angry	1	2	3	4	5
111						
	112 Hurt					
	113 Frustrated					
	114 Sad					
	115 Powerless					
	116 Hopeless					
	117 Ashamed					
	118 Strengthened					

SECTION III: In answering the questions in this section, PLEASE MARK THE <u>BEHAVIOUR OR BEHAVIOURS</u> THAT BEST DESCRIBE HOW YOU DEAL WITH RACISM:

When I experience RACISM FROM MENTAL HEALTH SERVICES, I generally deal with it by:

119) speaking up _____
120) accepting it _____
121) ignoring it _____
122) trying to change things _____
123) keeping it to myself _____
124) working harder to prove them wrong _____
125) praying _____
126) avoiding it _____
127) getting violent _____
128) forgetting it _____
129) OTHER (please list)_____

When I experience RACISM IN ACADEMIC SETTINGS, I generally deal with it by:

130) speaking up _____
131) accepting it _____
132) ignoring it _____
133) trying to change things _____
134) keeping it to myself _____
135) working harder to prove them wrong _____
136) praying _____
137) avoiding it _____
138) getting violent _____
139) forgetting it _____
140) OTHER (please list)_____

When I experience EVERYDAY RACISM (e.g., a restaurant), I generally deal with it by:

141) speaking up _____
142) accepting it _____
143) ignoring it _____
144) trying to change things _____

145) keeping it to myself ____
146) working harder to prove them wrong ____
147) praying ____
148) avoiding it ____
149) getting violent ____
150) forgetting it ____
151) OTHER (please list)_____

When I hear RACIST STATEMENTS, I generally deal with it by:

152) speaking up ____
153) accepting it ____
154) ignoring it ____
155) trying to change things ____
156) keeping it to myself ____
157) working harder to prove them wrong ____
158) praying ____
159) avoiding it ____
160) getting violent ____
161) forgetting it ____
162) OTHER (please list)_____

A. RACISM ON THE JOB: (If you have never been employed, please skip this section and go to page 2, question 11, section B).

		Not	Almost Never	Several Times	Several Times	Several Times	Several Times

1. Because I am Black, I'm assigned the jobs no one else wants to do.

   a. How often has this happened in the past year? 0 1 2 3 4 5
   b. How often has this happened during my life? 0 1 2 3 4 5

2. At work, when different opinions would be helpful, my opinion is not asked for because of my race.

   a. How often has this happened in the past year? 0 1 2 3 4 5
   b. How often has this happened during my life? 0 1 2 3 4 5

3. I am treated with less dignity and respect than I would be if I were white.

   a. How often has this happened in the past year? 0 1 2 3 4 5
   b. How often has this happened during my life? 0 1 2 3 4 5

4. I am watched more closely than other workers because of my race.

   a. How often has this happened in the past year? 0 1 2 3 4 5
   b. How often has this happened during my life? 0 1 2 3 4 5

5. Racial jokes or harassment are directed at me at work.

   a. How often has this happened in the past year? 0 1 2 3 4 5
   b. How often has this happened during my life? 0 1 2 3 4 5

6. Because I am Black, I feel as if I have to work twice as hard.

   a. How often has this happened in the past year? 0 1 2 3 4 5
   b. How often has this happened during my life? 0 1 2 3 4 5

		Not	Almost Never	Several Times A Year	Several Times A Month	Several Times A Week	Several Times A Day

7. Tasks that require intelligence are usually given to Whites, while Blacks get those that don't require much thought.

	Not	Almost Never	Several Times A Year	Several Times A Month	Several Times A Week	Several Times A Day
a. How often has this happened in the past year?	0	1	2	3	4	5
b. How often has this happened during my life?	0	1	2	3	4	5

8. I am often ignored or not taken seriously by my boss because of my race.

	Not	Almost Never	Several Times A Year	Several Times A Month	Several Times A Week	Several Times A Day
a. How often has this happened in the past year?	0	1	2	3	4	5
b. How often has this happened during my life?	0	1	2	3	4	5

9. Whites often assume I work in a lower status job than I do and treat me as such.

	Not	Almost Never	Several Times A Year	Several Times A Month	Several Times A Week	Several Times A Day
a. How often has this happened in the past year?	0	1	2	3	4	5
b. How often has this happened during my life?	0	1	2	3	4	5

10. A white co-worker with less experience and qualifications got promoted before me.

	Not	Almost Never	Several Times A Year	Several Times A Month	Several Times A Week	Several Times A Day
a. How often has this happened in the past year?	0	1	2	3	4	5
b. How often has this happened during my life?	0	1	2	3	4	5

Date_____   **Patient ID**_____

DRUGS ATTITUDES INVENTORY

Please decide whether you find the following statements 'True' or 'False', and tick the relevant box:

TRUE   FALSE

1. Medication makes me feel more normal

2. Medication makes me feel like a zombie

3. I only take medication when I am sick

4. By staying on medication I can prevent a breakdown

5. I feel more relaxed on medication

6. The bad things about medication outweigh the good

7. My thoughts are clearer on medication

8. I feel tired and sluggish on medication

9. I take medication of my own free choice

10. It is unnatural to take medication

Date_____   **Patient ID**_____
KEMP ET AL ADHERENCE SCALE
How does the patient's primary nurse rate their adherence? (Tick one box only.)

1) Complete refusal

2) Partial refusal (e.g., refusing depot drugs or accepting only the minimum dose)

3) Reluctant acceptance (accepting only because treatment is compulsory or questioning the need for treatment often – every two days)

4) Occasional reluctance about treatment (questioning the need for treatment once a week)

5) Passive acceptance

6) Moderate participation (some knowledge of and interest in treatment and no prompting needed to take the drugs)

7) Active participation, ready acceptance, and taking some responsibility for treatment

Date _____   Patient ID _____

4. Life Chart   8

LIFE CHART SCORE SHEET-Case Management Trial
Most Recent ▮▮ Years

Section: Residence

Ever in independent community living   indev04 ☐
0=no 1=yes

IF NO, GO TO ITEM 4

6. Level of supervision   spvis04 ☐
    1=24 hour onsite staff
    2=no 24 hour onsite staff

Months in independent community   indmon04 ☐☐
living

7. DAYS homeless/vagrant   vagr04 ☐☐☐
(describe at foot of page)

hecom04 ☐

3. Main Household composition
    1=alone
    2=nuclear family with spouse and/or children
    3=nuclear family with parents
    4=extended family
    5=joint family with siblings
    6=friends
    7=other

8. DAYS in jail   jail04 ☐☐☐
(include custody of any length;
describe at foot of page)

anysup04 ☐☐

Months in ANY supervised residence

9. Confidence rating residence section   conres04 ☐
        1= very few items
        2= some items
        3= most items
        4= almost all/all items

Months in a supervised residence for persons with mental illness   misup04 ☐☐

Comments

. Life Chart

LIFE CHART SCORE SHEET-Case Management Trial
Most Recent ▓▓ Year

ction: Work

jobb94

1 _obs   0=no 1=yes   [ ]
_0, GO TO ITEM 8

jobfult94

2. _onths in full time jobs   [|]

jobpt94

3. Months in part time jobs   [|]

jobsh94

4. _onths in sheltered work   [|]

jobpf94

_erformance in jobs held   [ ]
    1=very good   2=good
    3=poor   4=very poor

jobtp94

6. Type of usual job: registrar general   [ ]
Type of usual job:_____

jobiv94

7. Level of usual job   [ ]
    1=higher   2=the same/roughly equivalent
    3=lower   4=much lower

hswf94

_ull time housewife   [ ]
    0=no   1=yes

_0, GO TO ITEM 12

hwfmon94

_onths as full time housewife   [|]

hwfpf94

10. Performance in full time housework   [ ]
    1=very good   2=good
    3=poor   4=very poor

_ments

---

wrlgh94

11. Global Work/Housework rating   [ ]
    1=good   2=fair
    3=poor

stud94

12. Months as full time student   [|]

retir94

13. Months in retirement   [|]

unemp94

14. Months unemployed   [|]

IF NOT UNEMPLOYED, GO TO ITEM 19

Unemployment related to:
Use these ratings for items 15-18
    0=not at all   1=a little
    2=some   3=a lot

empm94

15. Mental Illness   [ ]

empdis94

16. Physical illness or disability   [ ]

empgen94

17. General employment situation   [ ]

empoth94

18. Other   [ ]

conemp94

19. Confidence rating employment section   [ ]
    1= very few items   2= some items
    3= most items   4= almost all/all items

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LIFE CHART SCORE SHEET- Case Management Trial
Most Recent ▓▓ Years

Section: Symptoms

symsev04 ☐

Usual symptom severity
1=severe   2=moderate
3=mild   4=recovered

neg04 ☐

Presence of negative symptoms over last two years
0=no   1=yes, usually mild
2=yes, usually prominent

course04 ☐

Course Type
1=episodic-no episode longer than 6 MONTHS
2=continuous-no remission longer than 6 MONTHS
3=neither episodic nor continuous
4=never psychotic in this period

IF EPISODIC, OR NEITHER EPISODIC NOR CONTINUOUS RATE ITEMS 4-6

rem04 ☐

4. Type of remission
1=mainly complete   2=mainly incomplete
3=mixed

numpsy04 ☐☐

Number of psychotic episodes

lgpsy04 ☐☐

Months of longest psychotic episode

IF CONTINUOUS, RATE ITEM 7

fluc04 ☐

7. Fluctuation in symptoms
1=minimal or none   2=medium
3=large

IF NEVER PSYCHOTIC IN THIS PERIOD, RATE ITEM 8.

rem204 ☐

8. Type of remission
1=mainly complete   2=mainly incomplete
3=mixed

Comments

SUICIDE ATTEMPTS/ASSAULTS

thsuic04 ☐

9. Thoughts about suicide
0=not at all
1=occasionally
2=often

atsuic04 ☐

10. Suicide attempt(s)   0=no   1=yes
(include any act of DSH & describe at foot of page, including dates of (para)suicide)

IF NO, GO TO ITEM 14

nmsuic04 ☐☐

11. Number of suicide attempts

FOR RATINGS 12 AND 13, USE THE SUICIDE ATTEMPT THAT CAUSED THE SUBJECT THE MOST INJURY:

avsuic04 ☐

12. Severity
1=mild 2=moderate   3=severe

insuic04 ☐

13. Intent
1=mild 2=moderate   3=severe

ass04 ☐

14. Assault(s)
0=no   1=yes

IF NO, GO TO ITEM 17

nmass04 ☐☐

15. Number of assaults

avass04 ☐

16. Severity
1=mild 2=moderate   3=severe

nonpsy04 ☐

17. Non-psychotic episodes
0=no   1=yes

consym04 ☐

18. Confidence rating for Symptoms section
1=very few items   2=some items
3=most items   4=almost all/all items

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LIFE CHART SCORE SHEET-Case Management Trial
Most Recent ██ Years

Section: Treatment

1. Days in the hospital for psychiatric problems [ ][ ][ ] hosmon04

2. Number of hospital admissions for psychiatric problems [ ][ ][ ] hosnum04

3. Days in longest hospital stay for psychiatric problems [ ][ ][ ] hoslg04

4. Days in the hospital for other reasons [ ][ ][ ] hosoth04

5. Months on anti-psychotics [ ][ ] antpsy04

6. Months on anti-depressants [ ][ ] antdep04

7. Months on lithium [ ][ ] lith04

8. Months on anti-cholinergics [ ][ ] antcho04

9. Months on other medication
(describe at foot of page) [ ][ ] othmed04

10. Who mainly prescribed anti-psychotics? [ ] whopre04
1=general practitioner 2=psychiatrist
3=other

Comments

FOR ITEMS 11-18 RATE WHETHER
RECEIVED TREATMENT OR NOT:
0=no 1=yes

11. ECT [ ] EC

12. Day treatment/rehabilitation [ ] da:

13. Counselling/psychotherapy [ ] psyt
(describe at foot of page)

14. Family meetings [ ] famm

15. "traditional" or "alternative" healing [ ] alt
(eg, spiritual; hypnosis; acupuncture; regression into previou
life, etc; include if not sure and describe at foot of page)

16. Other treatments for psychiatric problems [ ] othth
(describe at foot of page)

17. Treatment for drug problem [ ] drugtr

18. Treatment for alcohol problem [ ] alcotr

USE THESE RATINGS FOR ITEMS 19-21:
0=never   1=sometimes
2=most of the time

19. Family provided substitute for [ ] famsubf
Institutional care

20. Family monitored medications [ ] fammonf

21. Family involved in treatment decisions [ ] famdecf

22. Confidence rating treatment section [ ] confrt
1= very few items   2= some items
3= most items   4= almost all/all items

The next few questions are about things that may have happened to you since I last saw you, twelve months ago.

1. During that time, has anyone physically attacked you?
   (a) YES
   (b) NO

   If YES, how many times have you been attacked in the last twelve months?
   (a) ONCE
   (b) MORE

   If MORE, then enter number of times respondent has been attacked in the last twelve months_____

   Do you think you were attacked for reasons to do with your ethnicity?
   (a) YES
   (b) NO

2. In the last twelve months, has anyone deliberately damaged any property that belonged to you?
   (a) YES
   (b) NO

   If YES, how many times has this happened in the last twelve months?
   (a) ONCE
   (b) MORE

   If MORE, then enter number of times respondent has been attacked in the last twelve months_____

   Do you think any of these attacks were for reasons to do with your ethnicity?
   (a) YES
   (b) NO

3. In the last twelve months, has anyone insulted you for reasons to do with your ethnicity? By insulted, I mean verbally abused, threatened, or been a nuisance to you?
   (a) YES
   (b) NO

   If YES, how many times has this happened in the last twelve months?
   (a) ONCE

(b)   MORE

If MORE, then enter number of times respondent has been insulted in the last twelve months_____

The next two questions are about health services.

4. Do you think you have had a good standard of care from your mental health services?
    (a)   YES
    (b)   NO

    If NO, do you think it was because of:
    (a)   generally poor care being offered to everyone
    (b)   your being just unlucky
    (c)   the type of mental health problem you have
    (d)   your gender
    (e)   your ethnic group
    (f)   your race
    (g)   your religion
    (h)   your social class
    (i)   another reason_____
    (PLEASE CIRCLE THOSE WHICH APPLY)

5. If you have not received a good standard of care, did you complain to anyone about this?

    (a)   YES
    (b)   NO

    If NO, was that because:
    (a)   no one would listen
    (b)   you couldn't be bothered
    (c)   you didn't think it was important
    (d)   it wouldn't be taken seriously
    (e)   people would get angry
    (f)   there wasn't the time
    (g)   you could have got worse care
    (h)   another reason_____
    (PLEASE CIRCLE THOSE WHICH APPLY)