Racism in the Lives of Ethnic Minority Service-Users with Psychosis

By Nazakat Wagle

A thesis submitted in partial fulfilment of the requirements of the Doctorate in Clinical Psychology

University of Leicester
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Abstract

A literature review regarding the impact of racism upon ethnic minority clients found a small number of papers, mainly American in origin. These were centred mainly in the fields of trauma and stress-coping and, aside from war veterans, upon non-clinical populations.

A grounded theory investigation of the experiences of racism by ethnic minority service users with psychosis was conducted. After conducting eight interviews, a core category entitled ‘struggling against dehumanisation’ and a process model were developed which attempted to depict the processes underlying experiences of racism. The limitations of this model and possible future directions are discussed.

A critical appraisal of the research process is also presented which looks at specific problems encountered during research including the use of terminology, sampling considerations, emotional distress during interviews and the difficulties of analysis.
Section 1

Literature Review

Psychological research on the impact of racism upon mental health, especially with regard to ethnic minority service users with psychosis
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Psychological research on the impact of racism upon mental health, especially with regard to ethnic minority service-users with psychosis

Abstract

A literature review was conducted into how the experience of racism by the ethnic minority users of mental health services had been researched by clinical psychology in the UK. No such research appeared to exist. The bulk of the available research literature instead came from abroad, especially the USA and was confined to studies involving the general or student population and war veterans. It spanned two main areas: stress-coping and post-traumatic-stress-disorder.

In the UK, the discipline of clinical psychology would therefore appear to fail the need, highlighted in NIMHE (2003), to account for this type of aversive experience, specifically with regards to the profession’s research activity. A handful of studies are also reported that have looked at in-patient experiences. These have suggested the need to think about how ethnic minority clients in these settings might be being treated and their potential disempowerment.
Introduction

This review of the literature began in response to working with ethnic minority clients of the clinical psychology section of an adult Community Mental Health Team who had faced adverse racial events. It posed the following question: what psychological research had been conducted on the impact of racism upon mental health, both for service-users with psychosis or other mental health difficulties, and for the wider population.

National Institute of Mental Health in England - NIMHE (2003) highlighted various factors influencing the experience of ethnic minority users of mental health services. These included how various psycho-social factors (such as increased levels of social adversity, poorer social networks or less available support mechanisms) might operate to increase the stress burden upon ethnic minority service-users. The report also highlighted how differences in a number of service-related areas such as access to mental health services or experience of mental health interventions and their outcomes, might be interrelated and lead to poorer outcomes for people from ethnic minorities. The report highlighted the need for clinicians to take account of the role of racially aversive experiences in the lives of ethnic minority service-users.

Search strategies

A literature search was conducted that targeted articles from the field of clinical psychology that had made racism an *a priori* and main focus of research. This was done through using the following psychological and social science databases: OCLC First Search,
PSYCHINFO and BIDS IBSS. This revealed very few articles of relevance to the goal of the literature review. A number of ancillary searches were also run. These combined search terms, for instance ‘racism’, ‘ethnic minority’, ‘prejudice’ and ‘stigma’, with terms such as ‘trauma’, ‘post-traumatic stress disorder’, ‘stress’, ‘mental health’, ‘psychosis’, ‘schizophrenia’. These searches also furnished very few results.

Hand searches of peer reviewed, UK clinical psychology journals (including the *British Journal of Clinical Psychology* and *Psychology, Psychotherapy Research and Practice*) were also conducted but these elicited no new material. Although the experience of racism had long been researched by social psychology, the clinical implications of such events appeared to not have been a focus of research by the discipline of clinical psychology in the UK. Extensive searches revealed one research study, by counselling psychologists in Scotland, where the psycho-social impact of racism and victimisation had been investigated. A small amount of research had been conducted by psychologists in the USA.

The lack of research also appeared to be reflected in other disciplines and in wider mental health services. Much of the British literature found, though also appearing limited to theoretical and not research papers, came from the field of psychiatry. Such studies were found by a combination of methods. These included hand searches of the British Journal of Psychiatry, literature searches using PSYCHINFO and BIDS IBSS and through using references in published articles to source further studies.
Overview of the literature review

The current review begins with a brief overview of research regarding prevalence rates of psychosis and how stress and trauma can impact upon its course. Following this, the debate within the literature regarding the association of racism and mental health and some of the conceptual underpinnings used to understand this, is examined.

It should be noted that in the review of research studies that then follows, the limited domestic literature that was found regarding the interaction of racism and mental health, led to an examination of foreign, especially American, studies of racism. These studies mainly fell into the areas of stress-coping and trauma work and will form the next focus of examination. Literature regarding the impact of racism specifically upon clinical populations, will be examined last of all.

The role of trauma and stress in psychosis

Rates of psychosis amongst immigrant populations:

Studies such as King, Coker, Leavey, Hoare, Johnson-Sabine (1994) and Bhugra, Hilwig, Hossein, Marceau, Neehall, Leff, Mallett and Der (1996) have found significantly increased rates of psychosis amongst African-Caribbean samples of the population. These finding have conflicted though with studies from the West Indies which do not show similar elevated rates (Hickling and Rodgers-Johnson, 1995; Bhugra, Leff, Mallett, Der, Corridan & Rudge, 1997; Mahy, Mallett, Leff, Bhugra, 1999). Instead the rates in this population were comparable to those in the UK White population.
Other studies have not found the same results. The Canadian Task Force on Mental Health Issues (1998) for instance, reviewed the evidence base around psychosis and migration. They found that the number of studies suggesting that there were higher prevalence rates of psychosis amongst immigrant populations, was equalled by the number of studies showing no such elevation in rates. The most comprehensive British study of rates of psychotic illness in the UK population, the EMPIRIC study (Sproston and Nazroo, 2002), found that the rates of psychosis amongst ethnic minority men was only slightly higher than that of the White population. The overall inflation in rates for ethnic minority groups (approximately seventy-five percent higher) seemed to be due to a higher incidence amongst women. This was the only result to reach statistical significance. The overall rate for ethnic minority populations did not reach statistical significance.

The role of trauma in psychosis:

Various studies have also examined the role of trauma in psychosis (Morrison, Frame and Larkin, 2003; Read, van Os, Morrison and Ross, 2005; Steel, Fowler and Holmes, 2005). Jacobson and Richardson (1987) for instance, found that in a sample of one hundred psychiatric in-patients, eighty-one percent had suffered serious assaults. Other studies have found somewhat lower but still highly significant elevations in the rates of traumatic experience (Beck and van der Kolk, 1987; Greenfield, Strakowski, Tohen 1994).

Kuipers, Garety and Fowler (1996) noted that their clients had often been exposed to distressing life events prior to psychotic breakdown. These included not only traumatic experiences but also difficult experiences such as unwanted pregnancy (Myhrman, Rantakallio, Isohanni, Jones & Partanen, 1996) and disrupted attachments with their parents (Parker, Johnston & Hayward, 1988). Various authors have suggested that early experiences
can negatively influence information processing regarding self and others (Birchwood, Meaden, Trower, Gilbert & Plaistow, 2000 & Garety, Kuipers, Fowler, Freeman & Bebbington, 2001). These appraisal patterns or ‘schema’ could also become active in positive symptoms such as voices (Steel, Fowler & Holmes, 2005). Stampfer (1990) has also pointed out how the negative symptoms of psychosis appear close to those seen in chronic post-traumatic stress disorder.

The role of stress:

It has also been hypothesised that highly stressful life-events might contribute to the destabilising of the cognitive system (Ciompi, 1994). Various studies (Brown & Birley, 1968; Coleman, 1979; Nuechterlein & Dawson, 1984; Norman & Mella, 1993) have looked at how the occurrence of major stressful life events might precede the onset of psychosis. Brown and Birley (1968), for instance, found that as many as 50% of their sample had experienced such an event in the three weeks prior to onset or relapse.

A prospective study by Hirsch, Bowen, Emami, Cramer, Jolley, Haw and Dickinson (1996) suggested that the more life events a person with psychosis faced, the more likely there was to be a risk of relapse. Where the number of events faced was twice the mean for the sample as a whole, risk of relapse almost doubled.

The potential impact of racism upon psychosis:

Various authors have suggested that psychosis might flourish under certain types of adverse environmental conditions (Mirowsky and Ross, 1983; Mirsky, Silberman, Latz and Nagler, 1985). For instance, Mirowsky and Ross (1983) suggested that delusions might flourish in environments where factors, such as powerlessness or threat of victimisation,
might operate. Birchwood, Mason, MacMillan and Healy (1993) studied the relapse beliefs of clients and how negative self-beliefs could lead to feelings of failure and unworthiness. They suggested that two major cognitive themes in psychosis were 'powerlessness' and 'negative self-evaluations'.

Summary:

Such research appeared to indicate that facing racism might have various impacts upon the mental health of service-users with psychosis. It could generate stress and possibly contribute to overall distress in the build-up to a first episode of psychosis (FEP). Traumatic events involving racial assault might also play a part in the establishment of a psychotic illness. It therefore seemed pertinent to examine how racism had been investigated in this regard by clinical psychology. Themes such as powerlessness and negative self-evaluation also appeared vital in understanding how racism might have led to various psycho-social sequelae for a service-user with psychosis such as eroded self-esteem, loss of ambition or hope and depression.

Racism and mental health

In the wider fields of psychology, as well as in psychiatry and social studies, the impact of prejudice upon ethnic minority people has been demonstrated to be widespread, covering various domains such as employment and housing (Winder, 1952; Pettigrew & Meertens, 1995) and also mental health service provision (Johnson & Orrell, 1996). The EMPIRIC study (Sproston & Nazroo, 2002) looked at rates of psychiatric illness within the ethnic minority population of Great Britain. The study found heightened difficulties in social
functioning and, amongst certain ethnic minority groups, of higher rates of common mental health problems. The authors highlighted the need to research how racism might impact upon such findings.

Prejudice within the general population regarding mental illness has also been demonstrated (Bhugra, 1989; Brockington, Hall, Levings & Murphy, 1993) and is often characterised as forming the basis of 'stigma'. Goffman (1963) had earlier defined stigma as a type of attitude arising between individuals or social groups, or between a social group and an individual. An ascription would be made that 'others' possessed an attribute that marked them out as different and “less desirable...possibly bad, dangerous or weak” (p3). Various authors have characterised stigmatisation by wider society as one of the key obstacles in the path of persons suffering or recovering from mental health problems (Gingerich, 1998; Shepherd, 1998; Sayce, 2000). Additionally, a doubly vicious circle of rejection for ethnic minority service-users has been suggested (Repper, Sayce, Strong, Willmot & Haines, 1997; Sayce, 2000):

- firstly on the basis of colour stereotypes such as “young black men are violent”; and
- secondly on the basis of their mental health status or label, itself a conduit for stereotypes of violent, crazed and homicidal behaviour (Philo, Henderson & McLaughlin, 1993; Philo, Secker, Platt, Henderson, McLaughlin & Burnside, 1996; Sayce, 1995).

Racism, therefore, has often been cited as a significant additional burden for ethnic minority service-users facing mental health problems (Sayce, 2000).

As well as effecting emotional well-being, racism was also believed to dissuade ethnic-
minority service-users from attempting to access mental health resources. Possible reasons for this were the fear of additional racism, misunderstanding, misinterpretation and coercion (Perkins & Moodley, 1993; Johnson & Orrell, 1996; Singh, Croudace, Beck & Harrison, 1998). The biopsychosocial impact of additional prejudice, beyond the stigma of mental illness, has often been highlighted as requiring further scrutiny (Repper, Sayce, Strong, Willmot & Haines, 1997; Sayce, 2000).

Defining racism:

Fernando (1988) characterised racism as events involving “ridicule, scorn, contempt and degrading treatment by others and which elicits anger, rage and damage to self-esteem”. McConahay and Hough (1976) suggested that racism might extend from events ‘objectively’ viewable as racist, to ambiguous situations where stress was generated through interaction with belief systems. Thus Pierce (1995) and Solorzano, Ceja and Yosso (2000) suggested that additional stress might be created by ‘micro-aggressions’ such as being ignored whilst waiting for service or assumptions regarding occupation. Similarly, Outlaw (1993) depicted racism as a ‘continuous’ stressor that pervaded identity and daily experience, whilst Delgado and Stephanie (2001) suggested that racism should not be viewed as an ‘extra-ordinary’ occurrence in people’s lives, but rather an ‘ordinary’ one.

It has also been suggested that racism should be defined “as a categorical ascription of relative inferiority that suggests a prescription of inferior treatment” (Leach, 2005; p442). In such a definition a racist action would then only need to suggest inferiority to an ethnic minority person, as opposed to demonstrate the acting out of prejudice. In other words, defining racism in this way would allow psychologists to immediately focus upon psychological factors such as emotional impact. This might include events that might appear
innocuous, everyday or ambiguous to the outside observer but not to an ethnic minority person (Outlaw, 1993; Delgado and Stephanie, 2001).

**Possible psychological sequelae of racism:**

Previous authors have noted that racism appeared to be widespread and under-reported (Bowling & Saulsbury, 1992). Where the victim perceived an event as racial, there appeared to be a compounding of the distress suffered (Home Office, 1989). Fernando (1984) believed that such exposure could lead to various psychological and psycho-social sequelae. These included depression and helplessness (Seligman, 1975), threats to self identity or self-esteem, and the experience of ‘loss’ or hopelessness when faced with suddenly unattainable resources. The latter might include facing discrimination in the workplace or in housing for instance. No empirical research was found that investigated these suggestions.

Similarly Erikson (1968) suggested that where racial status rather than the “wish or will to learn....decide(d) worth....the human propensity for feeling unworthy may be fatefully aggravated as a determinant of character development” (p124). Rosenberg (1979) also suggested that young people might face feelings of shame when experiencing a negative event relating to their group membership. Rosenberg believed that this might lead to such a person’s sense of identity being eroded. In a qualitative study of the views of children in a multicultural school in London, Marshall, Stenner and Lee (1999) found that the racially stigmatising attitudes of the parents of their peers could have a grave impact upon young people from both ethnic minority and White backgrounds. Other studies have demonstrated that peer victimisation based upon ethnicity can have a more debilitating effect upon self-esteem than other forms of such bullying (Verkuyten & Thijs, 2001).
Dalal (2001) suggested that racism had often been viewed in a "reductive" fashion within the psychodynamic psychotherapy literature. Instead of questioning how racist events might have caused internal distress, the experience of racism was more likely to have been seen as an effect of other internal difficulties i.e. as symptoms or projections of such a state. Authors such as Keval (2001) suggested that the experience of racism could have a far-reaching impact upon the identity of a person. For instance, feelings of rejection (by society, peers etc.) might be generated. These, in turn, might strip personal defences and expose vulnerable areas of functioning. Anxieties relating to themes of separation and loss in an individual's personal history might then be at risk of revival. Miliora (2002) suggested that racism would make its victim feel the experience of being regarded as "less than human" by the surrounding social milieu. This might damage self-esteem, ambition and cause "depression of disenfranchisement" where the victim might feel "abjectly un-grandiose" (p44).

Guishard (1992) believed that the psychological impact of experiencing racism might be compounded by a belief that society, media and institutions such as the police and the mental health services perceived immigrant populations as lazy, parasitic or violent. Such views would appear to still operate today, for instance in our views regarding "asylum-seekers" (Pittaway & Bartolomei, 2001).

**Racism as a biopsychosocial stressor**

Clark, Andersen, Clark and Williams (1999) have formulated a biopsychosocial model (see Figure 1) of how racism might act as a stressor for persons of African-American background. They adapted a general model of stress-coping (Lazarus & Folkman, 1984)
recognition or first perception of environmental pressure

[Box]
- demands of situation + beliefs regarding ability to cope.
- interplay of various moderators (i.e., constitutional, sociodemographic, psychological, behavioural)

[Arrow] ->

occurrence of a psychological stress response with various repercussions:
- emotional
- behavioural
- sensory
- imaginal
- cognitive
- interpersonal
- physiological

[Arrow] ->

application of a coping response that is able to be made or is perceived as available to be made

[Arrow] ->

feedback - a reduction in stress or it stays static / increases. Therefore possible further sequelae - perception of self, having tried a strategy that did not work, as having failed.

Figure 1: A model of possible processes involved in a stress response to the experience of a race attack or other event perceived as racist (based upon Clark, Andersen, Clark and Williams (1999))
whereby a stress response began with the occurrence of 'stressors', such as an incident of racism, within the environment. Clark et al. (1999) believed that the triggering of such a stress response might be influenced by various moderating influences. These included various constitutional, sociodemographic, psychological and behavioural factors or responses. The manner in which such stressors were then mediated, the level of success or failure of these attempts to cope and the perception of this by the individual, were all believed to influence outcome. In the review of the literature that follows, some key findings in this area are discussed. It is important to note that the overall model, inclusive of the underlying processes that it implies, appears to have remained untested.

**Prevalence of racial stress**

Landrine and Klonoff (1996) compared prevalence rates and features of perceived discrimination to measures of physical and mental health and interview information regarding psychiatric symptomatology. The entire sample of 153 African-American people reported the occurrence of a racist event of some description in their lifetime. Almost all had found the event to be stress inducing. As the number of such events increased so to, it appeared, did the prevalence of psychiatric symptoms. These included symptoms of heightened anxiety and depression.

Sanders-Thompson (2002) looked at how levels of daily stress and experiences of racism affected different ethnic groupings. The minority groups were more likely to report discrimination in multiple domains of life, African-Americans with a significantly greater frequency than other groups. The impact of discrimination also appeared significantly higher
for African-American participants than other groups. It was unclear how a participant’s experiences of discrimination co-varied with work satisfaction, gender and income (varying from nothing for the unemployed participants to participants on high, possibly ‘executive’ scales of salary). Such variables might have shed light on the experiences of women in employment and the difference that ethnic and socio-economic status made to this. Over two-thirds of the sample was female but gender discrimination was a potential confounding factor in this study that was not adequately reported. In addition, Sanders-Thompson (2002) noted that Asian-American and Latino-American participants appeared to suffer the highest degrees of stress. For the Asian-American group, this was maintained throughout follow-up. This was unable to be investigated further because of the small number of clients from these backgrounds within the sample. In addition, the sensitivity of the measures in drawing out experiences of racism and discrimination within these populations was called into account.

Studies such as this and Landrine and Klonoff (1996) did not address how the process of coping with a stress-inducing event might be mediated though, for instance as suggested by Clark, Andersen, Clark and Williams’ (1999) model.

**Negative physical health outcomes**

Various studies have investigated how stress might be related to negative physical health outcomes (Palmer & Dryden, 1995; Pearlin, 1998; Wiebe & Williams, 1992). The possible contribution of racism to stress and physical health has also come under scrutiny, especially in the USA. Such studies have indicated an increased risk of hypertension and cardiovascular illness amongst African-American and other minority sectors of the US population.
An exploratory study by Krieger (1990) for instance, used a telephone survey to ask fifty African-American and fifty White women about their medical histories and their response to any aversive circumstances. Where African-American women reported that they had kept quiet about the occurrence of a racially aversive event, they were also over four times more likely to report hypertension in their medical histories, than those African-American women who had sought social support. This study was limited by a small sample size and the sensitivity of the information-gathering method. The influence of confounding factors such as physical fitness, socio-economic status and family history of cardiovascular illness were difficult to ascertain. The study did raise questions regarding gender responses to racial abuse and subsequent health outcomes. Future research, perhaps using qualitative interviewing methods, might uncover some of the underlying processes involved in:

i) the coping responses attempted

ii) the subsequent psychological or psycho-social ramifications

iii) the time course of the evolution of health problems.

Such a follow-up might also be able to investigate how psychological factors such as coping, attributions and identity had converged with racial events in the lives of these women.

The longitudinal CARDIA study (Krieger & Sidney, 1996) addressed some of the above methodological issues but was again limited in terms of the insight it was able to provide to psychological processes. It followed 5115 African-American and White men and women aged between eighteen and thirty from four different US cities, over the course of seven years. The sample was stratified by age, race, gender and education. Follow-up occurred at two, five and seven years. Attrition was approximately twenty percent over the seven years of the study. The measures undertaken included blood pressure, socio-demographic status and a
questionnaire regarding the experience of racism or other unfair treatment. Over seventy percent of the total sample reported being ‘unfairly’ treated at some point. Of the African-American sample, seventy-seven percent of women and eighty-four percent of men reported an experience of racial discrimination in one or more settings. The most commonly reported settings were in the streets or in a public-service situation. Blood pressure was found to be higher in this group. Also, the more incidents faced by African-American participants, the higher their blood pressure. Over fifty percent of African-American participants reported racial discrimination across three or more situations. Blood pressure differences were most exacerbated in African-Americans of working class, especially amongst women.

An additional finding was that African-American participants who said that they had experienced no racism had heightened blood pressure similar to those of the ethnic minority sample who had reported multiple incidents of discrimination. Krieger and Sidney (1996) suggested that these participants might have internalised any discrimination that they had faced (i.e. “these things happen to my people but not to me”) and were less able to express information about their experiences of racism. Such ‘internalised oppression’ appeared redolent of concepts such as erosion of ‘self-concept’ and ‘organismic valuing’ (Rogers, 1963) or to concepts of ‘entrapment’ or ‘defeat’ (Gilbert & Allan, 1998). Blood pressure also appeared higher where African-American, male participants accepted events as “facts of life” rather than doing something about it. This was despite attempted coping responses such as talking about it with others. African-American women were one and a half times more likely than any other part of the sample to report responding to a racist event by keeping quiet and, overall, they experienced the worst rises in blood pressure. Krieger and Sidney (1996) suggested that talking about such experiences might lead to a “validation” of their feelings. They also suggested that where men talked about such events, they were more likely to do so
in a “resigned” way and feel it was “unsafe” to articulate feelings of hurt or anger. This may therefore have led to as unsatisfactory a health outcome as in African-American women who kept quiet about these events. Krieger and Sidney (1996)’s suggestions regarding gender differences in responses, identity, self-esteem or lack of control of environment would, again, appear to have benefited from a qualitative follow-up attempting to elucidate the processes of this in greater detail.

**Moderating and mediating variables in the stress responses to racism**

A handful of studies have investigated how the stress response to racism might be moderated or mediated. For example, evidence from epidemiological and medical studies has suggested that constitutional factors, such as the perception of skin tone and colour, could interact with socio-demographic variables (like socio-economic status) to increase the risk of negative health outcomes such as hypertension (Klag, Whelton, Coresh, Grim & Kuller, 1991; Tyroler & James, 1978).

Other studies have looked at how psychological moderators might operate. Adams and Dressler (1988) for instance, have suggested the importance of socio-economic status and other variables as moderators in coping with racial stressors. They interviewed the members of 285 African-American households regarding mental health status, social interaction, perceptions of stress, demographic and socio-economic factors and experiences of discrimination. The latter appeared to be on a continuum from experiencing overt racism to facing insensitivity from local government, business and judicial institutions. Such experiences appeared to be affected by age, coping style, socio-demographic factors and self-
efficacy beliefs. For instance, discriminatory events appeared to have stronger effects upon younger participants, those who did not appear to employ an emotional control coping style and those who perceived themselves as unable to influence their environment.

Two other groups adversely affected were those under more financial stress and those higher in the community’s “occupational hierarchy”. This appeared to implicate factors that crossed economic, social and individual domains. Two major individual factors were:

i) ‘influence’ depicted by Adams and Dressler (1988) as similar to the locus of control concept in affecting a person’s ability to change “discrimination related circumstances” and

ii) ‘emotional control’: the extent to which a person might cope by ignoring or suppressing their own response. The authors believed that this led to participants finding interpersonal interactions with White people less distressing.

It is interesting to note the similarity of some of these ideas to those from community models such as feeling a reduced ‘dominance’ of one’s environment and thus withdrawing from it (Mehrabian & Russell, 1974) or feeling that one did not ‘fit’ (Lewin, 1951) with one’s environment, leading to rises in stress and the likelihood of ill health (French, Rogers & Cobb, 1981). This study provided some evidence for Clark, Andersen, Clark and Williams (1999) model as it implicated various underlying processes and effects such as that of the interaction of situational demands and moderators such as socio-economic status, beliefs regarding one’s ability to cope and emotional coping style. In highlighting ‘influence’ as an important variable the study suggested various pressures that might be present both prior to the attempt to initiate a coping response and in the evaluation of how this response had worked.
The influence of racial identity:

Various studies have also suggested the role of identity processes in buffering the stress-coping response to racism. A study by DuBois, Burk-Braxton, Swenson, Tevendale and Hardesty (2002) more directly examined the validity of models of stress themselves, for instance, using structural equation modelling to look at how different aspects might be related. They hypothesised that racial and gender related stressors would impact firstly upon:

i) corresponding identity processes such as gender or racial identity;

ii) levels of general stress (which would increase).

These impacts would result in deterioration in:

iii) global self esteem.

This in turn would mediate:

iv) emotional and behavioural problems

DuBois et.al. examined the impact of prejudice and discrimination upon 350 young people randomly selected from the school age children of a city in the USA and how this varied with ethnic and gender identity, self-esteem and adjustment. Discriminatory events were hypothesised as influencing levels of stress and emotional and behavioural problems. Twenty-five percent of the sample reported a prejudice or discrimination event. Eighty percent of these events were experienced by the African-American participants. Structural equation modelling revealed strong support for all aspects of DuBois et al. (2002)'s original stress-coping model. There appeared to be a direct effect of the experience of discrimination upon emotional problems for young African-American people. Girls from this group had lowered self-esteem and this had appeared to have mediated adjustment problems. These effects seemed more pronounced for the older African-American girls from low-income families. This study therefore provided some evidence that racism might firstly have effects
upon stress and identity and, in turn, upon the behavioural and emotional adjustment of a young person. Interpretation of DuBois et al. (2002)'s results was limited by their use of a cross-sectional design and the small sample size for an analysis of this type. The use of only self-report measures, as most of the studies in this field have done, also introduced confounding factors: behavioural and emotional problems might, for instance, have shaped the way that events in a young person's environment were then perceived.

Other studies have found that internalising negative racial stereotypes and rejecting positive stereotypes were linked to declining self-esteem (Brown, Sellers & Gomez, 2002). Nyborg and Curry (2003) found that experiencing racism led to increased internalising of symptoms, a lowering of self-concepts, increased depressive symptomatology and hopelessness. Their study of 84 African-American boys was unusual in that it used both parent reports as well as self-report measures.

Potentially positive mediating influences in buffering against these impacts have also been suggested. Bullock and Houston (1987) for instance, interviewed thirty-one ethnic minority medical students about their experiences of racism at high-school, college and medical school. Twenty-nine reported facing racism from both patients and from physicians. Psychological sequelae had mainly involved shock and anger. Students reported disruption to studies and periods of avoiding or not trusting White colleagues. They instead appeared to have placed an emphasis upon mutual support amongst themselves. The study had a number of limitations including a small sample size and recruiting from only medical students.

A study by Solorzano, Ceja and Yosso (2000) also found that a sample of African-American students suffered impacts to academic and social functioning from small acts of
racism or of situations where intentions appeared vague but possibly racist. This impelled
them to separate out and form counter-groups for which they then felt criticised.

Similarly, Howarth (2002) suggested that young, ethnic minority people struggled to
establish a self-identity within the context of the representations that 'others' made of their
group. A series of focus groups and interviews suggested that such representations might
impact self-image and self-esteem. Ethnic minority youth appeared to adopt various 'self-
strategies' in order to buffer their self-identity, sometimes collaboratively developing social
and psychological resources as protection against the prejudices of others (as with the medical
students in the study above). This would appear to fit with a suggestion made by Cochrane
(1983) that the evolution of non-secular "counter-culture" amongst second generation ethnic
minority youth might provide a means of buffering these young people against psychological
problems and stressors.

Thompson (1995) examined how racial identity might mediate the experience of racism.
Two hundred African-American people completed measures of racial identification,
experiences of racism and their intensity. A third of participants had reported an experience
of racism in the previous six months. As the seriousness of this event increased so did the
level of intrusion symptoms. She did not though find that racial identification helped to
buffer or mediate the impact of the event.

Fischer and Shaw (1999) assessed one hundred and nineteen, African-American college
students for experiences of racist events, mental health, beliefs regarding identity, experiences
of racial socialisation messages from care-givers. Racial socialisation has been defined as the
preparing of minority youth for situations where others would not be prepared to believe they
could be other than stereotypes. It prepared them not only for oppressive experiences but also to take pride in their cultural background (Stevenson, 1994).

 Increased exposure to racial socialisation messages during upbringing appeared to be related to reduced impact of racism upon mental health. A surprising finding was that the higher a participant's self-esteem, the worse his or her overall mental health appeared to be. High self-esteem might therefore not moderate the impact of racism on mental health. Fischer and Shaw (1999) suggested that persons with low self-esteem might believe negative experiences to be consistent with their poor view of themselves, so lessening the event's impact. For a person with high self-esteem, an event indicating less than expected control over their environment ('low influence') might have greater negative psychological sequelae. Unfortunately, as the authors stated, it was difficult to draw conclusions regarding causality from this study. Further research, specifically tied to these alternative hypotheses was needed to address such issues.

 Stevenson, Reed, Bodison and Bishop (1997) investigated how racial socialisation might moderate levels of depression and anger expression. For a sample of one hundred and seventy two female and one hundred and fifteen male African-American adolescents from a low income inner city area, they found that racial socialisation appeared to be significantly related to depressed affect, helplessness and low self-esteem. This was highest amongst young women, who had scored higher for racial socialisation. The reverse trend existed for young men but the relationship was not significant. Stevenson et al. (1997) also examined how 'cultural pride' might buffer young people. There appeared to be an interaction effect with gender and with the experience and expression of anger. For young men, the higher the score on 'cultural pride', the less likely they were:
• to experience or express anger unless provoked
• to suppress anger
• to express anger in multiple ways.

There were also higher levels of situational anger, but lower levels of temperamental anger. For young women though, higher scores on ‘cultural pride’ were not associated with such outcomes.

Thus, racial socialisation and especially ‘cultural pride’ did not appear to be as effective a moderating factor upon important mental health variables for African-American women as for men. Stevenson et al. (1997) suggested that African American women might simultaneously keep in mind the benefits of their cultural heritage but also the reality of its “stolen and suppressed legacy”. They suggested that historically, African-American women had carried additional burdens as the arbiters of this legacy. Though plausible, it would have been interesting for such assumptions regarding belief systems to be tested through qualitative research.

Summary of stress literature

As exposure to racism increased, so too did the psycho-social consequences such as anxiety, depression, locus and control (or ‘influence’). Various moderators appeared to exist such as socioeconomic status, beliefs regarding the ability to cope and emotional coping style. Women from low SES backgrounds appeared to be the most adversely effected. Positive mediating influences included creating social support networks and, for men especially, the
influence of ‘racial socialisation’ and ‘cultural pride’.

There appeared to be various physical health consequences of racism such as raised blood pressure. Amongst men there were worse outcomes for men who were unable to do anything about events. The worst outcomes amongst women were where they were unable to speak about events with anyone.

**Racism and post-traumatic stress disorder (PTSD)**

Loo (1994) suggested the importance of examining how experiences of racism might have a cumulative impact upon mental health and how the bi-cultural identities (for instance, holding an ‘American’ identity and that of ethnic origin) of ethnic minority people might be disrupted by such events. In the following section a review of the literature regarding trauma and exposure to racism will be considered.

**Research involving trauma perspectives**

A national, US epidemiological study by Ritsher, Struening, Hellman and Guardino (2002) suggested that African-American, Hispanic and Native American participants appeared more likely to report PTSD like symptoms than White participants. Ritsher et al. (2002) believed that this might reflect different levels of adversity and discrimination faced by ethnic minority populations in US society. They acknowledged various confounding factors such as the cross-cultural and internal validity of the instruments used, possible differences in
either response style or how distress was expressed by the various groups and, finally, by differences in service uptake. The study had sampled only those service-users who had attended various community health centres across the country.

Loo, Fairbank, Scurfield, Ruch, King, Adams and Chemtob (2001) found that experiencing racial prejudice and stigmatisation (for instance through contact with Caucasian soldiers who identified Asian-American colleagues as the "enemy") were stronger predictors for Asian-American veterans developing PTSD than actual exposure to combat conditions. When the effects of military rank and levels of combat exposure were controlled for, twenty percent of the variance that remained in how veterans went on to develop PTSD appeared to be due to race related stressors. Nineteen percent of general psychiatric symptoms also appeared to be attributable to these stressors. Thus Loo et al. (2001) suggested that experiencing racism was a major risk factor for PTSD as well as other forms of mental health problems.

Carson and MacLeod (1997):

The only British psychological research found during the course of this literature review, looked at the effect of racial victimisation upon ethnic minority people. This was a qualitative study conducted in Scotland by Carson and MacLeod (1997). They looked at how ascription of racial motive would impact upon the well-being of ethnic minority victims of crime.

Race was mentioned as the cause of crime, often in informal and unrecorded conversation, by eighteen of the thirty-five participants from ethnic minority backgrounds. These participants appeared to suffer more serious and persistent psychological effects. For the remaining participants there appeared to be less dissatisfaction expressed with the response
received from the police. Therefore, the authors suggested that imputing or not imputing a racial cause to a crime was an important psychosocial mediator. Belief in a racial motive was associated with poorer psychological adjustment. It had the potential to burden the victim with a conscious realisation of their ‘out-group’ classification i.e. their ethnicity. The authors referred to Perloff’s (1983) concept of the “illusion of invulnerability” as being broken with events now being perceived by the victim as beyond their control or ability to influence. They related this to cognitive models such as ‘learned helplessness’ (Seligman, 1975; Abramson, Seligman & Teasdale, 1978) whereby a person attributed a negative event to an enduring or non-controllable feature of the self and experienced a sense of hopelessness regarding the future. Peterson and Seligman (1983) had suggested that beliefs about the consequences of uncontrollable events were critical in adjustment. Good adjustment was deemed to follow from externalised or extraneous influences such as a belief in ‘chance’ or ‘bad luck’. This allowed the maintenance of Perloff’s “illusion of invulnerability”.

Carson and MacLeod (1997) also suggested that the concepts of ‘immutable’ and ‘mutable’ aspects of the self might be useful. Immutable aspects referred to characteristics that were not open to change, such as ethnic origin. They suggested that the active selection of non-racial explanations might be a coping strategy that placed less pressure upon immutable aspects of the self.

Alternatively though, as ascription of non-racial motives to the crimes was high, it may have indicated that the victims most likely to attribute racial motive to an event, and thus possibly the most likely to suffer from the highest degree of psychological distress, had been missed. The crimes suffered were also as disparate as a mugging and the longer-term stoning of a family home by gangs of youths chanting racist slogans. Carson and MacLeod did not
explain how such disparate events were matched between ethnic groupings. The repercussions of attacks in or upon homes, so that a victim was unable to escape the scene of an incident and family might also be exposed, was not addressed. The persistence of attacks or threats, further intimidation and prior history of punitive contact with the perpetrator were also unaccounted for. In addition, over a third of participants did not mention race at all in their accounts, raising the question what was the difference between what they experienced and what they felt able to disclose.

Summary of trauma research

Research would appear to suggest that facing racism under stressful circumstances (such as war or criminal victimisation) had the potential to lead to psychologically traumatic consequences for ethnic minority people. One study suggested that the attribution of racial motive to a crime could lead ethnic minority victims to suffer worse outcomes.

Recent foci in mainstream PTSD work might suggest various relevant interfaces. Joseph (1999) for instance considered the role of various attributional processes in the development of PTSD. These included ‘hopelessness’, suggested by Fernando (1984, 1988) as sequelae to acts of racism, and a form of internal attribution called ‘characterological self-blame’ (Janof-Bulman, 1992). This was ‘global’ in its attributional impact and not specific to a past event. Tennen and Affleck (1990) suggested that if an event was ascribed to external causes beyond an individual’s control, it allowed an individual to ‘unlink’ from the event. In addition, Rothbaum, Foa, Riggs, Murdock and Walsh (1992) suggested that the attribution of malevolence to an event could lead to higher levels of distress in the victims of violent crimes.
No further work though had been done to follow up these research leads. Carson and MacLeod's (1997) study remains the sole example of a UK psychological research report looking at the mental health impact of racism upon ethnic minority populations. Loo, Singh, Scurfield and Kilauano (1998) pointed out the paucity of the research examining the relationship between race-related stressors and trauma symptoms. Berberich (1998) suggested that this had led to gaps in how women in general and minority war veterans were therefore assessed, treated and involved in research. Within the UK, despite high rates of racially motivated crime, investigation of potential traumatic consequences also appears low.

**Research on clinical populations**

A limitation of the research outlined above is its concentration upon general population or student samples as opposed to clinical samples. Phillips, Barrio and Brekke (2001) suggested that ethnic minority service-users recovering in the community were more likely to suffer sustained deficits, especially in work functioning.

Studies such as Birchwood (1999) have also suggested the importance of social disempowerment in the experience of psychosis and the elevated risk of relapse faced by ethnic minority populations in Britain, often confined to urban conurbations (Bhugra, Leff, Mallet, Der, Corridan and Rudge, 1997). As has been previously noted, socio-economic factors are believed to be involved in the stress response to racism (see Adams and Dressler, 1988 above).
Experiences of services

Within mental health services themselves various concerns about the care received by ethnic minority clients have been raised. Snowden (1999) for instance found that African American people were less likely to seek help from mental health services than other groups.

Wood and Pistrang (2004), in a study which did not specifically target ethnic minority service-users, conducted a qualitative, thematic analysis of the accounts of nine patients in acute, in-patient mental health settings in the UK. They found that participants often felt unsafe and harassed. Some participants said that they felt unprotected and that staff were unable or unwilling to ensure their safety. Participants said that they felt powerless unless listened to and that some staff were so negative that they were deemed 'unapproachable'. Other major fears for service-users were the possibility of seclusion and restraint and of forced medication. Such events "evoked images of executions and molestation" (p24). Female participants talked of sexual harassment and humiliation by other patients, but also sometimes by staff. Three of the participants were from an ethnic minority but none mentioned racism or any other form of racial discrimination or prejudice. Seven members of ward nursing staff were also interviewed, and they echoed some of these beliefs. For instance they spoke of how some ward staff were difficult to work with or for service-users to approach with any difficulties. They themselves felt unsafe on wards. They also felt as if they were limited in how able to monitor and make themselves available to clients they could be. They acknowledged that this could have had a negative effect upon how safe the latter might feel.

Other research findings have highlighted the difficulties faced by ethnic minority clients
of the mental health services. Work by Cortis (2000) and Greenwood, Hussain, Burns and Raphael (2000) suggested that ethnic minority clients might face a degree of incongruence between what they expected from services and the actual care that they received. The latter appeared to be characterised by a poor understanding of cultural needs and the conscious or unconscious transmission of racist attitudinal stereotypes and behaviours. Greenwood et al. (2000) also found that ethnic minority service-users perceived there to be a severe lack of communication between staff and clients. In addition clients sometimes felt that staff would not bother with them due to their ethnic minority status. The intentions of staff were often highly unclear though their actions at times seemed to suggest some form of racism or indirect prejudice to participants. An example of this presented by Cortis's (2000) research was where staff did not advocate on behalf of an ethnic minority client where the latter felt that they had been racially abused by a fellow client. Such participants talked about feelings of hurt, isolation and the temptation to withdraw from services.

Discussion

Despite the lack of local research able to address the aim of this literature review, the wider available evidence would suggest that aversive experiences involving racism could have traumatic consequences for people from ethnic minorities. They could also impact the stress-coping abilities and health outcomes of ethnic minority people. Outcomes could include raised blood-pressure and hypertension. Various factors appeared to be implicated in this process. Lower socio-economic status appeared to lead to worse outcomes for young people, whereas higher occupational status and self-esteem were sometimes also associated with worse mental health outcomes when exposed to discrimination.
There was also evidence that racism could impact upon facets of identity such as self-esteem and helplessness. A recurring impact that emerged in research was that of ‘withdrawal’ and lowering of self-efficacy or ‘dominance’ beliefs. Racial socialisation appeared to be an important mediator in stress-coping and anger reactions for men, as were communal, non-secular responses to the perception of racism by young people.

Various questions were raised regarding coping styles such as the utility of suppression of emotions and of ascription of motive. Female victims of racism though appeared to have worse outcomes where they were unable to confide events to others. This raised questions regarding the role of social support in stress-coping for all ethnic minority victims of racism. A further consideration to account for in therapy appeared to be the level of trauma felt by the victim, perhaps especially the degree of ‘malevolence’ ascribed by him or her to the event.

Some of the studies also suggested that women, especially women from low socio-economic backgrounds, suffered some of the worst outcomes as a result of racism. This was of especial concern given that some studies have found that the main source of inflated numbers of African-Caribbean service-users with schizophrenia is from amongst women and not men (Sproston and Nazroo, 2002). The need to research the experiences of ethnic minority women with psychosis would therefore appear to be paramount.

A wide range of psychological paradigms appeared to be available to aid the understanding of the impact of racism upon ethnic minority people. Very few though had been operationalised in research. Various problems existed regarding the generalising of much of the reviewed research to this country. Much of the research was done in the USA and an especial concern would be the reliability and validity of instruments developed abroad.
for use in the UK. The cross-cultural validity of a predominately American literature regarding stress-coping responses was also unknown.

A further major deficit in the literature reviewed here, is the lack of study of how racism might operate in the lives of ethnic minority service-users with mental-health difficulties. Much of the research is based instead upon general population or student samples. Though it is possible to hypothesise how such models might apply to clinical populations, the research in this area appears minimal.

The studies outlined above have posed many questions regarding what the experience of ethnic minority clients of the mental health services might be with regards to experiencing aversive events involving racism.

A number of possible future studies were suggested. These included replication of studies regarding health outcomes and the buffering effect of racial socialisation. This would require the adaptation and testing of measures developed elsewhere or the design of indigenous measures. Much of the research relied upon self-report measures and the development of other types of assessment measures such as teacher and parent ratings for studies involving young people or clinician ratings for service-users might help to redress this imbalance.

Important questions were also raised regarding how men and women might cope differently with events. Studies looking at how social resources might help to validate female service-users’ experiences and feelings, or how male clients might perceive talking therapies as potentially unsafe or abusive, might be highly useful for clinicians working with such populations. Such studies would arguably appear best suited to qualitative methods.
Studies in the area of severe and enduring mental health also appeared urgent. The lack of examination of how processes such as those postulated by Fernando (1994) had impacted upon ethnic minority service-users, for instance in triggering further depression, anxiety or relapse in condition, would appear to require urgent rectification. This deficit in the literature also appeared compounded by the lack of study of processes effecting ethnic minority clients with severe and enduring mental health needs such as psychosis or schizophrenia. The few studies that have been conducted have suggested that ethnic minority clients have struggled with how their expectations of care and the reality have clashed. Further sources of worry were lack of person-centred care, little communication between staff and patients and seeing staff take no action when racism occurred upon wards.

A potential study might be to address the concerns raised by NIMHE (2003) and simply account for the role of aversive racial events in the lives of ethnic minority service-users. This might be done through various means but perhaps an especially salient one would be to approach and interview service-users themselves for their views and experiences regarding such experiences.
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Section 2

Research Report

Racism in the Lives of Ethnic Minority Service-Users with Psychosis
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Racism in the Lives of Ethnic Minority Service-Users with Psychosis

Abstract

**Background:** Research regarding the psycho-social impact of racism has indicated that it could be an important psycho-social or traumatic stressor and thus potentially harmful in either onset of a psychotic breakdown or in later relapse.

**Aim:** The aim of this study was to explore the impact of racism in the lives of ethnic minority service-users with psychosis.

**Method:** Seven participants were interviewed (one participant twice) and the transcripts analysed using a social constructivist grounded theory approach.

**Results:** A core category entitled ‘struggling against dehumanisation’ was identified along with a process model of seven main codes describing how racism and mental health stigma had both caused suffering and been actively resisted.

**Discussion:** The dual impacts of suffering racism and mental health stigma appeared to lead to cognitive-emotional and behavioural sequelae such as feeling a lack of influence or helplessness, fear and withdrawal. These appeared to be exacerbated by the course of the psychotic illness. The illness itself had the potential to be socially constructed by past experiences involving racism. Participants described various strategies for combating such effects, that included sharing experiences with trusted others and developing personal understandings. Further research into the negative psycho-social effects of racism, as well as how treatment modalities might be modified to incorporate or enhance ethnic minority service-users’ own strategies, are indicated.
Introduction

Various authors have suggested the need to map how stressful life events might precede psychosis (Brown and Birley, 1968; Coleman, 1979; Nuechterlein and Dawson, 1984; Norman and Malla, 1993) or lead to a destabilising in cognitive processes (Ciompi, 1994). Research has also suggested that it is vital to acknowledge ‘emotional disturbance’ (Fowler, Garety and Kuipers, 1995). Firstly, this might occur prior to psychotic illness and, following its onset, might come to be reflected in the content or character of any positive or negative symptoms. At a second level, emotional disturbance might also occur as ‘fallout’ from having developed psychosis.

Racism or racial stigma prior to illness could potentially generate such a disturbance prior to illness. Upon becoming ill though, the cumulative strain from either mental health or racial stigma would appear to comprise impact at Fowler et al’s (1995) second level of emotional impact. The ability of clients to effect recovery whilst facing such stigmatisation or exclusion by wider society has been highlighted as a key obstacle in the path of people suffering or recovering from mental health problems (Sayce, 2000). Various authors have highlighted the need to assess how environmental stressors have operated prior to and after onset of illness (Tarrier and Turpin, 1992) but racism appears never to have been researched in this regard.

Developing an understanding of how psychosis and exposure to racism might interact would therefore appear to cover at least two areas. Firstly, the manner in which service-users had faced and coped with racism prior to their illness would appear to be important. Leading on from this, the manner in which clients had coped with actual or potential incidents of racism or other forms of prejudice after the onset of illness would also appear important. The
need to account for these factors within the context of the lived experiences of clients would appear to be vital (Davidson, 1992; Chadwick, 1993, 1997a&b). An additional concern was whether racism might impact upon the content of psychotic symptoms such as hallucinations or delusions, and upon their involvement and engagement with services (Kazanias, 1970; Torrey, 1981; Mitchell & Vierkant, 1989; Nayani & Davis, 1996; Boyle, 2002).

The role of reasoning processes

Various research has suggested that reasoning processes form a central core to psychosis (Bentall, 1992). A skewing in these processes might allow the defusing of anxiety associated self-scrutiny or appraisal (Bentall, Kinderman and Kaney, 1994). It has also been suggested that negative experiences early in one’s life might establish small attributional anomalies that then might mushroom into positive psychotic symptoms (Bentall, Kinderman and Kaney, 1994; Birchwood, 1996). Sharpley, Hutchinson, McKenzie and Murray (2001) suggested that the facing of social adversity factors, such as racism, might lead to an increase in external attributions and perhaps lead to increased paranoid ideation.

A major caveat to an understanding of the role of attribution processes has been highlighted by Boyle (2002), namely that external attributions might sometimes be valid. In a situation where psychological therapy or psycho-social care involved the challenging of external attributions, a major dilemma might therefore arise for ethnic minority service-users. The potential for therapeutic breach or withdrawal from treatment would appear to be profound. Studies of in-patient settings have suggested that ethnic minority clients often felt ignored by staff and unprotected in racially hostile situations. They also struggled to
interpret staff behaviour where, for instance, workers ignored other service-users who were being racially abusive (Cortis, 2000; Greenwood, Hussain, Burns & Raphael, 2000). Various authors such as Outlaw (1993) and Pierce (1995) have highlighted how such moments of dilemma are an everyday stressor for ethnic minority people. Such dilemmas might exacerbate, or be exacerbated by, the distress of a psychotic illness.

**Aims**

In line with suggestions by Tarrier and Turpin (1992) and Chadwick, Trower and Birchwood (1996), it was decided to take a developmental perspective upon experiences of racism or other environmental stressors. It was hoped to develop an integrated account of the difficulties faced by ethnic minority service users with psychosis with regard to racism. The aims of the current study were:

i. To explore how the experience of racial difference or prejudice occurred prior to the onset of psychosis and how it might have contributed, either to an emotional disturbance or to the establishment of cognitive vulnerabilities before this period.

ii. To explore how racism might have operated after the onset of psychosis, perhaps contributing to or exacerbating various psychosocial sequelae (i.e. stigmatisation, involuntary subordination, humiliation, loss of self-esteem, withdrawal in social or occupational domains or disengagement from service providers).

iii. To explore how a network of stressors, such as those outlined in Aims i and ii, might be themselves inter-related or reflected in the content or character of the delusions experienced or the voices heard by clients from ethnic minority backgrounds.
Method

Design

The current researcher felt that various paradigms or theoretical models were of utility in understanding the psychological impact of racism upon mental health. Few had been researched in that regard. A particular concern for the current researcher was whether some of these paradigms had a greater internalising focus i.e. situating the problem within the individual rather than the social world that he or she lived in (Leeming & Boyle, 2004). There was therefore a concern for exploring participants' experiences in a manner that appreciated their process of sense-making, manner of coping and, finally, of relating their experience to their social world.

A constructivist revision of Grounded Theory (GT), using qualitative interviewing to collect and analyse accounts, was therefore chosen. GT has the explicit focus of generating theoretical accounts in areas of impoverished theory (Glaser and Strauss, 1967). Through a constructivist approach, it was hoped to target how context and experience interacted in accounts and to make explicit the researcher's perspectives and assumptions regarding the research (Charmaz, 1990; 1995; 2003a; 2003b).

Forestructure

The forestructure has been divided into sections that describe the researcher, some of his assumptions and the subsequent epistemological stance that was adopted. Charmaz (1995)
describes this as a method of being transparent about theoretical sensitivities that have been brought to the study by the researcher and that in some way may have moulded the account being generated.

Researcher:

The researcher was a clinical psychology Trainee studying for a Doctorate in Clinical Psychology. He was born and raised in Britain but of Asian descent. Prior to clinical training he had become interested in social inclusion, social justice, community approaches and work with ethnic minority groups.

During training the researcher had become aware of how ethnic minority populations appeared to have less involvement in clinical psychology services than did the White population. The researcher was also struck by the lack of profile that minority issues had in the research literature of the profession.

Researcher’s assumptions

The researcher had interests in community, person-centred, narrative and cognitive-behavioural therapy approaches and had spent a year’s placement in a psychosis rehabilitation service for people with psychosis. He was more familiar with quantitative research but had used qualitative methodology, template analysis (King, 1996), in a previous service-evaluation. This had been done from a positivist or objectivist position (Burr, 1995) and had led him to reflect on the more ‘holist’ nature of his analytic style (Madill, Jordan and Shirley, 2000), often speculating on the direction of results or what underlying causes or related factors might exist.
A literature review had made him aware of how racism could act as a psycho-social or traumatic stressor. He had also considered how theoretical concepts drawn from various paradigms such as community psychology, stress-coping, trauma and shame might inform his understanding of the psychological or psycho-social impact of racism.

Participants

Seven participants were recruited for participation in the current study. The final participant was also interviewed twice as the initial interview had generated new potential leads and questions for the study to explore. All were current service users, either being seen within a psychosis rehabilitation service or by local community mental health teams (CMHTs). Five had had some form of contact with clinical psychology services, three intermittently or through groups facilitated by them and two for individual work.

Information regarding the participants has been summarised in Table 1. For reasons of confidentiality, identifying information such as age and ethnic origin has been kept purposefully broad. Also, the “summary problem description” provided above is not intended to be a complete clinical picture of the participants, merely a brief summary of some of the information that they were willing to divulge in the course of the research.

A specific inclusion criteria of the study was that English be a primary language (though not necessarily first) of participants. This was based upon concerns raised by Fontana and Frey (2003) that nuances in accounts might be lost. None of the four Asian participants had English as a first language.
<table>
<thead>
<tr>
<th>Interview no</th>
<th>Name pseudonym</th>
<th>Age approx</th>
<th>Gender</th>
<th>Ethnic origin</th>
<th>Involvement with services</th>
<th>Summary problem description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Megan</td>
<td>30</td>
<td>Female</td>
<td>African-Caribbean</td>
<td>Rehab Services and Psychology Service</td>
<td>diagnosis of schizophrenia, onset approx 19 years age. Exp malevolent and benign voices and delusional beliefs</td>
</tr>
<tr>
<td>2</td>
<td>Shirley</td>
<td>60</td>
<td>Female</td>
<td>African-Caribbean</td>
<td>CMHT and Hearing Voices Group</td>
<td>diagnosis of schizophrenia and post traumatic stress disorder, onset (of psychosis) approx 50 years age. Exp voices</td>
</tr>
<tr>
<td>3</td>
<td>Asif</td>
<td>40</td>
<td>Male</td>
<td>Asian-Pakistani</td>
<td>CMHT and Hearing Voices Group</td>
<td>diagnosis of schizophrenia, onset approx 30 years age. Exp malevolent voices, paranoid delusional beliefs, depression and suicidal ideation, epilepsy, drug and alcohol abuse</td>
</tr>
<tr>
<td>4</td>
<td>Helena</td>
<td>60</td>
<td>Female</td>
<td>African-Caribbean</td>
<td>CMHT and Hearing Voices Group</td>
<td>diagnosis of schizophrenia, onset approx 14 years age; Exp malevolent voices, self harm, cancer</td>
</tr>
<tr>
<td>5</td>
<td>Rhupa</td>
<td>35</td>
<td>Female</td>
<td>Asian-Indian</td>
<td>CMHT and Support Group</td>
<td>diagnosis of schizophrenia, onset approx 20-25 years age. Exp auditory and visual hallucinations, anxiety and depression</td>
</tr>
<tr>
<td>6</td>
<td>Sanjay</td>
<td>45</td>
<td>Male</td>
<td>Asian-Indian</td>
<td>CMHT</td>
<td>diagnosis of bipolar disorder, onset approx 28 years age. Exp benevolent and malevolent voices and delusional beliefs, previous alcohol abuse</td>
</tr>
<tr>
<td>7 and 8</td>
<td>Nitin</td>
<td>45</td>
<td>Male</td>
<td>Asian-Indian</td>
<td>CMHT</td>
<td>diagnosis of schizophrenia, onset approx 20 years of age. Exp malevolent voices, depression and suicidal ideation</td>
</tr>
</tbody>
</table>
Sources of data

Interview and interview guide:

The main sources of data for the study were audio-taped, semi-structured interviews. These were transcribed and then coded. Semi-structured interviews are a common means of gathering qualitative data (Burman, 1994; Pidgeon and Henwood, 1996). Kvale (1983) described them as leading to more open expression of views than standardised questionnaires or interviews, including data regarding thoughts, emotions and other aspects regarding the impact of events.

A semi-structured Interview Guide (see Appendix 4) was devised that began by asking participants to give a brief history of the mental health difficulties that they had experienced. This included their experience of psychotic symptoms. Further questions were constructed around the aims outlined in the Introduction and took a developmental perspective. Experience about racial difference and prejudice was asked about in relation to:

1) experiences prior to illness;
2) experiences during illness and contact with services;
3) experiences as the client had attempted to recover.

As a result of the first interview, the researcher introduced new questions. Charmaz (1995; 2003b) for instance, has advocated such modification as a means of following up theoretical leads. The new questions were regarding how participants had:

4) coped with racism (especially emotional coping and patterns of distress) and
5) feelings regarding stigma and exclusion in their local communities.
In later interviews, questions were also asked regarding:

6) whether participants had seen racism happening around them rather than it happen to them directly;
7) the values and tactics that were important in facing racism;
8) if there might be alternative explanations for events perceived as racist;
9) what had made a participant feel safe or less safe on a mental-health ward;
10) how participants had coped with racism upon wards;
11) how aversive events had been brought up with ward staff and what reactions occurred.

The researcher tried to acknowledge that a participant would be active in constructing the interview and perhaps have a need to tell a particular story (Pidgeon and Henwood, 1996).

Pidgeon and Henwood (1996) also pointed out the need to observe rules of “dialogue and social interaction” (p.89) in order to facilitate interviewing. Also, in this study various factors led to the need for sensitivity in questioning of participants:

i) anxiety regarding taping and interviewing;
ii) anxiety regarding impact of interview information upon their future care;
iii) anxiety and hesitancy where English was not the participant’s main language
iv) fluctuating symptoms and illnesses;
v) the effects of multiple medication;
vi) distress regarding past events.

Such factors contributed to the need for care in interviewing and to a more restrained mode of interviewing with such participants (see Critical Appraisal).

Field diary:

Field notes were also kept in a diary during and after each interview. These included the
observations and thoughts of the researcher regarding the interview and any hunches that might have occurred to him. An example of a field diary entry is given in Figure 1 below.

Figure 1: Excerpt from the researcher’s field diary

23rd March, 2005. Reflections on meeting with Asif (participant 3)

Asif talked about suicidal ideation. Was a shock (for me) for this to come up prior to the interview and then later to be directly implicated in the events that Asif had faced. I felt quite angry as I heard Asif’s story and when he began to talk about dying I felt quite humble and angry at same time. Had the sense we were both on unfamiliar territory – struggling to talk about racism – perhaps not talked about before. Was more fluent when talking about things that he’d spoken about with family or wife: leaving or moving elsewhere for instance.

Procedure

Sampling

Upon receiving ethical approval from the local NHS Research Ethics Committee, the researcher briefed the local Rehabilitation, Early Intervention, Assertive Outreach and Community Mental Health Teams about the project. Keyworkers consulted with Responsible Medical Officers (RMO) to identify potential participants and go through Information Sheets with them (see Appendix 2). Where a client was interested in becoming involved, a meeting was established between them and the researcher at a place most convenient for them. On three occasions this meeting occurred at the home of the participant, three times at a voluntary centre and once at a community NHS base.
Interviewing procedure:

At the first meeting with a potential participant, the researcher would introduce himself and then use the Information Sheet to introduce the research and to answer any questions that he or she had. If they remained interested in taking part, the researcher asked for their written consent to proceed (see Appendix 3). The right to withdraw at any time despite this consent was emphasised. Two participants withdrew at this stage. On one occasion a participant requested her son be involved in the interview as an advocate.

Prior to beginning the interview, some basic information regarding age, ethnic origin and age of first contact with acute mental health services was taken. The interviews themselves were audio-taped and lasted between thirty and sixty minutes. This did not include the time taken to introduce the research or gaps in recording due to participant distress (see critical appraisal for a description of how participant distress was dealt with).

The researcher, whilst guiding the interview, also attempted to follow leads taken by the participant and to adapt the interview guide as appropriate (see above). When it was felt that the Interview Guide had been covered or the participant was becoming fatigued, the interview was stopped. After the recorder had been switched off, the participant was asked how they had found the interview and what the emotional impact of the issues discussed had been. The information that could be fed back to keyworkers by the researcher was also agreed with the participant. Follow-up contact with keyworkers had been arranged to happen after the interviews: on six occasions this occurred within hours of the interview finishing and on two occasions in the following forty-eight hours. The researcher then made notes in his diary regarding his thoughts and feelings about the interview.
On two occasions a follow up interview was arranged in order to ask further questions regarding the study aims. The first was abandoned during the session due to the researcher’s concerns regarding the health and coping ability of the participant. The second was more successful and lasted approximately thirty minutes. It focused mainly upon experiences of being an inpatient and of reasoning processes in decision-making surrounding racial or potentially racial incidents.

Transcription of interviews:

The first four and the last interview were transcribed verbatim by the researcher. The intervening three interviews were transcribed by a department secretary and then adjusted for corrections by the researcher. The latter listened to an audiotape of the interview whilst correcting, paying especial attention to parts of the recording that had been difficult to hear clearly. In the main, only linguistic features of the recordings were transcribed, as suggested by Willig (2001).

A pseudonym was selected for each participant in order to preserve confidentiality around the identity of the participant. Also, as the interviews were transcribed, any information that might identify a participant was changed to protect anonymity.

Procedures of analysis:

In order to analyse each transcript the researcher primarily used Grounded Theory (GT) techniques described by Charmaz (1995; 2003a; 2003b). These comprised line-by-line coding, focused coding, memo-writing, constant comparison and conceptualisation. These will be described in turn:
Line-by-line coding

Each line of the transcript was coded with a brief statement that attempted to encapsulate its content (Glaser, 1978; Charmaz, 1995). Charmaz (2003b) described this as an aid to analysis and to ensuring that the latter remained ‘close’ to the data. Thus it helped to establish a ‘bottom-up’ type of model. An example of such line-by-line coding from this study can be found in Appendix 5.

Focused Coding

Line-by-line codes that continually reappeared or which appeared to be significant in terms of their explanatory power were used to sift through and organise the remaining data (Charmaz, 1995; 2003b). Therefore, this was a decision-making time where the researcher enacted his judgements regarding what might be interesting or which might answer the research questions of the study. Examples of focused coding are found upon the example page of a coded transcript in Appendix 5. Two focused codes that had developed (‘dissolution of adult identity’ and ‘losing protection of the community’) can be seen in the right hand margin.

Memo-writing

Charmaz (2003b) suggested explicitly mapping the data used to theorise how higher codes were believed to organise the data. These theories were captured through ‘memo-making’ or ‘memo-writing’, the use of analytic notes to describe and explain the content of higher codes (see Figure 2 for example). Thus each focused code that was developed had a memo assigned to it. Memos would also be used to explicate higher order categories (see ‘Conceptualisation’ below).
Figure 2: **Example of a memo from the researcher’s field diary**

<table>
<thead>
<tr>
<th>22&lt;sup&gt;nd&lt;/sup&gt; March, 2005. (From Shirley’s account)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Focused code: Feeling mistreated by staff in services (14)</td>
<td></td>
</tr>
<tr>
<td>I'd asked about racial diff or prejudice in service. Following interpreted as 'racism' by Shirley. Described being man-handled, facing seclusion and disregarding of personhood (i.e medical conditions such as diabetes). She felt personhood had been diminished and she had lost hope of effecting change and of receiving more person-centred care. Felt silenced.</td>
<td></td>
</tr>
</tbody>
</table>

**Constant comparison**

As well as comparing line-by-line codes within a focused code, focused codes were themselves considered against each other to see if they might reveal further variation or commonality. Sometimes this allowed similar focused codes to be collapsed into one, whilst at others it led to new category formation in order to account for variation.

This process of ‘constant comparison’ (Glaser and Strauss, 1967) also occurred between cases in an iterative process that pitted each consecutive case against the ones that had gone previously. This was intended to encourage the development of the theory and also to try and map the full complexity of the data being collected. An example of a memo that attempted to capture such a process is given in Figure 3 below.

**Conceptualisation or raising focused codes to conceptual categories**

Charmaz (2003b) described ‘conceptualisation’, or the act of raising focused codes to conceptual categories, as choosing to “go beyond using a code as a descriptive tool” (p99) and instead to now use it to develop those codes which “best capture what you see happening in
In both accounts, Asif and Shirley talk of striving harder in the face of racial hostility. It was a theme implicit in Shirley’s (and Megan’s too) accounts, but was explicitly drawn by Asif.

Shirley also described the problems of being a Black, single mother and facing a combinatory hostility or stigma that included race i.e. trying to find accommodation. She also described difficult situations involving possible slurs or ‘micro-aggressions’(?) that might have been difficult to interpret. Megan described this too and perhaps Asif’s description of paranoia faces similar metacognitive dilemmas?

your data” (p99). In the current study, recurring codes, those which appeared to hold especial resonance within accounts, or which were of interest to the researcher were examined in this way. Memos were again used to account for how certain codes were elevated in this way. With each successive interview these categories were exposed to further ‘constant comparison’ and memos were used to define and redefine their properties. These are described further below.

Theoretical sampling and negative case-analysis

Theoretical sampling can be used as a tool to challenge or develop the theory being generated (Glaser and Strauss, 1967). The researcher seeks out participants who might have certain characteristics or gone through certain experiences. Alternatively, it could be used to compare aspects of the theory being generated to new data-points to see if the theory will hold (Willig, 2001). Where participants or elements of their accounts actively challenge a
prevailing theory, this is sometimes called a ‘negative case analysis’ and acts as an important spur to test any previously held assumptions (Willig, 2001).

Much of the sampling in the present study was opportunistic. Sanjay (Participant 6), though suffering from voices and delusional beliefs, had a primary diagnosis of bi-polar disorder and this provided a limited perspective upon how someone with a somewhat different severe and enduring mental health profile might respond to the same questions. Towards the end the researcher had attempted unsuccessfully to recruit further female participants, as it was felt that previous interviews had not paid sufficient heed to their experiences in the workplace (male participants had all talked in detail about such experiences). African-Caribbean men were also not represented in the sample and two Asian male participants had suggested that their plight might indeed be worse than their own. Again there was a failure to recruit these participants.

Three negative cases however tested the theory. Helena (Participant 5) and Rhupa (Participant 6) both claimed not to have faced racism at all. Also, Megan (Participant 1) claimed she had not faced racism but then talked in her account of events that seemed to contradict this.

Theoretical saturation:

This is the belief that at some point in the interviewing sequence, no further higher order categories, or variation in those categories, will emerge (Glaser and Strauss, 1967). Rennie, Phillips and Quartaro (1988) suggested that this might happen between five and ten cases. Glaser and Strauss (1967) however cautioned that saturation was only ever provisional and thus more akin to a goal rather than a practical likelihood.
Charmaz (2003a) suggested that it might also be a highly subjective goal that could discourage one from facing the full complexity of one’s data: a researcher should instead not be afraid to keep their analysis open and enriching this with in depth but transitional descriptions or memos.

Quality:

Various means were employed to try and ensure quality within the study. Elliot, Fischer and Rennie (1999) suggested that a primary need was “owning one’s perspective”. This was attempted through making the ‘forestructure’ (see above) central to the Method and making ‘theoretical sensitivities’ (Glaser and Strauss, 1967) as transparent as possible (see Table 2).

In the present study this was done via a sequential examination of the literature. It initially concentrated upon stress and trauma research surrounding racism and the accounts of mental health service-users who had experienced in-patient settings. Later this expanded to an examination of literature regarding psychosis, especially the role of reasoning processes in symptoms.

Basic data regarding the participants has also been given and, where appropriate, their life positions were made clear (Elliot et al 1999). This included current medical conditions. For instance, Helena was struggling with cancer and her account is laden with reminiscence and emotional reflection. In addition, though keen to be involved in the study, she was also struggling under the influence of her various medications. By giving this basic information it was hoped to make it easier to understand the course of interviews and the concerns of the researcher to protect his participants from harm whilst conducting them.
Table 2: Accounting for theoretical sensitivities in the grounded theory analysis

<table>
<thead>
<tr>
<th>Theoretical sensitivity</th>
<th>Point of potential impact</th>
<th>Outcome</th>
</tr>
</thead>
</table>
| Personal and clinical experience of researcher of racism and potential reactions such as fear, withdrawal or confrontation | Main codes 3 and 4        | 1) checking grounding in Raised Codes File;  
2) using peer debriefing to compare interpretations;  
3) checking resonance of overall analysis with mental health professionals and with people from ethnic minority backgrounds. |
| Previous appraisal of community psychology literature relating to withdrawal           | Main codes 3 and 4        | 1) delaying return to literature till analysis advanced;  
2) checking grounding in Raised Codes File;  
3) using negative case analysis to integrate accounts where participants described confronting not withdrawing from racism. |
| Personal interest in social construction of psychotic symptoms                           | Main code 5               | 1) delaying return to literature till analysis advanced;  
2) checking grounding in Raised Codes File;  
3) using negative case analysis to integrate accounts where social construction of positive symptoms had led to benign or benevolent voices or delusions, rather than assuming that these would always be malevolent;  
4) homing in on relevant psychosis literature (i.e. dealing with buffering of self-esteem through delusional beliefs) only towards end of study. |
| Attributional research into psychosis                                                  | Main codes 5, 6 and 7     | 1) acknowledging possible conflict between this research and that regarding 'microaggressions' and the potential ambiguity of racism;  
2) delaying interpretation of participants' accounts within an attributional framework until more embedded in participants' accounts;  
3) delaying the raising of subcategories to main code status where insufficient grounding;  
4) checking resonance of interpretations with mental health professionals and with people from ethnic minority backgrounds. |
| Therapeutic models, where present conditions felt to be contingent upon past events    | Overall model             | 1) explicit ownership of past-present linkages in analysis;  
2) checking grounding of interpretations in accounts;  
3) delaying the raising of subcategories to main code status where insufficient grounding;  
4) checking resonance of interpretations with mental health professionals and with people from ethnic minority backgrounds. |
Charmaz (2003) advocated remaining as close to the data as possible during analysis. In order to try and demonstrate this, the following were provided:

(i) a complete Addendum of the interviews
(ii) examples of coding are given (Appendix 5)
(iii) the Analysis section is grounded in quotes from the transcripts.
(iv) the Raised Codes File of quotes that formed the backbone of each main code and its constituent subcategories has been provided in Appendix 6. The limitations of the analysis were therefore also apparent i.e. those subcategories with insufficient data points to allow their raising to a full ‘Main Code’ (Elliot et al 1999).

A ‘paper trail’ of how this final Raised Codes File was achieved was also maintained. This would allow someone to understand how the researcher had used the principal techniques of GT, such as constant comparison of codes and categories, to reach the analysis that they had (Bannister, Burman, Parker, Taylor and Tindall, 1994). Having chosen a constructivist revision of GT, the manner in which the procedures and analysis tried to investigate the processes of interaction between participants and their social worlds was explicitly monitored (Yardley, 2000). The final analysis presented here was intended to be the culmination of this concern with process.

In addition, nuances in the data were acknowledged (Charmaz, 1995). These included:

(i) negative case analysis – where, contrary to the main aims of the study, participants claimed no or little prior experience of racism (i.e. Helena and Rhupa)
(ii) theoretical sampling of a participant with a different symptom profile to the other participants (i.e. Sanjay who had a primary diagnosis of bipolar disorder)
(iii) negative case analysis – where within code differences were acknowledged through
the examination of differences in accounts (i.e. differing profiles of malevolent and benevolent voices and delusions).

During his time upon the Doctoral course, the researcher was able to use a qualitative support group in order to debrief regarding interviews and to compare how others might code his data. This provided a means of attempting a credibility check (Guba, 1981; Elliot et al 1999) that dissipated somewhat as the researcher began working, unfortunately out of the catchment area of the course. Despite this, contact was continued with former colleagues from his support group and with other qualitative research students. They attempted to act in the same manner once the Trainee had left the course.

‘Resonance’ has also been described as a key quality measure (Elliot et al 1999). In the present study the analysis was shared with the qualitative support group, interested mental health professionals, supervisors and lay readers in order to gauge how the analysis struck readers. An example of this was whether and how it expanded their appreciation and understanding of the area being researched.
Analysis

Overview of analysis

The model in Figure 4 represents the researcher’s understandings of the grounded theory (GT) analysis. It comprised one core or ‘conceptual’ category entitled ‘struggling against dehumanisation’ and seven accompanying main categories:

1) suffering racial violence
2) suffering mental health stigma
3) fearing blame, retribution and punishment
4) bottling up or confronting
5) struggling to cope
6) sharing experiences
7) developing personal theories

Figure 4: Grounded theory model of the effects of racism upon clients with psychosis

1) Suffering racial violence  
2) Suffering mental health stigma

Struggling against dehumanisation

3) Fearing blame
5) Struggling to cope
4) Bottling up, withdrawing or confronting
6) Sharing experiences
7) Developing personal theories
The process model that underlies Figure 4 is described first. This is followed by a description of each category, beginning with the core category. These descriptions are built around quotations from the interviews in order to demonstrate that code’s grounding within participants’ accounts. The final ‘Raised Codes File’ of how quotes were assigned to the various core and main categories or codes has been included in Appendix 6. This will allow the reader to further examine how interview data led to the formation of specific categories and subcategories.

The Process Model

The process model comprised the seven main categories or codes. Within the main codes themselves, potential but nonetheless only emerging processes, are sometimes depicted between subcategories. These would be potential targets for further investigation and development of the grounded theory in the future.

Two of the main categories were more static or descriptive categories where exposure to racism (Main Code 1) and to mental health stigma (Main Code 2) were depicted. A principal reason for portraying these events in this way, was the desire of the researcher to display the sheer spectrum of violence or abuse that participants had described.

The remaining five categories were organised into two sub-processes. The first sub-process depicted how participants’ fears (Main Code 3) impacted upon their decisions to confront situations involving racism or prejudice or to bottle up their emotions regarding these events and to suppress action (Main Code 4).
The second sub-process depicted how often ongoing struggles to cope with such events (Main Code 5) led to various attempts to regain a sense of empowerment. Principally this was through sharing experiences with others (Main Code 6) and through participants developing their own personal theories and understandings of why events occurred (Main Code 7). The struggle to cope was also seen as leading to withdrawal from the community. Therefore it is also seen as connected to Main Code 4 (Bottling up, withdrawing or confronting).

The Core Category – Struggling against dehumanisation

The core category was intended to signify the long struggles of the participants against racism and against mental health stigma. It was conceptualised as both suffering dehumanising experiences and also as seeking ways to reclaim a sense of humanity and community in otherwise difficult and sometimes hostile environments. Though the core category was not an in-vivo code, one participant, Shirley, had described an incident from her childhood when she had walked into a local shop:

[Shirley: 282] Made you feel like you wasn' t a person, you was just a.... they were saying these things to make you feel as though you was just inhuman...[286]....saying you know “You shouldn’t be in here” and all these kinds of things (makes monkey sounds) making these noises.

The participant Sanjay had described becoming progressively more ill before his psychotic breakdown. A major contributor to this had been racism and discrimination in the workplace:

[Sanjay: 558] ......they kept saying to me “Oh you’re learning”......I remember I asked for a pay rise after about three or four years I was there and they gave me about £5 a week
extra, not an hour....[570] it made me feel....it made me feel like they don't want to pay you for what you're worth

Other participants described seeing how fellow in-patients were treated on a mental health ward. Nitin for instance described how he had witnessed a patient threaten suicide:

[Nitin2: 168] I've seen one bloke, you know what he done? You know the window ledge? He just lean there and say he drop himself.....[171] the staff nurse say “Oh OK, I'll give you that....you go back and carry on. I couldn't give a shit”.

In analysing the data, a question was raised in the researcher's mind about how witnessing such an event might have led Nitin to feel that patients were not valued and should behave only in certain ways in order to obtain attention or resources. Another participant, Asif also described getting the sense that Asian inpatients were treated differently to others:

[Asif: 889] ......it was just like a feeling that, you know, that they didn't really care about the Asian people in the hospital......That was, that's my personal view......a lot of the ......Asians that were in there in the hospital, couldn't understand English properly. And I found that the nurses and that lot was treating them differently

In addition to this, participants also described feeling ignored and excluded.

Occasionally a participant would speak of how an experience from the present had evoked memories of similar treatment in the past:

[Shirley: 300] ......they wouldn't take any notice of me. Put your hand up to say someone had kicked you: “Put your hand down, stop telling tales” they'd say.....[305] They just didn't take any notice basically, the teachers.......[308] and it's like now, when I became ill, the first time they sectioned me......[317] instead of finding out why my environment was got so filthy, they didn't. They didn't. They put me in a place and said I was crazy

Shirley's experience had a particular poignancy for the researcher. She was able to describe in great detail her experiences as a child growing up in the 1950s and 1960s. The act of doing this in the interview had been greatly distressing for her and at one point she made a comment that had made the researcher aware of how deeply traumatised she still felt:
I got assaulted and got injured very badly....my features was changed and I was glad in a way because nobody knew who I was.

It seemed to the researcher that in all the remaining main codes that were raised in the analysis a similar sense of dehumanisation and the struggle to fight its effects was occurring. This made the core category appear especially relevant to the researcher. A useful counterpoint to this category is to remember that sources other than direct racism or mental health stigma, can be dehumanising influences. The researcher did wonder though, whether sometimes such events might still be interpreted as racist or institutionally racist (MacPherson, 1999). For instance, Rhupa described how sexual harassment by other in-patients on a mental health ward had led her to complain to staff. Staff had not acted upon her complaints and appeared to instead either increase her medication or to sedate her:

I was in one room and I keep going to the office to tell them what people are doing to me like and then I think they must have slip me an injection or what I don’t know

The researcher though was left wondering under what circumstances might staff have acted. Asif for instance commented:

All the other Asian patients that was in there, there was three all together, one guy had been in quite a few times like with mental health problems and he goes “they don’t listen to Asians, because they think, because (of) the barrier of communication”

To the researcher, Rhupa’s experiences, whilst in her most vulnerable state and with a limited grasp of English, appeared to have been summarily dismissed, leaving her isolated and potentially exposed to further victimisation.

Despite the overwhelmingly negative connotations that the term dehumanisation possesses, it is worth noting that the struggle against it was often described as an active one. It involved sometimes confronting injustice, sometimes seeking out others and
sharing experiences, developing theories and understandings of how the world operated
and using the opportunity of a listener (here, the researcher) to tell their stories and to
perhaps seek to inform the outside world or privileged institutions of these experiences.
Often the researcher felt as if he were perceived to be young, naïve and, like such
institutions, also privileged, but perhaps also worth informing and "bringing to speed"
regarding how the world operated or had operated in the past. Helena, who was dying
from cancer, had this to say:

[Helena: 294] .....and I just pray, please God don't let my children get anything like
that.....and even you are a young man...and you are talking to me and I pray that you
wouldn't get anything like that....and I hope that those people that see and put the stigma
on people, doesn't get anything like that...because...it's nothing to want

Main Code 1 – Suffering Racial Violence

This main code comprised seven subcategories (groupings of experiences that some,
though not all, of the participants had encountered). Six of these subcategories comprised
different forms of abuse. In this regard they were 'static' or descriptive categories. The
researcher felt that this was appropriate because of their theorised relationship to the
seventh subcategory: 'seeing no action' (see Figure 5 below). Here, participants described
how institutions charged with their protection had failed to act.

Conversely, two participants, Helena and Rhupa, had not recounted any experiences of
racism. Helena for instance said:

[Helena:165] I didn't come across no racial prejudice.....but people talk about it
now....but I didn't come across (it).
Similarly, Sanjay had this to say about racism and discrimination in mental health ward settings:

\[ \text{Sanjay: 847]} \ I \ had \ no \ problem \ with \ anything, \ anything \ like \ that. \ldots [862] \ If, \ if \ anything, \ when \ I \ was \ there, \ I \ mean \ you \ had \ three \ or \ four \ Indian \ people, \ you \ had \ English \ people \ up \ there, \ err, \ they \ just \ looked \ after \ everybody \ you \ know? \ Like \ everybody \ else. \]

Other participants though did describe, sometimes profound, experiences of abuse and violence. It became apparent how deeply distressing some of these experiences were (both within this main code and the next). The researcher made an ethical decision at such points in the interviews regarding the need to, first and foremost, care for the participants. The latter were, after all, service-users with some of the most profound mental health difficulties. Interviewing often entered a ‘listening’ and empathic mode at these times.

**Facing verbal abuse:**

Various participants described the verbal racial abuse that they had suffered in childhood. Sometimes this was alluded to but not picked up and probed effectively by the researcher:

\[ \text{Megan: 528]} \ ... I \ never \ had \ anything \ apart \ from \ a, \ probably \ a \ few \ things \ from \ parents \ at \ school \ or \ something \ like \ that \ and \ you \ get \ nicknamed \ for \ it \ or \ something \ or \ summat \ wrong \ with \ her. \]

At other times there was an explicit recollection of events where participants had been taunted with racial slurs and stereotypes.

**Facing physical attack:**

This subcategory comprised both memories from childhood and events in the more recent past. Shirley for example spoke of physical bullying at her school, whilst Asif’s
Figure 5: Breakdown of the main code ‘Suffering racial violence’ by its subcategories

Main code

Constituent subcategories

Facing verbal abuse
[Shirley: 80] They were calling me names, all these children calling me Black this and Black that
[Asif: 278] ...over the fence you’d hear the comments... “the Pakis are out” you know? Curry munchers and stuff like that... That the house smells

Facing physical attack
[Shirley: 927] ...they were beating me up all the time. I’ll go home with my blouse all torn or my blazer all torn
[Asif: 503] I went out there to kick off I did.... I had a metal bar and I was ready to go and cave some heads in and my wife was going “No, leave it, the police will sort it” and I was saying this is too much man. Every time my daughter goes out there I say, she’s being called Paki....and it’s like on a daily, daily basis. I says at the end of the day, I says, it’s not right (Asif now crying).

Facing sexual assault
[Shirley: 163] ...it was from the boys, talking about rape and all that.... they were saying they were going to do that to me.... [934] I was told by my erm Uncle to stand up to, to them. You’ve got to stand up to the leader. Which I did. He was the leader.... [940] He flung me up against the wall and started trying to rip off my, my top actually. Rip off, rip off my blouse.... [944] They were laughing things like that.... [946] and erm, talking about my skin colour and everything. Used to say I’m a monkey and, because my hands and my foot are white and I should be walking like a monkey. Anyway I ran after this one who was leading all the others.... [84] and he got killed (in a collision with a car) and I was expelled.

Facing attacks to property
[Asif: 231]...made me feel angry....because at first I couldn’t understand it when I was younger. I used to think, you know, nothing of it. But when bricks are being thrown through the windows and.... [239]...one time there was petrol poured through our letterbox.... [244] The house near enough went up in flames

Sanjay: 223 So next evening he.... went outside you know, as he was going home (and)....his car wouldn’t start and then when he took it in the garage, what had happened was somebody had put sugar in his car...... into the petrol tank.

Facing veiled threats
[Nitin: 842]...he was staring at me.... [843] you know what he said to me? “You’re getting on my nerves” and I thought what have I done to you?..... [860] before that...he wasn’t like that
[Nitin: 1284]...There’s this other....White bloke, he was in under a section.....[1288] and I think he, he was saying that he had a gun and he shot someone.....[1295] (a) Black bloke....[1300] he made that type of remark to James (fellow patient of African-Caribbean descent) and that’s when I said to James “He’s fucking racist ain’t he?” and he’s saying “You’re too right.”

Seeing no action
family had suffered a recent racial assault by a gang of youths. Asif’s daughter and boyfriend had been dragged from the doorway of the house and beaten. Asif described how he and his wife had first hidden the rest of their children before trying to intervene. The profound consequences of this event for Asif, are described through the subcategory losing hope (Main Code 5 – Struggling to Cope). They included a resurgence of the positive symptoms of psychosis and a relapsing course that resulted in a suicidal depression.

Shirley had also seen some of her treatment upon wards as racist: she described her rough treatment, on this occasion by ethnic minority ward staff:

[Shirley:448] ...they rugby tackled me and flung me in the wall and stabbed me...[453] with a needle ...injected me...because I had seen something that I shouldn’t have seen, I was talking about it, they wanted to keep me quiet...[457] I kept saying that they were injecting me and they kept saying that I was hallucinating, this wasn’t happening

Facing sexual assault:

In her first year at high school, Shirley had been singled out by a group of older, White, male teenagers. This victimisation had culminated in a traumatic encounter when they had lain in wait for her one afternoon as she walked off school grounds at home time. Shirley had been racially taunted before the gang leader had begun to tear her clothes off. Shirley had fought back and caused him to run. In the ensuing chase he had been run over by a passing vehicle.

Facing attacks to property:

Asif and Sanjay also described how they had witnessed their own or others’ property being damaged. This had included having windows smashed, damage being done to cars
and arson attacks. For Sanjay this attack to property had been a repeated and discreet acts of sabotage. His suspect for these crimes had remained at large and faced no sanctions.

**Observing or hearing of violence or abuse:**

Some of the clients also described hearing of racial violence or abuse occurring or seeing its effects upon others. Asif for instance described how he had seen his ethnic minority neighbours victimised through attacks upon property. For Asif this had evoked memories of childhood when he and his neighbours had suffered similar harassment.

**Facing veiled threats:**

Nitin described in some detail how he had perceived comments by other patients as racially motivated and threatening. On one occasion, Nitin described feeling unsure how to take a comment from another service-user (Nitin: 842). On another occasion he had made a much more rapid evaluation and shared it with a fellow in-patient. Sharing experiences was felt to be an important process that participants used to cope with threats to their personhood. It is described further in the sixth main code.

**Seeing no action:**

The final subcategory depicted where participants described various settings (from school or places of work, to wards) where racial incidents had occurred but no action was seen to be taken, or able to be taken, by authority figures. A feeling of hopelessness or powerlessness pervaded accounts at these points:

[Shirley: 254] *They talked to the children one by one, that was in my class. Nothing....(and later)....[257] Just was long in the playground saying I'm a sambo and all that....[268] I couldn't say who and who. I mean they all did it but I couldn't point and say anything because they would get me. I was so scared, what might happen in the playground.*
[Sanjay: 242] he call the police and everything but obviously couldn’t prove it was him... and then after a while it happened again and the same thing – somebody put sugar in his car. So he wasn’t happy and then he had the police come in and everything but they didn’t do anything you know? You can’t prove anything.

[Nitin: 1314] we could have done (approached staff) but you know, Steve – he was saying even if we do, we still won’t get anywhere.....They might just warn him but if he just say “Yeah”......and then even after that they’d say “Oh you’re all right cos we’re all White”.

Main Code 2 - Suffering Mental Health Stigma

As a result of developing a mental illness, almost all the participants described how the stigma of developing a mental illness had upset their lives. This main code comprised three subcategories (see Figure 6 below).

Facing verbal abuse and bullying:

Participants described how they had suffered a variety of verbal harassment and bullying once they had developed a mental illness. This had included labelling and using stigmatising statements around them [Rhupa: 274]. Helena also described how she had heard people describe her and the difficult emotions and behavioural reactions that this had evoked. These included an immediate withdrawal to her home followed by a period of isolation and deep depression and anxiety [Helena: 188]. Sanjay also described how he had perceived other people in his local community as trying to push him purposefully towards breakdown [Sanjay: 1125]. Sanjay had believed his neighbours of possessing a vindictive curiosity to see what it would take for Sanjay to relapse.
Figure 6: Breakdown of the main code ‘Suffering mental health stigma’ by its subcategories

Main category

SUFFERING MENTAL HEALTH STIGMA

Constituent subcategories

Facing verbal abuse and bullying

[Rhupa: 274] I think people they don’t, they don’t believe, they just label you from when they see (that you were ill) and that still goes on....like I’m not being well and put me in hospital

[Helena: 188] I experienced my own people....and they say “She’s been certified, leave her alone...”[218] Felt bit sick...[222] Can’t describe it....[399] You know you don’t want to go back out.

[Sanjay: 1125] I was asking for it you can say, because everything (was) bottled up, you were calm and everything and people sometimes they like to, you know, light a fire....and they like to cause problems....when er they got it in for you....they will try and make things worse

Feeling put down and a loss of status

[Shirley: 41] ......some of the erm, neighbours, would speak to me before and all of a sudden these neighbours they won’t speak to me. They just as soon as they see me, they shut the door, or they go around the corner quick or try and keep away from me

[Sanjay: 1105] ......sometimes they feel they are better than you, you know, because you’ve had a (psychological problem) so they tend to treat you as though you’re crazy....so whatever you say is always bound to be wrong and what they say is always right

[Nitin:1816] ......my mother was talking to someone and saying I want (to) get my son married....and the people who’d say “Well we know about him in that way, schizophrenia and all that....there’s some who might say you know “OK, we’ll ask around” but those who’d say “No, not if he’s schizophrenic”......you know it puts you down......(but) there’s not much I can do.....apart from just to carry on......you can be slightly sad....but I, I still you know, carry on with myself

Feeling threatened

[Rhupa: 300] I want to be there but....I don’t want to be there because of what they....what goes on there....[305] they’d be alright for a little while and then they start changing....[308] and once I’m there, they’re not safe.

[Shirley: 893] And there was a lot of people, I could have gone there and talked, but I says no. That would have been possible. Positive....[897] Coz there was something, you know, not looked at me. It was something away from me
Feeling put down and a loss of status:

Shirley described how she had felt shunned by her neighbours after the onset of her illness. She had felt ignored and at times actively avoided [Shirley: 41].

Sanjay also described how people from his local community and from his own family had taken less account of his opinion or what he had to say regarding matters [Sanjay: 1105]. Nitin also spoke of how his life choices had become limited by his illness. He had described missing the various autobiographical milestones by which life in his ethnic minority community (and also the larger community as well) were measured. An especial example of this was marriage and the efforts of his family to find a suitable match for Nitin [Nitin: 1816].

Feeling threatened:

Some of the participants also described how feelings of danger, threat and isolation had led them to withdraw from their communities or to not take up opportunities to participate in events in their community [Rhupa: 300; Shirley: 893]. The researcher also wondered how stigmatising comments by members of their local communities might have made participants like Helena and Rhupa feel [Helena: 188; Rhupa: 300].

Main Code 3 - Fearing Retribution, Blame and Punishment

This main code was divided into three subcategories (see Figure 7). The first two subcategories seemed to be intimately related and specific to experiences within institutions such as schools and hospitals: ‘fearing blame’ and ‘fearing retribution or
punishment from services’. The last subcategory was ‘fearing retribution from the perpetrators of abuse’.

Fearing retribution from the perpetrators of abuse:

As in Shirley’s account [Shirley: 254], there was often a fear of retribution from the perpetrators of abuse. Shirley and Sanjay, for instance, described worrying how perpetrators might feel thwarted or attacked or punished by the victim and any interceding institutions such as teachers, employers, the police and ward staff. Thus, upon a ward there might be a fear of how fellow in-patients might behave [Nitin2: 85]. There was also a fear of how one’s family might be targeted as retribution for standing up to racist bullying [Sanjay: 274].

Fearing blame and fearing retribution or punishment from institutions:

Two participants had described how they had feared being blamed by authority figures if they had been seen to retaliate in any way to racial attack (see ‘fearing blame’ in Figure 7). It seemed to the researcher that racism within services from both fellow patients and from staff was often an expectation of participants and that any action they took upon themselves, would result in negative consequences for them (see ‘fearing retribution or punishment from services’). In this latter subcategory stark power imbalances were revealed between participants and ward staff. The latter were seen as able to exercise retribution through various punishments. These included over-medication, seclusion and withdrawal of support. One participant described how he had worried that his housing application would not be supported and that he would have nowhere to go once he left the ward he was on. This appeared to have been used as a threat to keep him in order.
Figure 7: Breakdown of the main code ‘Fearing retribution, blame and punishment’ by its subcategories

Main code

FEARING RETRIBUTION, BLAME AND PUNISHMENT

Constituent subcategories

Fearing retribution from perpetrators

[Sanjay: 274] ....but he knew where I lived you see, so you never trust people like that because they could do things........[255] to your house or something. Some things let’s put it this way, if you can avoid them, avoid them. Don’t make things worse.

[Nitin2: 85] ......you might be minding your own business, but if there’s others who got it up here (participant points to head), or someone might even tell them, you know pick on this one...[89] you could get kicked in and battered really badly

Fearing blame

[Sanjay: 414] Er not anger, I mean if anything I used to keep it all bottled anyway......coz you couldn’t hit anybody ever, because if you hit anybody ever, you lose your job and the other person loses his job

[Nitin: 940] ......and I felt slightly scared and you know what happened in there if.......patients started fighting, as soon as the staff see......they’d stop it and decide what to do with whom. Like I was telling you about seclusion......[950] inject them and put them in seclusion until they’ve cooled down

Fearing retribution from services

[Nitin2: 232] We didn’t think that (that event might have a non-racial cause)....sometimes you take...his word for it....[239] What we both thought was that – we figure it out – that he was like racist yeah? And like he’s a gorah (White person) and the staff, most of them are gorahs and that type of thing. And if something did happen they’d still fucking favour him more than us two. That’s what I thought and even Steve (fellow African-Caribbean patient) thought that too.

[Megan: 608] Don’t have the hassles because you have hassles from a lot of things. They make your life a misery.....They can do things to you that, you know, you think “Oh God”, you know, “should have kept my mouth shut” or something, like a needle or anything that would have something in it that would mess you up. That’s all I’m saying.

[Shirley: 476] They had me locked in for hours and I keep banging on the door and they wouldn’t let me out. And that was a “lie” (staff said). I did that to get attention. Wee yourself, messed yourself to have attention....you indignifying yourself then. You make yourself look small and the shame for doing that.....[501] They do, do things Naz and you cannot prove it, you cannot win, you cannot. If they say you’re mad....You might be ill yes but some things are happening and they’re hiding it.

[Nitin: 1444] ......you know that type of thing if you’re in there you behave and all that.....until you get your place......and if you don’t they, say when they kick you out, they say you can go night shelter.......and spend the night there but you’re not coming on the ward
Main Code 4 – Bottling Up, Withdrawing or Confronting

This code was intended to describe the tension that existed in participants’ minds regarding how they should deal with racially abusive or stigmatising events. It had five subcategories, the first four spanning withdrawing from threatening or potentially difficult situations and also consciously avoiding trouble (see Figure 8). For instance, in the subcategory ‘bottling up’ participants spoke of how their fears regarding retribution from perpetrators of abuse had informed their decision to not confront these abusers. One participant (Sanjay) described the suppression of emotional response within withdrawal as a “bottling up”. Hence this was a partial in-vivo code. A fifth category comprised events where ‘bottling up’ or withdrawing were replaced by confrontation with the abuser.

Within the category as a whole, participants often did not speak of fear directly, but the researcher believed that anxiety could reasonably be hypothesised as being present. In this regard, the researcher saw this and the previous main code of ‘fearing blame, retribution and punishment’, as intimately tied together within this particular analysis.

Avoiding trouble and confrontation:

In an above quote [Megan: 605], the participant described how she made a conscious decision (despite seeing herself as normally assertive) to avoid trouble that would result in retribution or punishment by services. Similar choices appeared to be made by other participants in their childhoods, in the workplace and in the community. In regard to facing stigmatising attitudes from within his local community Nitin described how he would actively avoid people he regarded as having stigmatising attitudes [Nitin: 1894].
Figure 8: Breakdown of the main code ‘Bottling up, withdrawing or confronting’ by its subcategories

<table>
<thead>
<tr>
<th>Constituent subcategories</th>
<th>BOTTLING UP, WITHDRAWING OR CONFRONTING</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Avoiding trouble and confrontation</strong></td>
<td>[Shirley: 104] I used to see some of these adults, children that used to call me names and I used to try and hide.</td>
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<td></td>
<td>[Asif: 260] we used to go to the parks, my Mother used to always say to me “No, don’t go to the park” and that lot. “The White people are there. They’re going to be in gangs.” Coz there used to be skin heads about, you know NF, was you know, a big thing at that time...[276]...we just used to stay in the house all the time...play in the garden or wherever, but like event then, like, over the fence you’d hear the comments</td>
</tr>
<tr>
<td></td>
<td>[Sanjay: 260]...just made me feel as though you know, you just don’t go anywhere near him you don’t (get) involved with him, do you know what I mean? If you can avoid it......the other person sort of spoke back and I sort of kept quiet do you know because it’s not worth making things worse</td>
</tr>
<tr>
<td></td>
<td>[Nitin: 1894] And that’s why they’re doing it and I, I won’t really have much to do with them (Naz: So you try and steer clear of them?) Yeah, yeah, yeah</td>
</tr>
<tr>
<td><strong>Trying not to stand out</strong></td>
<td>[Helena: 59] People back there were brought up to believe in things. Black magic and superstition...and if you were mad, you were bad, so you don’t tell anybody that......something’s going on because, you know, if you were mad you were bad</td>
</tr>
<tr>
<td></td>
<td>[Nitin: 1501]...what if they didn’t ask, if they thought “he just looks like a Paki” and “start battering him”......[1509] I was getting scared myself...[1628] I came back here and stopped in myself</td>
</tr>
<tr>
<td></td>
<td>[Helena: 388] See I could go out there now and I could come home and I could be so withdrawn, that I don’t want to go back out again......but people don’t realise that you know......[395] Somebody might have said something. Somebody might have said: “oh she been given diagnosis of mad, leave her alone”......You know you don’t want to go back out......You don’t want your children to know</td>
</tr>
<tr>
<td><strong>Withdrawing</strong></td>
<td>[Megan: 605]......all he thought was just lack of time......Don’t have hassles because you have hassles from a lot of things. They make your life a misery......They can do things to you that, you know, you think “Oh God,” you know, “should have kept my mouth shut” or something, like a needle or anything that would have something in it that would mess you up. That’s all I’m saying</td>
</tr>
<tr>
<td></td>
<td>[Sanjay: 317].......I tried not to confront them. That’s the problem with me, I used to keep everything bottled up......[320] So it’s not, I wasn’t sort of confrontational</td>
</tr>
<tr>
<td><strong>Confronting</strong></td>
<td>[Megan: 581]......he was working out in the garden and all of a sudden (another client spoke)”Oh I didn’t know you could do tattoos on your arm.....[584] and I stood up and (said) “How dare you, you goddamn racist.....[589] she was being prejudiced. Yeah it ain’t seemed like it but underlying it that’s what she meant.</td>
</tr>
<tr>
<td></td>
<td>[Asif: 189] I watched people call my Mother Paki and that lot....the older generation used they used to say “Oh leave it, it’s alright, that’s fine” like, but with me it became like an issue. I used to think I shouldn’t have to take this shit....I’d like answer back....to retaliate.</td>
</tr>
</tbody>
</table>

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Trying not to stand out:

With regard to stigmatising attitudes, a possible consequence of feelings of threat was to act in such a way as to not stand out. Megan for instance, described how she would try to dress appropriately and without standing out as a mental health patient. She had observed how other patients had been labelled by virtue of appearing ‘irunghuly’ as she put it (dirty and unable to care for oneself) [Megan: 772 in the Raised Codes File].

Helena also described how she had tried to hide her illness when it had first happened for fear of being labelled as bad or evil because of her psychotic symptoms [Helena: 59]. Later, when she had had another breakdown, she had again tried to keep this information to herself.

Withdrawing:

Withdrawing from potentially difficult situations occurred in various circumstances. Three especial examples of this appeared to be in response to dehumanising treatment on wards, fear of anti-Islamic reprisals and in response to community stigma. Sanjay and Nitin for instance spoke of how recent events such as the attack upon the Twin Towers in 2001 and the London bombings in 2005 had made them fear for their personal safety [Nitin: 1501]. On hearing media stories of reprisals, they had made a conscious decision to stay indoors.

Other participants spoke of how they had responded to mental health stigma by withdrawing from their normal routines of daily existence, only using supermarkets at night or returning home when they had heard stigmatising labels being used around them by members of their community [Helena: 388].
Bottling up:

Sanjay used the term 'bottling up' to describe how he had avoided confrontation despite his difficult feelings [Sanjay: 317]. In all, five participants described how they had similarly suppressed their feelings of anger or frustration at their treatment. They described how fear of consequences, whether in the playground, the workplace or on a ward, had caused them to 'bottle up'.

Confronting:

Three participants spoke of confronting abusers and often this followed a period of 'bottling up'. As in the quote above [Shirley: 183] where standing up to physical and sexual assault was described, some of the participants spoke of the crucial moments when they had decided to challenge their attackers.

Asif for instance, described how after confronting staff on a mental health ward regarding the treatment of ethnic minority patients, he had felt so disgusted and disappointed that he had walked out of the ward and returned home:

[Asif: 899] You know ....it'd be like "Oh they can hold on, it doesn't matter because they can't understand English anyway". And like when I saw that happening....[907] I took myself out of hospital, because I was that disgusted with the, you know ....I just walked out, because I thought "These people, they never cared."

In Figure 8, the dashed arrow is intended to depict how confrontation and subsequent withdrawal might be intimately related. Shirley too had described how she had feared for her safety after her confrontation with the gang of teenagers led to one of them dying. In her description of how she had tried to hide from the remainder of the gang, there was possibly the most intense form of withdrawal that led her to welcome the disfigurement and disguise lent to her through an accident.
Main Code 5 – Struggling to Cope with Illness

This particular main code was divided into three subcategories – ‘battling symptoms’, ‘overburdening into illness’ and ‘losing hope’ as shown in Figure 9.

Battling symptoms:

Shirley and Asif described how their early experiences might have shaped the symptoms of their psychosis (see Figure 9). For Shirley her voices had seemed to take on an aspect of deep, characterological self-blame reminiscent of how she had felt blamed and responsible for the death of a teenager when herself only a child. Asif’s voices and his emotional and coping reactions to them suggested a re-experiencing of verbal racial abuse attacking his person-hood, self-esteem and his beliefs regarding self-efficacy [Shirley: 916; Asif: 43, 101].

Asif described how his feelings of paranoia would escalate first and these would contain racialised subtexts. As this racialised paranoia escalated, there was a surge in the malevolent voices. Asif described reacting to such symptoms by withdrawing as he sometimes had in his childhood when faced with acts of racism or on wards when he felt dehumanising treatment from ward staff. This suggested that this code could be connected to the previous main code by virtue of the behavioural response of withdrawing.

Megan also described a racial content to her feelings of paranoia and how this had left her unsure how to interpret certain situations (i.e. attributional dilemmas). This latter problem was to recur in later encounters with services [Megan: 324]. Rhupa also seemed to describe how her paranoia would escalate when she was out in the community. This
Figure 9: Breakdown of the main code ‘Struggling to cope’ by its subcategories

Main code

Constituent subcategories

**Battling symptoms**

[Shirley: 916] …"You’re a murderer" and all that….[971] the past comes up a lot….[973] “You’re a coward, you should have tackled them from the beginning and it would have never have happened. So you’re at fault. You are a murderer.”

[Asif: 43] They say derogatory things and nasty things. Sometimes they can be racial….saying that I’m worthless piece of shit and that….Black bastard and that lot, start calling me Pakis and stuff like that….they don’t hold no punches when they speak…. It makes me feel really low….I start isolating myself. I go into my bedroom….[62] I don’t speak to nobody….when I’m getting to that rut, I’ll isolate myself for days on end….in my room. I won’t eat….I don’t know, sleep properly.

[Asif: 101] I will think they are talking about me, and if they laugh…you know, like as they walk past me, I think they’re laughing at me….the paranoia like gets worse then…. [125] when I see normal White people, I see that, you know, I think that they’re being racial against me you know?…. [158] And usually I’ll make my way as quick as I can to my house….coz I know if I start it there I’ll end up hurting somebody or getting into a fight.

[Megan: 324] I probably was at that time very like err, thinking Black this, Black that, you know, that the reason why people don’t like me because I’m Black this and Black that. And I had to realise that it wasn’t that sort of colour harassment

**Overburdening into illness**

[Sanjay: 399] …it wasn’t just easy for me to come from work and then switch off, you couldn’t switch off, you just had to carry on….and while I’m sleeping at night I used to have to figure out what to do the next day going to work - this needs doing, that needs doing. So you’re working everything out in your head at night what you’re gonna do the next day.

[Asif: 623] …the pressure from the (event), did make me, that was a factor in there….You know what I mean? From the pressure I was taking…. [631] I couldn’t handle no more. I was thinking you know, life, life can’t carry on like, you know what I mean. I don’t want to live no more. I just built myself a noose and was ready to do myself in…..[640] I was just being low and depressed like and the voices had been playing up quite a bit…..[644] saying things like, you know do yourself in, you know and, that you know, you, you’re useless, you’re no good to your family…. [648] that you’ll never get better…. [650] you got no future.

[Shirley: 777] My son…. [778] he says “Don’t take any notice, because if you keep thinking about that, you’ll get ill”. And he was right I did. I kept thinking about it: “Everybody knows about me”. Silly thoughts “a mad woman, schizophrenic, ooh my God you got to be careful with your children. She’s on the loose”.

**Losing hope**

[Sanjay: 667] …..I realised I’d had a breakdown because I didn’t remember what day or all the things I did, trying to kill myself….you only do that if you really feel like you’ve failed in life….and that’s how low I got then because I thought I’d gone that low that nothing was worth living for and I’m not making things better for anybody, so that’s when I tried to kill myself.

[Shirley: 545] Make you feel weary, tired…..Endless. You know I keep thinking to myself…. from the time I came to (name of town or city) when I’m now nearly hitting fifty, nothing’s changed much…..It’s all a sham…. [634] Make you feel as if they don’t care about my race…. [1059] it’s just made me feel a less of a person now. And I think that’s because of what’s happened. There’s nothing out there, there’s nothing positive out there for people within my age group…. [1064] For Caribbean people there’s nothing out there. If you’re sick there’s nothing out there.
would especially target her worries regarding stigma and labelling of her mental ill health:

[Rhupa: 421].......my husband used to like taking me shopping, going into the supermarket and cos I was in there a while, I used to think as soon as we go out, somebody (can’t hear on tape) tell them that I’m coming. So everybody who was there to, there’s a lot of people there and they look, you know, they look at you in a different way. That’s how I see it and then I want to come home.

In contrast to the struggle with these symptoms, Sanjay described how he had gained hope through his symptoms.

[Sanjay: 737] I do receive messages......what happens is......when I say I bottle up, keep everything inside me? Then obviously you feel more connected to God......when you turn to somebody you know......and you’ve er got nobody else to turn to.

[Sanjay: 758] ......sometime you know, when I used to (be) really low, it used to upset me when I saw people happy......because I am sad and somebody’s laughing......it used to make me feel sadder......I used to look for news which were bad on TV so that it, it used to make me feel as though my situation wasn’t as bad as some other people’s......[789] it’s like saying......I’ve got problems but there are people out there worse off than me......so you get messages all the while, gradually building you up so that, you know, it makes you feel as though you’re not the only one suffering.

In this manner Sanjay had felt as if he had gained hope and fought his feelings of isolation through counter-beliefs that he was not only one amongst of a community of the suffering, but also connected to and looked out for by God.

Overburdening into illness:

Sanjay was the only participant to describe clearly how his early struggles with discrimination and racism had led to him having a psychotic breakdown and attempting suicide [Sanjay: 399]. It is important to note that sometimes Sanjay talked of other influences that had contributed to his breakdown such as problems in his marriage. It is difficult to know how his problems at work and coping through alcohol use had impacted upon his home life. Another factor he spoke of when thinking about what alternative
pressures to racism had been operating, was low pay in comparison to his fellow workers. This had made him feel devalued and worthless. To the researcher this only seemed like a further example of how discrimination had operated in Sanjay’s life.

Two other participants described how they had been driven to relapse by events. Asif for instance had relapsed after the attack upon his daughter [Asif: 623], whilst Shirley had faced an increased spiral of rumination regarding her loss of status in the community and being stigmatised by it for her ill health [Shirley: 777].

Losing hope:

In Asif’s account there is a stark appraisal of how the attack upon his daughter led, not only to an increase in the positive symptoms of psychosis, but also to feelings of hopelessness, suicidal ideation and construction of the means to end his life. Sanjay too described how his feelings of worthlessness had descended into a suicide attempt during the onset of his illness [Sanjay: 667].

In addition to this Shirley spoke of how she had continued to feel wearied by her ongoing and seemingly interminable struggles with stigma, exclusion and with services that had failed to meet her needs [Shirley: 545].

Main Code 6 – Sharing Experiences

This main code comprised the following two subcategories where sharing experiences operated due to the facing of racism. Sometimes though, the sharing that participants
described was regarding non-racial matters. Thus it seemed possible that the sharing
elicited through this study’s aims might be part of a much wider category of how service-
users would try to feel empowered within their struggles to become well. For instance:

[Helena: 141] I’m going out...to the groups and talking to people......I’ve lived with the
voices even better......It was meeting more intelligent people.....I see how they live with
their voices and they cope with their voices, you know?
Sharing beliefs to feel informed or prepared:

There was a sharing of beliefs for instance regarding staff and services and about events that had occurred on wards. Sometimes this was information that was received from others judged to have more experience [Asif: 958]. At other times there was an active comparison of beliefs regarding an event that had occurred [Nitin: 1202].

Comparing worries and other feelings:

Megan described how she had struggled to share her feelings and thoughts until she had established a therapeutic alliance with a Black social worker. Megan spoke of how this worker had been a ‘lifeline’ and helped her to cope with her feelings of racial paranoia (see [Megan:324] in ‘battling symptoms’).

Nitin had described how a fellow ethnic minority patient had encouraged him to withdraw from certain other patients in order to not get “wound up”. Their camaraderie had led to a sharing of feelings and an encouragement to each other to be calm, as well as a mutual appraisal of exactly where they stood as ethnic minority in-patients [Nitin2: 270, 281].

Main Code 7 – Developing Personal Theories and Understandings

In Main Code 7 participants described how they had developed theories and understandings of how and why racism operated. It consisted of four subcategories (see Figure 11).
Thinking about how racist attitudes form:

Here participants tried to understand how a person might have become racist. These understandings often led to thinking about the upbringing of abusers and the example set to them by their families [Megan: 861; Asif: 485].

Re-evoking the past:

Sometimes participants compared past to present and wondered aloud how environments had changed or not changed. Instances occurred in accounts where there was a re-evocation of old memories and conflicts and sometimes a feeling of hopelessness pervaded accounts at these times [Asif:771]. As well as examples given in the accounts above [Shirley: 300, 545], participants also spoke of how lack of choice in their current care evoked memories of their childhood where they had faced a similar lack of choice [Shirley: 527].

Empathising with others:

Here participants attempted to empathise with other patients (as with [Asif: 920] above). Sometimes this extended to how people whom they had thought of as racist or abusive might themselves be suffering from heightened symptoms or medical or medication problems [Nitin2: 413].

At other times this empathy extended beyond wards to the wider community. For instance Sanjay spoke of how other ethnic minorities other than his own had suffered even greater thwarted hopes and aspirations [Sanjay: 440]. It felt to the researcher that not only did Sanjay feel that he should be thankful that he was not as badly off as others, but that
his sense of social justice was ennervated, or fired, by his ability and willingness to empathise with the less fortunate.

**‘Finding a balance’ or using personal experiences to identify racism or stigma:**

Two participants spoke of how they would come to decide if a person was racist or prejudiced with regard to mental health.

In these accounts there was a reliance on cumulative experience or the careful and gradual building up of evidence regarding the potential prejudices another might hold. At other times it was apparent that participants used some form of heuristic in order to evaluate an event immediately in order to gauge threat (see above [Nitin: 1285; Nitin2: 232, 381]). Nitin described how a confluence of factors such as how a person might be looking or behaving and the time of day all contributed to this appraisal. Where levels of threat were perceived to be high this led to a rapid decision but one that Nitin was able to understand might also be faulty.
Figure 11: Breakdown of the main code ‘Developing personal theories and understandings’ by its subcategories

Main code

DEVELOPING PERSONAL THEORIES AND UNDERSTANDINGS

Constituent subcategories

Thinking about how racist attitudes form

[Shirley: 527] You weren’t given a choice of meal or a Caribbean meal. You just have to eat what was there...[532] That reminds me of school...[534] when you didn’t have a choice, in my day. You had to eat what was there...[537] Otherwise you stay hungry, that’s all they used to say to you

[Asif: 771]...when I see my kids have racism spouted at them...it always makes me think back to my childhood...you know, that’s how I connect it in my mind...because I think to myself I went through this exact same...you know, exactly the same, you know, the same words are being used, the same derogatory remarks are made...[783] when they call my daughter a Paki it really hurts...because I think to myself I went through this exact same event...

Re-evoking the past

[Asif: 485]......they’ve got kids who hang around here in a gang. And it’s because all their Mothers and fathers have taught them is racism......they’re taking it out on any Asian person they see......and usually they see that Asians are quiet, they don’t want no trouble you know. Same as when we was growing up, we was always told “Oh forget it, leave it, it’ll cause more trouble if you retaliate or say anything to them”. But now it’s not accepted is it?.....But still you got, still get it

Empathising with others

[Nitin2: 413] You do start thinking like that Naz (evaluating threat and wondering why an event has happened)...[417] I was thinking and saying to myself “Well what could it be that I’ve actually said to him or done to him?” because I couldn’t think of anything...[was it something] the day before, or evening before and that. And that what I started thinking...And the thing that night Naz, they check, they were checking his [596] blood pressure...(so) maybe that’s why he reacted in that way

[Nitin: 360] I would think the same if (a) person said that...I don’t know what it is, you know, like I was telling you, but if he was looking at me in that way and actually saying it to me and if it’s this type of time, nighttime.

Finding a balance

[Asif: 861]......when children are four, five, three or four and they start growing, you will see them hold a Black kid’s hand or a White kid’s hand. They don’t know anything about this. It’s us. It comes from out of the kids. You know that person’s Black because you’re told “You’re not hanging around with them”. That is what racism is, isn’t it? Kids do not see it. They don’t see difference....It’s what you instil in them when you get angry. How you say to them “I don’t like you hanging around with that nigger, little kid over there.”

[Asif: 785]...if somebody is going to be a racist, he’s not going to come out and tell you he’s racist. You gradually get to know that he is one just by the way he does things......[you get your experiences as you go along]

[Sanjay: 1161] So obviously, if you don’t know somebody, you have to let them go a certain distance before you turn around and say that (you’re) not having this anymore......[1067] I don’t just come out and say that but what happens is......you find your balance with them

[Nitin: 381] I think the same if (a) person said that...I don’t know what it is, you know, like I was telling you, but if he was looking at me in that way and actually saying it to me and if it’s this type of time, nighttime.
Discussion

The current study aimed to explore the lifetime experiences of racism of ethnic minority service-users with psychosis. The model developed appeared to resemble findings from wider social research on the effects of racism within the general population. Clark and Moody (2002) and Victim Support (2006) for instance highlighted a fear of retaliation or retribution by abusers, as well as a lack of belief in the ability of institutions to respond sensitively and effectively to race hate. That such factors were then implicated in the processes of the current model should perhaps hold little surprise.

'Struggling against dehumanisation' as a core category

Exposure to racism or to mental health stigma appeared to heavily erode participants' feelings of humanity or person-hood. The researcher picked this out as a core theme as it appeared both salient and recurrent in the accounts that participants gave. Various authors including Erikson (1968) and Miliora (2002) had suggested that racism might lead to a dehumanised experience for an ethnic minority person.

Participants from the current study felt devalued or dehumanised in a number of ways. Their fear of how they would be received or treated, appeared to clearly evoke Goffman's (1963) description of how stigmatised groups were marked out as “less desirable.....bad, dangerous or weak” (p3). Participants also felt that incidents of verbal, physical and sexual attack or humiliation were often ignored. In the wider community too they described facing disenfranchisement or exclusion across the life-span and including:
Despite this, during the interviewing participants seemed to only sporadically reveal the personal impacts of racism, stigma and being considered 'less than human' by others. Instead they spoke of themselves, not as 'victims' of racism, but as active agents in the struggle against difficult circumstances in which combinations of stressors, including both racism and mental health stigma, had been prevalent. Thus participants have been depicted not as the passive recipients of various processes of dehumanisation, but rather as men and women who had marshalled their resources, attempted reintegration to society and, on a daily basis, struggled to conquer their fears about the world that they lived in. It was felt vital that the model developed should reflect such processes as well as the assault upon personhood from exposure to racism or stigma.

Exposure to racism or stigma also appeared to involve ambiguity as suggested by Goffman (1963). Encounters were described where there was no clear expression of stereotyped judgements so that someone's motivations were clear and participants could firmly attribute motivations. McConahay and Hough (1976) suggested that such ambiguous events could generate stress, anxiety and re-evoke similar past events, including how self-esteem had been effected. This re-evocation of experiences also appeared to occur within the content of positive psychotic symptoms.
The potential ambiguity of external events is important because much psychological research in psychosis is predicated upon the idea that attributional biases occur in how events are interpreted. These have been hypothesised as acting to both preserve self-esteem by occluding self-scrutiny but also, as a consequence, to reducing a client's self-efficacy and empowerment (Bentall, Kinderman and Kaney, 1994). Various potential problems with attributional approaches have been suggested though (Garety and Freeman, 1999; Boyle, 2002). Boyle (2002) suggested that professionals might see external attributions as automatically without merit. Internal attributions might be deemed preferable, without first a study of how a 'subordinated' group might have reached its attributions. In the context of the current study, how "a systematically used repertoire of accounting for negative outcomes" (Boyle, 2002, p289) might have arisen through past racially aversive experiences, would appear fundamental. Boyle pointed out the possibility that such repertoires (and the conclusions reached through them) might be distinctly unpalatable to clinicians or to society and thus deemed implausible, valueless and safe to ignore. In 'therapeutic' encounters clients might instead be tasked with biasing causality for events internally rather than externally. Clinicians might also gauge outcome by whether a client had learnt to correct 'their self-serving bias'.

Low 'influence' and an external locus of control:

Adams and Dressler (1988) had suggested that feelings of having 'low influence' (which might also be hypothesised as forming part of a 'repertoire' of responding to negative racial incidents as Boyle (2002) would describe) were especially prevalent amongst young, low, socio-economic status (SES) African-Americans who had faced racism or prejudice. They also suggested that low SES and exposure to racism might also pose a risk factor for developing future mental health problems.
On the other hand, it had also been suggested that an external locus of control was not only associated with poor mental-health outcome later in life, but that it was also the strongest predictor of developing psychosis in later life (Frenkel, Kugelmass, Nathan and Ingraham, 1995). The latter authors suggested that feeling that one lacked control over events was tied intimately to self-esteem. Harrop and Trower (2001) also suggested that psychosis in early adulthood could disrupt the development of a sense of mastery of environment and of oneself as an autonomous or fully-functioning adult.

In the context of the present study, this suggested that exposure to racism or stigma could similarly impact upon service-users mental health or had already done so in the past. Where such exposure had gone unacknowledged and left a service-user feeling isolated, an external locus of control might have been exacerbated. Such sequelae could be seen as especially resonant with the core category – that participants were struggling against a myriad of dehumanising impulses.

With regard to Boyle (2002)'s point though, a second danger might also present that could ramify feelings of dehumanisation. If a service-user was encouraged to consider causality for the events that they had experienced as internal rather than external, then this might create further ambiguity and lead to an increasingly stress-evoking situation with potentially worsened psycho-social outcomes.

Main Code 1 - Suffering racial violence

The main code ‘suffering racial violence’ amalgamated the different forms of racial abuse
and violence that participants had suffered. It varied widely as had been found by Carson and MacLeod (1997) and included verbal taunting, physical assault, sexual assault, arson or other attacks against property and events where participants believed that threat had been intimated.

Attacks also covered various domains such as school, the workplace and in public spaces (Sanders-Thompson, 2002). Outlaw (1993) had suggested that racism could act as a ‘continuous stressor’ which pervaded existence on a daily basis. From the descriptions of racial abuse or intimidation given by three of the participants, this would sometimes appear to have been the case. For one participant it had been a major factor behind his psychotic breakdown, during which he had attempted to commit suicide. The near daily occurrence of these events appeared to echo Delgado and Stephancic’s (2001) suggestion that racism could sometimes be perceived, not as an ‘extra-ordinary’ stressor, but as an ordinary one.

Often interventions by institutions such as the police or NHS staff, were seen as ineffectual or biased. Participants feared not being believed by staff and often described seeing no action being taken by institutions. This happened across multiple domains and at different autobiographical points in participants’ accounts (i.e. childhood, the workplace and from within services).

This unease with the inability of institutions to stand up for ethnic minorities was also found by Adams and Dressler (1988), Cortis (2000) and Greenwood, Hussain, Burns and Raphael (2000). Cortis (2000) for instance had found a belief that staff inadvertently engaged in racism or ramified the effects of racism through not challenging racist verbal abuse from other patients. MacPherson (1999) had highlighted this type of inactivity as a substantial area of risk for engendering racism or allowing it to flourish. Blofeld (2003) also suggested that
such inactivity was a factor in the events leading to the death of David Bennet in NHS care.

**Main Code 2 - Suffering mental health stigma**

Many of the current participants described facing various forms of stigma due to their mental health status. Participants often felt feared, shamed and excluded within their own communities. These were factors found by Brockington, Hall, Levings and Murphy (1993), who also found 'authoritarianism': the belief that people with a mental illness were irresponsible and that their life choices should be made by others. In the current study, much of the behaviour described by participants appeared to resemble this factor. Such behaviour occurred within families, within local and ethnic communities and within the life choices available to the participants, including how and when a participant should re-integrate back into community settings. Similarly to the potential impact of racism, exposure to authoritarianism might be hypothesised as effecting locus of control and leading to reduced feelings of 'influence' and self esteem (Frenkel, Kugelmass, Nathan and Ingraham, 1995).

In the present study, stigma led to feelings of loss of status and of being 'put down' by others. Various studies had shown that seeing oneself as inferior was intimately related to depression (Swallows and Kuiper, 1988). Mechanic, McAlpine, Rosenfield and Davis (1994) had found that some of the ramifications of facing stigma were lowered self-esteem and a lowered quality of life. It is possible that the social comparison caused by facing stigma might also have caused participants to feel defeated or lesser (Gilbert and Allan, 1998). The relationship of this to withdrawal or to lowered community participation is discussed further below.
One participant also commented on how ethnicity and mental health stigma interacted:

[Shirley: 843] I know that they hate me because I'm sick. They hate me because I'm Black. My colour does come into it as well....[847]....they think that all Black people are mad don't they.

Various studies have suggested that racial stereotypes, such as Black people being crazed or homicidal, could occur in tandem with stigmatising attitudes regarding mental health, for instance that the mentally ill were also homicidal and crazed. Studies have suggested that this can lead to a doubly vicious cycle of rejection and exclusion with various concomitant impacts upon self-esteem, depression and disenfranchisement (Philo, Henderson & McLaughlin, 1993; Philo, Secker, Platt, Henderson, McLaughlin & Burnside, 1996; Sayce, 1995). Such impacts were, once more, suggestive of the core category and the struggle of participants against dehumanisation brought about by social responses to their illness.

**Main Code 3 - Fearing blame, retribution and punishment**

In the current study, fear appeared to be a major emotional response, both with regard to racism and to stigma. For instance, participants feared retribution from the perpetrators of abuse if they had stood up for their rights, or had involved a third party such as a teacher, the police, employers or ward staff (Clark and Moody, 2002; Victim Support, 2006).

A further example was the fear of being blamed for escalating racial incidents into physical confrontations, for instance on a mental health ward or in the workplace. Participants described fearing various consequences such as seclusion, over-medication and withdrawal of support for housing. This finding tallied with that of Wood and Pistrang (2004) who found that fear of seclusion, restraint and forced medication were widespread amongst
service-users as a whole. Coercion from mental health professionals, as well as the threat of increasing exposure to racial abuse, were fears that were also highlighted by Perkins and Moodley (1993), Johnson and Orrell (1996) and Singh, Croudace, Beck & Harrison (1998). These studies emphasised the potential for service users in such positions to withdraw from services. Such fears and their relationships to past experiences of clients and to current experiences such as encountering abuse upon mental health wards, appeared to call for meaningful dialogue about such issues when, or perhaps ideally before such situations arose.

**Main code 4 - ‘Bottling-up’, withdrawing or confronting**

On numerous occasions participants in the current study described how the fear evoked by events had led them to withdraw from situations or to suppress their instinctual responses. Such events included:

i) experiencing racial attack at school, in the community or in the workplace;

ii) facing shaming labels regarding mental illness and social exclusion;

iii) high profile national events such as terroristbombings

Fernando (1984) had also depicted depression as a major consequence of facing racism. He suggested that a potential consequence of exposure to racism might be the forming of low self-efficacy beliefs that could then lead to a form of learned helplessness (Seligman, 1975). Adams and Dressler (1988) had also noted that belief in a lack of “influence” was common to the part of their sample most adversely affected by racism.

Within the wider literature, Gilbert (1998) suggested that experiences involving shame
and humiliation could lead to increased ‘interpersonal distancing’. Mehrabian and Russell (1974) also suggested that when faced with a particular environmental setting or cue, a ‘primary emotional response’ occurred that went on to influence the behaviour of that person. Both the characteristics of the setting, as well as of the individual, would contribute to how this response was shaped. Mehrabian and Russell believed that there were three important dimensions to this type of response. Firstly, there were beliefs regarding ‘dominance’ or how much control was held over the setting. Where it was high, a sense of commitment or responsibility might exist for the environment. Secondly, there was a dimension of ‘arousal’. This influenced the amount of activity that occurred in a setting or perhaps evoked withdrawal from it. Lastly there was a dimension of ‘pleasure’. This influenced whether a person remained within an environment or would later return to it.

Such work appeared to provide a useful means of understanding how participants might have changed the way that they interacted with their environment. For example, participants who had experienced racism or stigma might feel that they had little or no ability to dominate their environment and thus might withdraw from it (Adams and Dressler, 1988). French, Rogers and Cobb (1981) suggested that where a person believed that they and their environment did not ‘fit’, stress and the likelihood of ill-health would grow. Fernando (1984) suggested that therapeutic models where racism’s roles in removing control of one’s environment were explicitly described and countered, were vital.

Confronting:

One participant’s description of how “bottling up” might occur prior to explosive confrontation appeared to be mirrored in releases of anger that were described by three other participants. Various authors have suggested the importance of ‘over-control’ prior to
explosive confrontation. In research upon psychosis, Chadwick, Birchwood and Trower (1996) had noted that paranoid defences were sometimes akin to an 'angry attributional style'. Novaco and Welsh (1989) had also noted that cognitive errors in attribution or the holding of rigid viewpoints were common in anger and aggression. However, other authors also suggested the need to not over-emphasise such factors at the expense of examining the events leading to anger or aggression (Berkowitz, 1993). Novaco (1993) himself suggested the importance of examining how aversive social, interpersonal and psychological stressors might have interacted prior to an anger event. Indeed, in this manner, the release of anger and frustration following prolonged exposure to racial stressors has been suggested as a major antecedent to the death of David Bennet in NHS care (Blofeld, 2003).

Main Code 5 - Struggling to cope with illness

The direct struggle to cope with schizophrenic illness appeared to be impacted on three levels by racism and mental health stigma in the current study. These three levels or subcategories were by no means saturated and would demand further sampling or alternative means of investigation.

'Battling symptoms' and their social construction:

One current participant described the emergence of voices relating to a traumatic racial and sexual assault in her childhood. Janoff-Bulman (1992) suggested that 'characterological self blame' might sometimes be a response to traumatic experience and lead to feelings of hopelessness. At times during Shirley's interview and in off tape discussion with her, this type of pervasive self-blame and loss of hope appeared prevalent. Self-blame was also
evident in her voices, which took on the persona of her abusers from childhood.

Another participant had also suffered childhood racial abuse, including verbal threats and taunts, and arson attacks upon his home. To the researcher, his voices appeared to be re-abusing him in a similar manner and to be explicitly targeting his beliefs regarding his self-efficacy and thus his self-esteem. When these persecutory voices were at their strongest, the participant responded by withdrawing, becoming depressed and increasingly without hope. Other participants described similar cognitive-emotional and behavioural reactions, especially upon facing mental health stigma. This subcategory and perhaps the main code as a whole therefore appeared to be closely linked to the previous main code that had also involved 'withdrawal' (see previous code).

Fear of racial abuse also appeared to be present where two participant's feelings of paranoia had escalated. An example of this was a description of her restraint and subsequent seclusion by male ward staff. Some of the staff involved had been of ethnic origin, but the participant had still interpreted their actions as racist. This made the researcher wonder how the act of being forcibly restrained by male staff had re-evoked memories of childhood assault, especially as some of the conditions were the same (being restrained by males against a wall).

Part of the grounded theory therefore suggested that the positive symptoms of psychosis could sometimes be socially constructed (Kazanias, 1970; Torrey, 1981; Mitchell and Vierkant, 1989; Nayani and Davis, 1996; Boyle, 2002). Nayani and Davis for instance had found evidence for a gender bias in the abusive content of voices heard by clients: male and female participants were more likely to hear abuse targeted at their particular gender, rather
than the opposite one. Boyle (2002) argued that there was therefore a need to account for the role of social influences in constructing perception and meaning for voice-hearers.

Racism or stigma in ‘onset’ or in ‘relapse’:

For all but one of the participants, racism and stigma appeared to have led to depression, feelings of hopelessness and suicidal ideation or action. Three participants described how stressful life events involving racism or mental health stigma had contributed to either the first onset of their illness or to a psychotic relapse. Studies such as Brown and Birley (1968) had suggested the importance of mapping the influence of such life events prior to onset or relapse.

For two participants, such life events and a concomitant surge in symptoms had culminated in a suicide attempt. For one, exposure to racism in the workplace appeared to have led to depression, intense feelings of anxiety and worry, alcohol abuse as a means of coping, a lowering of self-esteem and hopelessness. This had culminated in a suicide attempt at the height of a first psychotic breakdown. Another participant’s suicide attempt had followed a traumatic racial assault upon his daughter. Following this, he had suffered a rise in racially malevolent voices as well as becoming depressed, withdrawn and increasingly hopeless until finally attempting suicide.

Depression has been shown to have a major impact on the course of a psychotic illness (Jackson and Iqbal, 2000) and often appears to occur prior to ‘first episodes of psychosis’ (FEPs) (Green, Nuechterlein and Mintz, 1990). For one current participant, this would especially appear to have been the case. Fernando (1984) suggested that the failure to achieve ‘normal’ developmental goals, such as at school or in the workplace (as described by some of
the participants), would constitute a loss event. Similarly, exposure to stigma from within one’s own ethnic minority community might also constitute a loss event. Drake and Cotton (1986) also argued that it was depressed mood and the psychological aspects of depression (including guilt and hopelessness) that impelled people with schizophrenia towards suicide.

This particular participant’s account also clearly depicted the guilt that he felt regarding his belief that he had failed his family and his feelings of hopelessness regarding how he might improve matters in the future. Gilbert, Pehl and Allan (1994) and Gilbert (1998) suggested that shame or self-judgement might exacerbate how a person viewed him or herself, for instance through thoughts of the self as being bad, useless or worthless. Self-attacking thoughts encompassing isolation, desolation, desperation, ‘invisibility’ and being misunderstood, could spiral and cause various behavioural sequelae such as withdrawal and interpersonal distancing. Gilbert and Allan (1998) found that measures of ‘entrapment’ and ‘defeat’ were significantly correlated with those of depression and other rank variables thought to underlie social comparison.

The participant’s grandiose delusional beliefs regarding his connection to God could be seen as buffering him against the loss, isolation and hopelessness that he faced during onset. Bentall, Kinderman and Kaney (1994) suggested that delusional beliefs could act to preserve self-esteem. They suggested that persecutory delusions might allow a person to escape self-scrutiny by ascribing the causes of events to external factors. The participant’s more benevolent delusional beliefs on the other hand, might instead have allowed him to delay not just self-scrutiny but, and more germane to his account, the psycho-social consequences of the racism that he had suffered and his failed coping responses to this (Clark, Andersen, Clark and Williams, 1999).
On the other hand, the participant who had spoken of the attack upon his daughter had also described how he had tried to cope and behave in its aftermath. This included getting the support of the police and the local council. Despite this though, and perhaps under attack from resurgent malevolent voices, he had begun to perceive himself as having once more failed his family. Generic stress-coping models (Lazarus and Folkman, 1984) as well as those geared specifically to understanding the impact of racism (Clark, Andersen, Clark and Williams, 1999) have suggested that a victim who perceives their coping response to a stressor as having failed, faces increased psycho-physiological stress. For the current participant, this and the consequent impact upon his self-esteem and self-efficacy beliefs appeared to be the major drivers behind his suicide attempt.

Withdrawal and learned helplessness in response to positive symptoms:

Withdrawal from social and community settings appeared to be a factor shared with the previous main code. Stampfer (1990) highlighted how the negative symptoms of psychosis, such as loss of pleasure or social withdrawal, appeared close to those seen in chronic post-traumatic-stress-disorder. Birchwood and Chadwick (1997) had also suggested that depression and experience of voices could be linked. Malevolent or persecutory voices could arouse hostility, fear, anger and depression (Chadwick and Birchwood, 1994; 1995). The more malevolent the voice, the more likely a person was to be depressed (Birchwood and Chadwick, 1997). Where such voices were perceived as 'powerful' by the voice-hearer, the risk was even greater.

It has also been suggested that if a voice hearer felt weakened in comparison to their voices, this might reflect how they had previously judged rank and social worth (Rooke and Birchwood, 1998; Birchwood, Meaden, Trower and Gilbert, 2002). Rooke and Birchwood
(1998) found that amongst people with psychosis, events, including facing stigmatising attitudes, could lead to feeling of "low rank" or of not "fitting" with one's social group. Birchwood, Meaden, Trower and Gilbert (2002) had also suggested that both interpersonal environments (perhaps involving racism) as well as how a service-user interacted with their voices, could trigger an involuntary subordination reaction. Attendant cognitive, emotional and behavioural responses included lowering of self-esteem, humiliation, entrapment, anxiety, depression and withdrawal. This code therefore seemed a key sequelae to positive and negative symptoms involving racism.

'Jumping to Conclusions' versus a 'fast heuristic mode':

Garety and Hemsley (1994) believed that delusions were formed and maintained much like normal beliefs, but that there would be perhaps over-confidence in any judgements that were made based upon them. For instance, control groups appeared to be significantly slower than a sample of participants with delusional psychosis in how long it took them to reach conclusions (Garety, Hemsley and Wesseley, 1991). Bentall (1992) suggested that a bias in processing might explain this. Clients might selectively attend to threatening stimuli or have a certain type of attributional style concerning the causes of events that they were involved in. They might therefore reach a judgement quickly. Drawing conclusions based upon incomplete evidence has been termed "jumping to conclusions" (Garety and Freeman, 1999).

Various participants in the current study described how they had attributed the causes of certain events to racism or prejudice. Some also reflected upon their attributions and realised moments where they had made errors of judgement. Despite this, it is worth noting Garety and Freeman (1999)'s point that there was no evidence that jumping to conclusions comprised an actual deficit in functioning. Indeed Maher (1992) had pointed out that a 'jumping to
conclusions' type bias might not necessarily lead to an inflated error rate and that there might be adaptive value in deploying such a heuristic. Also, Iqbal, Birchwood et al (2002) pointed out that self-serving processing biases also existed in the normal population: amongst people with psychosis there might simply be heightened threats to self-esteem through stigma, role-invalidation and, perhaps, racism that made a self-serving bias adaptive during illness. In this present study, 'jumping to conclusions' appeared to be a value-laden term that could potentially ignore or refute experiences from an ethnic minority service-user's past. The potential for breach of therapeutic alliance as a result might also be increased.

Therefore, a useful way to frame what was happening when the current participants perceived danger, was that a 'fast heuristic mode' was entered into. For instance one participant, in describing how she had fought back against male nurses who were restraining her, described both the incident (despite it involving ethnic minority staff) and her subsequent treatment as both racist and dehumanising. This suggested that past events involving racial and sexual assault may have been instinctively re-evoked and that she had gauged threat during restraint as high.

Another participant most clearly described how his assessments of threat were based upon conditions of isolation, timing and content. Where he felt isolated, it was late at night and where threat was believed to have been implied by another, he had opted for a rapid but potentially crude assessment of risk and acted accordingly (for instance by discontinuing a social interaction or withdrawing). In subsequent main codes the operation of a 'slow heuristic mode' as opposed to the fast one described here, will also be theorised.
Main Code 6 - Sharing experiences

Participants in the current study described how sharing experiences with others, whether ethnic minority workers or fellow service-users, had allowed them to feel informed or prepared for life upon mental health wards or in the wider community. Through comparison of feelings and thoughts they had found ways to cope with paranoia or heightened anger and arousal.

These findings echoed those of Bullock and Houston (1987) where ethnic minority students had been found to privilege mutual support as a means of buffering themselves against discrimination. Cochrane (1983) and Howarth (2002) also highlighted how sharing could lead to a buffering of self-identity and help provide social and psychological resources as protection against racism. For some participants such buffering might have been blunted by the mental-health stigma that they faced from within their own communities. In such situations, the potential buffering effects of cultural pride and group status (Stevenson, 1997; Fischer and Shaw, 1999) may have been unavailable.

Various authors have argued that social and interpersonal resources are a vital component for regulating anger (Novaco, 1993). This is not to say that participants were possessed of high levels of temperamental anger, only that at times situational anger occurred in response to events around them. Where they had decided that their own judgements might be clouded or that they wanted a fresh perspective, they sometimes sought to share experiences.

Clues as to how sharing might operate also came from differences in how information was divulged or shared with the researcher. The three male participants often spoke in very
‘matter of fact’ ways and of themselves as ‘copers’ who felt only slight amounts of emotional distress. Emotional distress increased dramatically though, whilst retelling traumatic experiences. This suggested that at other times in the interview they might have felt it was unsafe to articulate any feelings of hurt or anger that they had. Krieger and Sidney (1996) had suggested that this was a potential danger for ethnic minority men.

Sharing under such circumstances may therefore have taken specific paths. For instance, comparing versions of events and validating thoughts and beliefs might have taken priority over sharing of emotional states. For instance, one participant described how a fellow African-Caribbean service-user had tried to help him calm himself, perhaps breaching such a protocol in order to keep the participant out of trouble.

On the other hand, Krieger and Sidney (1996) also believed that female participants privileged an emotional validation of their experiences and, where this was prevented, it resulted in more unsatisfactory health outcomes. Three of the participants in the present study clearly valued using the interview process in this way. Emotional retelling, as well as an emotional experiencing during this that was congruent with that retelling, permeated these accounts.

Main Code 7 - Developing personal theories and understandings

The current participants also strove to understand the social circumstances that they had been exposed to and the implications of these for their coping during illness. Heider (1958) described all human beings as essentially “scientists” who would try to link what they had
observed about events or behaviours in their social worlds to more unobservable factors such as causes or motivations. The participants in the current study appeared to have done this and, in so doing, to have challenged the dissonance that may have arisen through feeling different or stigmatised, or indeed feeling uncertain or fearful about how they were perceived by their wider communities (Goffman, 1963).

An example of this was through seeking to understand how racism might arise in society. At least four participants considered how abusers might themselves have had racism modelled to them by their care-givers. Thus participants seemed to be attempting to understand how exposure to certain conditions might engender race hatred.

Participants also tried to empathise with two additional groups:

i) those who had racially abused them in ward settings or who were believed to have intimated racial hostility;

ii) those who were in a worse position to themselves such as other ethnic minority groups who were perceived as having an even harder time than themselves.

These two examples of empathy resembled the two means by which Heider (1958) had predicted causal decisions would be arrived at. The first way relied upon internal sources (personal or dispositional means of making inferences) that allowed exploration of alternative meanings for a person's actions. These included empathising with another's illness or with their fluctuating symptom profile. For instance, one participant was able to consider how a lack of sleep or a relapsing course of illness might have led to a lack of inhibition regarding what someone had said to them. In this way a crude formulation was arrived at that allowed
the participant to step into the shoes of the fellow service-user.

The second example of empathy relied upon external sources (situational or environmental knowledge), derived perhaps from a number of sources including the media or their own observations. For instance, two participants spoke of how Afro-Caribbean people were afforded few choices or only encouraged if they had shown flair in certain areas (sports for instance).

Such methods of deploying empathy and reasoning may also have helped participants to 'unlink' from racial or potentially racial events. For instance, Rothbaum, Foa, Riggs, Murdock and Walsh (1992) suggested that if victims of crime were able to attribute less 'malevolence' to an event, their distress levels would be concomitantly lower. Similarly, if victims attributed the causes of traumatic events to external and not internal sources, they were more likely to 'unlink' from the event (Tennen and Affleck, 1990). Carson and Macleod (1997) suggested that ascribing cause of a crime to one's racial background (an 'immutable' aspect of self as they termed it) could confound this type of adjustment. They suggested that 'unlinking' was more likely to occur if the ethnic minority victim could not only attribute causality externally, but also ascribe it to factors such as chance or ill-luck.

The potential danger might be that attributional biases had arisen which served a defensive 'unlinking' function: the removal of such a defence without an adequate formulation of how they had arisen and how they should be replaced would appear to be a major danger (Fenton, 2000a&b).
A slow heuristic mode

The acts of sharing experiences and of developing theories and understandings also suggested a ‘slow heuristic mode’, in opposition to the ‘fast’ one that was depicted in ‘struggling to cope’. For instance, two participants described how sharing experiences with someone that they trusted had led them to re-examine an event and to seek alternative explanations for events. This does not necessarily imply that the original, rapid attributions of these participants were incorrect (Maher, 1992): they might well have been encountering hidden prejudice or attitudes. Instead, developing their understandings of events and seeking to empathise with others’ plights, might lead to better psycho-social outcomes for themselves. For instance, self-esteem might be encouraged. Such ‘helping’ efforts have been described by Roberts, Salem, Rappaport, Toro, Luke and Seidman (1999) as a valuable means of increasing self-esteem amongst service-users. They might also be better placed to combat feelings of helplessness through the encouragement of self-assertion and of beliefs regarding their control or ‘influence’ over events (Adams and Dressler, 1988).

The final two codes therefore seemed to be examples of how participants actively struggled against the dehumanising impulses set in train by exposure to racism or mental health stigma.

Conclusion

Facing racism, as well as the twin prejudice of mental health stigma, appeared to have negative psycho-social sequelae for ethnic minority service-users with psychosis. Early
events involving racism influenced the construction of positive symptoms that included racially malevolent voices, voices that echoed past traumatic racial violence and persecutory delusions involving the fear of environmental racism.

Major cognitive-emotional responses identified included fear of retribution from abusers, punishment by services, feelings of disenfranchisement, exclusion and loss, lowered self-esteem, diminished self efficacy beliefs, depression and loss of hope. Negative behavioural sequelae to such cognitive-emotional responses, or to the positive symptoms of psychosis, included withdrawal, isolation and suicidal or para-suicidal ideation and action. Heightened awareness and vigilance may also have occurred with the possible operation of a 'fast heuristic mode' that allowed any continuing threat to be quickly gauged. Such psycho-social events occurred not only in pre-illness but also in mental health settings. To not explore such issues as racial experience, both prior to entry into services and once in services, with ethnic-minority service-users would appear to run the risk of incubating unseen, iatrogenic (or 'illness exacerbating') consequences for such service users (Gomm, 1996).

Various positive behaviours were also identified in the struggle of participants to reclaim humanity or personhood. A major example of this was the seeking of similar others in order to share experiences. This helped participants to challenge both their devalued status and the operation of positive symptoms. The latter appeared to occur through the careful consideration of alternative explanations, often in the company of trusted others. This may have comprised a 'slow heuristic mode' able to be deployed when threat levels were low or reduced or when social or therapeutic support was available.
Clinical implications

Such findings might suggest the utility of paying heed to how both positive and negative symptoms might be influenced by an ethnic minority service-user’s experience of racism. Kuipers, Garety and Fowler (1996) had noted that their clients had often been exposed to distressing life events prior to psychotic breakdown and that such events could also revive within positive symptoms such as voices. In addition, Birchwood (1996) suggested that uncontrollable events in childhood might act to remove agency from an individual and lead to externalising attributions that would allow the preservation of self-esteem, but would reduce agency even further. The reduction in agency might manifest through various negative symptoms including anxiety, depression, learned helplessness, withdrawal and suicidal ideation. A key formulation target for professionals might therefore be to map how past experiences had interacted with coping or perceived coping.

Socialising clients into a model where fast and slow heuristic modes could be safely compared (perhaps terming them ‘fast and slow problem solving’ styles) might allow the challenging of either attributions or of feelings of helplessness. Various authors have written about the need for psychologically therapeutic processes where clients’ beliefs about their symptoms are challenged and weakened (Chadwick and Birchwood, 1994). For instance, if the omnipotence or power of racially malevolent voices could be lowered, then emotional distress and problem behaviours might also be alleviated. From Fernando (1984) it might be taken that such therapeutic models should be specifically tailored for ethnic-minority service-users by assessing racialised content within positive as well as negative symptoms. These might then be addressed through the sensitive application of cognitive restructuring techniques. Here, the adaptation of clinical jargon to incorporate a potentially useful or
possibly preferred way of analysing events (through considering how gauging threat and speed of appraisal might interact) might be a useful aim.

McGlashan (1984, 1987) though, depicted the possibility that clients might oscillate between a ‘sealed over’, or non-reflective coping position and an ‘integrated’ one where a client felt well and empowered enough to reflect upon events. Bentall, Kinderman and Kaney (1994) also suggested that where a client was faced simply with arguments or counter-evidence that challenged positive symptoms, they might not engage. This suggested that racial narratives might form an important part of an ethnic minority client’s history and therefore need to be sensitively explored and in a manner that accounted for the occurrence of environmental stressors and their role in generating emotional distress (Fernando, 1984; Tarrier and Turpin, 1992).

Chadwick, Trower and Birchwood (1996) also suggested that it was vital to listen to a service-user’s personal experience of psychosis and integrate this into treatment and intervention. Davidson (1992) and Chadwick (1993; 1997a&b) had highlighted how it was vital to the success of an intervention to elicit narratives regarding how life had been impacted or changed by experiences. This could include those experiences generated by racism, mental-illness, stigma or a combination of these stressors. Helping a client to develop these narratives and to promote a sense of empowerment, have been seen as integral to good outcome. Birchwood, Iqbal, Chadwick and Trower (2000) have suggested the need to navigate a client’s experiences of loss and entrapment (or lack of control) and how this had impacted upon life experiences and functioning.

Tarrier and Turpin (1992) also advocated reducing such environmental stressors through
teaching enhanced coping strategies and reducing symptoms. Birchwood and Chadwick (1997) and Birchwood, Meaden, Trower, Gilbert and Plaistow (2002) have suggested that how one related to auditory hallucinations might relate to one’s interactions in the social world and that both could be enhanced through:

i) improving status and position

ii) identifying with a group

iii) assertiveness training

iv) problem solving therapy.

Such approaches were highlighted by Fernando (1984), as useful treatment approaches for tackling depression after facing racism.

In reviewing the efficacy of social skills training for people with schizophrenia, Benton and Schroder (1990) suggested that it was vital to rehabilitation. For instance, Hogarty, Anderson, Reiss, Kornblith, Greenwald, Ulrich and Carter (1991) found increased resilience to social stressors and reduced rates of relapse after a social skills training intervention. The current findings therefore suggested the utility of developing group-based interventions for people from ethnic minority communities where withdrawal and empowerment in the face of racism or stigma were key issues that could be targeted.

With regards to stigma, interventions at the level of the community might also be vital and considered in line with the National Service Framework regarding health promotion (Department of Health, 1999). This might include psycho-educational approaches, liaison with community or service-user groups and the establishment of mutual aid networks in order to facilitate recovery back into the community (Mental Health Foundation, 2004; National
Limitations and future directions

This study suffered from various limitations. Firstly, it involved only seven participants making generalisability or 'coherence' difficult to predict. Certain populations were not represented in the make up of the sample, for instance African-Caribbean men. One participant (Sanjay) commented that their lot was far worse than his own situation. Therefore, this would be an important avenue down which to continue sampling.

In addition, despite the participation of four women in the study, the researcher was left with the feeling that he had not effectively followed up leads regarding women's experiences. An example of this was in the workplace where twice participants intimated experiences that were not elaborated (Megan and Rhupa). Denzin (1989) has pointed out that the experiences of women involved in research could be "filtered" out due to a predominately 'masculine' bent to the research process. Oakley (1981) for instance talked of the exclusion of feminine traits in research, such as sensitivity and emotionality. Considering the difficult stories that were elicited through the interviews, this was felt to be of massive concern and one that can hopefully be addressed through future research. This was especially so as research had suggested that women from ethnic minority backgrounds might be potentially more vulnerable than men to both psychosis (Sproston & Nazroo, 2002) and to the aversive consequences of facing racism (Krieger & Sidney, 1996; DuBois, Burk-Braxton, Swenson, Tevendale and Hardesty, 2002).
The coherence of the model could also be called into question in two further regards. Thirty-nine potential participants were approached, but (normally due to fluctuating symptoms or to a change of heart) only seven continued into the study. This raised the possibility that interviewing the remaining parts of the attempted sample might have led to a different model. A future study might consider alternative methodology such as open-ended questionnaires. Participants who had had a change of heart might have been more comfortable with this. In this manner a potentially different subset of participants and their experiences might have been accessed, whilst such questionnaire results could also have been included in the GT analysis.

In addition, the sample came from amongst the most seriously ill of mental health service-users. A different model might have been achieved through sampling amongst other populations, for instance those who, after a first episode, had recovered back into the community without further relapses.

Much of the wider model outlined in the above discussion, though perhaps seductive in theoretical range, also runs the risk of over-reliance upon subcategory data. For instance, the findings of social construction of symptoms or of potential psycho-social sequelae such as 'overburdening into illness' and 'losing hope' remain at the sub-category level as they were not able to be investigated further within the time constraints of this study. Further sampling might have unearthed useful data. Contrary to the suggestions made above, such sampling would most likely not be from within recovered populations, but from those in which psychotic illness was longstanding.

Other alternative methods also existed. One idea might be a case note analysis where
information regarding symptoms might be searched out and coded either using grounded theory, template analysis or content analysis. A study of how staff had logged such information and their beliefs regarding its importance might also be useful and highlight systemic and organisational changes that could facilitate care and not exacerbate the distress of ethnic minority service-users.

A pertinent additional future study might look at the subcategory 'seeing no action' in response to facing racism, to see what experiences service-users had had of this and what its psycho-social impact might be. The MacPherson Report (MacPherson, 1999) had suggested that it was critical to examine institutional responses to racial events. This study, similarly to wider findings such as those of the Blofeld Inquiry (2003), has suggested that the ignoring of racial incidents can lead to heightened distress and the possible exacerbation of service-users' illnesses. It would therefore appear fundamental to the spirit of the MacPherson Report that any institution, whether clinical psychology or the wider mental health services of the NHS, should consider how it could best avoid iatrogenic (or exacerbating) effects upon an ethnic minority service-user's mental health problems. This would appear to be, at the very least, a fundamental component of the basic duty of care of these institutions.

Beyond this basic level, the simple lack of research based inquiry to this area by clinical psychology in this country, would indicate a failure to engage with issues of, sometimes fundamental importance to ethnic-minority service-users. Despite this, paradigms and models exist within psychological theory and research to redress this imbalance. The grounded theory produced in this study has hopefully helped to highlight potential theoretical research pathways. All that would appear to be needed is the initiation of a sustained and wide-ranging research effort and the will to implement this.
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Section 3

Critical Appraisal of the Research Process
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Critical Appraisal of the Research Process

Introduction

The current study originated in my clinical experiences upon placements where ethnic minority service-users had spoken of incidents of racism. One such service-user, for instance, had suffered a racial physical assault. This appeared to lead to an increase in her previous anxiety problems, the development of a degree of agoraphobia, an increase in symptoms of depression, a loss of hope and a temporary withdrawal from the therapy process and services in general.

A second service-user, suffering from psychosis, described how he had withdrawn from all services apart from his family doctor, after being an inpatient on a mental health ward. Whilst trying to engage with this client in an “assertive outreach” mode, the service-user and I had had conversations where the formers’ experience of prejudice and racism and his mistrust of services had come to light.

Planning the study

Early on in this project various considerations arose in how it should proceed. A major consideration was which client group to centre a study of racism upon. With much of the research literature unearthed based upon non-clinical samples, the decision was taken to examine the views of some of the neediest populations i.e. those with severe and enduring
mental health problems, specifically psychosis. A number of factors contributed to this
decision aside from their marginal or socially excluded status within society:

- an ethnic minority client with psychosis had helped to first instigate this project in the first
  year of the course;
- I had a substantial interest in working with this population in my final year placement and
  felt that the research would help to provide a more complete consideration of ethnic
  minority issues which had troubled me throughout training (i.e. relating to: the accessing
  of services by ethnic minority populations; training, teaching and supervision in diversity
  issues; and minimal address to such issues in the professional literature, especially peer-
  reviewed);
- I had an interest in how a social milieu could influence the construction of psychosis i.e.
  how might facing racism in life effect the construction of psychosis (Bentall, Kinderman
  & Kaney, 1994);
- the needs of this vulnerable client group felt the most likely to be overlooked in any study
  attempting to investigate this area.

Methodological concerns

The studies unearthed through a literature review posed many questions regarding what
the experience of ethnic minority clients of the mental health services might be with regards
to aversive events involving racism. Unfortunately, various problems also existed in
generalising any research done, for instance in the USA, to this country. An especial concern
would be the reliability and validity of research and clinical instruments developed abroad,
within this country.
Use of qualitative methodology:

Qualitative study suggested itself as a useful way of examining the convergence of some of the psychological and psycho-social constructs that were suggested in the literature, with a clinical and UK based sample of participants. This might include interviews where participants were asked about their beliefs regarding identity, social support, ability to share information regarding an event and how this then converged and impacted upon their feelings of self-efficacy, ‘dominance’ and wider mental health concerns. This might be done with a number of different populations including with clients of the mental health services.

As the generation of theory in an area that seemed research impoverished was an explicit aim, the qualitative methodology of Grounded Theory (GT) proposed by Glaser and Strauss (1967) seemed most appropriate. Glaser and Strauss (1967) were interested in mapping theory generation, as opposed to devising theory subjectively and then attempting to validate it through quantitative means. They viewed the latter as an ‘impoverished’ approach to research. In the current setting GT might allow theory generation to be explicitly wedded to service user-accounts. Pidgeon (1996) for instance, suggested that GT could be used to look at how events and interactions with psychological impacts could be related to their social contexts.

GT has been successfully used in various studies of mental health functioning. A study by Lukens, Thorning and Lohrer (2004) used it to examine the adjustment of family members to the development of mental health difficulties in a fellow member of the family.

The method has also been used in research involving severe and enduring mental health problems such as psychosis. Robertson and Lyons (2003) for instance used it to look at the
experience of puerperal psychosis, whilst McCann and Clark (2003) looked at how nurses tried to encourage the accessing of services by young people with a first episode of psychosis. The method has also been used with ethnic minority inpatients of the mental health services (Cortis, 2000; Greenwood, Hussain, Burns & Raphael, 2000).

**Barriers of language:**

A further important consideration in planning this research was the need for a qualitative researcher to personally examine and code in detail the interview transcripts that they had obtained (Charmaz, 2003). This would seem to impact upon the manner in which ethnic minority participants whose primary language was not my own could be involved in research. Freeman (1983) suggested that the use of ‘naïve’ (in terms of research rather than other areas of expertise) interpreters might lead to embellishment or simplification of statements made by participants.

Also, there might be a possible risk in a researcher over-relying on his or her own language skills. Fluency might not extend to the ability to encourage participants to express their views in the language and terminology of their choice. Fontana and Frey (2003) for instance, point out how simple fluency may not be enough on its own to capture either underlying meanings or the connections of the language being used by participants, to underlying cultural discourses.

Therefore, for studies aiming for wider access, the interpreter(s) would possibly have to be much more heavily involved in the research and, ideally, be recruited and trained specifically for the purpose of conducting, transcribing and finally coding interviews. In the current study though, with only myself to rely upon, participation was limited to those
service-users who had English as a primary language and felt comfortable to use this language in the interview.

**Considering locale of research**

It was assumed that the experiences of clients or potential participants would be highly disparate and perhaps also a function of locality and time of upbringing (Cochrane, 1983; Littlewood and Lipsedge, 1997). I hypothesised that a grounded theory might change massively simply as a function of age or locality of the participants that were recruited. Different results might also be found if interpreters or language competent researchers had been employed in the study, or if the study had been conducted in a different area of the country.

In addition, the study was only able to tap certain sectors of the ethnic minority population, leaving a huge swathe of experience unaccounted for, both in terms of un-represented populations or communities and in terms of gender imbalances. Therefore, it was assumed that whatever was generated through this study, would merely be a joint construction of social influences that I myself, the participants and the consumers of the research had brought to the research. An example of this was my desire to generate a clinically useful model to be tested out through sensitive questioning in clinical settings with ethnic minority clients or through further research.
Terminology and the ‘presentational self’

During the planning stages a number of issues also arose with regards to terminology. It will be noted that in the participant information sheet for instance, the term racism is not used but that the terms racial difference and prejudice have been substituted. This softening of language was suggested by numerous interested parties and used throughout the ethics application. It was believed to have various benefits including widening the scope of the areas that participants might feel able to talk about. It also created a sense of ‘palatability’ with regards to the research and its aims, in order to pass through ethics and be introduced to teams.

During the interviews though, some of the participants said something akin to “You mean racism?” as I introduced the research to them. This raised the possibility that the participant information sheet had, in ‘hedging’ its language, confused participants with regards to my aims and my intentions. I felt that they had worried about a number of things that included the following:

- what they could say in interview;
- whether I would find their experiences of racism unpalatable or dangerous;
- whether they were safe to speak about such issues.

This made the sense of feeling contained or of ‘alliance’ especially vital in overcoming such worries or inhibitions during the interviews. Fontana and Frey (2003) also talk of the ‘presentational self’ that the researcher projects towards a participant. At various points of the interviewing, I was aware of how projecting myself as “young, interested but without
much knowledge” might encourage older participants to open up more by assuming a role akin to ‘teacher’ or ‘responsible adult’.

I was also aware from my experience in clinical interviews with ethnic minority mental-health clients that I would sometimes allow my ethnic minority status to enter into the construction of a therapeutic alliance. Often this was simply through the mode of a respectful listener. Reinharz (1992) had suggested the need in a research enterprise to acknowledge and map such influences where possible.

In addition, how I chose to emphasise different parts of my dual status within the NHS and the University appeared to vary with the perceived need of the client: where they were quite well and had been for a while, the ‘still-learning, university’ self was emphasised. With participants in distress and who struggled to have interviews on certain days and had to postpone, I strove for a more ‘professional carer and researcher struggling to improve services’ self. This perhaps allowed for a more caring or sensitive tone to interviews and one that might feel continuous with a participant’s need for support. This was, of course, not without ethical issues, but merely the way that the situations appeared to unfold.

**Sampling considerations**

As sampling had proceeded though, it became clear that both the field clinicians and I had perhaps been labouring under an unconscious assumption. This was the assumption that any ethnic minority client would have experienced, and have something to say regarding, the subject of ‘racism’. This turned out to be either error or oversimplification, possibly due to a
number of reasons that were not well understood by me at the time and not investigated further. Reasons for such over-inclusion may have included:

- my own opacity regarding who I would like to interview
- participants had felt unable to resist approaches by field clinicians
- participants had not been fully briefed regarding the research
- participants were simply curious about the study’s aims.

In these circumstances the potential participant seemed sometimes bemused at the study and wondered what they might have to offer to it. For instance, the fourth (Helena) and fifth (Rhupa) participants claimed to not have experienced racism at all. Though in one way this may have proved unfortunate, it also allowed me to actively challenge my theorising. Therefore, under these circumstances, I asked the potential participant whether it would be possible to proceed anyway in order to see what emerged and how this might affect my ideas and the developing grounded theory.

One such participant was Megan, who gave an account of how she had not only attempted to self-actualise and cope with psychosis, but also tried to theorise about racial difference or racism and incorporate this into her way of life. As constant comparison of the data occurred, these parts of her account became important codes to which later interview data could be compared.

After the fifth interview, I actively encouraged keyworkers and clinicians involved with the study, to bear in mind that I was seeking participants who felt that they had something to say regarding racism. This was hoped to expand the grounded theory regarding actual experience of racism.
Recruitment problems:

In all thirty-nine potential participants were approached regarding this project. The rate of continuation into the project might have been greater had the participants recruited not been long-standing sufferers of such enduring mental health difficulties. This might have been achieved through sampling from amongst fully recovered ex-service-users or from an early intervention service where perhaps some of the participants would not have experienced the same debilitating courses of illness as the present participants. Although this is a valid position for a researcher to take, there might also be a loss of data regarding the developmental progression of a service-user back into the community after a longer and more debilitating psychotic illness. Despite this, the local Early Intervention team was approached but declined to take part as they felt they had their own research commitments to safeguard.

A further suggestion might be to provide incentives to participate such as vouchers. This was suggested by a community psychiatric nurse who had been involved in recruiting to the study. Alternatively, service-users might have felt safer if the agency conducting the research was not affiliated or paid for by the NHS. A second path might therefore be to recruit an outside agency to conduct the research and to do this, not through NHS auspices, but through community groups who might be able to support and encourage participation without participants feeling threatened.

This is not without its own issues though, as participants might not be afforded the protection or sensitivity deriving from mental health professionals conducting the research. For instance, such interviewers might be better placed to monitor participants for emotional distress or fatigue. Contrary to this, if participants were from more recovered samples and therefore perhaps more robust, then outside agencies might still be better able to conduct the
research. The monitoring of participants before and after the interviews by Responsible Medical Officers or community psychiatric nurses might be replaced by non-clinical supports such as mutual-aid groups, local voluntary organisations or family members. Though not ideal for current service users this might be sufficient for recovered samples where such resources were well established and in use by the potential participants.

**Emotional distress in the interviews**

Emotional distress was a feature of six interviews. On three occasions this was related to experiences of racism. On other occasions it was related to feelings of overwhelming isolation or hopelessness resulting from the consequences of illness. These included stigma, relationship worries and a difficult life review process. The latter was a theme inherent in all the interviews and the interview schedule itself sometimes highlighted these issues through its developmental progression.

A surprising finding in this study was that six participants revealed suicidal or para-suicidal activity during the course of their illness. Department of Health (1992) had suggested that there was an estimated 10% completed suicide rate amongst people with schizophrenia. These were believed to be most closely linked to persecutory delusions or hallucinations. Birchwood and Preston (1991) suggested that the rate of para-suicidal risk was even higher at 20-30%, whilst McGlashan (1984) had estimated that suicidal thinking could be as high as 40%.

With the high levels of distress that were present in the interviews, it often felt
inappropriate to enter a conversational dialogue with the participants regarding racism. Instead basic therapeutic skills such as active listening were called upon. These not only felt more appropriate under the circumstances but also led participants to feel a sense of alliance and security.

Negotiating the continuing of an interview:

Thus, in the present study there were also additional concerns for the mental well-being of the participants. At these points the interview process ceased in order to allow withdrawal if so desired. On three further occasions, where distress began whilst going through the Information Sheet, the participant chose to withdraw.

On other occasions, when I suggested turning the recorder off, participants sometimes indicated that they were willing to continue. Where they indicated that they would like to pause or where they gave no sign either way, I ceased recording. Reasons for distress were then ascertained and I made a decision about whether it was ethical to continue. The making of this decision was shared with the participant. Where they were willing to continue, I allowed the participant to decide whether they wished to continue talking about the distressing area or they would prefer to move on to other questions. One participant for instance became distressed prior to the interview whilst informally talking about how their illness had developed. This participant asked though that this area not be addressed in depth during the interview and I respected this.

Proceeding interviewing with a distressed participant:

On such occasions I dropped into a person-centred mode (Rogers, 1967; Mearns and Thorne, 1999) to allow the participant space to talk about issues, to negotiate how we could
proceed and what, if any, of the material discussed in a recording break could be talked about subsequently on tape. The longest breaks of this nature were for 'Shirley' and 'Rhupa' and lasted approximately half an hour. Participants were thus treated as service-users first, with the needs of the research taking a back seat to this where necessary. This was reflected in the interviews, where often I would simply reflect what the participant was saying or indicate that I was ‘actively listening’ to him or her, rather than probe for information that might lead the interview to become a negative or intrusive experience for that participant.

Asif’s family for instance had suffered recent physical and verbal racial assault and this formed a major part of his account. In this interview I omitted questions regarding stigma and instead allowed Asif to tell the story that was important to him. Through actively listening to a participant’s account and not seeking to press the research agenda it was hoped to avoid the danger of a therapeutic and ethical ‘breach’ where directed and continuous questioning created damage (Bentall, Kinderman and Kaney, 1994). For instance all the participants, except for Asif, spoke of mental health stigma. Towards the end of the interview, as Asif had become physically and emotionally exhausted, he had been describing how events in his life had driven him towards suicidal despair. Out of respect for his distress, additional questions were not asked.

Impact of polypharmacy on interviews:

All of the participants were also on anti-psychotic and other medication, creating various interview difficulties such as slowing of verbal and motor function. Towards the end of the interview participants often became fatigued making the funnelling of questions into more specific areas difficult.
As a result of such considerations and rather than burdening the participants with new questions in a dynamic, conversational style, I felt ethically bound to deploy active listening techniques and to respect the position of the participants as, firstly and foremostly, clients of the acute mental health services of the NHS.

Helena for instance was undergoing multiple pharmaco-therapeutic regimes for psychosis, depression, cancer and pain-management. She was though a willing participant. I allowed her to express her story which was dominated by themes of life-review and getting others (including her son, who was present at the interview as an advocate, and myself) to understand the journey that she had been on.

"Awaiting" participation

I felt that the overriding participant-researcher imperative was therefore the safe-guarding of a participant or a potential participant’s welfare. This led to periods of sometimes months as I would wait for potential participants who had expressed an interest in becoming involved, to feel well enough to participate. This required close liaison with community mental health teams and with services such as Assertive Outreach.

At no point during the research did I believe that the categories I had raised had been saturated. There were far too many new questions and leads that were forming through the analysis. Various researchers though, such as Charmaz (2003), have preferred to see GT sampling as a potentially endless task that comes to an end for pragmatic concerns rather than any arrival at a saturation point. A major problem towards the end of the research period was
whether to write the dissertation up as the analysis stood or to wait to see if potential participants would be able to become involved. Unfortunately, due to relapse or fluctuating symptoms, there was no way of knowing for certain when they might feel able to take part. As time pressures for the re-submission of the thesis escalated, the decision was therefore taken to end sampling.

**Analysing the data**

One of the major difficulties that emerged in the analysis stage was how to organise the data and conduct a grounded theory analysis upon it. This was exacerbated by various factors but a major issue was the different 'brands' of GT that seemed to exist. I started with the approach laid out by Strauss and Corbin (1998) but abandoned this for the one taken by Pidgeon and Henwood (1996). After indexing the entire complement of open codes from three interviews (i.e. line-by line codes as Charmaz, 1995 referred to them), this felt:

1) distant from the data;
2) sterile and lacking in creative insight;
3) unwieldy in the mass of cards it created.

This may simply have been due to my own inadequacy with their method but at this point I became more interested in how Charmaz (1995) had used focused codes to creatively analyse and organise line-by line codes. This seemed a sensible way to proceed for a number of reasons. In the main, it felt as if it kept me closer to the transcripts and able to relate the ideas that I was developing, to those transcripts.
Presumptions regarding analysis

As I began analysing transcripts, I considered filtering experiences through emotional and behavioural responding codes but these only occurred on a limited basis. Prior to the analysis, I expected that this would be how the analysis proceeded. Therefore, this was a surprising finding given the intensity of some of the events described. Much of the emotional responding occurred when service-users were describing their most hopeless moments (six of the seven participants broke down into tears at this point, three due to descriptions of racism, two due to descriptions of stigma and one for unknown reasons). Prior to reflecting on such moments participants seemed stoical or composed.

The stoical or composed stance may have been a consequence of an understandable lack of trust or ‘therapeutic alliance’ between myself and a participant. Only when the most profound experiences were touched upon did participants’ emotions emerge. A second explanation for this aspect of the analysis might be that during the events themselves, participants coped in a stoical or a composed way. This might then have been replicated in the interview up until the point the event was described that had breached composure (both at the time of the event and subsequently in the interview). At this point hopelessness appeared to be a key emotional element. For most of the female participants, the release of emotion and how this was handled in the interview, seemed central to their decisions to continue and to open up further in the course of that interview. The male participants often seemed to retract back to the stoical or composed stance.

Following on from the suggestions of Comas-Diaz and Jacobsen (1991) and King (1996), it was decided to make a note of the points where a participant became distressed and began
to cry and whether this was accompanied by a break in recording. Suzuki, Prendes-Lintel, Wertlieb and Stallings (1999), in a qualitative study of the experiences of Cuban refugees, had found that stories were often told in a quite “level” manner that belied the nature of the experiences in accounts. The authors suggested that this might indicate early, stoical patterns of coping and suggested that the emotional states expressed in interviews might be reflective of such earlier experiences.

This had an effect upon the analysis in two ways. Firstly, there was the recognition that participants had actively struggled against the effects of their experiences and not simply succumbed to them. Secondly, differences in emotional retelling styles indicated potential ways that participants of different genders might differ in their retelling of experiences. This indicated potentially important implications for their psychological well-being in interviews. Men for instance seemed to prefer to speak of themselves as coping and able and only allowed emotional retelling to emerge as they described some of their most hopeless times. This is discussed in more depth in the research report.

An early presumption I had had was that various ideas put forward by participants were sometimes either difficult to understand, difficult to fit with the rest of the data or were simply potential by-products of illness or of preferring to ignore reality. For instance, Megan had spoken of her belief that there was no such thing as racism, despite previously talking about such incidents. As the analysis went on, her words were to have a telling effect upon the analysis and caused me to challenge my own assumptions and prejudices. A key theme that was developing was how, if time and threat levels allowed, someone might try to think through his or her position, perhaps reflecting or sharing experiences with trusted others, empathising with others difficulties and seeking alternative explanations. This was termed
the ‘slow heuristic mode’. As a result, it became possible to hypothesise that when Megan spoke of there being no such thing as racism, an alternative, non-literal meaning was intended. For instance, she may not have been speaking of actual beliefs regarding reality. Rather she might simply have been speaking of an internal, belief-based mnemonic, which, if faced with ambiguous racial situations, would cause her to seek alternative solutions to problems and also potentially defuse her anxiety regarding events.

A potential danger of this strategy would be that it might be potentially disempowering if actual racism had been intended, as Bentall, Kinderman and Kaney (1994) might suggest. I wondered how a ‘fast heuristic mode’ that allowed rapid appraisal and action would perhaps therefore be a necessary complement to the slower mode. An alternative to bear in mind was that through a ‘slow’ mode, Megan could seek other people’s opinions and ideas and perhaps rethink her position: that a person might actually have meant something racist or stigmatising.

The sheer ambiguity of some forms of racism and prejudice made me wonder at the difficult task that was faced by these participants in making their way in the world. It highlighted how important clinical or community-based work might be that could provide participants or other service-users with resources that sought to empower them in their processes of evaluation and engagement during recovery.
References


Appendix 1

Ethical Approval Forms
15 December 2004

Mr Nazakat Wagle
Trainee Clinical Psychologist
Leicestershire Partnership NHS Trust
University Of Leicester
104 Regent Road
Leicester
LE1 7LT

Dear Mr Wagle

Full title of study: The impact of experiencing racial difference or prejudice upon the development of psychosis: ethnic minority service-users’ perspectives.

REC reference number: 04/Q2501/97
Protocol number: 04-Q2501-97rp040819

Thank you for your letter of 22 November 2004, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

The favourable opinion applies to the research sites listed on the attached form. Confirmation of approval for other sites listed in the application will be issued as soon as local assessors have confirmed that they have no objection.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

An advisory committee to Leicestershire, Northamptonshire and Rutland Strategic Health Authority
Management approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final management approval from the R&D Department for the relevant NHS care organisation.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Notification of other bodies

The Committee Administrator will notify the research sponsor that the study has a favourable ethical opinion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.
With the Committee's best wishes for the success of this project,

Yours sincerely,

[Signature]

Dr Cai Edwards
Chair

Enclosures

Standard approval conditions

Site approval form (SF1)
5th December 2005

Mr Nazakat Wagle
Flat 4
4 Allandale Road
Stoneygate
Leicester, LE2 2DA

Dear Mr Wagle

Study title: The impact of experiencing racial indifference of prejudice upon the development of psychosis: ethnic minority service-users' perspectives

REC reference: 04/Q2501/97
Protocol number: N/A

Amendment number: 2
Amendment date: 27/10/2005

The above amendment was reviewed at the meeting of the Sub-Committee of the Research Ethics Committee held on 02/12/2005.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

- Notice of Substantial Amendment
  Dated 27/10/2005
- Research Protocol
  Version 3.0
  Dated 27/10/2005
- Participant Information Sheet
  Version 3
  Dated 14/11/2005

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.
Research governance approval

All investigators and research collaborators in the NHS should notify the R&D Department for the relevant NHS care organisation of this amendment and check whether it affects research governance approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

04/Q2501/97: Please quote this number on all correspondence

Yours sincerely

Ms Linda Ellis
Committee Co-ordinator

E-mail: linda.ellis@rushcliffe-pct.nhs.uk

Copy to: R&D Department for NHS care organisation at lead site- LRI

Enclosures List of names and professions of members who were present at the meeting and those who submitted written comments
Appendix 2

Participant Information Sheet
Participant Information Sheet

Title: The impact of experiencing racial difference or prejudice upon the development of psychosis: ethnic minority service-users' perspectives.

Chief Investigator: Naz Wagle

You are being invited to take part in a research study. Before you make a decision about this, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and to discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

1./ Who is conducting this study?

Naz Wagle, a trainee clinical psychologist at Leicester University, is conducting this study. This study will form part of his Doctorate in Clinical Psychology.

2./ What is the purpose of this study?

The study asks whether people from ethnic minority backgrounds who presently suffer from psychosis have experienced events involving racial difference or prejudice? It will ask how these experiences might have affected that person before the psychosis, during it and whilst trying to recover.

It is hoped that the findings will help people who run services for people with psychosis to think about how they might make these services better for people of ethnic minority backgrounds.

3./ Why have I been asked to take part?

As a member of an ethnic minority you may be in a unique position to describe how events involving racial difference or prejudice, if you have experienced them, have affected you. Therefore what you have to say about this issue could be very helpful.
4./ **Do I have to take part?**

It is up to you whether or not to take part. If you decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision to not take part at all, will in no way affect the services that you are currently receiving.

5./ **What will happen to me if I take part?**

a) You will be asked to come to a community base convenient for you, where Naz will book a room to use for the interview. This will be an informal interview, very much like a conversation. He will ask you to describe your experiences of racism and how they have affected you at different times in your life.

b) This will last for no more than ninety minutes and will be tape-recorded. You can stop for breaks at any time and if you don’t feel able to finish the interview in one day, another session can be arranged.

c) Naz will arrange for your Key-worker to visit you afterwards so that if you have any concerns after the end of the interview, you can discuss them with someone.

d) Naz will then write up the interview and look at what you have said to try and find common themes between all the people who have been interviewed.

e) When he has written the findings up he will put together a summary of the findings. If you would like to receive a copy of it, he will arrange this for you.

6./ **Will the information that I provide be confidential?**

Yes. During the interview only first names will be used and, when the interview is written up, all names will be changed to make sure no one can identify you. The tape will be labelled with a number, not a name. Only Naz will know who has been given what number. Any tapes and write-ups will be kept locked away. Any computer files will be protected by a password.

None of the information that you give will be written into your case-notes or be used as a basis for changing your treatment in anyway. The people normally involved in your care will not be told what you have said. The only exception to this is if Naz feels that something that you have discussed places your safety or that of others in jeopardy; then he will have to tell your Key-worker about this, but will discuss it with you first.

7./ **Am I allowed to change my mind about taking part?**

Yes. You can change your mind at any time and you do not have to give a reason for doing so. Your comfort in taking part is the most important thing here. Any information
that has already been collected will be destroyed immediately. Again, any treatment you are having will be unaffected by your decision.

8./ **What if I am harmed by the study?**

If, in the course of the interview, you discuss upsetting or emotional events that have occurred to you, it may be that by talking about them this upset returns. If this happens please let either Naz or your Key-worker know and they will help you to explore what might be helpful to you. Naz will arrange for your Keyworker to contact you after the interview so, if you prefer, you can tell them how it has gone and your feelings about the process.

This research is covered for any mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

9./ **Will I be paid for taking part in the study?**

No. However, you will be paid travel expenses (at public transport rates) should you have to make any journey especially to take part in this study.

10./ **What will happen to the results of the research study?**

When the study is completed, Naz will write a summary of the findings. He can give this to you if you would like to receive a copy.

The research will be written up for a doctoral dissertation and later, it is hoped, be published in a journal of clinical psychology. Your confidentiality will be strictly protected and at no point will you be identified in any report or publication.

11./ **What if I have more questions?**

You can contact Naz to discuss any questions that you still have on 0116 2522 162, and he will call you back. Or you can talk to your Key-worker. Please feel free to discuss any participation in this study with anyone you feel is relevant.

Thank you,

Naz Wagle
Appendix 3

Participant Consent Form
Participant’s Consent Form

(Will be on letter headed paper of the University of Leicester, School of Psychology - Clinical Section)

Title: The impact of experiencing racial difference or prejudice upon the development of psychosis: ethnic minority service-users’ perspectives.
Chief Investigator: Nazakat Wagle

I ____________________________ have read the participant’s information leaflet and the nature of the research has been explained to me by Nazakat Wagle.

I have had the opportunity to discuss taking part in this research with Nazakat, with my psychiatrist / psychologist and with anyone else I considered important. I agree to take part in the above study.

I understand that the interview with Nazakat will be tape-recorded and written out and that all information about either me or my views will remain confidential. If my views are expressed in the write-up of the study, no names or identifying details will be included i.e. no-one will be able to identify me.

I understand that I may withdraw from the study at any time without saying why and without this affecting my normal care.

I understand that if Nazakat feels that anything I discuss places my safety or that of others in jeopardy then he will have to tell my psychiatrist / psychologist about this, but that he will discuss it with me first.

I understand that this research is covered for mishaps in the same way as for patients undergoing treatment in the NHS i.e. compensation is only available if negligence occurs.

Signature of Participant

Name of Participant

Date

Principal Investigator’s declaration: I, Nazakat Wagle, confirm that I have explained the nature of the study, as detailed in the Patient Information Sheet, to the above participant.

Signature of Principal Investigator
Appendix 4

Interview schedule
Proposed Interview Guide For Semi-Structured Interview

Title: The impact of experiencing racial difference or prejudice upon the development of psychosis: ethnic minority service-users' perspectives.

Chief Investigator: Nazakat Wagle

Introduction
   reiterate background to research
   confidentiality reminder
   interview plan explained
   is Participant ok to talk about their experiences?
   does Participant have any questions?

Psychosis and Involvement with Services
   Can you describe your experience of psychosis or schizophrenia to me?
   Include if necessary:
   When did the voices or problems start?
   Was that a particularly hard time for you in any way?
   How did you try and make sense of what was happening?
   How did you become involved with services?
   What sort of path did this take?

Experience of Racial Difference Before Onset
   Can you tell me about your experiences of racial difference or prejudice before the problems started?
   Do you think these experiences had an effect on the problems?

Experience of Racial Difference During Onset and Long Term Course
   Did you encounter racial difference or prejudice once the problems started?
   Did you experience prejudice in any way from services?
   How did that effect you and the problems you were facing?
   How did it effect how you coped?

Experience of Racial Difference During Recovery or Improvement
   As you have got better have you experienced racial difference or prejudice?
   How did these events influence your recovery?
Appendix 5

Example of Line-by-line coding
Naz: Ok
Shirley: Thats disastrous in itself.

Naz: Ok
Shirley: Hmm, when I came out, I didn't notice at first, but then I'd lived on the street for several years and nobody will talk to me. The children wasn't talking to me and all of a sudden these children would be calling me by my name, which I found very strange.

Naz: You mean your first name?
Shirley: Yes, they would shout out Shirley, you know and I'd be looking around, I wonder who said that, how did they know my, my name? But, some of the erm, neighbours would speak to me before and all of a sudden these neighbours they won't speak to me. They just, as soon as they see me they shut the door, or they go around the corner quick, try and keep away from me.

Naz: Yeah. How did that make you feel?
Shirley: I feel very upset and even now and I've decided. At first I decided I was going to move out of the area, Naz: Uh huh
Shirley: Coz I felt so ashamed that everybody knows now, I'm mad.

Naz: Hmm
Shirley: Coz that was the word that someone called to me one day, Oh there's that mad woman.

Naz: Oh dear
Shirley: And erm but I've decided now, a few years
Appendix 6

Raised Codes File
CORE CATEGORY: Struggling against dehumanisation

feeling ignored

[Shirley: 206] At school you would be ignored by the teachers, they didn’t take any notice of you, just forcing you to run in PE, do PE. That’s all they highlighted you into.

[Shirley: 300] ……they wouldn’t take any notice of me. Put your hand up to say someone had kicked you: “Put your hand down, stop telling tales” they’d say……[305] They just didn’t take any notice basically, the teachers…….[308] and it’s like now, when I became ill, the first time they sectioned me…….[317] instead of finding out why my environment was got so filthy, they didn’t, they didn’t, they put me in a place and said I was crazy

[Shirley: 1094] And sometimes I do feel when I come here I’m just a number [1077] I’m just making up the number…..[1106] it’s very depressing…. [1108] no wonder I had a breakdown

[Asif: 920]….There was an old, Asian lady. Couldn’t understand a word of English and she wanted a drink of water…. [923] I couldn’t understand her (her language)…. [934] so I went to ….[935] the nurse’s station and I said to him “Look the lady there needs something alright” and I says “She’s been sitting there for the past two and half, three hours and like, she keeps on asking for something but I don’t know what she wants and could you have a word?” And the nurse, the nurse looked at me. He was a bloke. He just looked at me as if to say well, she’ll have to wait then wouldn’t she.

[Rhupa: 125] I don’t know what day or what……I must have fell down……I keep going to the office to tell them what people are doing to me like and then I think they must have been slip me an injection or what I don’t know…….I don’t know how many days

feeling excluded

[Shirley: 369] You know you would go in a store and they’re amazed you know. Straight away you go in the shop and she says “It’s very expensive in here”…. [383] she’s just assuming.

[Shirley: 385] So that and it still goes on today. In certain shops you go in. If I walk in (name of department store) you can see they’re looking at you, you know they’re thinking “She trying to steal something from something.”

[Shirley: 787] I do sometimes go for a walk in the middle of the night or I just get in the car and drive to (name of supermarket). Coz. Coz I don’t like crowds and I like to have peace. You know and sometimes people are looking and you can’t stop people from looking…. [793] And you know that they know what you are and they’re, what they’re thinking. Well you don’t know what they’re thinking but you’re just assuming what they’re thinking…. [798] And I find it embarrassing sometimes.

[Sanjay: 116] …….where I was when I was working was err that the English people sort of get things done in a group and because you’re Asian you’re so always left out…….[135] you didn’t feel like you’re working as part of a team…..we had no help, hardly any help…….so it’s a bit more difficult because I mean it’s harder to get things done

[Nitin: 423] …….and there’s so many who leave school, can’t get a job…… [429] even when er people were thinking of…….[432] what’s gonna happen to……us who are still at school……. [438] if people keep losing their jobs, redundancies everywhere…… [441] and there’s no hope for us…… [443] and it wouldn’t matter how hard we tried
I think there is that type of thing about racism with English people. If they do employ someone, they would rather employ an English lad than an Asian lad.

sensing dehumanisation

... my Stepfather, when he used to go to work, they used to call him Joe. Meaning Joey... as in a bad way... but he... thinks to himself "Oh they're calling me Joe because they're my mates". But Joe meant Joey... meaning do all the dirty work... sweep up the factory, clean the toilets, you know all the down jobs which you know, the, the White man wouldn't take on.

the only thing like I, I had which was a bad experience was like when I was in hospital. Not so much racism, it was just like a feeling that, you know, that they didn't really care about the, Asian people in the hospital... That was, that's my personal view... a lot of the... Asians that were in there in the hospital, couldn't understand English properly. And I found that the nurses and that lot was treating them differently.

feeling personally dehumanised, devalued or worthless

... saying you know “You shouldn't be in here” and all these kinds of things (makes monkey sounds) making these noises. Made you feel like you wasn't a person, you was just a, they were saying these things to make you feel as though you was just inhuman.

You weren't given a choice of meal or a Caribbean meal. You just have to eat what was there. That reminds me of school when you didn't have a choice, in my day. You had to eat what was there. Otherwise you stay hungry, that's all they used to say to you.

They didn't know anything about my skin when they helped me to get washed. They left me with my skin all dry and horrible. They didn't know anything about my hair.

Make you feel weary, tired... Endless. You know I keep thinking to myself... from the time I came to (name of town or city) when I'm now nearly hitting fifty, nothing's changed much... It's all a sham... Make you feel as if they don't care about my race... it's just made me feel a less of a person now. And I think that's because of what's happened. There's nothing out there, there's nothing positive out there for people within my age group. For Caribbean people there's nothing out there. If you're sick there's nothing out there.

You know... it'd be like “Oh they can hold on, it doesn't matter because they can't understand English anyway”. And like when I saw that happening... I took myself out of hospital, because I was that disgusted with the, you know... I just walked out, because I thought “These people, they never cared.”

... you're always having to prove yourself... they expect you and all the nasty jobs that come up you know, they'll expect you to do it... very rarely a English person wanted to get his hands dirty and you know what I mean, they just leave that for the dirty Asians if they can.

... they kept saying to me “Oh you're learning”... I remember I asked for a pay rise after about three or four years I was there and they gave me about £5 a week extra, not an hour... it made me feel... it made me feel like they don't want to pay you for what you're worth.

But you always on the constant in the sense that you had to prove yourself, more than they had to
Sometimes they’d be willing to listen to what you’ve got to say, sometimes they’ll ignore you for what you got to say.

I’ve seen one bloke, you know what he done? You know the window ledge? He just lean there and say he drop himself... the staff nurse say “Oh OK, I’ll give you that... you go back and carry on. I couldn’t give a shit”.

welcoming disfigurement / taking shelter in illness
also Nitin and his delusions, Megan talking about people who change their features

I got assaulted and got injured very badly... my features was changed and I was glad in a way because nobody knew who I was.
Main Code 1 - SUFFERING RACIAL VIOLENCE

6 subcategories

Facing verbal abuse:

[Megan: 528] ....I never had anything part from a, probably a few things from parents at school or something like that and you get nicknamed for it or something or summat wrong with her

[Shirley: 282] Made you feel like you wasn’t a person, you was just a, they were saying these things to make you feel as though you was just inhuman…..[286] saying you know “You shouldn’t be in here” and all these kinds of things (makes monkey sounds) making these noises.

[Shirley: 80] They were all calling me names, all these children calling me Black this and Black that

[Asif: 278] …..over the fence you’d hear the comments…..“the Pakis are out” you know? Curry munchers and stuff like that….That the house smells

[Asif: 303] …..you’d get… the older kids, ‘bout fifteen, sixteen and you’d only be eleven years old… and these fifteen sixteen year olds say “Oh the Pakis are on the bus, bud, bud, ding, ding” and all that… and making noises and, you know, taking the piss out of the accent

Facing physical attack:

[Shirley: 927] they were beating me up all the time. I’ll go home with my blouse all torn or my blazer all torn

[Asif: 439] …..to give you a perfect example, my daughter and you know, her boyfriend were assaulted. Right outside the front door here by twenty kids…..[444] Four weeks, a month and a half ago like, and it was all racial then…… calling them Pakis. Every time they walked around, they were calling them Pakis…..[453] (the boyfriend) had a tawpi on right, and they was trying to knock his hat off, you know, them calling him names and things. And in the end it just blew up, they retaliated back. If they shouted names, they shouted names back.

(Later knock at door and dragged out)

[Asif: 503] I went out there to kick off I did…. [521] I had a metal bar and I was ready to go and cave some heads in and my wife was going “No, leave it, the police will sort it” and I was saying this is too much man. Every time my daughter goes out there I say, she’s being called Paki…..and it’s like on a daily, daily basis. I says at the end of the day, I says, it’s not right (Asif now crying).

Facing sexual assault:

[Shirley: 163] …..it was from the boys, talking about rape and all that…..they were saying they were going to do that to me…..[934] I was told by my erm Uncle to stand up to, to them. You’ve got to stand up to the leader. Which I did. He was the leader…..[940] He flung me up against the wall and started trying to rip off my, my top actually. Rip off, rip off my blouse…..[944] They were laughing things like that…..[946] and erm, talking about my skin colour and everything. Used to say I’m a monkey and, because my hands and my foot are white and I should be walking like a monkey. Anyway I ran after this one who was leading all the others…..[84] and he got killed (in a collision with a car) and I was expelled.
**Facing attacks to property:**

[Asif: 231] made me feel angry... you know, err, angry, because at first I couldn't understand it when I was younger. I used to think, you know, nothing of it. But when bricks are being thrown through the windows and...[239] one time there was petrol poured through our letterbox...[244] The house near enough went up in flames

[Asif: 858] It'd be like Pakis and this, that and the other... They'd go around and damage the car, whatever. If the car was parked outside, they'd slash the...tyres... and you know obviously do it, and it'd be done like with people watching... And nobody would say anything to them like

[Sanjay: 223] So next evening he...[went outside you know, as he was going home (and)...his car wouldn't start and then when he took it in the garage, what had happened was somebody had put sugar in his car.....into the petrol tank.

**Observing violence or abuse:**

[Shirley: 414] Oh you get things in the windows: "No Blacks Here" and all that

[Asif: 314] ....we'd sit at the front of the bus, because we knew at the back...they'd start trouble with us....and...I used to see them tip out people's bags....sometimes take their dinner off of them

[Asif: 377] ....when we moved up here...[380] it all started again...[382] they go around busting Asian people's windows here, they throw bricks, excrement through the door...[386] It's happened to the lady up the road...[394] they do a lot you know, there's graffiti around, you know the National Front sign, you know the swastika and all that

[Sanjay: 201] ....he used to sort of wind people up...[204] one day he had this problem with this Muslim person and er obviously it was something about religion

[Nitin: 193] We used to hear about it...[200] what used to happen in the past...[202] you'd hear the elders who went there when we were still at school...[217] however it might have resulted in the end...[219] who got done, who didn't...[221] who er had to go to hospital for help

**Facing veiled threats:**

[Nitin: 842]....he was staring at me... you know what he said to me? "You're getting on my nerves" and I thought what have I done to you?.....[860] before that.....he wasn't like that

[Nitin: 1284]....There's this other... White bloke, he was in under a section...[1287] and I think he, he was saying that he had a gun and he shot someone...[1294] Black bloke...[1299] he made that type of remark to James (fellow patient of African-Caribbean descent) and that's when I said to James "He's fucking racist ain't he?" and he's saying "You're too right."

**Seeing no action:**

could then maybe add Asif on ward / Asif child cars being wrecked example

[Shirley: 254] They talked to the children one by one, that was in my class. Nothing....(and
later)....[257] Just was long in the playground saying I’m a sambo and all that....[268] I couldn’t say who and who. I mean they all did it but I couldn’t point and say anything because they would get me. I was so scared, what might happen in the playground.

[Shirley: 305] They just didn’t take any notice basically, the teachers...[308] and it’s like now when I became ill the first time they sectioned me....[328] They don’t listen to you.

[Asif: 181] You went to school they called you Pakis. You know err, even the teachers like were a bit, you know, iffy....Coz at that time you couldn’t go and tell the teachers about racism and that lot because they didn’t really want to know, know or listen

[Asif: 872] ....when the police came.... “ah we’ll investigate it”. They never used to go knock on no neighbours doors. If they did knock on a neighbours door, the neighbours never seen nothing. Yet all the neighbours would have been out watching them doing it.

[Sanjay: 242] ....he call the police and everything but obviously couldn’t prove it was him......and then after a while it happened again and the same thing – somebody put sugar in his car. So he wasn’t happy and then he had the police come in and everything but they didn’t do anything you know? You can’t prove anything

[Nitin: 1314] ....we could have done (approached staff) but you know, Steve – he was saying even if we do, we still won’t get anywhere......They might just warn him but if he just say “Yeah”.....and then even after that they’d say “Oh you’re all right cos we’re all White”.

Anti-code:

Helena and Rhupa recounted no experiences of racism
[Helena: 165] I didn’t come across no racial prejudice.....but people talk about it now....but I didn’t come across (it)

Was sometimes alluded to but I failed to pick up on it at the time
[Megan: 525] I think there was over at (name of her former employee) yes.....but in the main no, I mean I never had anyone call me nigger or wog or anything like that

Anti-code on wards

[Sanjay: 847] I had no problem with any, anything like that....[862] If, if anything, when I was there, I mean you had three or four Indian people, you had English people up there, err, they just looked after everybody you know? Like everybody else
Main Code 2 - SUFFERING MENTAL HEALTH STIGMA

3 subcategories

Facing verbal harassment and bullying:

[Shirley: 33] I didn’t notice at first, but then I’d lived on the street for several years and nobody will talk to me...[35] The children wasn’t talking to me and all of a sudden these children would be calling me by name, which I found very strange...[39] they would shout out Shirley, you know and I’d be looking around...[50] I felt so ashamed that everybody knows now. I’m mad...[53]...that was the word that someone called to me one day “Oh there’s that mad woman”.

[Helena: 188] I experienced my own people...and they say “She’s been certified, leave her alone....[218] Felt bit sick...[222] Can’t describe it...[399] You know you don’t want to go back out.

[Rhupa: 274] I think people they don’t, they don’t believe, they just label you from when they see (that you were ill)...and that still goes on......like I’m not being well and put me in hospital

[Sanjay: 1125] ......I was asking for it you can say, because everything (was)......bottled up, you were calm and everything and people sometimes they like to, you know, light a fire......and they like to cause problems......when er they got it in for you......they will try and make things worse

Feeling put down and a loss of status:

[Shirley: 832] Yeah and I know they talk and they get in the shops, coz there’s shops nearby and they all get together on pension there, and they’ll all this talking

[Shirley: 42] ......some of the erm, neighbours, would speak to me before and all of a sudden these neighbours they won’t speak to me. They just as soon as they see me, they shut the door, or they go around the corner quick or try and keep away from me

[Shirley: 704] ......in my street, they just think that because I’m disabled and I’m been in the hospital, they can do what they want and say what they want......[711] for example coming and flinging their rubbish in my, in my drive....I’ll open the door and I’ll say “Hey! Get that rubbish out. Put it in your yard. What do you think you’re doing?” You know, because they sometimes do tread on you

[Sanjay: 1095] ......(if) you’ve had a problem psychologically, people think you’re crazy

[Sanjay: 1105] ......sometimes they feel they are better than you, you know, because you’ve had a (psychological problem) so they tend to treat you as though you’re crazy......so whatever you say is always bound to be wrong and what they say is always right

[Sanjay: 1151] ......When I say take over......I mean because I’m soft er, he just sort of presumed that he can just...... What do you call it?......(Naz: Quite assertive or...) ......Yeah that’s it, that word, because he is that and I’m soft, he just thinks he can walk over me every time

[Nitin:1816] ......my mother was talking to someone and saying I want (to) get my son married....and the people who’d say “Well we know about him in that way, schizophrenia and all that.......there’s some who might say you know “OK, we’ll ask around” but those who’d say “No, not if he’s schizophrenic”.......you know it puts you down.......(but) there’s not much I can do....apart from just to carry on......you can be slightly sad....but I, I still you know, carry on with myself

202
[Nitin: 1871] And you know they, way they, in which Hindu people talk about each other....[1883] and they keep marking it to whoever they're gonna get introduced to

Feeling threatened:

[Megan: 254] OK there were a couple of incidents, usually with kids. There was, there was a school up from the road where I was staying and some of the kids used to take the 'P' out of some of the residents who looked kind of like they have problems you understand me

[Shirley: 843] I know that they hate me because I'm sick. They hate me because I'm Black. My colour does come into it as well....[847]....they think that all Black people are mad don't they.

[Rhupa: 300] I want to be there but....I don't want to be there because of what they....what goes on there....[305] they'd be alright for a little while and then they start changing....[308] and once I'm there, they're not safe.

during a night-time arson attack on a car
[Shirley: 893] And there was a lot of people, I could have gone there and talked, but I says no. That would have been possible. Positive.....[897] Coz there was something, you know, not looked at me. It was something away from me
Main Code 3 - FEARING RETRIBUTION, BLAME AND PUNISHMENT

3 subcategories

Fearing blame:

[Sanjay: 422] coz you couldn't hit anybody ever, because if you hit anybody ever, you lose your job and the other person loses his job

[Nitin: 59] ......whatever might......[60] result, who, who did what and if the police were called and what the police think about it

[Nitin: 940] ......and I felt slightly scared and you know what happened in there if ......patients started fighting, as soon as the staff see......[944] they'd stop it and decide what to do [946] with whom. Like I was telling you about seclusion.....[950] inject them and put them in seclusion until they've cooled down

[Nitin2: 69] ......you know like how when they say: "Oh yeah, you got schizophrenia and if you start blowing your top and going around causing trouble and all that and then we find out and hear about it, we, the police, get you and straight there (name of unit) and if it's really bad, it'll be the (name of secure ward)

Fearing retribution from attackers:

[Shirley: 254] They talked to the children one by one, that was in my class. Nothing....(and later)....[257] Just was long in the playground saying I’m a sambo and all that....[268] I couldn’t say who and who. I mean they all did it but I couldn’t point and say anything because they would get me. I was so scared, what might happen in the playground.

[Shirley: 132] “We’re going to get you, you killed our friend, you’re a murderer, we’re going to murder you, you Black bastard.....[149] I used to say to myself what kind of life can I have? They’re going to know who I am.....[260] I used to say to my Mum, why on Earth have you come to this horrible place for?

[Sanjay: 274] ......but he knew where I lived you see, so you never trust people like that because they could do things.......to your house or something. Some things let’s put it this way, if you can avoid them, avoid them. Don’t make things worse.

[Sanjay: 330] You can’t tell them outright “you’re racist” can you because what they can do is they can make your life really difficult ......give you jobs which are really hard tasks.....[306] and when things are not done they put the pressure on you

[Sanjay: 613] I have noticed people who used to confront them and they didn’t last long with people up there......Anytime redundancies come, they’ll be the person’s out.......so if you did confront anybody and made things worse, when the time comes they just.....found ways to get rid of you anyway

[Sanjay: 909] .........where I’m living at the moment.......[831] it’s not too bad because everywhere.....there are all Asians up there.......[957] You feel a lot safer then when you’re surrounded by your own people

[Sanjay: 1075] ......I can look after myself but I feel more, making things worse you know what I mean? Because obviously if you sort of getting into problems with people they tend to take it out on your families

204
fearing retribution on ward – but not necessarily racial-

[Sanjay: 876] I knew that people were hyper (on the wards) so you just had to stay calm......you gotta be careful what you say to any of the patients......because some of them can take things wrong so it’s best not to sort of say anything even if you know they’re doing something wrong......you don’t want to make things worse......or even when they’re low......they get upset very easily

[Sanjay: 817] You gotta be very careful what you say because they take things wrong in their head......[819] They’re not thinking right so......[820] they could interpret something you know? They could take it in completely wrong and have a go at you......[823] You’ve got to be careful.

fearing retribution when another attacked but can’t be stood up for

[Sanjay: 219] he did something and he upset him so he went and told the manager or the director it was and er obviously they said, you know? They, don’t make any fun of religion or something. So next evening he......went outside you know, as he was going home (and)......his car wouldn’t start and then when he took it in the garage what had happened was somebody had put sugar in his car......into the petrol

Fearing retribution from services:

[Megan: 608] Don’t have the hassles because you have hassles from a lot of things. They make your life a misery.....They can do things to you that, you know, you think “Oh God”, you know, “should have kept my mouth shut” or something, like a needle or anything that would have something in it that would mess you up. That’s all I’m saying.

[Shirley: 352] And all they want to do is to inject you to keep you quiet, make you more zombified and that’s what they did to me

[Shirley: 476] They had me locked in for hours and I keep banging on the door and they wouldn’t let me out. And that was a “lie” (staff said). I did that to get attention. Wee yourself, messed yourself to have attention......you indignifying yourself then. You make yourself look small and the shame for doing that....[501] They do, do thingsNaz and you cannot prove it, you cannot win, you cannot. If they say you’re mad....[504] You might be ill yes but some things are happening and they’re hiding it.

[Nitin: 1444] ......you know that type of thing if you’re in there you behave and all that......until you get your place......and if you don’t they, say when they kick you out, they say you can go night shelter ......and spend the night there but you’re not coming on the ward

[Nitin: 940] ......and I felt slightly scared and you know what happened in there if.......patients started fighting, as soon as the staff see......[944] they’d stop it and decide what to do.....with whom. Like I was telling you about seclusion......[950] inject them and put them in seclusion until they’ve cooled down

[Nitin2: 99] ......similar to prison, “oh, you behave good, you mind your own business and everything, you can get discharged before your time”

[Nitin2: 138] And if they go too far sometimes, you know what they do, they give them an injection and lock them in seclusion till they cool down
Raised Code 4 – BOTTLING UP VERSUS CONFRONTING

5 subcategories

Avoiding trouble and confrontation:

[Megan: 605] ……all he thought was just lack of time……Don’t have hassles because you have hassles from a lot of things. They make your life a misery……They can do things to you that, you know, you think “Oh God,” you know, “should have kept my mouth shut” or something, like a needle or anything that would have something in it that would mess you up. That’s all I’m saying

[Shirley: 104] I used to see some of these adults, children that used to call me names and I used to try and hide.

[Asif: 260] ……used to go to the parks, my Mother used to always say to me “No, don’t go to the park” and that lot. “The White people are there. They’re going to be in gangs.” Coz there used to be skinheads about, you know NF, was you know, a big thing at that time……[276]……we just used to stay in the house all the time…….play in the garden or wherever, but like event then, like, over the fence you’d hear the comments

[Sanjay: 260] ……just made me feel as though you know, you just don’t go anywhere near him, you don’t (get) involved with him, do you know what I mean? If you can avoid it……the other person sort of spoke back and I sort of kept quiet do you know because it’s not worth making things worse

[Sanjay: 1075] ……I can look after myself but I feel more, making things worse you know what I mean? Because obviously if you sort of getting into problems with people they tend to take it out on your families

[Nitin: 17] And if you said the same, if you said something like “you fucking honkey” or whatever……[20] and then that’s how……it would turn into a fight……[23] that’s how people retaliate by saying something back……[26] that’s how it can turn into a punch-up

[Nitin: 93] ……and all of us just cooled down……[117] we were all thinking the same……[118] a brawl in the pub……[120] or even outside……[122] and then just about all hell can break loose can’t it?……[123] it could even result in a death……[129] sometime a person could pass away……[131] if they got battered so badly

stigma

[Nitin: 1894] And that’s why they’re doing it and I, I won’t really have much to do with them (Naz: So you try and steer clear of them?) Yeah, yeah, yeah

Shirley examples – going shopping in middle of night + not talking to neighbours when she thought it might be possible. Slotted below

Trying not to stand out:

[Megan: 254] OK there were a couple of incidents, usually with kids. There was, there was a school up from the road where I was staying and some of the kids used to take the ‘P’ out of some of the residents who looked kind of like they have problems you understand me

[Megan: 722] So sometimes when we go for a holiday or a daytrip……[726] people say to me “Oh you’re really good with them”. No one will say to me……you look strange, because you don’t look like you’ve got mental health problems……[730]……you look more like a member of staff, especially the way you dress and everyone else is happy……[732] “Oh you look like an nurse” and err “Oh you look nice”. People used to look at us, people like myself, in a strange way you understand? Because some of them,
some of them were dressed ‘irunghuly’, if you understand what I mean by ‘irunghuly’. Nothing matches you know what I mean? It’s all a bit dirty, got stains on the front of their (jumpers). Irunghuly.

[Helena: 59] People back there were brought up to believe in things. Black magic and stupidity...and if you were mad, you were bad, so you don’t tell anybody that.....something’s going on because, you know, if you were mad you were bad

[Nitin2: 154] If a schizophrenic behaves that way, that’s what they always say “Ahh” as soon as. What the staff do at the hospital, if they need the police help they’ll phone them, and then they’ll go get them

**Withdrawing:**

[Asif: 899] You know.....it’d be like “Oh they can hold on, it doesn’t matter because they can’t understand English anyway”. And like when I saw that happening....[907] I took myself out of hospital, because I was that disgusted with the, you know....I just walked out, because I thought “These people, they never cared.”

**fear of anti Islamic reprisal**

[Sanjay: 963] And what do you call it er that bombing they had in er London....it was a bit scary for people to sort of walk out because obviously they, English people, tend to lash out at everybody who’s Asian....[1074] with me it’s not too bad because I....can look after myself...(but)....they tend to take it out on your families....so that’s why I try not to...interfere

[Nitin: 1500] .....what if they didn’t ask, if they thought “he just looks like a Paki” and “start battering him”.....[1508] I was getting scared myself...[1628] I came back here and stopped in myself

**stigma**

[Shirley: 787] I do sometimes go for a walk in the middle of the night or I just get in the car and drive to (name of supermarket). Coz. Coz I don’t like crowds and I like to have peace. You know and sometimes people are looking and you can’t stop people from looking....[793] And you know that they know what you are and they’re, what they’re thinking. Well you don’t know what they’re thinking but you’re just assuming what they’re thinking....[798] And I find it embarrassing sometimes.

during a night-time arson attack on a car

[Shirley: 893] And there was a lot of people, I could have gone there and talked, but I says no. That would have been possible. Positive.....[897] Coz there was something, you know, not looked at me. It was something away from me

[Helena: 338] See I could go out there now and I could come home and I could be so withdrawn, that I don’t want to go back out again.......but people don’t realise that you know......[395] Somebody might have said something. Somebody might have said: “oh she been given diagnosis of mad, leave her alone”.......You know you don’t want to go back out.......You don’t want your children to know

[Rhupa: 168] I didn’t go anywhere......[171] just visit doctor......my husband used to take me....and ...go do shopping........my husband, my daughter, they used to come and collect me.....and help me out

[Nitin2: 199] .....they’d like start and (I’d) say “I’m not going to say nothing. I don’t really want to get involved”

**Bottling up**

[Megan: 605] ......all he thought was just lack of time.....Don’t have hassles because you have hassles from a lot of things. They make your life a misery.....They can do things to you that, you know, you think “Oh God,” you know, “should have kept my mouth shut” or something, like a needle or anything that would have something in it that would mess you up. That’s all I’m saying
[Sanjay: 348] I tried not to confront them. That's the problem with me, I used to keep everything bottled up... So it's not, I wasn't sort of confrontational.

[Sanjay: 414] Er not anger, I mean if anything I used to keep it all bottled anyway... coz you couldn't hit anybody ever, because if you hit anybody ever, you lose your job and the other person loses his job.

[Shirley: 268] I couldn't say who and who. I mean they all did it, but I couldn't point and say anything because they would get me... I was so scared what might happen in the playground.

[Asif: 189] I watched people call my Mother Paki and that lot... the older generation used they used to say "Oh leave it, it's alright, that's fine" like, but with me it became like an issue.

Confronting:

[Megan: 581]...he was working out in the garden and all of a sudden (another client spoke) "Oh I didn't know you could do tattoos on your arm..." and I stood up and (said) "How dare you, you goddamn racist..." she was being prejudiced. Yeah it ain't seemed like it but underlying it that's what she meant.

Shirley with her attackers

[Shirley: 934] I was told by my er... Uncle to stand up to, to them. You've got to stand up to the leader. Which I did.

[Shirley: 665] I challenge. I always challenge because that's the only thing that you can do.

[Asif: 189] I watched people call my Mother Paki and that lot... the older generation used they used to say "Oh leave it, it's alright, that's fine" like, but with me it became like an issue. I used to think I shouldn't have to take this shit... I'd like answer back... to retaliate.

[Asif: 205] I joined the army whilst I was still young... There was quite a bit of rife, you know? It was rife with racism. There were loads of them... but I stuck to my guns like, and I thought "No", you know, "I'm going to make this, you know, work"... and obviously when I got my stripes and that lot, when I started to work my way up the ladder... I had the bigger hand then... because like the same racists, I showed them that, that no matter what they threw at me, I was still going to come out of it... you know, on top.
Main Code 5 - STRUGGLING TO COPE WITH ILLNESS

3 subcategories

Overburdening into illness:

[Shirley: 777] My son...[778] he says "Don’t take any notice, because if you keep thinking about that, you’ll get ill". And he was right I did. I kept thinking about it: “Everybody knows about me”. Silly thoughts “a mad woman, schizophrenic, ooh my God you got to be careful with your children. She’s on the loose”.

[Asif: 623] ...the pressure from the (event), did make me, that was a factor in there....You know what I mean? From the pressure I was taking....[631] I couldn’t handle no more. I was thinking you know, life, life can’t carry on like, you know what I mean. I don’t want to live no more. I just built myself a noose and was ready to do myself in....[640] I was just being low and depressed like and the voices had been playing up quite a bit....[644] saying things like, you know do yourself in, you know and, that you know, you, you’re useless, you’re no good to your family....[648] that you’ll never get better....[650] you got no future.

[Sanjay: 399] it wasn’t just easy for me to come from work and then switch off, you couldn’t switch off, you just had to carry on and while I’m sleeping at night I used to have to figure out what to do the next day going to work - this needs doing, that needs. So you’re working everything out in your head at night what you’re gonna do the next day.

[Sanjay: 488] I was getting through maybe three bottles of whiskey a week......used to just put me to sleep......but the pressure was coping at work, because you know, you’re always tensed up

[Sanjay: 377]  but I got used to it over the years, coz then what I used to do was come home from work, the only way I could sleep was if I had a drink and I used to have to drink quite a lot......so that it used to just, you know, put me to sleep......because I couldn’t sleep

[Sanjay: 514] it played a part........it obviously played a part.....But a lot of it wasn’t just racial, it was a lot like er you know, they expect sometimes too much from people........[538] other things sort of made things worse........than just race........what they paid me compared to others, I mean very low in the beginning (ongoing struggle)

uncertainty / not picked up on

[Megan: 10] I got offered a job in (name of town)... job was burdening, there was a lot of internal politics going on there....I got dragged into it....feeling paranoid, feeling a bit err suicidal and later

[Megan: 525] I think there was (racism) over at (name of workplace)

[Rhupa: 355] ...then they change the staff....[357] work get a bit more heavier and err work takes longer....[365] they should (have) share(d) it out (more evenly) and earlier

[Rhupa: 79] I think I wasn’t doing a very good job and then erm, I was just bursting out in tears....and erm I went to see the manager and I say I want some time off

Losing hope:

[Shirley: 545] Make you feel weary, tired.....[547] Endless. You know, I keep thinking to myself you know, from the time I came to (name of town or city) when I’m now nearly hitting fifty, nothing’s changed much.....[552] It’s all a sham.

reminds me of her earlier quote
[Shirley: 260] I used to say to my Mum, why on Earth have you come to this horrible place for?

[Asif: 572] You know like, every time, near enough......they come across these kids they’ll always get the same thing – Paki, Paki, Paki......and like it’ll be Paki this, or Paki that.

[Asif: 771] ...when I see my kids have racism spouted at them.....it always makes me think back to my childhood....you know, that’s how I connect it in my mind...because I think to myself I went through this exact same, you know. It’s exactly the same, you know, the same words are being used, the same you know, err, derogatory remarks are made.....[783] when they call my daughter a Paki it really hurts.....because I think to myself, you know, this is what they used to call me....And now twenty, thirty years down the line it’s still happening....[819] It leaves you in nowhere really doesn’t it. You’re like in no man’s land.

[Asif: 623] ...the pressure from the (event), did make me, that was a factor in there....You know what I mean? From the pressure I was taking....[631] I couldn’t handle no more. I was thinking you know, life, life can’t carry on like, you know what I mean. I don’t want to live no more. I just built myself a noose and was ready to do myself in.....[640] I was just being low and depressed like and the voices had been playing up quite a bit....[644] saying things like, you know do yourself in, you know and, that you know, you, you’re useless, you’re no good to your family....[648] that you’ll never get better....[650] you got no future.

[Asif: 687] I start thinking.....maybe I’m, I’m never going to get better. Maybe this is how it’s going to be for the rest of my life.....[692] Sometimes I can’t switch off....It’s like, you know, in the night, my mind just keeps on churning and churning.

[Helena: 105] Well that was about eight years ago.....I had a nervous breakdown.....I burnt, nearly burnt the house down That’s what they told me and I cut myself to pieces [121] my faces and legs (with a) razor

Helena also describes cancer diagnosis + effect on anti-psychotics. Immediately had remembered death of aunt from cancer and tried to evade implications of own diagnosis. Recapitulating or reminiscing no matter the background or experience of racism.

[Sanjay: 667] ......I realised I’d had a breakdown because I didn’t remember what day or all the things I did, trying to kill myself.....[677] you only do that if you really feel like you’ve failed in life........and that’s how low I got then because I thought I’d gone that low that nothing was worth living for and I’m not making things better for anybody, so that’s when I tried to kill myself

Battling symptoms:

voices

[Shirley: 916] ..."You’re a murderer" and all that....[971] the past comes up a lot....[973] “You’re a coward, you should have tackled them from the beginning and it would have never have happened. So you’re at fault. You are a murderer.”

[Asif: 43] They say derogatory things and nasty things. Sometimes they can be racial.... saying that I’m worthless piece of shit and that....Black bastard and that lot, start calling me Pakis and stuff like that....they don’t hold no punches when they speak....[62] It makes me feel really low.....I start isolating myself. I go into my bedroom....I don’t speak to nobody.....when I’m getting to that rut, I’ll isolate myself for days on end....in my room. I won’t eat....I can’t, you know, sleep properly.

attributions

[Asif: 101] I will think they are talking about me, and if they laugh......you know, like as they walk past me, I think they’re laughing at me.....the paranoia like gets worse then....[125] when I see normal White people, I see that, you know, I think that they’re being racial against me you know?.....[158]
And usually I’ll make my way as quick as I can to my house…coz I know if I start it there I’ll end up hurting somebody or getting into a fight.

**racialised positive symptoms leading to withdrawal**

[Asif: 158] Kinda syndrome you know I get. And usually I’ll make my way as quick as I can to my house

[Megan: 324] I probably was at that time very like err, thinking Black this, Black that, you know, that the reason why people don’t like me because I’m Black this and Black that. And I had to realise that it wasn’t that sort of colour harassment

[Rhupa: 421] ……my husband used to like taking me shopping, going into the supermarket and cos I was in there a while, I used to think as soon as we go out, somebody (can’t hear on tape) tell them that I’m coming. So everybody who was there to, there’s a lot of people there and they look, you know, they look at you in a different way. That’s how I see it and then I want to come home

**Anti-code - gaining hope through symptoms:**

[Sanjay: 737] I do receive messages……what happens is……when I say I bottle up, keep everything inside me? Then obviously you feel more connected to God……when you turn to somebody you know……and you’re er got nobody else to turn to

[Sanjay: 758] ……sometime(s) you know, when I used to (be) really low, it used to upset me when I saw people happy……because I am sad and somebody’s laughing……it used to make me feel sadder……[781] I used to look for news which were bad on TV so that it, it used to make me feel as though my situation wasn’t as bad as some other people’s……[789] it’s like saying……I’ve got problems but there are people out there worse off than me……so you get messages all the while, gradually building you up so that, you know, it makes you feel as though you’re not the only one suffering

**Anti-code – positive symptoms deriving from other sources**

[Nitin: 686] ……mostly to do with my Dad Naz, yeah……[688] and about my past from the time when he passed away……[691] and I was still fif……[698] I can remember during my breakdown……[700] I could picture scenes of myself……[702] in my past……[704] right from the time when I started college……[716] The day I felt suicidal and did what I did……[718] still plates in my legs you see……[720] from the knee down to the ankle……[722] both legs……[724] and er I think yeah, I like, that type of thing, I reacted to the voices……[731] said to me er jump and ……[733] that type of thing about we don’t care about you or your father or things like that.
Main Code 6 – SHARING EXPERIENCES

3 subcategories

Sharing beliefs:

[Asif: 958] All the other Asian patients that was in there, there was three all together, one guy had been in quite a few times like with mental health problems and he goes “they don’t listen to Asians, because they think, because (of) the barrier of communication”

[Nitin: 1068] ……there was this West Indian bloke there……[1070] he were telling me you don’t want to say too much in a place like this about yourself……[1074] and you don’t really want to get too involved with the go-re (White people)

[Nitin: 1202] That’s what that er Steve/James (both pseudonyms), the er Black bloke who was telling me…..[1209] when I said to him “You know they’re racist”, he was saying “You’re too right”.

[Nitin2: 232] We didn’t think that (that event might have a non-racial cause)….sometimes you take…his word for it…..[239] What we both thought was that – we figure it out – that he was like racist yeah? And like he’s a gorah and the staff, most of them are gorahs and that type of thing. And if something did happen they’d still fucking favour him more than us two. That’s what I thought and even Steve (fellow African-Caribbean patient) thought that too.

Comparing worries and feelings:

[Megan: 286] ……they didn’t recruit any Black people. I wanted to have something that was more, could understand my culture….Err, at this stage I had a Black social worker and we got on very well and you know we had this rapport that we could really talk to each other, we could say things you know, our kind of things that we couldn’t discuss with other people…..And, at this stage….my life-line was out to her

[Megan: 324] I probably was at that time very like err, thinking Black this, Black that, you know, that the reason why people don’t like me because I’m Black this and Black that. And I had to realise that it wasn’t that sort of colour harassment

[Nitin: 473] Yeah we all used to think that and say that…..[475] and say, you know, we hope we get in somewhere (a job)…..[477] but if we don’t, you know, we’re gonna be struggling

[Nitin2: 270] Steve was telling me, “Nitin don’t get too involved with those White people” in the sense that they could even make you do something daft….[276] you could get wound up

[Nitin2: 281] ….bit of anger and that and how we’d think and say “We know where we stand”. You get me?

Feeling informed leading to unity:

[Nitin: 193] We used to hear about it……[200] what used to happen in the past……[202] you’d hear the elders who went there when we were still at school……[205] and if there used to be that type of problem……[211] Because of Whites saying it to Indian people and all Black people……[214] things like you know, “Fuck off” and all that, and then if it did turn into a big punch-up

[Nitin: 261] ……just like I was saying it gets passed down, the elders saying to the ones who’s slightly younger
[Nitin: 539] there used to be you know, a group of elders and even if they weren't working they used to hang around that college...[543] in the sense that er if there was gonna be that type of fighting...[546] racism...[567] they played that type of role of just being there in case...[576] they were saying that type of thing was er something useful to do...[579] to help each other out

[Nitin: 290] we all used to think and say...OK, so we know now...[294] we thought we'd unite and stick together...[297] and stick up for each other

[Nitin2: 322] Well I'd think and say you know: "Is it a White patient, or a man or a woman and what is it he or she said to you?"

[Nitin2: 334] "this is what I would do"...[I would say]..."but I'm not asking you to do what I'm telling you that I would do. It's up to you. See for your own self." Is that alright?

Social construction - still fearing consequences; still wondering if what he is saying is acceptable or will lead to something. Checking with me, fearing me. Constructed. Maybe Fear main Code needs a subcat devoted to fear of me?

Anticode:

[Megan: 271] I went there for a year. It was like a confirmation for me, coz I made a lot of new friends...Not just clients, there was other fellow, err patients, but also members of staff who I still keep in contact now

[Helena: 228] But nobody knows what it's like. You know that's why I want the children to be aware of it...that if it should (happen to them), you know?

sharing but non racial and non stigma - illness focused

[Helena: 141] I'm going out...to the groups and talking to people...I've lived with the voices even better...It was meeting more intelligent people...I see how they live with their voices and they cope with their voices, you know?
Main Code 7 – DEVELOPING PERSONAL THEORIES AND UNDERSTANDINGS

4 subcategories

Thinking about a racist’s motivation:

[Megan: 861] ……when children are four, five, three or four and they start growing, you will see them hold a Black kid’s hand or a White kid’s hand. They don’t know anything about this. It’s us. It comes from out of the kids. You know that person’s Black because you’re told “You’re not hanging around with them”. That is what racism is, isn’t it? Kids do not see it. They don’t see difference. It’s what you instil in them when you get angry. How you say to them “I don’t like you hanging around with that nigger, little kid over there.”

[Megan: 843] And that’s why I think prejudice and racism don’t exist….It can manifest itself in different forms, racism in people, but you see, you can get good and bad in people…White, Black or indifferent,…[852] It just depends on how you been brought up.

[Megan: 796] It depends. Like if you’re a Black person like….myself and my partner, if you know your identity, I mean where you’re coming from, you’re coming from a skin and you can accept that. Alright Michael Jackson…bleaching his skin….to get whiter.…[818] Jesus it comes and turns you. Like I’ve got thicker lips. Do you understand? I’m well sick of it. You know what I mean? What is that teach?… I wanna be more White, more Black? Some don’t know if they’re Black or White. They don’t know which way to go. Now you see it all depends on how you brought up and what kind of side you see of things.

Questioning mode vs an answering mode???

[Asif: 401] It makes you feel like, you know, why, you know, these people, why are they doing this still?……[405] When I look at things like that, I think to myself: “What’s your problem?” Coz when they say “Oh they’re taking all our jobs” what jobs are they taking? At the end of the day, the, the shitty jobs you won’t touch. They will do ‘em. And then, then you know, you knock ‘em for it.

[Asif: 485] ……they’ve got kids who hang around here in a gang. And it’s because all their Mothers and fathers have taught them is racism……they’re taking it out on any Asian person they see……and usually they see that Asians are quiet, they don’t want no trouble you know. Same as when we was growing up, we was always told “Oh forget it, leave it, it’ll cause more trouble if you retaliate or say anything to them”. But now it’s not accepted is it?……But still you got, still get it

[Asif: 601] Because nobody’s telling them it’s wrong. If, if someone actually put the point to them, in the direction of saying “What you’re doing here is bang out of order” like. Say the Mums and Dads say to me “You don’t use the word Paki, it’s wrong”……then you know the children wouldn’t use that on their own, but if their dad’s saying “Oh that Paki down the road……”……the children are picking that up.

Re-evoking the past and questioning the future:

[Shirley: 300] ……they wouldn’t take any notice of me. Put your hand up to say someone had kicked you: “Put your hand down, stop telling tales” they’d say…. [305] They just didn’t take any notice basically, the teachers…… [308] and it’s like now, when I became ill, the first time they sectioned me…… [317] instead of finding out why my environment was got so filthy, they didn’t, they didn’t. they put me in a place and said I was crazy

[Shirley: 385] So that and it still goes on today. In certain shops you go in. If I walk in (name of department store) you can see they’re looking at you, you know they’re thinking “She trying to steal something from something.”
Shirley: 527 You weren’t given a choice of meal or a Caribbean meal. You just have to eat what was there....[532] That reminds me of school....[534] when you didn’t have a choice, in my day. You had to eat what was there....[537] Otherwise you stay hungry, that’s all they used to say to you

Shirley: 545 Make you feel weary, tired....[547] Endless. You know I keep thinking to myself....from the time I came to (name of town or city) when I’m now nearly hitting fifty, nothing’s changed much....[552] It’s all a sham....[634] Make you feel as if they don’t care about my race....[1059] it’s just made me feel a less of a person now. And I think that’s because of what’s happened. There’s nothing out there, there’s nothing positive out there for people within my age group....[1064] For Caribbean people there’s nothing out there. If you’re sick there’s nothing out there.

Asif: 377 ...when we moved up here....[380] it all started again.....[382] they go around busting Asian people’s windows here, they throw bricks, excrement through the door.....[386] It’s happened to the lady up the road.....[394] they do a lot you know, there’s graffiti around, you know the National Front sign, you know the swastika and all that

Asif: 771 ...when I see my kids have racism spouted at them....it always makes me think back to my childhood....you know, that’s how I connect it in my mind...because I think to myself I went through this exact same, you know. It’s exactly the same, you know, the same words are being used, the same you know, err, derogatory remarks are made.....[783] when they call my daughter a Paki it really hurts...because I think to myself, you know, this is what they used to call me.....And now twenty, thirty years down the line it’s still happening....[819] It leaves you in nowhere really doesn’t it. You’re like in no man’s land.

Nitin: 1667 ....have you heard of the (name of area in town or city).....[1670] They say that it’s all Whites there , they just don’t like Black people or Asian people or Chinese.....[1678] them being like how they are and they’re not gonna change.....[1681] they just want to carry on being how they are, staying racist against Asians, Blacks and Chinese and everything.....[1685] do I think racism will ever die out, it might in about say 40, 50 years or even longer than that.....[1690] but then it, then it might not

Empathising with others:

Megan: 733 People used to look at us, people like myself, in a strange way you understand? Because some of them were dressed “irrunghuly”.....[737] Nothing matches you know what I mean? It’s all a bit dirty, got stains on the front......[749] You can’t look after yourself or something....I expect that the majority of these men looked like they couldn’t look after themselves........Used to have stains down the front of their jumpers....[759] They may get looked at but I don’t

Helena: 282 When (the voices) first start, you don’t know that.....They asked me (about that).....But when you live with them...it’s different....Can you understand? Voices nearly making you burn the house down and cut yourself and you don’t feel anything?.....You don’t feel anything......I just pray, “Please God, don’t let my children get anything like that”.....And even you are a young man.....and you are talking to me and I pray you wouldn’t get anything like that.......And I hope that those people that see and put the stigma on people doesn’t get anything like that.....because it’s not, it’s nothing to want

Asif: 920 ....There was an old, Asian lady. Couldn’t understand a word of English and she wanted a drink of water ... [923] I couldn’t understand her (her language)....[934] so I went to ...[935] the nurse’s station and I said to him “Look the lady there needs something alright” and I says “She’s been sitting there for the past two and half, three hours and like, she keeps on asking for something but I don’t know what she wants and could you have a word?” And the nurse, the nurse looked at me. He was a bloke. He just looked at me as if to say well, she’ll have to wait then wouldn’t she.
I mean not just me, all, every Asian person will experience if you go to work. It’s not even too bad for me, but I mean I’ve been there what say 20 years. In all them 20 years they err, they employed one Black person for about two weeks and within two weeks they got rid of him, so I mean if it’s bad for Asian people, can you imagine what it’s like for Black people, because how often do you ever see them getting a chance? Can you imagine what it’s like for a Black person because they’ve got nothing, nobody ever gives them a chance, so it was hard for us Asians in the beginning because we went through all that but obviously we’ve gone through things and they’ve accepted us, but Black people they’ve never even given them a chance.

Nitin example of the elders

there used to be you know, a group of elders and even if they weren’t working they used to hang around that college in the sense that if there was gonna be that type of fighting they played that type of role of just being there in case they were saying that type of thing was or something useful to do to help each other out.

I don’t know if he was having a problem with getting sleep and sleep problem develops as well with mental health.

We were both thinking and saying “But what if this was Jamaica or if it was India and the White people lived there. We could be believing in the same attitude as they’ve got with us being in Britain.

the next day Naz, and the day after that that bloke was alright again. So I don’t know what could have got into him, his head at night time it might have been something different say someone told him “He’s no good,” meaning me and “he’s like this...like that”. And he think “OK, I’ll be on your side...” and think of him in that way too.

You do start thinking like that Naz (evaluating threat and wondering why an event has happened) I was thinking and saying to myself “Well what could it be that I’ve actually said to him or done to him?” because I couldn’t think of anything... (was it something) the day before, or evening before and that. And that what I started thinking...And the thing that night Naz, they check, they were checking his erm blood pressure... (so) maybe that’s why he reacted in that way.

Using experience to identify racism

future questions – how do you decide these things? then organically you’re into attributions.

I’ve known other people to get the racism but not me... that’s not because I’m different...I think it’s... because I, people get to know me, then they realise: “Actually, she’s the same like us”.

they say, you know, they’re bringing all these laws in and everything, but at the end of the day if somebody is going to be a racist, he’s not going to come out and tell you he’s racist. You gradually get to know that he is one just by the way he does things... you get your experiences as you go along.

you don’t know what they’re like (work colleagues) then you get to know them more and you judge for yourself about what you might, how you might think of them.

I would think the same if (a) person said that (before I became ill for the first time). I don’t know what it is, you know, like I was telling you, but if he was looking at me in that way and actually saying it to me and if it’s this type of time, night time.

heuristic to deal with stigma but same as one used to gauge racism by Nitin and Sanjay.
So obviously, if you don’t know somebody, you have to let them go a certain distance before you turn around and say that (you’re) not having this anymore. [1067] I don’t just come out and say that but what happens is....you find your balance with them.

You don’t just err, snap out because somebody’s done something wrong, but you get to know them and you know that this person will go further and further and further....and instead of letting him get to that stage, you just put a stop to it and say right now, this is your distance. You keep your distance and I keep my distance.