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**UNIVERSITY OF SOUTHAMPTON**  
**FACULTY OF MEDICINE, HEALTH AND**  
**BIOLOGICAL SCIENCES**  
**FACULTY OF MEDICINE**

**Adapting Cognitive Behaviour Therapy for  
Psychosis for Black and Minority Ethnic  
Communities**

by

Peter Phiri

Thesis for the degree of Doctor of Philosophy

October 2012



UNIVERSITY OF SOUTHAMPTON

**ABSTRACT**

**FACULTY OF MEDICINE, HEALTH AND BIOLOGICAL  
SCIENCES**

**Doctor of Philosophy**

**Adapting Cognitive Behaviour Therapy for Psychosis for  
Black and Minority Ethnic Communities**

**By Peter Phiri**

**Background:** Studies of cognitive behavioural therapy (CBT) for psychosis ‘*a debilitating illness of the mind, often characterised by symptoms such as hallucinations, delusional beliefs, thought disorder and bizarre behaviours*’ demonstrate that African Caribbean and Black African patients have higher drop-out rates and poor outcomes from treatment.

**Aims:** a). To produce a culturally sensitive adaption of an existing CBT manual for therapists working with patients with psychosis from African-Caribbean, Black-African/Black British, and South Asian Muslim communities. b). To assess the effectiveness of culturally adapted CBT for psychosis in this population.

**Method:** Part 1: A two centre qualitative study consisting of individual semi-structured interviews with patients with a diagnosis of schizophrenia, schizo-affective, delusional disorders or psychosis (n=15); focus groups with lay members (n=52); CBT therapists (n=22) and mental health practitioners (n=25). Data was analysed thematically using evolving themes and content analysis. NVivo 8 was used to manage and explore data. Part 2: The recommendations were used to inform adaptation of CBTp. A randomised controlled trial was conducted in three centres in the UK. A total of 35 participants were recruited. Assessors blind to randomisation and treatment allocation administered outcome measures at three-time points; baseline, post-therapy and at 6 months follow-up using the Comprehensive Psychopathological Rating Scale (CPRS) and Insight in Psychosis Scale. Participants in the CaCBTp arm (n=16) were offered 16 sessions of therapy and completed Patient Experience Questionnaire (PEQ) post-treatment. Treatment as usual (TAU: n=17) arm continued with standard their treatment.

**Results:** Analysis was based on the principles of intention to treat (ITT). This was further supplemented with secondary sensitivity analysis. Post-treatment the intervention group showed statistically significant reductions in symptomatology on overall CPRS scores, CaCBTp group, Mean (SD) = 16.23 (10.77), TAU = 18.60(14.84);  $p = 0.047$ , with a difference in change of 11.31 (95% CI: 0.14 to 22.49; CPRS subscales showed significant effect in CaCBTp over TAU. Adjustment was made for age, gender and medication. Overall satisfaction on the PEQ was significantly correlated with the number of sessions attended ( $r = .563$ ;  $p = 0.003$ ).

**Conclusion:** Participants in the CaCBTp group achieved statistically significant improvement post-treatment compared to the TAU. Attrition rates were low and therapy experience and satisfaction were highly rated. The findings will have implications for a definitively powered phase III RCT. A CaCBTp training manual in is preparation.



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## Author's declaration

I Peter Phiri declare that the thesis entitled

Adapting Cognitive Behaviour Therapy for Psychosis for Black and Minority Ethnic Communities

and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
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- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
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**Signed:**

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**Dedicated to the loving memory of my father, my  
sister and my auntie:**

**Benigino Matthew Hambahamba Phiri**

**Selina Ndlovu**

**Mary Dimba**



## List of Definitions and abbreviations

<b>AESOP</b>	Aetiology and Ethnicity of Schizophrenia and Other Psychoses
<b>ACL</b>	African Caribbean Lay participant
<b>AOT</b>	Assertive Outreach Team
<b>APA</b>	American Psychiatric Association
<b>BF</b>	Befriending
<b>BL</b>	Bangladeshi Lay participant
<b>BME</b>	Black and Minority Ethnic
<b>CBT</b>	Cognitive Behavioural Therapy
<b>CaCBTp</b>	Culturally adapted Cognitive Behavioural Therapy for Psychosis
<b>CMHT</b>	Community Mental Health Team
<b>CDW</b>	Community Development Worker
<b>CPRS</b>	Comprehensive Psychopathological Rating Scale
<b>CSO</b>	Clinical Studies Officer
<b>CRB</b>	Criminal Records Bureau
<b>DOH</b>	Department of Health
<b>DRE</b>	Delivering Race Equality
<b>EDIE</b>	Early Detection and Intervention Evaluation
<b>EIP</b>	Early Intervention in Psychosis
<b>EU</b>	European Union
<b>FIS</b>	Focused Implementation Site
<b>GP</b>	General Practitioner
<b>HO</b>	Home Office
<b>IAPT</b>	Improved Access to Psychological Therapies
<b>ITT</b>	Intention To Treat
<b>MHA</b>	Mental Health Act
<b>MHP</b>	Mental Health Practitioner
<b>NHS</b>	National Health Service
<b>NICE</b>	National Institute for Clinical Excellence
<b>NIMHE</b>	National Institute for Mental Health Excellence
<b>NSF</b>	National Service Framework
<b>ONS</b>	Office of National Statistics
<b>PAC</b>	African Caribbean Service User
<b>PALS</b>	Patient Advice Liaison Services
<b>PEQ</b>	Patient Experience Questionnaire
<b>PICU</b>	Psychiatric Intensive Care Unit
<b>PL</b>	Pakistani Lay participant
<b>RCT</b>	Randomised Controlled Trial
<b>SAD</b>	Seasonal Affective Disorder
<b>SANS</b>	Scale for Assessing Negative Symptoms
<b>SLEH</b>	Specialist Library for Ethnicity & Health
<b>SPSS</b>	Statistical Package for the Social Sciences
<b>SRS</b>	Simple Random Samples
<b>T</b>	Therapist
<b>TAU</b>	Treatment as Usual
<b>UK</b>	United Kingdom
<b>ZINATHA</b>	Zimbabwe National Traditional Healers Association



# **Chapter 1 - Literature Review**

## **1.1 Introduction**

This chapter provides a background to the qualitative study by critically analysing empirical studies on the efficacy of CBT for schizophrenia and related psychotic disorders. It discusses evidence on prevalence of schizophrenia and risks associated with its high prevalence in Black and Minority Ethnic (BME) groups including immigration. It will also highlight the limitations of CBT intervention in BME patients and sets the scene for the study 'developing culturally sensitive cognitive behaviour therapy for psychosis for ethnic minority groups by exploring and incorporating service users' and health professionals views and opinions.

This section provides the necessary background on CBT for schizophrenia and BME groups. Literature review discussed here will facilitate and direct developing the study.

## **1.2 Background**

England is a diverse country with an estimated 4.6 million non-white population, nearly 9% of the UK population (ONS, 2001). The table below shows the population breakdown of the South Asian group by heritage. Within this group the Indians make up 2.0% followed by the Pakistani (1.4%) and Bangladeshi and other Asian at (0.5%). The recent 2011 census analysis revealed a sharp population surge with a 7% increase over the last 10 years (ONS, 2011). The BME figures increased by 2.5 million partly due to Eastern European commonwealth countries and African migrants seeking asylum, Both Indian and Pakistani population rose to over a million.

<b>ASIAN &amp; ASIAN HERITAGE</b>	<b>Total</b>	<b>% of population</b>
Indian	1,036,807	2.0
Pakistani	741,826	1.4
Bangladeshi	280,830	0.5
<b>Total South Asian</b>	<b>2,032,463</b>	<b>3.9</b>
Other Asian	241,274	0.5
<b>Total Asian (not incl. Chinese)</b>	<b>2,273,737</b>	<b>4.4</b>

**Table 1: Population breakdown by ethnicity: Asian group (ONS, 2001)**

<b>Black &amp; Black British</b>	<b>Total</b>	<b>% of population</b>
<b>Caribbean</b>	<b>563,843</b>	<b>1.1</b>
<b>African</b>	<b>479,665</b>	<b>0.9</b>
<b>Other black</b>	<b>96,069</b>	<b>0.2</b>
<b>Other black</b>	<b>96,069</b>	<b>0.2</b>

**Table 2: Population breakdown by ethnicity: Black & Black British (ONS, 2001)**

### **1.3 Search strategy**

Literature searches were conducted using the following electronic databases: EMBASE, PsycInfo, Medline, Web of knowledge, in order to identify relevant literature on Cognitive Behaviour therapy for schizophrenia. No restrictions were placed on the year of publication and the main keywords used in various combinations were; schizophrenia, psychosis, psychotic disorders, cognitive behaviour therapy, CBT, psychotherapy, ethnic minorities, African, Caribbean, Pakistani, Bangladeshi, population, culture, ethnicity, race, cultural sensitivity, racism, and migration. Additional hand searches were conducted including reference lists of relevant articles identified by the search strategy. Studies were

not limited to the UK, and included international studies, but were limited to English language.

The search also included relevant dissertations and thesis in the subject area. Ethnic minority websites and journals were considered for relevant BME studies. Books and health report searches were also conducted.

### **1.3.1 Terms used**

It is important to clarify the definitions of the following terms: culture, ethnicity and race.

Defining ethnicity can be complex and fraught with confusion even amongst researchers in this field. Accordingly Fernando (1991) notes that ethnicity is characterised by a sense of belonging and determined by the identity of a group that shares common values and norms including language, religion, culture and racial background (Tseng et al. 2005).

Both authors agree that ethnicity is not stagnant but amenable to change over time.

Ethnicity does not imply ethnic minority', as both the minority ethnic groups and the native white (majority) groups have ethnicity.

To discuss the issues associated with race presents a dilemma. On the other hand the notion of race has been described by some as "a fallacy that cannot be substantiated in biological terms" (Lago, 2006) as social and cultural categories arguably may have little to do with actual biological differences. A traditional view of race defines it as a group of individuals distinguished by certain physical features. Whereas a geographical premise views race as a human population that has inhabited a certain geographical location long enough to develop distinctive genetic compositions (Fernando, 2010). However, a current scientifically held view holds the premise that there are greater racial variations within groups than among them.

On the other hand culture is defined as a value system that is real and symbolic and transmitted through various avenues including, beliefs, art, religion, mythology, language, rituals and so forth (Mason & Sawyer, 2002). Unlike race and ethnicity, culture can be both resilient and fragile.

#### **1.4 Prevalence of schizophrenia in BME groups**

The prevalence of mental illness in the UK, is estimated at one in four adults at anyone time (Goldburg & Huxley, 1992). However, the ONS (2000) quotes an estimate of one in six people in England having mental health problems at some point in their life (Sainsbury Centre of Mental Health, 2007). On the contrary, the prevalence of schizophrenia has been estimated at one in three adults at any one time; furthermore, this prevalence varies across the world (Selten et al., 1997; Jackson et al., 2007) and within countries (Kirkbride et al., 2006). These estimates can have impact on stigma, moreover, advocates favouring a stress/vulnerability model argue that anyone could suffer with stress subsequently; excess levels of stress can lead to vulnerability and mental illness (Turkington et al, 2009).

Literature indicates that the rate of schizophrenia is between 2 and 14 times higher in African Caribbean population in comparison to their white counterparts (Fearon & Morgan, 2006). Furthermore, African Caribbean patients are more likely than their white counterparts to be admitted with a diagnosis of schizophrenia and effective psychosis (Littlewood & Lipsedge, 1988, Bhugra et al. 1997, Fearon et al, 2006). The fourth consecutive 'count me in census' reported another elevated increase in rates of BME inpatient admissions (ONS, 2008). Table 3 below illustrates the increases in Black Caribbean in comparison to the predominantly white population and other ethnic groups. A huge blow came in 2011 when the 6<sup>th</sup> and final 'Count me' in census was published; a similar trend of continued increase mental health admissions and detention rates in BME was reported. Of note, were the significantly higher rates of detention for Black African and Chinese, contrary, the White British group had lower than averages rates of

admission. However, it has been shown that in developing countries the prevalence of schizophrenia is lower than in the western countries. For example, Hickling (1991) found that hospital admission rates in Jamaica were lower than those of British African - Caribbeans. In North America for instance, the statistics for African American were similar to their British counterparts (Adepimpe, 1984; Jackson et al., 2007). Likewise, Selten et al. (1997) reported high rates in Caribbean immigrants in comparison to their native Dutch counterparts.

Ethnic group	2008 census		2007 census		2006 census		2005 census	
	%	Number	%	Number	%	Number	%	Number
White British	76.5	23,738	77.6	24,198	78.6	25,170	79.2	26,762
White Irish	1.8	567	1.7	538	1.8	582	2.2	727
Other White	4.5	1,399	4.6	1,449	3.8	1,210	3.1	1,055
White and Black Caribbean	1.1	336	0.9	288	0.9	287	0.8	255
White and Black African	0.4	110	0.3	91	0.3	102	0.2	71
White and Asian	0.4	117	0.3	91	0.3	109	0.3	104
Other Mixed	0.5	148	0.6	180	0.5	173	0.5	167
Indian	1.4	426	1.3	393	1.3	411	1.3	434
Pakistani	1.3	396	1.0	315	1.1	349	1.0	325
Bangladeshi	0.5	144	0.4	130	0.5	158	0.5	153
Other Asian	1.0	300	0.8	261	0.8	262	0.8	264
Black Caribbean	4.7	1,468	4.3	1,330	3.9	1,264	4.1	1,369
Black African	2.3	715	2.1	648	2.0	652	1.9	645
Other Black	1.2	376	1.7	545	1.7	535	1.7	569
Chinese	0.3	91	0.3	82	0.2	78	0.2	81
Other	1.2	362	1.1	356	1.1	338	1.1	357
Not stated	1.1	327	0.9	292	1.1	342	1.2	416
Invalid	1	0.1	31					

Total	100	31,020	100	31,187	100	32,023	100	33,785
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**Table 3: Mental health inpatients by ethnic group**

**Source:** taken from the Healthcare Commission Count me in census 2008

The report highlighted higher than average rates of between 2-10 times in admissions for African and Caribbean groups including those of mixed parentage in contrast to the White British which had lower than average.

Similarly, the Asian groups had average rates of admission (Healthcare Commission, 2008). This disparity when compared to African Caribbeans is attributed by some scholars to supportive family structures within the Asian communities (Raleigh, 2000). Kirkbride, Errazuriz, Croudace et al. (2012) conducted a systematic review and meta-analysis in England covering the period of 1950-2009 on the incidence of schizophrenia and other psychoses to determine the extent to which the rates varied in particular focusing on gender, age and less accepted epidemiological gradients such as ethnicity and migration. The results echoed previous findings of elevated rates of disorders in ethnic minority groups in particular African Caribbean and black African, when compared to the white British population. In schizophrenia the black Caribbean (pooled RR: 5.6; 95% CI: 3.4-4.5; N = 5), black African (RR: 4.7; 95% CI: 3.3-6.8; N = 5) and South Asian groups had a smaller risk ratio (pooled RR: 2.4; 95% CI: 1.3-4.5; N = 3). Overall this study maintains that the incidence of schizophrenia has remained stable over 60 years. Of concern is the fact that this trend of elevated rates in African Caribbean group has continued (Pinto, Ashworth, Jones, 2008) despite efforts by Delivering Race Equality (DoH: DRE, 2005) a government initiative to reduce these figures. Although the census shows average rates among the South Asian groups, higher rates of mental illness have been reported among the South Asians, in particular higher rates of self-harm and suicide in previous studies (William & Hunt, 1997; Bhugra et al., 1999; Fearon et al., 2006). Most recently, the risk of self-harm in young South Asian women when compared to their white counterparts was reported at 1.5 fold increase (Copper, Husain, Webb, Waheed, Kapur, Guthrie, Appleby,

2006). Moreover, in relation to gender, South Asian women had higher rates in comparison to men. On the contrary, within the African Caribbeans, a study conducted by Bhui et al. (2007) reported higher mortality rates in young man and women aged between 25-39 years. Moreover, suicide within the African Caribbean group was associated with higher rates of schizophrenia. According to Johns, Nazroo, Beddington et al. (2002) their analysis of cross-cultural studies in the UK revealed that hallucinatory experiences were more common in African Caribbean community (10%) compared to whites (4%), and South Asian a low (2%). The lower marginal rates within the South Asian require further investigation given that they also experience migration and acculturation and discrimination similar to African Caribbean group (Bhugra et al., 1997). Laurens et al (2011) study found that children of African Caribbean and black African were more likely to present the triad of putative antecedents of schizophrenia relative to the white British however; south Asian children were less likely to do so. Levels of social isolation and family support have been referred to as a contributory factor (Cantor-Graac & Selten, 2005; Kirkbride et al., 2008; Sharpley et al, 2001). Although the Asian Indians make up the largest ethnic group in the UK, they have a substantially lower prevalence rate of in comparison to the indigenous group (Goodman, Patel & Leon, 2009). Another attempt to justify this marginal rate amongst South Asians argued that their lower unemployment rates in comparison to the African Caribbeans (Bhugra et al., 1997) might have contributed to improved socio-economic status (Sharpley et al., 2001). Stigma should be considered a factor within the South Asian group and may actually account for lower levels of reported and diagnosed mental illness and in part due to access issues (McGoldrick et al. 2005). Of note Coid et al. (2008) argue that these elevated levels in minority groups can not be solely attributed to migratory stresses as they persist with subsequent generations. Furthermore, genetic risk factors are alluded by Kirkbride et al. (2012).

Across the pond, in the USA, there is a diverse Asian American culture constituting over 30 groups including a 12% Asian Indian group. Although eastern cultures share some common similarities including family unit, arranged marriages and collectivist concepts, there are stark differences in these groups worth noting (McGoldrick et al. 2005) e.g. religion, education, socio-economic status, differing concepts and attributions of mental illness and help-seeking behaviours as well as prevalence of mental illness (Rathod et al. 2010).

## **1.5 Schizophrenia and migration**

There is an accumulation of literature on migration and the incidence of psychosis in African Caribbeans in the UK and Caribbean Islands (Fearon et al., 2006; Morgan et al., 2008). As postulated by Bhugra (2000) study conducted in the Caribbean (Trinidad and Barbados) and London on African Caribbean population they found high rates of schizophrenia amongst second generation African Caribbean group. When compared with the country of origin those in Trinidad and Barbados had lower rates of schizophrenia than London. Conversely, the author hypothesised that this may be due to psycho-socio-economic factors rather than genetic vulnerability. These findings were endorsed by a recent meta analysis of 18 studies by Canter-Graae's and Selten's (2005) it established significant risks of developing schizophrenia in the migrant population, particularly the Black and minority ethnic groups to host western countries like the UK.

### **1.5.1 Historical context**

1948 marked the historical arrival of the Caribbeans to Britain on the, '*s.s. Windrush*' (Rack, 1982), since then there has been an influx of West Indies migrants to the UK. Likewise, the Asian migration followed afterwards in the late 1950s. Both groups were economic migrants and settled in lowly paid jobs that the indigenous white people were not interested in. While the vast majority of migration has been from developing countries within Africa and Asia (McKenzie et al., 2008); Most recently the UK experienced a

massive influx of Eastern European migrants from the A8 countries that joined the European Union (EU) in 2004. This EU group is reported to have filled the gaps in the UK job market that attract low-income wages of £4.50 - £5.99 per hour (HO: Accession Minority Report, 2007). Although a similar trend to the BME migrants is noted here, the subject of EU groups is beyond the scope of this thesis and will not be discussed here. Section 1.6 discusses the risks associated with psychosis in the BME groups.

## **1.6 Risk of Psychosis in BME groups**

In an attempt to investigate the incidence variability in the incidence of psychotic disorders Kirkbride et al. (2006) AESOP study conducted in three centres in England concluded that migrants were more vulnerable to developing psychosis and highlighted that factors such as urban city (van Os, 2004) including social deprivation amongst other unknowns contributed significantly to the remarkably high incidence rate of 95% of all psychotic disorders. The rate of psychosis was highest in the Southeast London centre, confirming the hypothesis that the incidence is higher in urban cities in comparison to rural areas (Krabbendam & van Os, 2005).

However, Kirkbride et al (2006) acknowledge that the study centre effect may have been influenced by socio-environmental risk factors not investigated in this study and suggest inclusion of these variables in future studies. General socio-economic factors impact on such problems as poverty and discrimination; hence a combination of these stressors with impact of migration can result in high levels of distress making individuals vulnerable and susceptible to mental illness. Concurrently, stigma associated with mental illness can result in isolation, unemployment and subsequent dependence on statutory benefits (there is stigma associated with this as well). The overall outcome of the AESOP study was that ethnic minority groups have a higher risk of psychoses in comparison to the predominantly white group. Furthermore, the authors state that the African Caribbean and Black African

groups indicated a significantly higher risk of both schizophrenia and manic psychosis (Fearon et al., 2006b).

Inequalities in the provision of mental health services for BME patients when compared to the majority of White population continue to be a subject of debate (Bhui et al., 2003; Audinin & Leliott, 2002). The term 'Black and minority ethnic' groups is used in the census to classify all groups presented in England and Wales, other than the native White British group. Amongst researchers, use of the term 'Black and minority ethnic' remains a controversial subject of on going debate with some advocating for its continued use (Ingleyby, 2009) whilst others argue for its demise and replacement, in particular its association with race and ethnicity (Fernando, 2009). The term BME according to Fountain (2009) acknowledges the diverse nature that exists within the UK societal structure thus identifying not only the black ethnic group but also the white ethnic groups such as eastern Europeans or Gypsies and indeed the White Irish, who although White are still considered a minority in Britain. Proponents for change in the term argue that the 'and' in BME implies that Black people are not part of the minority ethnic people (Fountain, 2009). Tables 1 & 2 in section 1.2 above exclude other white ethnic groups like the Irish, Eastern Europeans and the Asian (Chinese). These will not be discussed here and are beyond the scope of this thesis. BME groups are clustered across the country and concentrated mainly in urban areas.

When compared to their white counterparts, patients from minority ethnic groups with Schizophrenia are likely to be misunderstood and misdiagnosed (Fernando, 1988; Sashidharan, 1989) and according to Dunn & Fahy (1990) the African Caribbeans were more likely to be treated with medication and or brought in to hospital under detention of the mental health Act. Earlier on Bhui (1998) and Bhugra (1997) reported higher rates in

involuntary admissions and this has been echoed in the most recent Healthcare Commission's report (Count me census, 2008). Furthermore, dissatisfaction of statutory healthcare provision by ethnic groups was noted (Keating, 2007). The authors emphasised the significance of race and its impact on establishing and developing therapeutic rapport. Implications and impact of these key factors will be discussed later in the health seeking behaviours and pathways section. Lack of understanding of BME cultural backgrounds and application of 'Euro-centric approaches' on the migrant population has previously been highlighted as problematic and probably influenced by historical assumptions (Thomas & Sillen, 1972; Lewis, 1965). Other factors include limited family supportive structure brought about in some instances by family fragmentation resulting from migration. As a matter of fact, a study conducted in the USA on African American groups and the UK on African Caribbean groups identified and thus confirmed the impact of isolation and loneliness as contributory factors to elevated levels of vulnerability in the migrant population (NIMHE, 2004; Banks et al., 2006).

Concerns that psychological needs of BME groups were not being met have been highlighted in literature before and more so now. For example, literature has shown that African Caribbean people are just as likely as White people to consult the GP for psychological problems but less likely to receive medication (Nazroo, 1997). Another study by Cochrane & Sashidhran (1996) concluded that in comparison to their white counterparts African Caribbean and South Asia women were least likely to be diagnosed by their GP as having a psychological disorder. However, this assertion is likely to change given the current drive by the government on improved access to psychological therapies.

Common stereotypes have been used to explain the under-representation of the South Asian and the over-presentation of the African Caribbean people from ethnic minority

backgrounds in mental health services (Bhui, 1998). Furthermore, the notion that Asians are more likely to somatise than any other group and the assumption that Asian people perceive general practitioners to treat only physical complaints is not supported by evidence.

In 2008, the Secretary of State announced that the Department of Health had allocated substantial funds amounting £173m to fund improvements in access to psychological therapies (Turpin et al., 2008) over a three year period, although this was a welcomed investment, there are still concerns about cognitive models being Eurocentric (McCulloch et al., 2005; Bakhsh et al., 2007), thus may not meet the needs of BME patients (Rathod et al., 2008). How will the IAPT address the gap highlighted by literature that BME patients are less likely to be offered psychological therapies (Littlewood & Lipsedge, 1988) and are instead prescribed medication (Lloyd & Moodley, 1992). Therefore, any investment of this magnitude will have to take into account these underdeveloped areas in the provision of psychological therapies for BME patients.

In conclusion, the following section will discuss the theoretical underpinning for CBT in schizophrenia.

## **1.7 Cognitive Therapy of Schizophrenia**

CBT is now a plausible treatment of choice for schizophrenia and associated psychotic symptoms (Clinical Guidelines, 2009)

### **1.7.1 Theoretical Review**

Theories behind cognitive therapy assume that unhelpful or negative thinking is related to the distress experienced by people; consequently CBT was initially developed as a comprehensive theory of depression (Beck et al., 1979). However, it has since been extended to relate to the explanation of a range of other disorders (Blackburn & Twaddle,

1996) including personality disorders (Beck et al, 1990) and psychosis (Kingdon & Turkington, 1991; Tarrier et al., 1990; Morrison, 2001; Garety, Kuipers, Fowler, Freeman, Beddington, 2001). Beck described the application of normal cognitive techniques with psychosis to challenge beliefs previously considered non-susceptible to psychological therapies as early as 1952. Since then, there was a gradual development in literature of cognitive approaches to psychosis until early 1990s when authors like Chadwick, Birchwood, and Trowler (1996) began to investigate and publish work on psychosis. The current advances in cognitive therapy for psychosis emphasis and target emotion (Freeman, et al., 2004) worry intervention in psychosis. Notably, the role of attribution biases is implicated in the development and maintenance of psychotic phenomenon in the presence of anomalous experiences.

Cognitive therapy emphasises the role of unhelpful negative ways of thinking in the origin, maintenance and worsening of negative automatic thoughts or thinking errors and rigid depressive schemata. Beck et al. (1990) postulate that depressive schemata develop over a period of many years and remain ready to be activated by a combination of stressful circumstances. This early development of negative life experiences causes the formation of beliefs and assumptions/rules about oneself.

#### Cognitive Models of Psychosis

Maher's theory of delusions purports their origin from the application of normal reasoning processes to abnormal experiences (1986; 1992; 1999). He argues that delusions reflect rational attempts to making sense of anomalous experiences. Simply put, he sees delusions as an explanation. The premise of this model is based on two assumptions. Firstly, on the anomalous experiences which drives a search for meaning, which would be biased by pre-existing beliefs and assumptions about the self, others and the world-view (Maher 1988). Basically Maher argues that there are no significant differences between

the inferential reasoning of normal and deluded individuals. His second assumption that delusions do not come about through biased reasoning processes has been refuted to date (Firth, 1999; Garety & Hemsley, 1994; Garety & Freeman, 1999) and more recently by Coltheart et al., (2010) they argue that basic cognitive disturbance are linked to data gathering biases such as jumping to conclusions style of thinking, such patients tend to reach decisions with less evidence resulting in delusional experience. This factor implies bias by deluded individuals in their ability to evaluate for beliefs. This work has been continued by clinicians in the field, notably authors such as Chadwick, Birchwood & Trower (1996), explored this work by focusing on the role of the beliefs formed about anomalous experiences. Accordingly Coltheart (2007) supports hypothesis that delusional formation involves abnormal reasoning. This model can be sensitive to cultural differences as self-construct can be based on one's culture. Notwithstanding limitations in Maher's second assumption, his theory has impetus in the psychopathology of psychosis.

Bentall et al. (2001) argue that persecutory beliefs may be the consequence of genuine persecutory experiences, and they note literature that supports particular environmental conditions associated with paranoid thinking, (e.g. Mirowsky & Ross, 1983; Harris, 1987; Fuchs, 1999). Delusions result from a psychological defence against underlying negative emotion and low self-esteem (Hassan, 2011). An attempt to make sense of anomalous experiences may according to Bentall result in 'blaming others' as influenced by the theory of mind deficit. The emphasis on this model is the impact of externalising biases and consideration of sensitive ways to addressing paranoid beliefs.

According to Morrison et al. (2000) persecutory delusions are implicated when information is accurately perceived, and then misinterpreted due to faulty self and social knowledge, influenced by threat beliefs or traumatic experiences rather than faulty perceptions. Therefore their model argues that individuals experience auditory hallucinations following misattribution of intrusive thoughts to an external source in order to reduce the feeling of discomfort resulting from a discrepancy between beliefs and behaviours. Morrison model

draws on cognitive behaviour literature of anxiety disorders. Of particular interest is the emphasis of misinterpretations in the ways that are considered to be culturally unacceptable. This model considers cultural influences, although widely adopted by clinicians its' empirical basis is limited.

### **Theory of Mind**

There is more evidence supporting differences in the recall of autobiographical information between schizophrenic individuals and non-clinical populations (Corcoran & Frith, 2003).

Theory of Mind refers to an individual's ability to understand that other people have desires and mental states, and explains how individuals comprehend the knowledge and intentions of others.

Frith (1992) argued that deficits in ToM could be implicated in the formation of persecutory delusions due to, for example; difficulties arising from monitoring other's thoughts and intentions resulting in paranoid ideation and delusions of reference (Corcoran et al., 1995; Frith & Corcoran, 1996; Bentall, 2001). As stated earlier on by Corcoran & Frith (2003) autobiographical memory differences maybe implicated in schizophrenic individuals resulting in the recall of negative or traumatic events.

Freeman & Garety et al. (2002)'s multi-factorial model of psychosis posits that vulnerability to developing psychosis can be explained through bio-psychosocial factors. The model clearly explains the formation and maintenance of psychotic phenomenon with onset from significant life events leading to cognitive deficits such as attention, perceptual and jumping to conclusion biases (Garety et al., 1991). The authors emphasise the role of emotion in this process in particular threat arousal as a contributory factor to processing of anomalous experiences (Freeman et al., 2002). Integrating multi-factorial factors in this model makes it ideal for use with ethnic groups as it supports impact of social background in particular traumatic experiences as contributory factors that can exacerbate negative self-schemata and predisposition to psychosis. Furthermore it considers that threat beliefs

could result from a number of cognitive biases that the authors implicate in the maintenance cycle such as prejudices that may maintain biased belief systems.

Freeman & Garety (2004) model of persecutory delusions focuses on delusional formation and maintenance. Garety's premise has global applicability as the model posits a cognitive bias that is putatively implicated in the formation of any delusion (Gold & Gold, 2012). The authors posit that any individual with JTC bias from any culture is likely to be influenced by the changing beliefs held by the members of that culture, as reflected by the changes in the content of delusion. Strengths also include normalisation and targets emotion through re-evaluation of the threat beliefs. Furthermore, it addresses reasoning (Huq et al., 1988) and attention biases including safety behaviour and avoidance (e.g. Papageorgiou & Wells; Dugus 2010). The diagrammatic presentation of this model can be shared with patients to help them make sense of their presenting problems, of particular interest here is the ability to consider possible plausible explanations.

Gumley et al. (2006) cognitive interpersonal approach to recovery identifies patient experiences express developmental adaptation to the critical events and transitions. Attachment theory informs this model. Although clinically relevant in practice, in that it promotes emotional recovery and reduces risk of relapse, it has a limited evidence base.

### **1.7.2 Stress-vulnerability model**

Another widely used theory behind CBT for psychosis is based on a stress-vulnerable model initially developed by Zubin & Spring (1977) and further modified by Nuechterlein et

al. (1994); it has been effective in enhancing therapeutic rapport. The model proposes that psychotic symptoms occur as a result of a combination of vulnerabilities in the presence of stressful experiences (Kingdon & Turkington, 2005). Therefore, by learning skills and developing alternative ways of dealing with stress, it is likely that the symptoms will abate. However, this theory continues to be challenged by the proponents of the biological theory who advocate for biological vulnerability as a consequence of genetic predisposition in the development of psychosis. This is despite reports from clinicians, service users and researchers that psychosocial factors do influence the development of psychosis (Hammersley et al, 2008).

Kingdon & Turkington (2005) emphasise that CBT for psychosis is not identical to standard CBT that is used for axis one problems. What's more, Turkington et al., (2006a) postulate that cognitive therapy techniques are modified in order to deal with some limitations resulting from schizophrenia, thus list four key therapy stages namely: *(i) developing a therapeutic alliance based on the patient's perspective, (ii) developing alternative explanations of schizophrenia symptoms, (iii) reducing the impact of positive and negative symptoms and (iv) offering alternatives to the medical model to address adherence p367.*

The fundamental premise in psychological frameworks within cognitive therapy is working collaboratively and the development of shared formulations of individual experiences and an experiential approach to modify beliefs and developing alternative explanations of psychotic phenomenon. This is hoped will result in the patient learning new coping strategies or enhancing helpful strategies and weakening the potency of hallucinations through such strategies as reality testing and behavioural experiments in session and in-between session activities (homework). The fundamental premise of CBT for psychosis is

to reduce distress associated with psychotic symptoms (Birchwood & Trower, 2006).

Where a patient is asymptomatic therapy may focus on developing social skills and relapse prevention. A more detailed review of the efficacy of CBTp will be discussed in Chapter two.

## **1.8 Summary**

This chapter has briefly discussed the prevalence of schizophrenia, highlighting its over-presentation in the migrant population and the risk of psychosis in this group.

Furthermore, theories commonly used in CBTp were briefly explored. This part of the review has highlighted several limitations and gaps within the literature of CBTp on BME groups. Theorists agree in part, as to which factors are implicated in the formation and maintenance of psychosis. A significant development recently has been the merging of biological, psychological, socio-economic factors. Thus this thesis will add that cultural and religious factors should be incorporated in the psychopathology of psychosis. The following chapter will discuss the evidence base for CBT for schizophrenia, methodological issues and provide a platform for discussing further gaps in literature relating to efficacy of CBTp in BME groups despite its success in the predominantly white population and conclude with recommendations for clinical implications and future research.

## **Chapter 2 - Cognitive Therapy for Schizophrenia**

### **2.1 Evidence for CBT for Schizophrenia**

This chapter aims to scrutinise the efficacy of CBT for schizophrenia. It determines the impact of ethnicity in relation to CBT related outcomes (Phiri & Kingdon, 2008). Although studies in this area differ in many ways their conclusions favoured CBT in comparison to treatment as usual (TAU; Butler et al., 2006; Dickerson, 2000; Kingdon & Hansen, 2007; Rathod et al. 2008; Rector et al. 2001; Grant et al., 2011) or any other individual psychotherapy (Turkington, Kingdon & Weiden, 2006a).

The NICE guidelines recommend CBT as a treatment of choice and put forward that it should be offered to any individual with persistent (positive and negative) symptoms of psychosis and those on remission (NICE, 2009). Furthermore, the guidelines stipulate that duration of more than 16 planned sessions should be offered, an increase from more than ten sessions previously (NICE, 2002). Likewise, the American Psychiatric Association (APA: 2004) practice guidelines recommend this intervention with moderate clinical confidence for schizophrenia.

In an earlier randomised controlled trial (RCT) of CBT for medication-resistant schizophrenia (Sensky et al., 2000), CBT was found to be superior to Befriending<sup>1</sup> (BF) in managing negative symptoms (BF: Kingdon & Turkington, 1989). More recently, in another study conducted by Turkington et al. (2008) CBT's superiority over BF was sustained long term. The results at 9 months showed significant improvement in CBT group over BF on the scale for assessing negative symptoms (SANS). Subsequently, at

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<sup>1</sup> Befriending is a scheme involving trained volunteers working to engage clients in such activities as attending local leisure centres etc, to reduce isolation (Kingdon & Turkington, 1989).

18 months and 5 year follow up, the CBT group continued to reduce the SANS, therefore maintaining it's superiority over BF.

CBT has been found effective when used in conjunction with family interventions. Pilling et al. (2002) reviewed a total of 18 RCTs of family interventions in schizophrenia and concluded that family interventions reduced chances of relapse when compared with standard care. Moreover, individual family interventions showed a two-year sustainability following treatment. Furthermore, the authors argued that family therapy enhanced adherence to medication (Kemp et al., 1996). Superiority of CBT was associated with low drop out rates.

A significant limitation in these studies was generalisability to the population with schizophrenia and no significant change in positive and negative symptoms (Turkington et al., 2004). However, the authors suggest that family interventions could complement individual CBT given its strength in relapse prevention (Sellwood et al., 2001).

According to Gould et al. (2001) meta-analysis on cognitive therapy for psychosis consisting of seven studies with a total of 340 subjects aimed at analysing effect size, concluded that an effect size of 0.65 (residual symptoms) at the end of therapy and 0.93 in sustainability over a period of time indicated that CBT has a significant effect on positive symptoms (TARRIER et al, 1998). Furthermore, the mean duration here suggests a chronically ill patient sample was used, indicating that CBT can be effective in severe schizophrenia. Acceptability of therapy can be indicated by dropout rates, in Gould and colleagues' study there was a 12.4% dropout rate, which is remarkably low when compared to other studies. A different meta-analysis by Zimmerman et al, (2005)

concluded that CBT for schizophrenia was effective in the treatment of positive symptoms and postulate that it has long-term effects. The authors acknowledged the limitations of the studies included in their review, including methodological issues such as lack of a satisfactory validity assessment.

Tarrier et al. (2004) conducted an 18-month follow-up of a RCT in first episode schizophrenia in which patients were randomised into: CBT in addition to TAU or Supportive counselling with TAU or TAU alone. They found that CBT and supportive counselling with TAU significantly improved compared to TAU alone. However, there was no significant difference between the patients receiving CBT and supportive counselling with TAU. The authors could not explain these results. The overall high relapse rates were similar across the three groups. The overall beneficial effects of CBT over TAU alone remained to be significant at 18-months follow-up. Further research is needed in this area to test biomedical and psychosocial compounds to justify the cost effectiveness of long-term therapy.

The EDIE trial aimed at exploring whether CBT could prevent or ameliorate psychosis in at risk people (Morrison et al., 2004) was conducted on 58 subjects who were randomised to CBT group (35) and monitoring (23). They concluded that CBT reduced transition to psychosis over 12 months. Furthermore, the authors hypothesise that therapy reduced the likelihood of being prescribed antipsychotic medication and for meeting diagnostic criteria for psychotic disorders. Marlowe (2005) contends that a reframed and normalised explanatory language may have been taught to the high-risk individuals, consequently, reducing and masking a psychotic episode at 12months. Therefore, Marlowe suggests that the results should be taken with caution as he assumes the intervention-delayed treatment with medication. On the contrary, Morrison (2005) argues that Marlowe's view

advocating for use of medication stigmatises against this group. To consider generalisability of the EDIE trial, authors were requested to provide ethnic breakdown of their trial, they reported they did not include ethnicity as a variable.

Rathod et al. (2005) insight into schizophrenia study replicated the previously stated superiority of CBT. When results were broken down by ethnicity, the Black Caribbean group showed significantly lower change in insight compared with their white counterparts. Black Caribbean group: ( $p = 0.004$ ; C.I = - 4.14 to - 0.766) and the Black Africans ( $p = 0.02$ ; CI = 0.532, to 6.142). The dropout rate in the Black African and African Caribbean group was 54% ( $p < 0.001$ ). In addition, the authors noted that dropouts had higher insight score in the African Caribbean population. CBT was found to be more effective for the White group than the BME groups. Moreover, this finding can be attributed to the high dropout rates in the BME groups. This study highlights issues of generalisability of CBT for schizophrenia across-ethnic minority cultures. As alluded to before, several studies recruited very small sample sizes on ethnic groups in comparison to the predominantly white population (Turkington et al., 2002a; Lewis et al, 2002; Turkington et al., 2002b; see table 4). Although these figures appear proportionate to the general UK population breakdown of BME groups, they do not seem to correspond to the over-representation of African Caribbean groups in psychiatric inpatient services. Therefore, it is important to have a significant ethnic minority representation in future CBT studies in order to evaluate its effectiveness with ethnic minority groups. This also makes sense given that literature have shown an over representation of African Caribbean patients in hospital admissions (Bhugra, 1997; Bhugra et al., 1997; Lombard, 2008).

Table 4 Summary of Cognitive Behavioural Therapy (CBT) for psychosis trial sample size broken down by ethnicity

Study	Patients	Total sample	Ethnicity reported		Ethnic breakdown by allocation	Outcome	Attrition Rate	BME dropouts	
			yes	no					
Tarrier et al. (1993)		39				effective in +ve symptoms			unclear
Edwards et al (2011)	1st episode	48							
Garety et al. (1994)		20				positive symptoms/ depression			unclear
Kuipers et al. (1997)	psychosis	60	x		not stated	effective in +ve symptoms	11% 4CBT/7TAU		
Tarrier et al. (1998)	Chronic Schizophrenia	87	x		not stated (n=1) non-English speaker?	effective in +ve symptoms	11 dropout		not stated
Durham et al. (2003)	med resistant psychosis	66	x			effective in +ve symptoms		9	not stated
Birchwood et al. (2004)	CTCH		Y		5 Black/Asian			5	unclear
Rector et al (2003)		42					3 cbt/5 tau		
Turkington et al. (2002)	Schizophrenia	422	y			effective in depression			unclear
Gumley et al. (2003)		144	x		(not stated)	both +ve/-ve symptoms/depression		11	unclear
Lewis et al. (2002)	Acute Psychosis	315	y		w262/SA10/ac22/o15	positive symptoms	(4cbt/4sc/7rc		
Terrier et al 2004		309	y		13/17/10 cbt			73	unclear
Jolley et al. (2003)	Schizophrenia	21			not stated		4CBT		

Startup et al. (2004)	Acute Psychosis	90			both +ve/-ve symptoms		
Morrison et al. (2004)	psychosis	58		Not stated		(n=9/7) 14%	unclear
Barrowclough et al.(2001)	Schizophrenia /substance abuse	36			positive symptoms		
Rathod et al. (2005)	Schizophrenia	422	y	w358/AC20/BA14/BO8/A7/C1/O11/UN3		46 cbt 40 tau	54%; p>0.001
pinto et al. (1999)	psychosis	41			positive symptoms		
Sensky et al. (2000)	persistent symptoms of schizophrenia	90	y	white n=80) non-white n=10		n=4 cbt/ n=2 bf	unclear
Cather et al. (2005)	psychosis	30					
Valmaggia et al. (2005)	Chronic schizophrenia	62					4
Drury et al. (1996)	acute psychosis	40			positive symptoms		
Haddock et al. (1999)	acute psychosis persecutory delusions	21					
Foster et al. (2010)	delusions	24	y	WBN=8/N=2 BB7 BA4 A2 SA 1			3 unclear

**Table 4: Summary of CBT for Psychosis trials sample size broken down by ethnicity**

### **2.1.1 Poor outcomes of CBT in BME patients**

We can attempt to speculate on why ethnic minority patients do not respond favourably well to CBT for schizophrenia. Rathod and colleagues (2005) study partly confirms what is already known about efficacy of CBT for schizophrenia within the predominantly White population and poor outcomes for ethnic minorities before now emphasised by Bhugra et al. (1997) amongst others. There are assumptions and speculations as to why ethnic minority communities do not respond favourably well to CBT for schizophrenia. Some of the factors identified by Nazroo (1997) included communication barriers, for instance, where English was not the first language, patients are likely to be misunderstood or misinterpreted therefore, end up with inaccurate diagnoses (Fernando, 1998).

Previous studies have drawn from the likes of Rosenthal and Frank (1958) to explain poor outcomes with ethnic minority groups using psychological therapies, including perceptions and attitudes of professionals (Byford et al., 2001) that BME patients are 'a difficult to engage' group, hence the reluctance of primary and secondary care professionals to refer them for psychological therapies. Furthermore, earlier work by Sabshin et al. (1970) reported that the African Caribbean group was stereotyped as 'hostile, impulsive and not psychologically minded'. Similarly, a recent report by Prins et al. (1993) entitled 'big, black and dangerous' highlighted the extent of misperceptions about African Caribbeans in particular young man and argued they are exacerbated by prejudices, cultural misunderstanding and racism (Keating, 2004; DoH, 2005).

Cultural factors play an important part as beliefs, behaviours, emotions and even psychological responses to situations will vary depending on the cultural background of

the client. Moreover, CBT has been criticised of being 'Eurocentric' (McCulloch et al., 2005) and therefore may not fit in with other cultures. In western cultures, predominant schema values individualism. In Eastern or collectivist cultures the predominant schema is being part of a group (Tseng et al., 2005; Hays & Iwamasa, 2006; Mason & Sawyer, 2002). Additionally, Laungani (2004) identified more core values that distinguish western and eastern cultures. Furthermore, perceptions of illness in schizophrenia differ across cultures as emphasised by McCabe & Priebe (2004) who argue that a biological explanatory model was related to enhanced treatment satisfaction but not to treatment adherence.

Despite significant findings regarding the efficacy of CBT on treatment resistant schizophrenia, negative and positive symptoms, Lynch et al., (2009) meta analytical review of CBT for schizophrenia, Bi polar and major depression, concluded that,

"CBT is no better than non-specific control interventions in the treatment of schizophrenia and does not reduce relapse rates..."

This is almost 'déjà vu' in the history of traditional psychotherapy. Poppen (2001:43) reports of Eysenck's (1952) controversial review of treatment outcomes in psychotherapy, which concluded that,

"Psychotherapy was no better than general supportive care, and in some instances was inferior to it..."

Lynch et al (2009) critical view point on well controlled trials should be taken with caution, the authors highlight the impact of blinding of assessors and controls in the studies they

reviewed as one aspect they focused on and posit that in studies where blinding was evident the outcomes of therapy were inconclusive. Furthermore, Lynch and colleagues criticise the meta analysis procedure and the studies included in them, by reanalysing blinding as a moderator variable and conclude that current evidence for CBT is less convincing in treating schizophrenia. This review contradicts previously positive analysis (by Gould, Zimmerman and Pilling just to mention a few) already discussed earlier on in this section. In their review, studies with a sample size less than ten participants in either group were excluded, likewise pilot studies. In view of the 2009 NICE guidelines of schizophrenia, the updated evidence base supported CBT for schizophrenia. Lynch's criticism of current CBT for schizophrenia evidence base has already been challenged by the proponents of its efficacy (Kingdon, 2010) who refutes the findings of this review and concludes by emphasising that Lynch's exclusion of relevant studies may have indeed influenced negative outcomes. However, CBT is acceptable to practitioners (Kuller, 2009) patients and carers (Rathod et al, 2005).

Following the review of literature a common trend becomes apparent in most studies that have demonstrated efficacy of CBT for schizophrenia over TAU or other interventions.

In conclusion, cultural adaptations and understanding of ethnic, cultural and religious interpretations of mental illness in particular schizophrenia and cognitive therapy remain underdeveloped. Models of mental ill health, including cognitive behavioural approaches, have been criticised for being Euro-centric (McCulloch et al., 2005) and for their assertion that they are applicable across cultures. This thesis will attempt to address this gap in knowledge base by conducting a qualitative investigation aimed at developing culturally sensitive CBT for psychosis. However, it is pivotal to acknowledging that to date efficacy of CBT has been well researched in the predominantly white population and very few studies have included significant BME sample sizes in their trials (Turkington et al., 2002;

Rathod et al, 2005). It is imperative for future trials to be clear which population interventions are targeted and which specific strategies will benefit particular groups.

## **2.2 Methodological Issues**

### **2.2.1 Introduction**

The previous section identified evidence to support the efficacy of CBT in the treatment of psychoses. Several gaps in literature were identified. CBT for psychosis continues to accumulate evidence of its efficacy in ameliorating distress as evidenced in the literature review. However, various methodological issues including differing outcome measures and designs used by researchers in this review have both strengths and limitations. Given the high prevalence in schizophrenia in BME populations in particular the second generation African Caribbean in the UK, most studies have had small sample sizes of BME groups in interventional studies and clinical trials. Studies report efficacy in the predominantly white population and not in BME groups (Rathod et al, 2005). Therefore this thesis attempts to address the gaps most relevant to CBT in the treatment of ethnic minority patients with psychosis. This section discusses the most commonly used methodologies and provides examples of studies in this area and also considers advantages and disadvantages of the relevant methodologies used.

Designs prevalent in this area when assessing the relationship between an intervention and an outcome include case studies, for example: (Beck, 1952, Birchwood & Chadwick, 1983; Bentall et al., 1994). Common limitations from case studies include confounding, selection bias and recall bias (Lu, 2009). Besides, individual case studies cannot be generalised to a broader population, as a consequence provide a weak empirical basis. Notwithstanding this limitation, they do provide a hypothesis for further investigation using better study designs.

Uncontrolled follow-up studies were conducted by, for example Kingdon & Turkington (1991) and also by Perris & Skagerlind (1994).

The use of the terms pilot and feasibility studies are unclear and in most instances are used interchangeably by researchers (Arain, Campbell, Cooper and Lancaster, 2010). The authors conducted a review of pilot studies in 2004 to investigate the differences in methodological components of studies described as pilot or feasibility studies and supplemented this with a survey to grant awarding bodies and medical journal editors. Of the 54 studies published in 2007-8 they found that 48% were pilot studies and 52% were feasibility studies. Although a majority of the studies incorporated hypothesis testing and intended further investigation only 8.8% (8) out of 90 pilot studies led to subsequent main studies (Arain et al. 2010). Consequently, a pilot study is defined as “a small study for helping to design a further confirmatory study” (Arnold et al. 2009). Pilot trials are considered as an exploratory phase II in the process of developing and evaluating complex treatments (Campbell et al., 2000). Fundamentally they aim to test the study procedures, validity of tools, recruitment trajectory and parameter estimates (Arain et al, 2010). Following their review of pilot studies Arnold and colleagues recommended clear distinctions between pilot work, pilot study and a pilot trial. They aim to test the feasibility of treatment interventions (Dodd & Williamson, 2002) by testing a small sample size; consequently, they provide preliminary findings (either supporting or disputing a hypothesis) on the phenomenon being investigated. In contrast, a feasibility study is defined as a piece of research done before a main study and aim to estimate parameters needed to design the main study. The authors argue that feasibility studies for randomised controlled trials are not meant to evaluate outcome of interest as that is solely for the main study, furthermore power calculations are not usually done and rely on sample size to estimate parameters. This significantly differs from a pilot study, which normally resembles the subsequent main study. In addition the results of the pilot could contribute to the final analysis or set aside (Arain et al. 2010). Use of appropriate terminology has

implications with funding bodies. Indeed this process can result in a phase III definitive trials known as RCTs. Strengths and limitations of using pilot designs include flexibility to adapt and modify treatments as trial progresses (this would be suitable for our trial as the focus is on specific ethnic minority groups considered to be over-presented in mental health services and at high risk of developing schizophrenia). Moreover, given that one of our aims is to adapt a treatment manual for CBT therapists to use with this population, a pilot trial will be the 'right fit' at this stage. A significant benefit is their ability to inform and provide power calculations for phase III RCTs. They are ideal at helping identify any potential snags in the trial process from recruitment to follow-up phase, this trajectory is vital for problem solving and preparing for any likely challenges a RCT might have. Pilot controlled studies have been reported in this area for instance, (Garety et al., 1994; Drury et al., 1994; Kingdon et al., 1995). Notwithstanding their strengths, they have been criticised for being underpowered and lacking in rigour and in some cases findings could not be generalized to wider population. Pilot findings at times need to be taken with caution due to skewed distribution at baseline.

Phase III trials are known for maintaining rigorous procedures and keeping to the trial protocol. Designs include control and treatment allocation with a large sample size. Participants are usually assigned to either a treatment intervention or control arm (which in some designs would follow a defined treatment as usual or waiting list or an alternative intervention, such as supportive counselling or befriending). RCTs are considered as the gold standard in evaluating interventions; they have accumulated most evidence in CBT for schizophrenia as shown in the table 5 below.

**Table 5: Evidence for CBT in RCTs**

<b>Randomised Controlled Trials (evidence so far)</b>	
<b>UK</b>	Tarrier et al. (1993; 1998), Haddock (1999) Kingdon & Turkington (1996) Sensky et al. (2000) Turkington et al. (2002) Drury, Birchwood et al. (1996) Trowler et al. (2004) Kemp, David et al. (1996) Gumley et al (2003), Durnham et al. (2003), Startup et al. (2004) Lewis et al. (2002; 2004) Morrison et al. (2004), Jackson (2005; 2007), Cather et al. (2005), England et al. (2007), Garety et al. (2008)
<b>North America &amp; elsewhere</b>	Lecompte & Pelc (1996), Lecomte et al. (2008) Pinto et al. (1999), Valmaggia et al. (2005) Jenner et al. (2001), McGorry et al. (2002) Rector et al. (2003), Granholm et al. (2002)

Although RCTs remain the design of choice for healthcare studies, and continue to benefit from internal validity through the randomisation process thereby minimising bias and confounding factors. However, a criticism against this design is its strict inclusion and exclusion criterion arguably may result in limitations of its generalisability to the general population with schizophrenia. As evidence based treatments become readily available within the NHS, it is becoming difficult to control for treatment as usual, although several studies do define TAU as standard treatment provided within a setting. In most Early Intervention in Psychosis (EIP) services CBT is a standard treatment as usual, this becomes a dilemma for trials recruiting this population and comparing CBT against TAU. They may be a need to have standard TAU definition to ensure interpretation of findings is not biased by this dilemma. A challenge for researchers at design stages might be to

provide a clear well defined TAU terms of reference to ensure replicability of trial. In the absence of RCTs, clinicians and policy makers rely on non-randomised studies to provide evidence on the efficacy of interventions. Controversy, over validity of non-randomised evidence due to selection bias is a likely limitation. However, some ethical issues related to use of randomisation have been widely debated in the past, in particular when trials do not provide participants (control) interventions that would otherwise benefit them. Another dilemma for RCTs is whether it is ethical to keep participants on treatment once it is known that one intervention is superior or harmful. The principles of beneficence, benevolence still apply and bind researchers not to do harm. Its rigorous procedures (sterile or laboratory based) may in practice (real life settings) infringe on external validation of findings. Nonetheless, researchers and scientists agree that RCTs are the most rigorous methodology for treatment experimentation. Conversely, several meta-analyses have been conducted in CBT for schizophrenia (Gould et al., 2001; Rector & Beck, 2001; Pilling et al., 2002; Tarrier & Wykes, 2004; Tarrier, 2005; Zimmerman et al. 2005).

Statistical techniques for analysing clinical research are varied and differ significantly although researchers may give rationale for choice; this may pose challenges in assessing efficacy of findings. Depending on the design analytic techniques can employ a non-parametric or analysis of variance (ANOVA) or covariance (ANCOVA) for between group comparisons. Although these techniques are different they provide the same outcome. Regression (a statistical procedure to estimate the linear dependence of one or more independent variables on dependent variables) analysis is widely used for analysing mechanisms of change (Gray & Kinnear, 2012). A commonly applied analytic technique in CBT trials is Intention to Treat (ITT) analysis. This procedure utilises data of participants as randomised to the trial regardless of whether they go on to receive treatment (Altman et al., 2001). A limitation of this analytic methodology is how trials handle missing data. The significance of managing missing data in trials plays a pivotal role in the final analysis

and interpretation of findings. Several methods are applied to missing data, these include Last observation carried forward (LOCF: Spokas et al., 2008). The implicit premise of LOCF is that a participants' last observation has not changed; an assumption that has been criticised for increasing the likelihood of rejecting a null hypothesis that is actually true (Type I Error). In contrast to the above, Mixed Linear Models (MLM) and Expectation-Maximization (EM) algorithm rely on estimating missing data based on the observed sample data (Graham, 2009). Although, these methods assume similarity between participants who dropout and those that remain in treatment, they may be missing out on some of the reasons as to why these participants discontinue treatment. One way of addressing this problem would be to interview all participants who discontinue and provide a qualitative analysis to justify this methodology. One such study was conducted by Tarrier, Yusupoff, McCathy, Kinney, and Wittkowski, (1998) aimed at finding out why chronic schizophrenia patients had discontinued psychological therapy from a RCT of CBT and supportive counselling in the treatment of persistent positive symptoms. Patients were invited to complete a questionnaire consisting of 22 items rated at true or false. Nine participants responded out of a total of 12-drop outs. Results revealed varied reasons including belief that therapy would not work or would worsen their symptoms, one participant reported that their CPN had told them therapy was exacerbating their worry and advised against attending further sessions. The authors also identified some possible characteristics of dropouts for instance gender, male; single; low IQ; and a median duration of 8 years of illness. This information although anecdotal provides information that otherwise would be unavailable to researchers. Moreover, this could be useful for screening plan. Determination for clinical significance of change in clinical trials is vital for policy makers and clinicians alike when it comes to commissioning and funding or indeed training staff to use new evidence-based interventions. Consequently, Thomas and Traux (1991) developed a criterion for assessing this change and proposed four levels of change namely; (i) recovered; (ii) improved; (iii) same; and (iv) deteriorated. This would be

deemed a reliable way of assessing change and determining clinical significance of treatment under investigation.

Evaluation of the literature review gives the impression that CBT for schizophrenia offers a convincing hypothetical framework that is supported by decades of empirical studies and is becoming more attractive to clinicians. However, the evidence base rarely includes adequately powered randomised trials of CBT where specific ethnic groups are included in adequate numbers to assess treatment efficacy and effectiveness. Nonetheless, this should not dissuade researchers from meticulously scrutinising models of CBT for schizophrenia, the cost effectiveness (Knapp & Healey, 1998; Startup et al, 2004) and long-term sustainability.

## **2.3 Summary**

In conclusion, CBT successfully complements medication in reducing the severity of positive and negative symptoms of schizophrenia and minimising relapse rates and reducing hospital admission.

Moreover, it has been effective in reducing suicidal ideation in schizophrenia (Bateman et al., 2007; Slee et al., 2008) and Haddock and colleagues have reported good outcomes in substance misuse. Morrison et al. (2004) suggest that it is beneficial for at risk populations, and complements the work of Seligman (2006) on learned optimism.

Methodological issues in this area have been considered including some of the statistical procedures commonly used in trials. A number of strengths and limitations of these methods has been considered in this review. However, there is a dire need for appropriate theoretical modifications (Tseng et al., 2005) and sensitivity to address the needs of the ethnic minority patients. This was further endorsed by the National Service Framework

(NSF) for mental health (1999) which recommended that all mental health users should receive care that optimizes engagement with the services and supports the need to develop and demonstrate cultural competence with staff having the knowledge and skills to work effectively with diverse communities. A fundamental proposition of the present study is that training programmes and psychological therapy manuals need to focus on explanations that are in line with the patients culture. The following chapter will now provide phase I, a qualitative methodology aimed at addressing this key area.



# **Chapter 3 - Developing culturally sensitive cognitive behaviour therapy for psychosis for ethnic minority patients by exploration and incorporation of service user's and health professionals' views and opinions**

## **3.1 Introduction to study**

The previous two chapters have given an overview of CBT for schizophrenia and its efficacy within the predominantly White population. Paucity in studies on CBT for schizophrenia in ethnic minorities is evident and needs to be addressed. In order to overcome the limitations highlighted in the literature review chapter earlier, this chapter will discuss the aims of this qualitative study to develop culturally sensitive CBT for psychosis for ethnic minority patients by exploring and incorporating service users' and health professionals' perspectives. This study draws from the earlier discussions arising from literature review and has important clinical implications for practice both locally and internationally.

## **3.2 Aims and objectives of the study**

### **3.2.1 Aims**

The main aim of the study is to produce a culturally sensitive adaption of an existing CBT manual that is (a) well suited to the needs of clients with psychosis from the specified ethnic minority communities (Black Caribbean, Black African, Black British, Bangladeshi and Pakistani); and is (b) accompanied by guidance for health professionals to enable them to deliver CBT that is culturally sensitive and responsive for patients with psychosis from these communities.

### **3.2.2 Objectives**

The following objectives have been designed to fulfill these aims:

- 1) To gain meaningful understandings concerning the way members (lay and service users) of the above minority communities typically view psychosis, its origin, and management
- 2) To elicit those cultural influences, values and attitudes that shape a client's degree of participation and response to CBT.
- 3) To elicit from CBT therapists and Mental health practitioners (MHP) from these communities their experiences and interpretations of the way a client's culture influences their attitude and response to CBT.
- 4) To identify those strategies that CBT therapists and other Mental health practitioners identify as being supportive or non supportive with clients from the above ethnic communities.
- 5) To analyse these data to make culturally specific adaptations to the existing Kingdon and Turkington manual (2005). This will include an accompanying good practice guide and recommendations for the training of therapists delivering CBT to clients from the ethnic communities.

### **3.3 Methodology**

#### **3.3.1 Study design**

The study adopted an overarching qualitative methodology informed by an ethnographic<sup>2</sup> approach. In this case, qualitative methodologies were particularly suited to 'exploring and understanding the meaning individuals or groups ascribed to a social or human problem' (Creswell, 2009). Furthermore, the qualitative design was felt most appropriate given that empirical studies have demonstrated the efficacy of CBT in psychosis within the White population and there is paucity on ethnic minority patients' experiences of this intervention

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<sup>2</sup> Ethnographic accounts are generally descriptive and detail the group or individuals ways of life (Richie & Lewis, 2003)

(Forchuck & Roberts, 1993). Leiningers' (1985) definition of qualitative research describes several methods and techniques used to investigate the phenomenon at hand. These include observational, documentation, analysis and interpretation of attributes, patterns and underlying meanings.

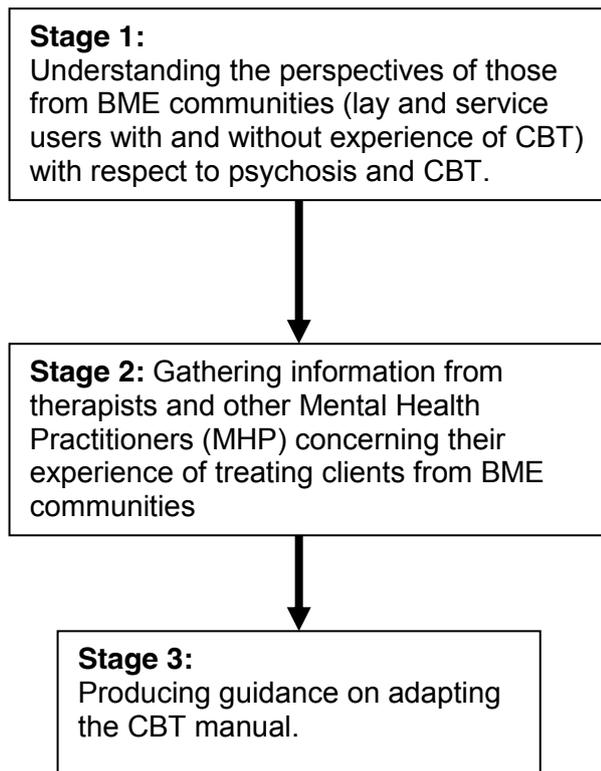
Given the study's aim to elicit any cultural factors that influence the patient's response to their illness and therapy, an ethnographic approach to data gathering allowed focus on understanding the perspective of people participating in the study within their cultural context (Spradley, 1980). Through this approach the researcher learns from the people participating in the study. This is contrast to the quantitative research, which seeks absolute knowledge, prediction and controlling the phenomenon (Moccia, 1988).

Other qualitative methods that the research team had considered included historical research that emphasises investigation and analysis of data pertaining to past events.

Acknowledging the sensitive nature of the topics to be explored, and the vulnerability of the service users, in depth face to face semi-structured individual or group interviews with participants were considered the most suitable method of data collection. In addition, focus groups (as a form of group interview) were used to clarify, explore or confirm ideas with a range of participants on a 'predefined set of issues'. Thus, using different but complementary data collection methods (Mathers & Huang, 1998), validation was achieved through triangulation. Other sources of information gathering utilised included field notes, audiotapes, observations and experiences of the researcher.

The researcher acted as a data collection instrument. The researcher trained in qualitative methodologies and in conducting focus group interviews. My experience as mental health practitioner and cognitive behaviour therapist meant that on my initial interview I did take a therapists' stance, this was highlighted at supervision with a qualitative expert. I had to be aware that during this process my role was that of a researcher and not therapist thus maintaining a balance in utilising self as a research instrument and ensuring that my views did not lead participants to respond in a particular way that introducing bias (Robinson & Thorne, 1988). Appendices 1-3 outline the interview guides used for the participant groups and thereby elicit information to address the research objectives (Goodman and Evans, 2006). These pre-determined topics were derived by the researchers from a literature review and information from the Insight study by Rathod et al.(2005). The principle of 'emergent design' was followed when respondents raised issues that required further exploration or verification (Polit and Hungler, 1999; Creswell, 2009), These points were then tested appropriately with subsequent participants. Occasional telephone or email communications with participants enabled clarification of areas of uncertainty when the data were being analysed.

The study was conducted in three stages as outlined below.



**Figure 1: Flow chart outlining stages of the study**

### **3.4 Study Centres**

The study was conducted in 2 centres in the UK: Hampshire and London. Hampshire represents a mixed inner city area and a small rural population of ethnic minorities.

Therefore the issues of urban and rural areas were addressed. Within Hampshire three sites agreed to participate representing 3 different areas. These were Southampton, Portsmouth and Winchester. Study Participants and rationale for their selection

**Group 1.** The African Caribbean group comprised Black British/Black Caribbean and Black African clients with psychosis with a need for but without experience of CBT and those with experience of CBT and lay members of the community.

**Group 2.** Comprised South Asian Muslim ethnic minority participants including Pakistani and Bangladeshi lay members and those clients with a need for but without the experience of CBT and those with experience of CBT - to reflect the diversity between different groups.

### **3.5 Justification for ethnic groups**

#### **3.5.1 Group 1. Black African/African Caribbean and Black British**

The term African Caribbean in this study is used to describe lay people or service users with African ancestry who migrated from the Caribbean isles, the majority of whom came in the early 1950s following shortage of manual labour in this country (Karmi, 1996).

Included in this group are the second generation who identify themselves as Black-British, some of whom are from the mixed race parentage. The African group is included here as well. The rationale for selecting this ethnic group follows previous and current studies on ethnicity and mental health subject which concluded that there were disparities in health provision (SLEH, 2009), significantly higher rates in the diagnosis of schizophrenia in

African Caribbean group in the UK (Sharpley et al., 2001) when compared with the general population (Pinto et al., 2008) and those in English speaking Caribbean (Hickling & Fredrick, 2005). Moreover, this group is overrepresented in mental health settings and specially in inpatient services with high rates accessing services through detention on the Mental Health Act sections (Lombard, 2008; ONS, 2008). The healthcare Commission , survey revealed a 1% increase in BME inpatient admission rates following the fourth annual Count Me in Census. As outlined earlier they are reported to be less satisfied with standard care (Bhui 1998) and are also subject to racial discrimination (Bhui, 2002). They are concentrated in urban areas mainly in the South East of England. Although this group is over-presented in in-patient services, it is concerning that the 2008 draft of the NICE guidelines on section 8.4.7 states:

“notes that there is a paucity of information on the ethnicity of participants included in the studies.....the GDG were unable to make any recommendations relating to practice”p.206

Since the publication of the new guidelines in 2009 recommendations relating to working with ethnic minorities have been included.

### **3.5.2 Group 2. South Asian Muslims**

The choice of South Asian Muslim groups was based on inclusion of ethnic group of similar socio-economic status but with differing needs when compared to the African Caribbean group in terms of language, religious and cultural background. Unlike the African Caribbean group, the South Asian group is under presented in mental health services raising debates about reasons for not using these services. Both Pakistani and Bangladeshi groups originate from the Indian sub-continent. The majority of the Bangladeshis migrated from Sylhet region in North Eastern Bangladeshi. The vast majority are Sunni Muslims. Their difficulties in accessing healthcare services have been

complicated by language barriers and differing help-seeking behaviours and pathways. Although the Pakistani and Bangladeshi share Islamic religion as a common factor they are differences with respect to their culture, language, social class or caste and philosophical beliefs (ref supporting). There is also a sectarian divide which resulted in the two states (Rack, 1982).

By exploring within three groups: Black Caribbean, Pakistani and Bangladeshi, challenges can be identified that any generic adaptation for culturally diverse groups should be able to embrace (Nazroo, 1997; DRE, 2003).

### **3.6 Sampling and recruitment**

Purposive<sup>3</sup>, targeted sampling was adopted to recruit the study participants who comprised service users, lay members of the respective ethnic communities, mental health practitioners and therapists. Research in ethnic minority has had difficulties recruiting in the past for several reasons, namely, BME population tend to be concentrated in urban cities such as London, Midlands and North England. They are widely dispersed making it difficult to consider cluster sampling. It was considered appropriate to use non-probability sampling rather than probability sampling as it allows for in-depth examination of information from the subjects (Patton, 1990). The following reasons were considered as problematic in the later. Take for instance, simple random samples (SRS); they require accuracy and a sampling frame. They are expensive in particular where data is collected by interviews and requires travelling long distances which can be time consuming.

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<sup>3</sup> As a non-probability sample, this technique ensured that some people had a greater chance than others of being selected into the study (Patton, 1990). In non-probability samples parameters of a population are not known. On the contrary, within the probability sample they are known.

On the other hand, stratified sampling, although a more accurate method has similar difficulties to SRS. Through purposive sample technique the researcher selected participants based on the criteria described above (Polit & Hungler, 1999). Moreover, this technique was cost effective. Limitations here include interviewer bias in selecting individuals easier to interview. A key strength of probability sampling includes increase in external validity through a sample representative of the population. However, when researching vulnerable individuals this technique becomes unethical and impractical. Sample size was determined pragmatically by three considerations, namely the:

- a) Likely number of informants required to gather meaningful data (typically at least 6-8 per focus group. (see Krueger, 1994; Merton et al, 1990 and Shamdasani, 1990)
- b) Extent to which data was saturated and no 'new information' was being generated.
- c) Availability of participants from the ethnic groups concerned

Participants received information leaflets outlining the study (Appendix 4). Information leaflets were also translated to Urdu language for the Pakistani participants (Appendix 5'). Information on psychosis was also given in Bangla and Urdu to participants.

### **3.7 Recruitment of participants**

Gaining access involved firstly obtaining both ethical approval and Trust Research and Development approval. The study was also scrutinised by the data protection department of the trust to ensure that all data was handled and managed according to the Caldecott standards. The researcher had to obtain honorary status with two sites in London and Portsmouth. This involved an application to the criminal records bureau (CRB) for an

enhanced check, which is required when accessing vulnerable participants. Recruitment of individuals with schizophrenia was through the local mental health teams (CMHT) and specialist services including Rehabilitation services and Assertive outreach teams. Lay participants were recruited through local BME communities.

The researcher held presentations of the study to relevant CMHTs and specialist services as part of the recruitment process. Patients were approached only after their Consultant Psychiatrist had given permission. All participants were given full details of the study and time was spent explaining the study and answering any questions or queries. Both verbal and written information (Appendix 4) was given to potential participants. They were also invited to discuss the study with their family or contact patient advice liaison services (PALs) or the Trust R&D personnel before making a decision. Written informed consent (Appendix 6) was obtained from all participants before the interviews were conducted. The researcher reiterated to participants that they could withdraw from the study at anytime without this action affecting the quality of their care. Participants who consented to taking part in the study were given a copy of their signed consent form for safe keeping, another copy was then sent to their team to be kept with clinical notes. A copy was kept by the researcher. The General Practitioners of the participating patients were sent a standard letter informing them that their patient was participating in this study (Appendix 5). An interesting paradox arose during the recruitment phase, when a white African patient verified she was black and wanted to be included in the study.

### 3.7.1 Inclusion and exclusion criteria

Inclusion Criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>• Defined ethnic minority group with a diagnosis of Schizophrenia/Schizoaffective disorder/ lay member from the ethnic minority group / MHP / CBT therapist</li> <li>• Willing to participate in the interview and have notes made and / or be tape recorded.</li> <li>• Had capacity to consent and understand the interview</li> </ul>	<ul style="list-style-type: none"> <li>• Severe illness which affected mental capacity or markedly affected their ability to participate in interview, e.g. very thought disordered or distressed by symptoms.</li> <li>• Lacked mental capacity</li> <li>• Not agreeing to consent</li> <li>• Those clients who in the opinion of the key worker would be thought to be distressed by the interview due to low insight.</li> </ul>

**Table 6: Inclusion and exclusion criteria**

### 3.7.2 Recruitment of lay members and health professionals

Community Development Workers (CDWs) and local BME community organisations were approached to identify potential lay participants. The researcher as part of the recruitment process arranged presentations and discussions with relevant organisations. The recruitment process for CBT therapists and MHPs involved approaching mental health services and local community mental health teams in Hampshire and London centres. The therapists who declined taking part in the study reported that they had no experience in using CBT with BME patients for psychosis.

This study was adopted by the North London and West Hubs of the Mental Health Research Network. One of their services involved assisting with recruitment of potential participants. The Clinical Studies Officers (CSOs) therefore assisted with recruitment following adoption to the network.

### **3.7.3 Ethical and governance issues**

Ethics approval for the study was obtained REC: 08/0504/5. Research and Governance approval was granted at all sites. Being mindful of the nature of the client group and the potential difficulties that could be encountered associated with their current or past symptoms of social anxiety and paranoia, the researcher was experienced in working with patients suffering from severe and enduring mental health problems, and therefore could respond if needed, to any patient problems that may emerge. This became an important decision, when during one interview, a service user participant revealed that she had been ruminating about deliberate self harm earlier that day due to unresolved psychological distress and had not told her key worker. Although ambivalent about whether she would do this, support and reassurance was given as required. She consented to the researcher contacting her care team for further support and risk management. It is important to note that her distress was not associated with taking part in the research interview, clarification had been sought that she was happy to continue with participation. She reported that she found the interview helpful.

While no incentives were provided in this study, participants were reimbursed travel expenses and time, often at the request of their supervising practitioners and according to local customs. The issue of incentives and tokens in recruiting for studies is a subject of debate. In one particular site, the researcher was informed that previous studies had given participants incentives of up to twenty-five pounds. Therefore they were expecting a similar token from this project. However, the researcher reiterated that most participants

had taken part out of goodwill, hoping that their experiences would be of help to those who access services in the future. Site Interviews occurred at times and venues that were convenient and accessible to the participants.



## **Chapter 4 - Data collection and analysis**

### **4.1 Introduction**

This chapter aims to discuss data collection methods and analysis in section 5.2. Chapter 6 discussing the results of the study will follow this.

### **4.2 Data Collection and analysis**

Several data collection methods were considered, including observational, focus groups, diaries, questionnaires and interviews. The observational method would not provide the descriptive data and therefore was not suitable in this study. Focus groups and individual interviews would be suitable in that they would be conducted at a time and place convenient to the participants. These methods provide descriptive style and opportunities to probe and clarify on experiences. Various definitions of focus groups exist including Kitzinger's (1995) which describe a focus group as:

“a form of group interview that capitalises on communication between research participants in order to generate data. Although group interviews are often used simply as a quick and convenient way to collect data from several people simultaneously, focus groups explicitly use group interaction as part of the method” (pp.299-302)

Similarly, Madriz (2000) defines focus groups as tool used within a political arena to for people to air their views. The authors state that

“focus group may facilitate women of color ‘writing together’ by exposing not only the layers of oppression....But also the forms of resistance” (p.836).

Notwithstanding their possible criticisms of subjectivity and not being a replicable technique, they are the best method in this study. Additionally, when compared to the mechanical nature of survey-based methods, interviews provide for emotional quality based on the personal qualities of the researcher (Kvale, 1996). Furthermore, focus groups offer some level of support allowing people to open up. By exploring the attitudes and needs of health professionals, the researcher can learn a lot by watching the dynamics of the group. Conversely, focus groups do not discriminate against illiterate people and can operate within a given cultural context.

Research data was therefore gathered through one to one semi-structured interviews and focus group interviews. The researcher between May and December 2008 conducted a total of thirty-eight interviews. All interview data were audio-recorded, and transcribed. The researcher noting non-verbal communication and behaviours took Field notes. Data was collected in tandem with analysis. Transcripts were coded and anonymous. Access to data was limited to the researcher and the research team.

The researcher was conscious of the importance of gender issues within the South Asian Muslim group; consequently Bangladeshi and Pakistani focus groups were conducted accordingly. Men were seen separately from women, thereby respecting their religious and cultural norms. The researcher recorded focus group interaction using a socio-gram (Appendix 14) this was completed by the co-moderator. The role of the co-moderator involved taking comprehensive notes including seating plan and noted any non-verbal cues from participants. This was useful when the group dynamics were being dominated or when some participants were not contributing. The researcher facilitation enabled all members of the focus group to contribute in discussions.

Focus groups followed a standard set of steps (1) arrangements, (2) introduction, both moderator and observer introduced themselves, ground rules were set and confidentiality

and consent was re-affirmed, (3) warm up: involved participants introducing themselves, (4) discussion: from general to more specific topics, (5) Closure: a summary was given at the end of the discussion and (6) feedback from group to clarify any inconsistencies, (7) Debriefing: the moderator and the observer then discussed their impressions of the group discussion and reflections (8) topic guide review, this final step allowed for any modifications of prompts and issues for further triangulation in subsequent groups. The co-moderator also completed an observation checklist for each focus group (Appendix 15) Focus group discussion data were analysed according to the principles recommended by Kreuger (1994). The level of data analysis was largely descriptive with most themes emerging in response to the interview guides. Some of the themes were predetermined from literature review and background reading (Anjoulet et al., 2007).

Through regular supervision with an expert in qualitative methodology, categories were then refined into broader themes (see attributions of psychosis section) (Simmons et al., 2008). During the initial interviews it was apparent that some questions were not sensitive to the patients in that they avoided answering them, for instance, “ what are your views about your treatment?” this was then modified to “How did you think the doctors were trying to help you” (Appendix 2).

The data were analysed by systematic content and question analysis (Morse and Field, 1996). Unlike other types of thematic content analysis (Millward, 2006) which place emphasis on frequency of words and utterances thereby generating numerical values from verbatim excerpts (Hsieh & Shannon, 2005) the analysis conducted here involved the researcher immersing himself in data by reading the interview transcripts carefully (sometimes more than once) and identifying emerging themes and categories (Simmons et al., 2008) was not quantified. Content analysis is a systematic and objective method for identifying, analysing and describing the data in depth. It involves coding participants’ open ended verbatim into categories that summarise data and is sometimes treated as similar to thematic approaches (Braun & Clarke, 2006) NVivo 8 (computer-assisted

qualitative data analysis software) was used to manage and explore the qualitative data in-depth. The benefits of using a computer package included accuracy, speed and consistency. Moreover, Lewins & Silver (2007) postulate that packages do provide an audit trail for analysis and facilitate the linking of ideas to data. This cognitive map provided a pathway of how we got to the broader emergent themes. NVivo was the most appropriate package following Lewin & Silver (2007) step-by-step guide to using software in qualitative research. The researcher attended training on qualitative software; this was useful in making a choice of suitable package. NVivo system was useful in organising emerging themes using free nodes that were later categorised. According to Braun & Clarke (2006) themes capture essential aspects of data in relation to the phenomenon under investigation. The flexibility of thematic analysis allows the researcher to determine the emergent themes and prevalence this is an advantage of content analysis (Gomm et al. 2000). Furthermore, content analysis can generate anticipated insights and its findings can be comparable to similar studies undertaken with a similar framework. Notwithstanding its strengths there are limitations with content analysis in particular, sections of excerpts that are both representative of data and compelling to the reader can be challenging. It has limited interpretive power beyond mere description if not used within an existing theoretical framework.

Thematic content analysis was utilised to identify themes, concepts and meaning and according to Braun & Clarke (2006) it should be seen as a method in its own right and not as a process of qualitative research (Bambrick & Hines, 2011). A fundamental strength of content analysis is the ability to enable the qualitative researcher to investigate sensitive topics without altering the phenomena under investigation (Krahn & Putnam, 2005). Furthermore its data can be subject to re-analysis enabling therefore allowing for reliability checks (Robinson, 2002). Unlike grounded theory and IPA, thematic analysis is relatively an easy method to use and is accessible to a wide audience. It can also be useful for informing policy development (Braun & Clarke, 2006).

Thematic analysis differs from other analytic methods in qualitative data and the following were considered; discourse analysis, Interpretive Phenomenological Analysis (IPA: Smith et al. 2009) and grounded theory. Grounded theory (Strauss & Corbin, 1990) and IPA were not suitable for this study because they are both theoretically bounded (Braun & Clarke, 2006). Moreover, IPA is primarily about understanding people's everyday (subjective) experiences of reality in great detail so as to understand the phenomenon under investigation (McLeod, 2001; Harper, 2012). Whereas grounded theory analysis approach primarily aims towards theory generation and development (Braun & Clarke, 2006) a practical difficulty identified by Robinson (2002, p192) relates to deciding when to ones categories are 'saturated' or indeed when theory is sufficiently developed. The focus of our study was not to develop a model of social processes as suited by grounded theory (Harper, 2012). The role of the researcher and participant interplay emphasised. There is a high risk of interviewer bias. Discourse analysis focuses on use of language; in particular how certain issues are constructed in people's accounts and consider the function of such dialogue or discourses in the context of on going interaction (Georgaca & Avdi, 2012). Although an ideal approach it best suits small sample sizes because of its demanding analysis. To conclude, thematic analysis involves searching through a data set to identify repeated themes of meaning and was an appropriate choice for our research question.

In preparation for this project the researcher received two days training on qualitative research methodologies. A further half-day training session covered 'managing your references' using reference manager. The researcher met on a regular basis with the research team and also with the Steering group committee. A member of the research team, an expert in qualitative methodology, also provided supervision. This invaluable support ensured progress and development of the project.

### 4.3 Reliability and validity

In order to increase conformability in the data collection process and reduce researchers' influence in the way data was collected; known as the 'Hawthorne effect', triangulation was applied. Triangulation<sup>4</sup> of themes and concepts was then undertaken to compare and contrast the data from the different participating groups (Tesch, 1990). In this study between-method triangulation using differing but complementary methods (that is, face to face semi-structured in-depth-interviews and focus groups) was utilised in order to obtain 'a better fix on the phenomenon under investigation'. This enhanced the reliability and validity of the analysis. Three researchers independently reviewed a sample of transcripts to check for reliability of the interpretation, coding and interrelationship of themes. One of the challenges that came up through transcription and analysis was the use of 'patois' in some of the Afro-Caribbean interviews. The three independent reviewers only differed with the lead researcher in areas where patios themes or metaphors had been used by African Caribbean groups and where South Asian Muslims used Urdu terms like '*dewana*', *moonhalf* (meaning crazy or mad) to express or describe a phenomenon. The transcriber indicated areas of uncertainty in translation, and non Afro-Caribbean members of the research team had difficulty interpreting some speech and meaning. A simple example is this quote that includes an idiomatic expression similar to the English expression 'round the bend',

...*And* come back, and you one up in the hilltop. And you don't talk. [ACL1,

Interview with African Caribbean Lay participant]

The specific relevance of Patois to the experience of Afro-Caribbean is further discussed in the section on social factors influencing the Afro-Caribbean. The research team and

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<sup>4</sup> Triangulation is the process whereby information from one source corresponds to and reinforces that obtained from other independent sources

steering group enabled these linguistic and cultural difficulties to be addressed. This reinforced the methodological importance of using 'cultural informers with linguistic competence' to conduct or assist with interviews and to support interpretation and analysis.

Concept mapping techniques were employed to explore interrelationships between themes and participants, to triangulate the data and to generate appropriate schematic models of client experience (Appendix 8). The data were therefore analysed to generate themes, narrative accounts and theoretical models (Creswell, 2009). Themes were derived from more than one source as the quotations will indicate. Finally, the data were interrogated with respect to the implications for mental health practice and the experience of the service user. The following chapter will discuss the findings of the qualitative study in detail.

Social interaction can be described in ways that can subject it to empirical scrutiny (Perakyla, 1997 p201). Reliability has been defined as 'the degree to which the finding is independent of accidental circumstances of the research (Kirk and Miller, 1986:20) as In other terms, an ethnographic researcher analysing same results would expect to obtain similar findings. In this study, sharing the same interview transcript to 3 independent researchers to measure for consistency and repeatability tested this. When comparing their themes to those generated by the lead researcher and the concept map thereof (see appendix 8) it was noted that similar findings were obtained therefore validating the reliability of the results in this study. Similarly by including verbatim excerpts from the raw data the reader could in essence make their own interpretation, which could either confirm the researcher's commentary or disconfirm it.

Whereas validity in quantitative research can pertain to such instruments as questionnaires or outcome measuring scales. Face validity refers to subjective

assessment and relevance of a given instrument without further investigation. On the other hand content validity with respect to questionnaires or interviews and focus group refers to the extent with which the instrument covers relevant issues. This form of validity has sound theoretical basis in comparison to face validity as it is meant to provide more systematic impressions. In this study for instance the question: "*Can you tell me about how you feel about your treatment?*" had to be refined and improved following some in depth semi-structured interviews with service user participants who initially avoided answering the question but after refinement to: "*Can you tell me about how you feel about the way the doctors were trying to help you?*" this improved response from participants. In stark contrast validity in qualitative research in its simplest form refers to honesty and accuracy (Lowe, 1993).

Independent researchers conducted validity checks to ensure that the themes generated by the researcher were from the raw data. Where some members of the research team during analysis deleted verbatim statements they thought were irrelevant and did not make sense to them, the researcher had to reinstate that data and explain that it was patio and therefore conveyed the meaning. Steering group members from the Caribbean group as discussed above backed this.

## **Chapter 5 - Findings**

### **5.1 Introduction**

In this chapter the findings will be discussed in six sections. Verbatim quotes from participants will be included together with the authors' commentaries. The chapter will conclude by providing a summary of the results and recommendations.

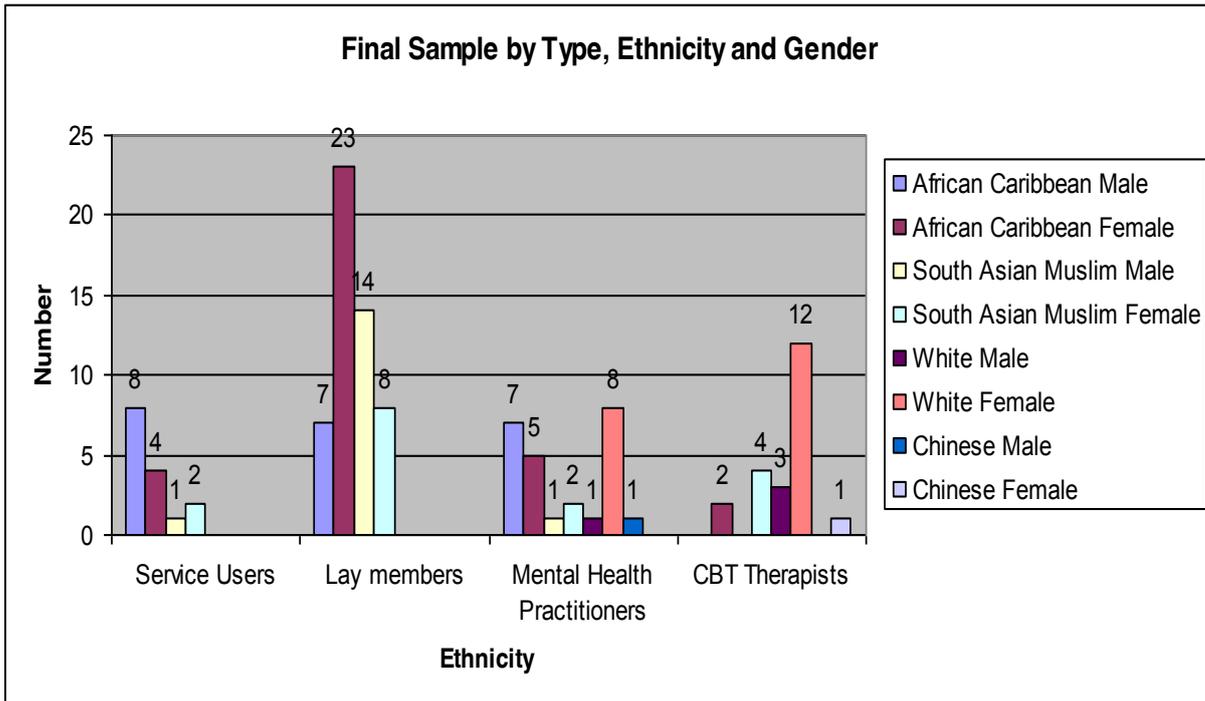
### **5.2 Final sample**

Interviews were conducted with the different groups until the data were saturated. In total, the data set comprised 114 participants as follows:

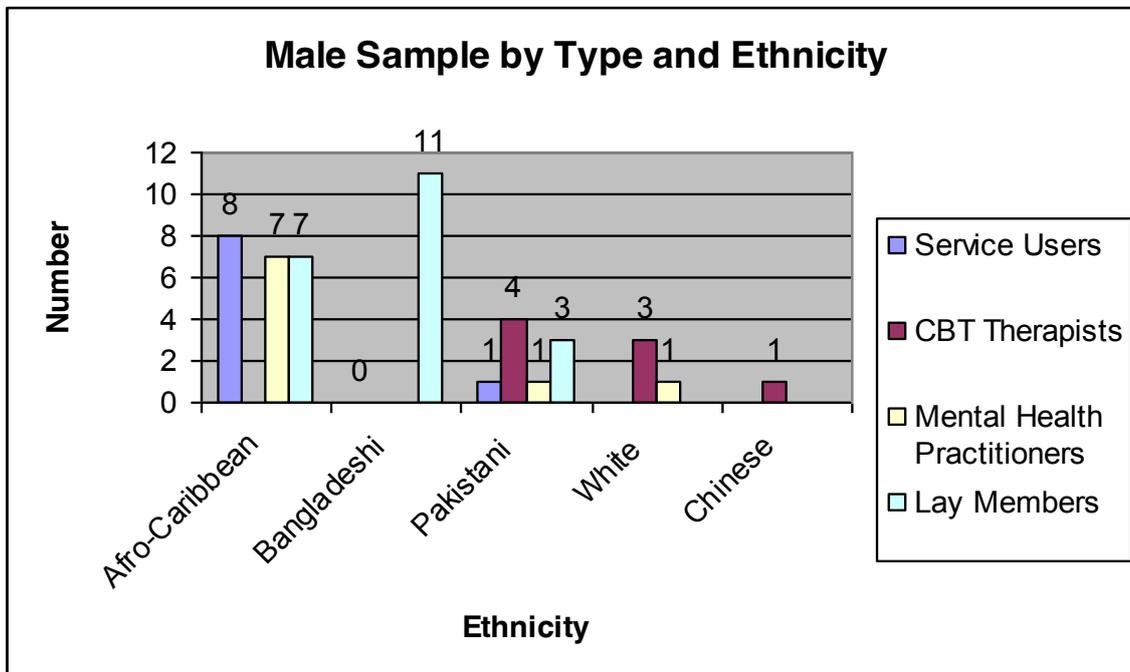
- a) Twenty face-to-face individual interviews (fifteen of which were with service users; three lay participants and one mental health practitioner and one therapist).
- b) Eighteen focus groups comprising 99 participants as follows:
  - a. 5 focus groups with therapists (n=21)
  - b. 4 focus groups with mental health practitioners (n=24)
  - c. 9 focus groups with Lay participants: Hampshire (n=23); London (n=26)

The following graphs outline the final study sample and summarises the data collected.

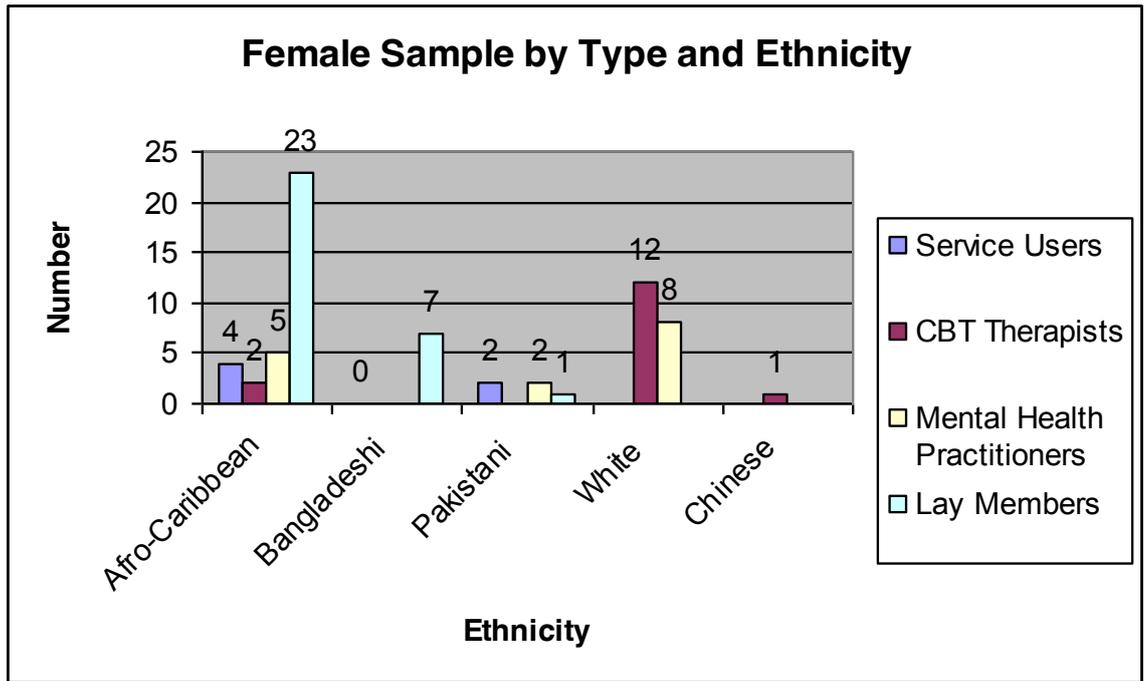
Graph 1 outlines the total sample.



Graph 1: Final Sample by type, ethnicity and gender



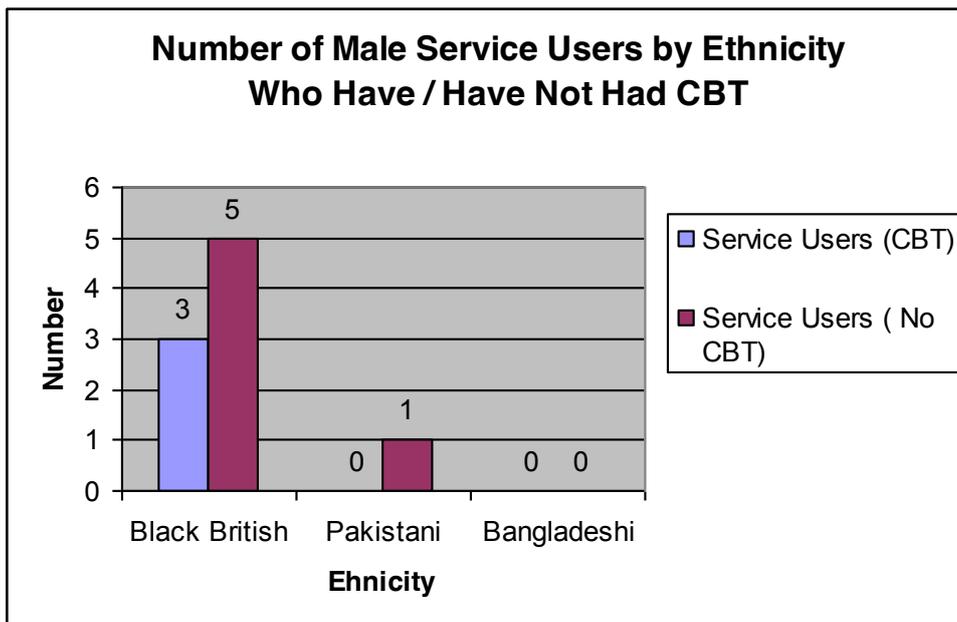
Graph 2: Male sample by type and ethnicity



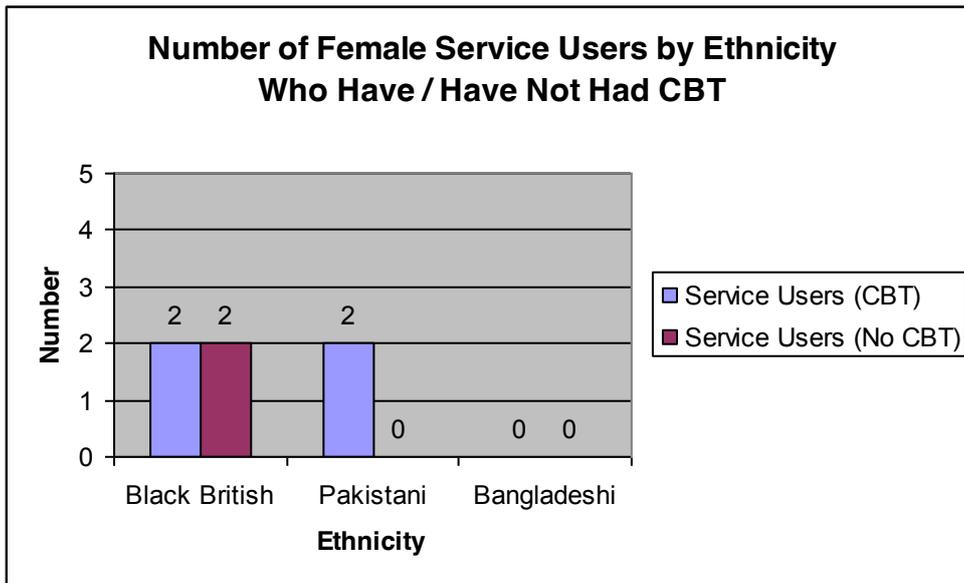
Graph 3: Female sample by type and ethnicity

### 5.3 Service user individual interviews

The following graph illustrates the ethnic background, CBT experience and/or not of the service users who participated in the study.

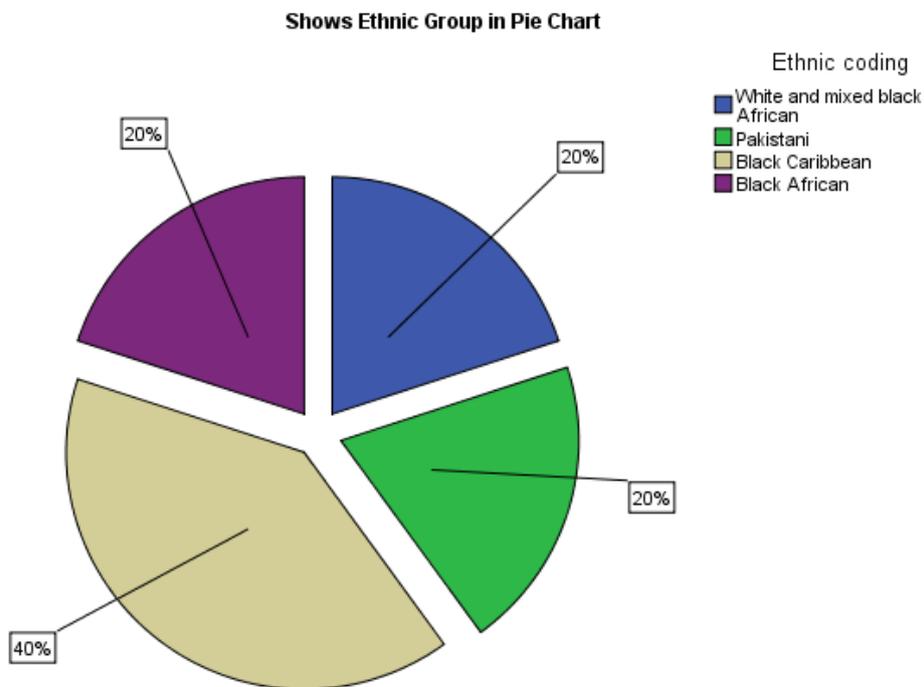


**Graph 4: Male service users by ethnicity**



**Graph 5: Female service users by ethnicity**

The following pie chart below shows service users based on ethnic coding

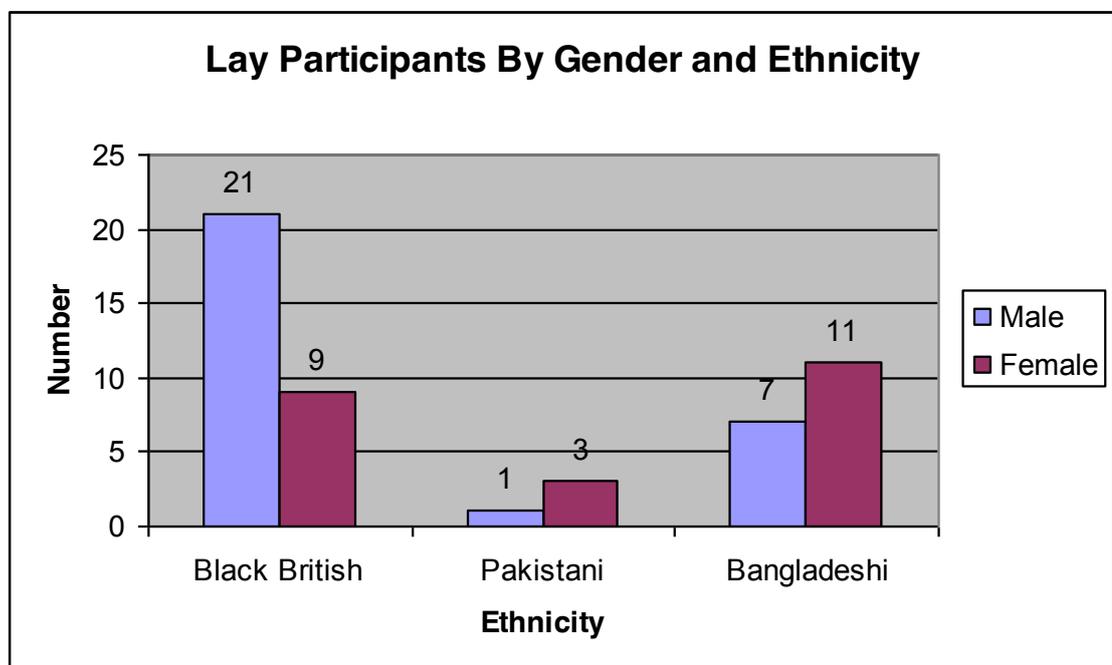


**Figure 2: Ethnic groups in a Pie Chart**

The interviews indicated that approximately fifty percent of BME participants had accessed CBT. From 15 service users interviewed, seven had accessed CBT.

## 5.4 Lay participants

The following graph illustrates the background of the lay members who participated in the study.



Graph 6: Lay participants by gender and ethnicity

### 5.4.1 Bangladeshi participants

A total of four focus group interviews were held between two sites. There was interest and motivation at both sites. The groups were split by gender taking into account cultural and religious norms. A total number of 18 lay participants were interviewed in four focus groups, two from each respective area. Eleven men and seven women participated. Age

range was 20-60yrs. The groups had a mixture of first and second-generation backgrounds.

#### **5.4.2 African-Caribbean, Black-African and Black British**

The Focused Implementation Site (FIS) Co-ordinator enabled access to the Afro-Caribbean community. They showed interest in the project but did not respond to invitations to participate in focus groups. Links with CDWs were re-established to recruit from this community initially with no success. Contact with a prominent member of the Afro-Caribbean Heritage Centre resulted in two face to face interviews and a focus group. Four formal interviews were held with members at the centre. At the London site, two focus groups were held after the CDW link helped recruit twenty-one members from a local church organisation. In total, thirty participants were interviewed in the study (excluding four formal individual interviews).

#### **5.4.3 Pakistani participants**

Southampton has 0.8 % Pakistani, 0.4% Bangladeshi population by local authority (ONS, 2001) census. Despite this, recruiting from these groups proved difficult although there was good reception of the project but response was poor. Initial interviews involved a professional lay participant. This was later followed by a focus group with three participants (all general practitioners). In addition a lay member consented to providing informal information concerning the respective culture and was used as a reference point. A local third age centre was approached and a total of 25 lay South Asia Muslim men consented to provide informal information concerning the respective culture through an interpreter at the centre.

### **5.5 Mental Health Practitioners**

The focus group make up had a mixed ethnic profile of practitioners including White, Black British, Afro-Caribbean, African, Irish, and Asian and Chinese participants. A total of 25 participants were interviewed across Hampshire and London sites.

## **5.6 Cognitive Behaviour Therapists**

A total of 22 therapists participated in the five focus groups, two held in Hampshire and three at the London site. Many of the therapists who did not participate in the study felt they did not meet criteria as they had not done work with the BME groups, but were keen to find out the outcome of the study. The majority of therapists, 19 in total, were also qualified psychologists and there were only three CBT trained nurse therapists.

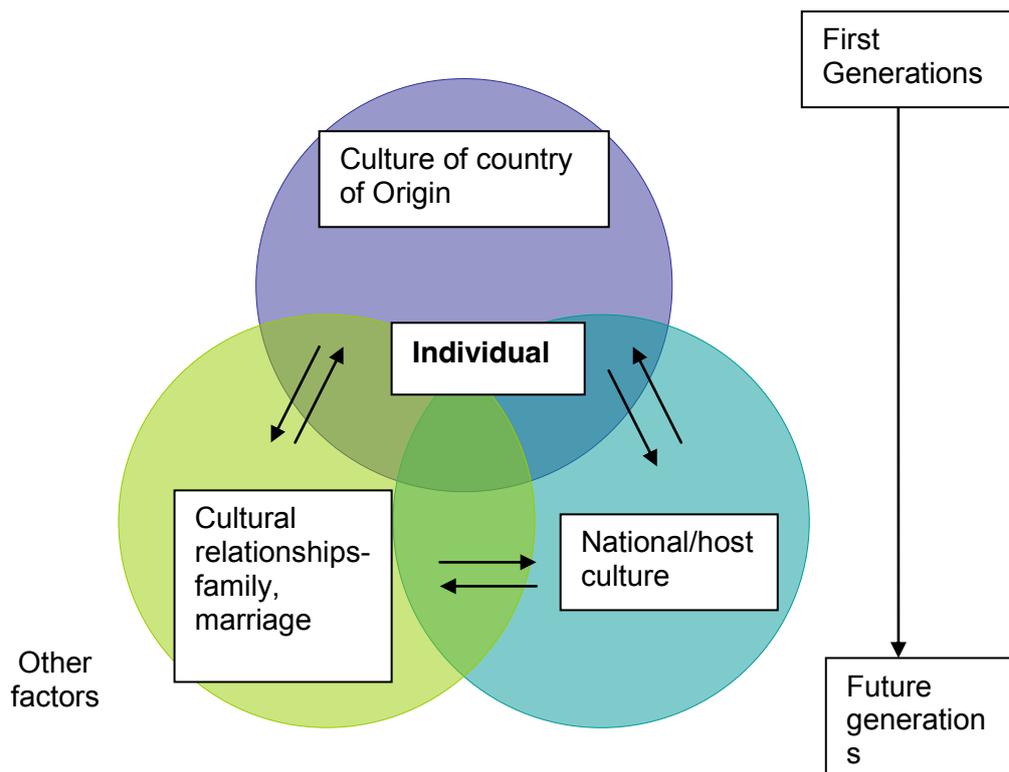
A total of 9 focus groups were held for MHPs and CBT therapists. Two additional individual interviews were held in London when the rest of group members did not arrive for the scheduled focus groups.

## **5.7 Philosophical considerations**

Helman (2000) defines culture as a set of guidelines inherited by members of a particular society that tell them how to view the world, how to experience it emotionally and how to behave in relation to other people. Culture is transmitted by symbol, art, ritual and language. The fundamental view of life in different cultures that affects choice of lifestyle, view of illness, services and treatment and goals of therapy are important to understand as they determine whether a therapy like CBT is acceptable and suitable if adapted. Acculturation occurs due to the merging of two cultures during a period of prolonged contact. Cultural modification of individuals' behaviours and attitudes occurs through a process of adaptation. The cultural shifting process is not an abrupt event; it tends to be a gradual blending of two cultures (Garcia & Zea, 1997). Due in part to the continuous process of change and adjustment demands made on bicultural individuals, they need to hold on to their culture of origin in order to use it as a coping resource. Many bicultural individuals, in order to adapt successfully, learn the essential components of the majority culture. The culture of origin is maintained, but in such a way that it coexists with the majority culture (Flix-Ortiz et al., 1994; Guarnaccia & Rodriguez, 1996; Melville, 1983).

As shown in Figure 3, for many clients two or three cultural contexts co-existed, namely the culture of their country of origin; a local UK based community culture; and the wider UK based societal culture.

**Figure 3**



**Figure 3: Co-existence of cultural contexts: Acculturation model**

Individual's values can oscillate between the above parameters depending on circumstances, conflict or dissonance at relational interfaces. With successive generations individual's values adapt to their country of residence. Arranged marriage, especially in the South Asian second/third generation Muslim men and women from villages of country of origin reinforces deep-rooted value systems. Illness may swing beliefs towards family influences. In the South Asian Muslim cultures, it is acceptable to seek help from elders

and priests rather than mainstream health services. Help givers are figures of authority and have paternalistic attitudes. There is a need to be respected but the stigma of mental illness affects life in society, especially prospect of marriage.

## 5.8 Health beliefs and attributions to Psychosis

In this study data gathered was shared and triangulated between service users, lay participants, therapists and mental health practitioners. The following section will look at the emergent themes relating to participant’s explanatory models of what causes mental illness, in particular psychosis.

Theme: Causation	Afro-Caribbean	Bangladeshi	Pakistani
Previous wrong doing	+++++	+++++	+++++
Supernatural beliefs	+++++	+++++	+++++
Social factors	++++	++++	++++
Biological	+++	+++	+++
Being arrested	+++		
Drug induced	+++		

**Table 7: Attributions to Psychosis**

The above themes, stated in order of strength of belief describe the way in which the three ethnic minority groups explain causes of mental illness.

### 5.8.1 Previous wrong-doing

Explanation of wrong doing by the patient or a member of their family was a consistently strong theme across all the groups. This was typically described as someone 'being punished or the 'sins of the family have fallen on the particular individual (who may be innocent)'. These ideas of sin, wrongdoing and punishment were sometimes associated with a religious explanation of mental illness. For example,

'Your past issues are now coming out and so, some people believe that when they lose their mind, their sins are being washed away. So they are becoming more pious as they suffer. Therefore, they are closer to God and actually any ill person is considered closer to God....' [PL11, Interview with Pakistani Lay participant]

This respondent also remarked that this explanation was similar to a Buddhist concept.

### 5.8.2 Supernatural beliefs

Another aspect of the belief systems, common to the three groups, was the identification of an external agent that has caused the illness. For example, this could be 'Jinn(s) and ghosts' in the Pakistani community, evil spirits, demons, magic curses or spells by someone who is 'jealous' of them. Casting of an evil eye is called **Nazar lagana**<sup>5</sup> by the South Asian Muslim participants and the **Obeah**<sup>6</sup> by the Afro-Caribbean. These attributions are illustrated through the next quotations, which also reveal the role of other community members in the management of the 'external' cause and the actions to be taken. Here we see the use of sacrifices to remove the jinn

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<sup>5</sup> Nazar lagana: to cast an evil eye or spell

<sup>6</sup> Obeah: means someone has put/cast an evil spirit on you

'I think there are two or three different groups. One would be from the villages and they would be the ones not educated. They would actually go to the religious leader or there would be somebody who is known to help with psychotics. So it is like you got the skills to get rid of Jinns and ghosts. So they would advise those people or they would sacrifice an animal and the black goat and hen'. [PL11, Interview with Pakistani Lay participant]

In this next example difficult dreams are attributed to a restless dead spirit

'...her grandma died in her absence in India. So she (grandmother) was coming in her dreams, so she was talking to her. And somebody told her from India "your grandma's spirit is not comfortable because she loved you and she is not comfortable and she has come to haunt you in England. So you need to come to India and visit her grave to put her spirit to rest. And then you will be fine." And so she sought the special permission to go.' [PL12, Interview with Pakistani Lay participant]

While here, attribution is accorded to being possessed by the devil

'...so and so's daughter is experiencing this and she has gone crazy you know. She is babbling, she is talking, and she is being possessed by the devil. You know people can't control her.' [BL35, Interview with Bangladeshi Lay participant]

Confusion might arise because particular behaviours, that might seem bizarre to one culture, might have been a recommended course of action by the elders in another community. For example there are rituals in the Caribbean associated with feeding (appeasing) the ancestral spirits as this respondent described,

‘...you would be asked to by the chief of the community to turn your clothes out on the wrong side, inside out. And you put the left foot on the right shoe and stuff like that. Because things like that, they said prevent the spirit from coming up on you.’ [ACL16, Interview with African Caribbean Lay participant]

Sometimes spells and curses are associated with special community days, like emancipation from slavery in the Caribbean, as outlined here in this discussion of the role of ancestors.

‘You have emancipation time which is 1st August. During emancipation time they would have to feed the ancestors. That predominantly happens in St Anne and St Thomas and Trelawney and those parishes where they had the larger sugar plantations.’ [ACL15, Interview with African Caribbean Lay participant]

Belief in superstitions <sup>7</sup> is common across the world and not limited to the BME groups only. A widely practiced custom even by the Caucasian population involves the expression “touch wood” followed by behaviour of touching an object or item ‘supposedly’

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<sup>7</sup> Superstition is defined as “a widely held but irrational belief in supernatural influences, especially as bringing good or bad luck” (Oxford, 2009) It originates from the Latin word *super* (over) and *state* (to stand), relates to ‘fear of the supernatural’.

made of wood. The underlying belief is the hope that whatever has been talked about will be protected from misfortune or the ritual will prevent bad luck from occurring.

### 5.8.3 Social Factors

Social factors were a consistent theme across all the BME group participants although the strength of the theme varied between the groups. Within the Afro-Caribbean group social inequalities and family stresses were highlighted as a contributory factor. Change of environment was a common explanation across all the groups. Social isolation brought about by migration from country of origin was noted by most. A common Jamaican belief was that individuals who migrated to the UK would return to Jamaica with a mental illness. These two quotations typify responses.

'In parts of Jamaica you walk around mad and the first thing they say is, "that one has been to England.' [ACL1, Interview with African Caribbean Lay participant]

This layperson attributed the 'anti-social' culture of England as a cause of mental illness.

'...because of how anti-social they are (in England). Yeah. Because the culture (at) home everybody is warm and friendly and nice. And you come to England and spend four years (there). And come back, and *you one up in the hilltop*. And you don't talk.' [ACL1, Interview with African Caribbean Lay participant]

This extract also illustrates how speaking in Patois may be a challenge to the English reader who might have difficulty understanding another cultural group.

#### **5.8.4 Biological explanations**

A consistent theme across all the groups was the negative impact of genetics as exemplified by the following respondents:

‘...there is one other reason. If you dig up your background -your genes. If your parents, one of your parents, especially your father ...was a man with stress, sometimes one or two of his kids might carry or inherit the genes’. [ACL13, Interview with African Caribbean Lay participant]

Another illustration is ‘chemical’ imbalance as this client explains

‘...I am not mentally unwell. I was unbalanced. Your body is at dis-ease, you are not at ease. You have to balance your mind.’ [PAC73, Interview with African Caribbean service user]

#### **5.8.5 Attributions specific to African-Caribbean**

Two themes were unique to the African Caribbean community. One was the belief that mental illness was a consequence of being misunderstood and misinterpreted by the arresting police officers. The other belief was related to drug induced psychosis.

##### **5.8.5.1 Being arrested by the police officers**

Unique to many Afro- Caribbean respondents, was the belief that mental illness could be caused by a series of events whose origins were misunderstandings with the police, which then resulted in an arrest. These next two examples illustrate misunderstandings through use of Patois and the accompanying physical expressions, particularly when some one is angry or emotional.

'I have heard of cases where people haven't been suffering from mental illness...They don't have a mental illness at all. But the police have arrested them and they have been loud and moody. Waving their hands shouting and began to speak in the Patois. Because when somebody gets angry their normal slow way of speaking English that is heard and understood goes out of the window. Especially when they feel that they are being wronged.' **ACL17**

The respondent then describes how the person's body language and mannerisms change as they shout, and the consequences of this change,

'What are you arresting me for, what you want with me? The police officer doesn't understand your language because this person was speaking English before. But now it sounds like it is not English. Because it is **Patois** {respondent is waving hands in the air} or it is a mixture of French-or...something else....they are misunderstood. They are shouting. They are yelling. They are waving their hands about, they get arrested. And before you can say two words somebody has pumped them with some sort of drug .....Because they didn't have an illness, certainly now they have got one.' **ACL17**

A different participant discusses not only the effect of patois but also the reaction caused by an injection:

'I am talking about somebody who has been diagnosed as being a psychotic....because he has been arrested by the police- he struggled. And he has

just gone. And his brain has gone and he is just bubbling out. And he is talking in Patois and nobody understands him and he has gone and he is really mad now. He is given an injection. Then his body is having a chemical reaction to the injection. And really and truly that is, that person is psychotic. So how do you then find the cause there? What do you say? Do you then say the police caused it?’

**ACL19**

The view that gestures can be misconstrued was common, for example,

‘...the police are forever arresting people (black people) and saying they think that they were going to be dangerous, because of their gestures....’ **ACL21**

### **5.8.5.2 Drug induced psychosis**

This attribution was only found within the Afro-Caribbean group in this study; although literature has highlighted that the prevalence of drug use is no different to other groups (Patel & Wibberley, 2002). During a focus group with Afro-Caribbean lay participants they discussed how cannabis was used in the Caribbean emphasising indirect inhaling of this drug by minors and suggesting likelihood of vulnerability to future use and subsequent links with drug induced psychosis later in life.

‘...and therefore people will never understand that a six year old child will have drug induced psychosis. It is drug induced because it is a ritual for the father to sit in a little circle at home and smoke and blow (cannabis) in the child’s face and the child is inhaling it.’ **ACL15**

‘...with drug induced psychosis... people tend to think it is always voluntary. ...You have the Rastafarians, because the Rastafarians thinks that using the *ganja*, marijuana...makes you intelligent and brilliant. So from a child they start giving you little marijuana tea, the brew to drink. And then what happens is that you have the father he has his *chilon* pipe in the house and he smokes it ever so often and the child inhales it. So it is both from inhalation and the fact that the child has a little cold on his chest, they don’t give the child cough medicine. Instead, they give the child the *ganja* to drink. So from a very tiny age the child has been exposed both to inhalation and for medicinal purposes. And it blows out of proportion from there...’

**ACL18**

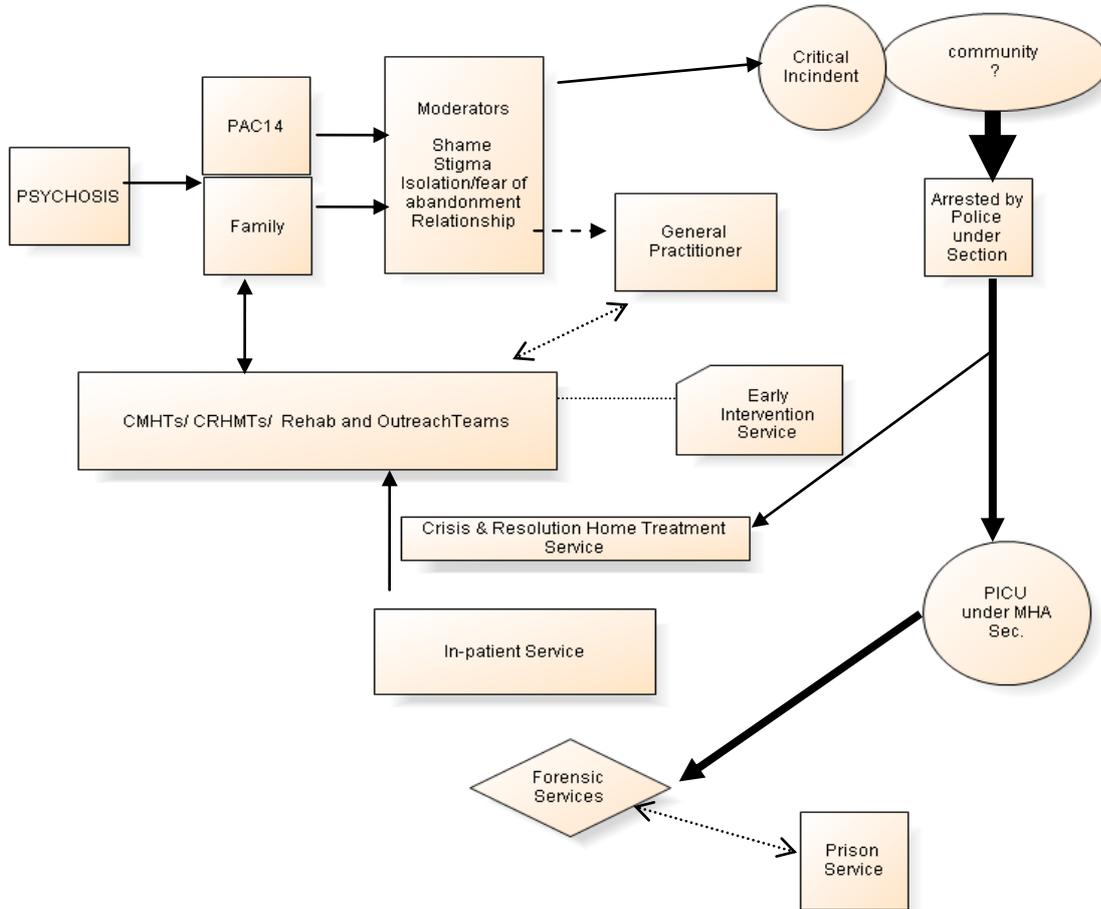
## **5.9 Help seeking behaviour pathways**

Through the interviews, a number of themes emerged on help seeking behaviours and pathways.

### **5.9.1 African Caribbean case example**

The following pathway illustrations are drawn from experiences of Afro-Caribbean respondents in the study. There were similarities and differences in the cases, which included an Afro-Caribbean service user, African migrant and African service user who came in contact with mental health services via forensic services. Within the Afro-Caribbean pathways some participants reported a common practice of seeking help from faith healers but another important driving factor in this group is fear of services, mistrust and lack of confidence in the system especially where differing beliefs in attributions of ‘mental illness’ have been noted.

**Figure 4: Afro-Caribbean case example 1**

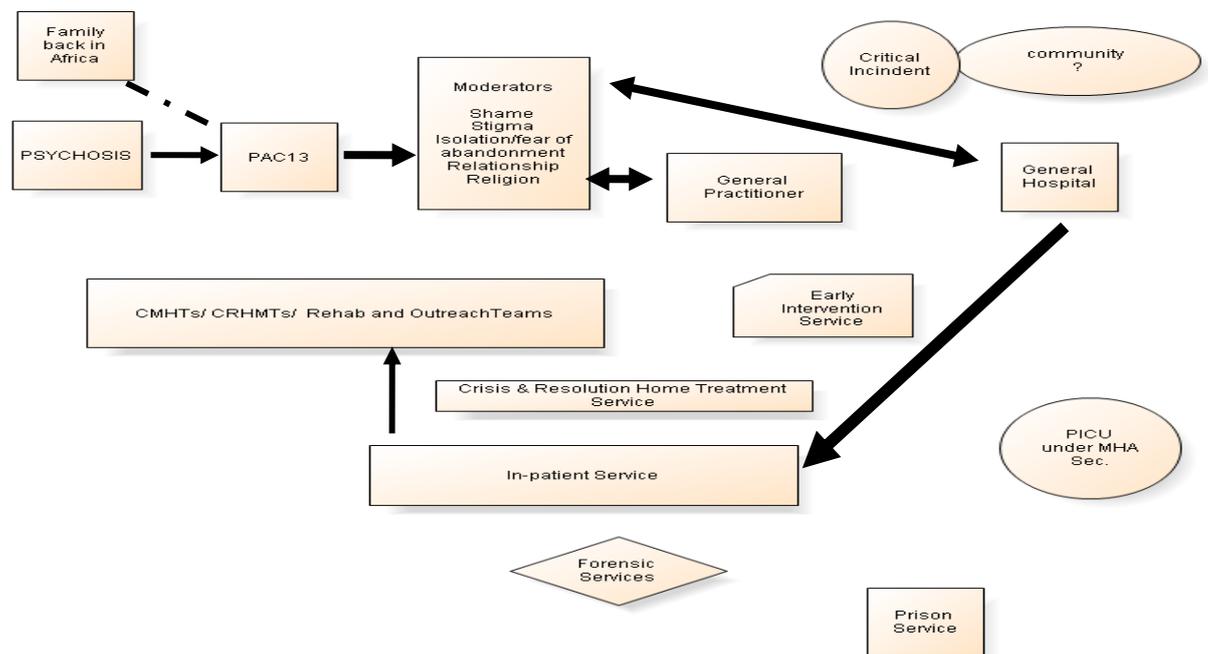


**Figure 4: African Caribbean case example 1**

In **figure 4** the respondent described several factors contributing to psychotic episode. These included social factors such as change of environment, social class, isolation and related stresses. This participant had a supportive family who suggested contacting GP for help. The participant did not contact their GP and noted the moderators (diagram 3) as influential in his decision-making. In addition, participant noted issues related to denial and possible lacks of awareness. Critical incident involved conflict with a neighbour consequently and police were involved and subsequently he was arrested and detained under the Mental Health Act (1983). He was admitted to a psychiatric intensive care unit (PICU). During recovery he was transferred to an open ward and later discharged to an

early interventions in psychosis (EIP) team were he accessed CBT and has so far completed 15 sessions.

**Figure 5: African case example 2**

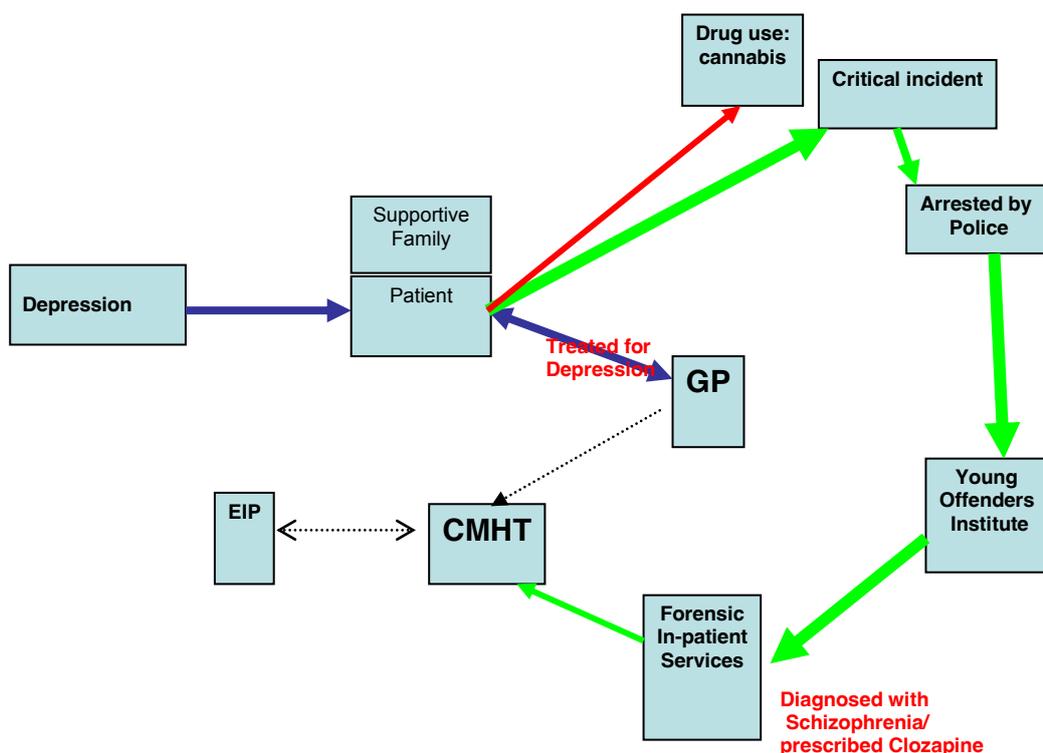


**Figure 5: Black African case example 2**

**Figure 5** describes a respondent who migrated from Africa and therefore did not have family support in the UK. Although the respondent was in a relationship at the time, her partner left her when she became unwell. She frequently presented at the local general practice and general hospital for help. Eventually, the general hospital referred her for admission to inpatient services where she was detained under section of MHA (1983). She did not agree with the diagnosis of mental illness at the time, but admitted to being stressed. Following discharge to a local community mental health team the participant was offered CBT and completed 20 weekly sessions. During the interview the participant reported coping well and tolerating auditory hallucinations using CBT skills learnt in

therapy. The participant benefited from a diagrammatic formulation of her problems. She continues to use thought diary and breathing exercises and regularly refers to her relapse 'blue print'.

**Figure 6: African case example 3**



**Figure 6: Black British case example 3**

The respondent in **figure 6** described onset of depressive illness during late teens. His family referred him to the GP and he was treated with antidepressant medication. The respondent acknowledges that drug misuse in particular cannabis exacerbated his illness. Subsequently, he was arrested by the police for a minor offence and sent to a young offender's institute. He was later transferred to local forensic inpatient services unit where

he was diagnosed with schizophrenia. He was initiated on a treatment of Clozapine antipsychotic medication. He was later discharged to a local CMHT and is under their care. The respondent has yet to be offered CBT. It was noted that if offered this intervention, he would accept therapy.

### **5.9.2 South Asian Muslim case example**

Similar pathways exist in the South Asian Muslim communities. These are influenced by shame to the community, family and to the individual. In the South Asian Muslim group, maintaining 'family honour' by hiding anything that would be perceived to 'disgrace the community or family' is paramount. People decline help from counsellors or therapists fearing that distress may be linked to the family gene, or may reveal issues that will impact not only on their family but community as a whole. Community views e.g. gossip / rumours from the grapevine are influential. Mental illness is thus dealt with in the family or extended family. Recommendations of remedies or advice of elder's or Imams is preferred. This includes belief in 'talisman' or arm lockets with Qur'an verses inscribed on them. The General Practitioner (GP) may be the second preference. Sometimes return to country of origin may be the chosen option.

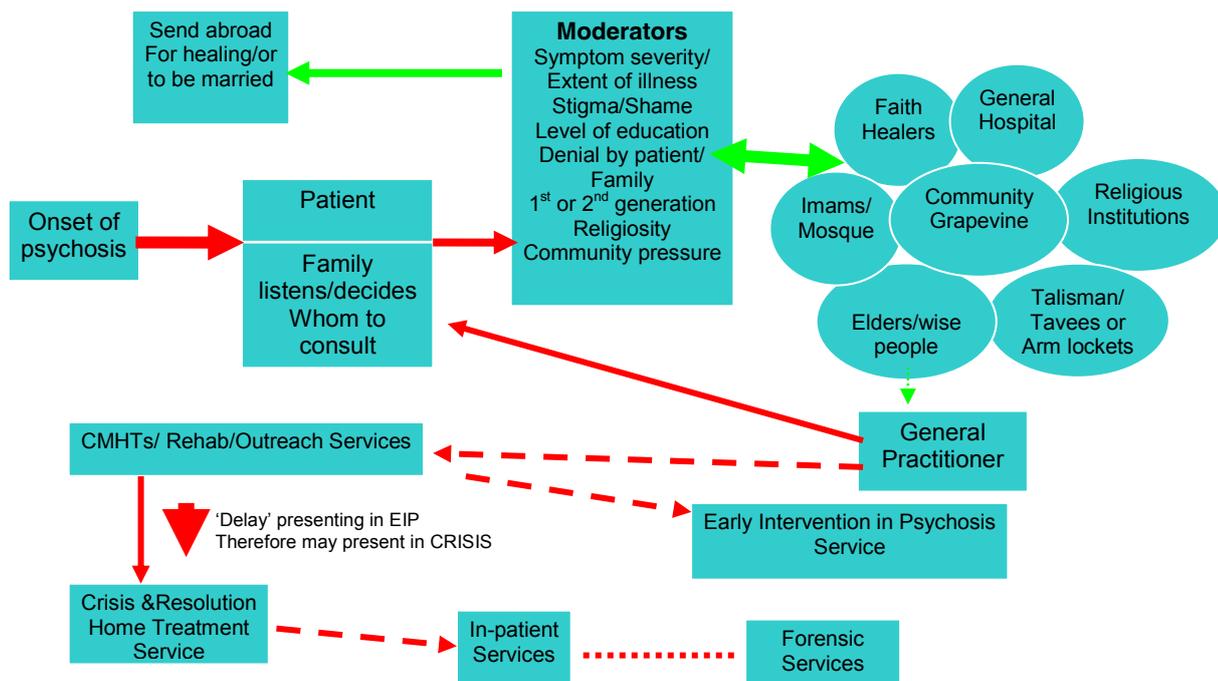
'...it was the fact that it was his mental health problems and his neuro-psychological problems were something that was very shameful. So what they did to support him was really to try to cope with those difficulties and support him as best they could, within the confines of the family. And they were very unhappy for him to access other services that might have really offered him some rehabilitation.' [T21, Interview with CBT Therapist]

Therapists consistently mentioned problems relating to the experience of shame. This could then lead to clients disengaging from therapy as this therapist explains

'I have worked with a lady who wanted to disengage because of issues around shame. The person I am working with now, is ashamed about the fact that she can't be a proper mother. For her being a mother is an honorary position in her culture and not being able to fulfil her role as a mother is extremely shameful for her. That's another difficulty, for whilst she's found it hard to talk about those particular issues, when I have thought about it, it has been an issue why people have disengaged, ...I have tended to lose people when it's caught on to or when they've been exposed to issues like this – shame.' **T22**

Pakistani and Bangladeshi communities as part of their help seeking behaviours may use faith healers and traditional remedies as indicated in figure 6 below. When they go to the Imams or Faith healers it is not known whether they describe the problems in the same way as they do when they see a general practitioner.

**Figure 7: Bangladeshi and Pakistani Help Seeking Behaviour pathways**



**Figure 7: South Asian Muslim Help seeking behaviour and pathways**

The key moderators contributing to the BME communities help seeking behaviours in this study can be summarised in **table 7** below:

**Table 7: Moderators influencing help seeking behaviours**

South Asian Muslims	African-Caribbean
<ul style="list-style-type: none"> <li>• Person’s mental illness, dealt in the family/extended family</li> <li>• Denial</li> <li>• General Practitioner (seek medical treatment usually medication- ‘pill’/ injection)</li> <li>• Symptom severity/extent of illness</li> <li>• Stigma/Shame</li> <li>• Community pressure/denial</li> <li>• Community grapevine</li> <li>• Faith healers/ Imams</li> <li>• Return to country of origin for healing or arranged marriage</li> <li>• Religiosity</li> <li>• Use of talisman or arm lockets with Qur’an verses inscribed</li> <li>• Level of education and awareness</li> <li>• 1<sup>st</sup> or 2<sup>nd</sup> Generation</li> <li>• Language/terminology</li> <li>• Fear of being detained</li> </ul>	<ul style="list-style-type: none"> <li>• Denial/ resilience</li> <li>• Stigma/Shame</li> <li>• Isolation</li> <li>• Mistrust of mental health services</li> <li>• Fear of mental health services (incarcerated/medicated)</li> <li>• Fragmented family support (in some cases)</li> <li>• Racism</li> <li>• Drug misuse</li> <li>• Religiosity/ spirituality</li> <li>• Previous experience of mental services</li> <li>• Faith healers</li> <li>• Bush doctors</li> <li>• Traditional remedies</li> </ul>

**Table 8: Moderators influencing help seeking behaviours**

As illustrated by the help seeking behaviours and pathways from the BME groups in the study, a trend was noticed whereby the service user participants had not used the specialist early intervention in psychosis services. Statutory mainstream services were avoided and presenting in crisis or being detained (Keating et al, 2002; Hill, 2003). This reluctance to seek help from statutory services may have resulted in delays presenting early however, the South Asian group seemed to prefer its community resources instead of mainstream services, could this explain their under presentation in the services?

The following section will discuss stigma and shame in particular their impact on BME groups and influence on help seeking behaviours and pathways.

## **5.10 Stigma and Shame**

In this section the extent of mental illness discrimination and impact of stigma and shame pose on the BME communities' will be discussed in detail. As major moderators in helping behaviour and pathways, this section will give insight on how this influences response to mainstream services.

Stigma of mental illness must be understood in the context of the individual, family and of 'respect' in the respective BME communities. Given its association with shame, work on targeting stigma should also be directed to family and communities' at large bearing in mind moderators such as community pressure, traditional norms and cultural beliefs. These influence choice of help seeking behaviours. The subject of mental illness in the BME groups involved in this study was described as a taboo that is still not talked about openly, even when living in a western society like the UK. The nature of the stigma

associated with mental illness is intense and complex, in particular within the South Asian Muslim communities that participated in this study. Its impact on the patient and family is so strong that it interferes with help seeking behaviours. Consequently, families and individual patients often avoid mainstream mental health services and prefer traditional usually non-scientific pathways and interventions.

Associated with stigma is the concept of shame that mental illness brings to individuals and their immediate families. This theme was consistent in all the three groups in this study. Women seemed to be more affected than men, especially within the Pakistani and Bangladeshi communities. This gender difference may be attributed to their cultural and legal status and rights. Some participants reported that women were seen as 'half person'. For instance, given differing cultural beliefs and values, stigma associated with divorce is worse for Asian Muslim women as compared to men and therefore, a South Asian Muslim woman may not contemplate divorce. Moreover, if she suffers with a mental illness and is consequently divorced she would be stigmatised and labelled as '*pagal*' (mad) and *talaq-yافتا* (divorced). Once a person has been labelled as '*pagal*' that stigma is bound to stay with them for the rest of their life. It also limits any prospects of getting re-married. Moreover, the impact of this stigma will affect any siblings in her family as any potential suitors can be wooed away due to the possibilities that the family may have a genetic defect, as demonstrated by the following expressions:

'I think its like - its back to stigma. They don't want to have that label attached to them. And I think it goes beyond that because people see that if you have got this illness and then it affects you later on in life. If you are a young woman you know you want to get a proposal for a wedding next year and someone in the community lets leak, 'oh actually she experienced this last year, 'that was it.'

People don't want to know...If your parents are experiencing it and you know you are a child, then it's like 'oh my god her mother is mad. So maybe she might have inherited it or get it later in life.. Do we really want to get our son married to this family?' **BL5**

Here the respondent describes the impact of stigma on the persons' social status within the community:

'...like your market value, your social value will drop if you have a mental illness. So, if you are unmarried, young with depression your marriage prospects will be affected' **PL3**

For those that successfully get married to unsuspecting suitors, soon find themselves in a predicament which results in them being divorced (*talaq-yafta*). Asian Muslim women dread the notion of one having the "*pagal-talaq-yafta*" (mad or crazy and divorced label). The impact this has on the supportive family structure is noted as illustrated here:

'There are two aspects of this. One is them is the impact it may have if one of the parents has got the illness. There is the worry that the child may get it. But also when marrying into a family, you want a family that will support each other. So say if I married my daughter into that family but the mother-in-law wasn't so well, how would she support my daughter? How would she be there as sort of like surrogate mum -so to speak? It is also sort of her life. And so every individual within the family has an impact on everybody within that family' **BL6**

This may explain why South Asian Muslim communities as well as the Afro-Caribbean 'hush hush', or are secretive when a family member suffers from mental illness. The following expressions on Stigma and shame illustrate this issue.

'Its' still taboo and we still get the derogative comments out when someone is unwell.' **ACL3**

The Bangladeshi respondents described how community perceives any association with stigma as negative to the family and bound to bring shame to them. Therefore family members tend to keep within the family any mental illness problems as much as they can.

Similarly this Afro-Caribbean respondent highlights the impact stigma and shame and how this is hidden by the family

'...but don't tell me that I have lost my mind. Tell me that I have the worst communicable disease because with bush medicine I can do anything and it will get better. But when **I have lost my mind** the whole world is going to know about it. I can't hide it. For my mother, for my child, for my husband to have mental problems you bring disgrace on the whole family. How could you have lost your mind? So you hid them away. What's wrong with Joe? You say he has gone on a holiday or something like that.' **ACL11**

Indeed for some in BME communities, mental illness can be seen as 'contagious like leprosy'. This often results in individuals with mental illness being isolated and excluded from community as this respondent describes

'my depression even later on when they realised that I had a psychiatric illness, some members of the extended family were keeping away from my immediate family they don't want to be associated. Because the first assumption is that it is contagious. That could affect the spirit that could transfer to other people.' **PAC11**

Stigma gets worse if someone is from abroad due to fear and implications of being labelled as mad as this therapist pointed out:

'...when she came over to England her initial appointment I think all of her appointments were in the psychiatric hospital. That was really hard for her because she had a real fear that initially she didn't want to write her name down and sign in when she came in. She was worried that the visa people (immigration) might find out and she might get labelled as having a mental health problem. And then they wouldn't let her stay in the country...she was scared about being in the hospital, with people that have mental health difficulties. . So actually understanding a bit about her sectioning, what it meant to her difficulties was really important I think and being kind of sensitive to that was really important.' **T12**

In relation to CBT some respondents reported that there was stigma associated with being seen for therapy within the Afro-Caribbean community as 'brain washing'. This was also

noted in statements from practitioners who work with young black men who perceived 'therapies' as a way of incarceration and conforming them to think in a certain way.

Denial regarding mental illness influences individuals or families helps seeking behaviour. Some of the mediators identified by the groups included ignorance, lack of knowledge or awareness of mental illness and moderators like education levels, strength of religious affiliation and whether the individual is first/second or third generation immigrant. However, presenting in crisis may not necessarily be due to denial, but assurance of seeking help behaviour, type of help sort and the sequence.

### **5.11 Community Grapevine**

Reliance on the word of mouth has been emphasised by the members of the South Asian Muslim communities. Families when seeking help use the South Asian Muslim community 'grapevine'. Both the Pakistani and Bangladeshi participants in the study reported that often members or patients would go to their general practitioners and request that they be prescribed the same medication as 'that person' because they have been told that it works. They would also act on informal information to see a particular 'faith healer' because a member of the community has recommended them. Within the community short-term benefits are influential in using a particular service. The community trusts its network and prefers it to mainstream services initially. Ball & Vincent (1998) emphasised that the grapevine knowledge is socially embedded in the networks and localities. Furthermore its use will vary across social classes.

### **5.12 Opinions regarding CBT and treatment**

The majority of service users highlighted that although medication was helpful, it was probably being overused in BME patients. Side effects were identified as a contributory factor to non-concordance with treatment. High doses of medication were disliked both by

service users and some therapists who felt that it made it difficult for some patients to engage in therapy as a result. Preference of talking therapy with medication was noted. However, a difference between the Afro-Caribbean group and the South Asian Muslim group was that being prescribed medication was preferable in the Muslim group as one respondent pointed out:

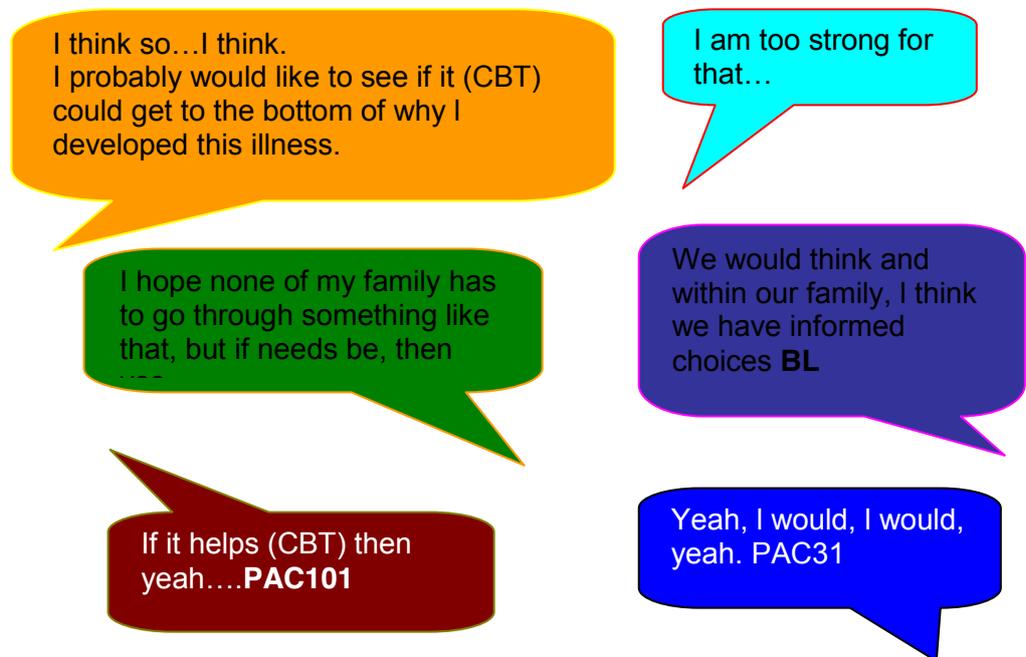
‘They believe in physical ‘would take pill rather than talk to’...Preference of intramuscular injections rather than oral tablet. Drips are seen as effective and reinforced by medical professions and private hospitals. The colour of drip matters, the more colourful the better. This appears to have a placebo factor and is seen as psychologically effective. Saline or glucose was apparently used more often in Pakistani. The concept of the ‘drip hanging and the person lying supine is embraced in belief that ‘strength is being transferred to a person.’**PL1**

The concept of a ‘cure’ is deeply ingrained in the South Asian Muslim culture. They expect ‘full cure’ to a problem and will go to great lengths to find someone to ‘cure them.’ This supports what the majority of participants reported that often patients are flown abroad for treatment. ‘*They don’t want treatment, but immediate cure*’. A conjecture on our part in reference to medication is the notion that there is a strong preference on external factors so that one does not have to change anything about them. They seek to get rid of a problem, rather than learning alternative ways of coping or tolerating distress.

Treatment differences by country of origin were noted and some respondents felt that health provision was much better in the UK than their country of origin. Majority of participants highlighted that they would like to be treated as individuals and as human

beings, not categorised as a 'number'. Some felt doctors are too busy and therefore don't have time to discuss sensitive issues related to psychological distress.

From the interviews, there is a reported lack of awareness of the availability and value of CBT as a treatment option in psychosis. The majority of the participants in interviews and focus groups reported that CBT would be acceptable with adequate information and cultural sensitivity. One participant declined offer for therapy stating that they did not want to be scrutinized (PAC4). Some Bangladeshi and Pakistani lay members emphasized that within their communities influencing factors on whether to consider CBT will be based on 'word of mouth from a community member who would have successfully completed therapy and recommended it'. This (grapevine) was suggested as a means the community uses to seek and consider help pathways. The following illustrations are from participants in response to acceptance of CBT,



The following statements highlight the benefits of CBT perceived in BME groups:

‘She (Therapist) helped me get over my problems in my family...It’s helped a lot and after that I get on quite well with my family after seeing her...I am not hearing as many voices as I used to... the ones that I do hear don’t really bother me that much.’ **PAC12**

‘It was ok you know..... I can only speak for myself.’ **PAC71**

‘It (therapy) was helping, but now it doesn’t help because I have become very low.’  
**PP81**

‘.....it (therapy) stopped me actually getting into trouble.’ **PAC21**

From the data, Afro-Caribbean participants would appear to prefer talking therapy first rather than being medicated.

## **5.13 Barriers to accessing CBT**

### **5.13.1 Access and referrals**

The first issue highlighted in the study related to access of CBT and difficulties with the referral process. Therapists argued that they only provided therapy to patients referred to them. Some highlighted the fact that they did not actively seek referrals and are limited by resource constraints to do so as one therapist pointed out,

'I think I am definitely guilty of not seeking referrals. I am aware of a number of people in our service from BME community and from white backgrounds that I haven't got to know, that I don't have a sense of them in the sense of their difficulties, and I haven't sought referrals, simply because of current workloads. So I end up responding to the referrals that come in rather than seeking them out... I was aware of, probably, a disproportionate number of white middle class referrals and I think probably as a tradition in CBT we haven't addressed this ourselves and. ...referrals in the past have been along the lines of 'please could you see this delightful young woman who is intelligent, able to talk about her problems.... So, yeah, articulate, often-young white, middle class people...who probably are familiar with CBT. Its people who are much more familiar with CBT, - people who are more able to ask for it as well, probably get it. I think that's a real problem and we are certainly not addressing it where I am at the moment.'

**T23**

A service user described his experience of not being followed up:

Well I feel maybe there is a slip in the services maybe. I mean there was not enough staff because the psychologist I was seeing then was on part time. So immediately she left I couldn't see anyone else.'

**PAC11**

The lower number of referrals of BME clients in comparison to Caucasian population remains an area requiring further attention.

### **5.13.2 Referrer's perceptions**

One of the barriers to accessing therapy was highlighted in the perceptions of the referrers. Some mental health practitioners who also are care co-coordinators admitted to being influenced by their perceptions when it comes to referring patients to therapy. The

referrer's belief system is important, for e.g. if a referrer did not understand what CBT was or believe it to be an effective intervention for BME clients, it was unlikely that they would consider or refer these patients for CBT.

'...from my perspective, our client group don't, even when we refer them, very rarely get picked up because people view them as not workable. But from my perspective they can. I have promoted CBT quite a lot within our service because of the way it's changed a lot....it's possible to do that within the tier two services.'

**T25**

'...I read something recently about people's beliefs and therapies. They do better with people who share similar values or beliefs systems even though you might not explicitly state it...'

**T32**

### **5.13.3 Therapist's experience with ethnic minority patients**

The majority of therapists reported that they had limited experience working with BME in CBT for psychosis. The following quote highlights a therapist's working experience with these groups:

'My experience has been that it is often difficult to establish common goals with these clients, as their expectations of therapy are often very different. They often seem unclear as to how psychological therapy can be of benefit to them. And they view psychology as an opportunity to chat about things and get things off their chest, rather than to develop skills to manage their distress and symptoms.'

**T**

On working with interpreters, one therapist told us that her experience of using CBT for psychosis with interpreters was minimal. She highlighted that this was probably a reflection of care co-ordinators not referring clients for psychological therapy when their English is very limited. On the other hand, some therapists who had experience of working with interpreters emphasised the need for therapists to be observant and not solely rely on interpretation. Consistency in relation to using interpreters was emphasised as well as briefing them prior to therapy session in order to clarify their role. The majority of South Asian lay participants reported negative experiences of using interpreters, citing fear of breach of confidentiality, especially where interpreters were from their community. Where a family member took upon the role of interpretation, issues were raised on conflict of interest in cases where the family member may have been the contributing factor to the service user's distress. These remain challenges and areas for development.

A common belief voiced by some therapists in the study was the assumption that therapy is the 'same for everyone', arguing that they would do the same things for a BME patient as would for a Caucasian patient, This is in contrast to the concept of 'self and the collective' of some BME groups in particular the Asian Muslim groups who value the family group more than the individualist concept of the west. Therapists also expressed the belief that CBT was a collaborative individualised therapy which should be able to take into account the varying perspectives and presentations of patients from all backgrounds and therefore there was the implication that cultural adaptation was unnecessary.

Contrary to this was the perception by many of those from the BME communities that their background and models of illness were not understood. It seems that to effectively collaborative and individualise, it is necessary to have an understanding of the individual's culture and context and adapt to it and sometimes therapists do not believe that this is necessary.

### 5.13.4 Cultural Barriers to Therapy

The following were identified as cultural barriers to therapy through the interviews:

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#### Cultural Barriers to therapy

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Mistrust of services/ practitioners

Worries about confidentiality/ breach

Poor information on psychological therapies/accessibility

Language and terminology leading to being misunderstood

Fear of being stigmatised

Previous experience

Stereotyping by therapists

Doubt regarding CBT being empowering enough

Lack of understanding of cultural norms, values by therapist

(Cultural incompetence) or Euro-centric approach

Clinician's beliefs in the power of drugs

Faith/spirituality and religion

Individualism vs. collectivism

Gender issues

Racism/ colonial history

Interpretation problems

Financial implication

Practical issues e.g. environment of therapy, transport

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**Table 9: Cultural barriers to therapy**

All the groups in the study identified cultural barriers. These included differing background and its association with trust. The Afro-Caribbean group voiced the issue of white and black dyad vehemently. Following is a quote that highlights the black and white dyad

‘And this is a fact... now I never met you before. The first time we met, I knew that I trust you (referring to the researcher and pointing out that this was due to the sameness of colour. This was demonstrated by respondent pointing to his hand and nodding) to bring you to my house. I trust you and you come again and again and I make you welcome. It’s the trust and because we are the same, I trust you.

...If I go to the doctors (meaning general practice) and I meet an Afro-Caribbean doctor, I suddenly relax. Whether they (are) going to make me better or (are) going to make me worse, I just relax speaking to him. Because it’s part of my culture and that’s the way we have been brought up. He’s a part of me -you know...and I’m a part of him...not that I don’t trust a European doctor. But as soon as I see an Afro-Caribbean doctor I feel a lot more relaxed. And I relax talking to him, -you know’

### **ACL3**

The therapists’ interviews discussed that trust needs to be earned at the outset given that BME groups often mistrust mental health services and practitioners.

‘I think it’s about making sure we develop trust. There might be natural distrust if you are from a different ethnic origin. It is about getting the referral in the first place or thinking about where they are in the service and perhaps being more

proactive...having a good understanding of some of the cultural differences...Further than that, it's more similarities than differences. It's more about working with the person, who is in distress in front of you. And there's kind of bits that surround it in the beginning, once you get beyond that, it's just about the person. [T6, Focus group interview with therapists]

'...Disproportionate number of white, middle class referrals, is that because they are more familiar with CBT and also because the therapist perhaps more, you know, feel like they can relate better to that patient group?' [T8, Focus group interview with therapists]

Where respondents identified with the therapists of similar background, they felt they shared the same values and beliefs and reported better engagement. BME therapists reported that they related much better to BME patients in particular those with Afro-Caribbean background as they shared similar experiences and understanding of culture and beliefs. This was felt to have helped addressing cultural issues with some clients.

On the other hand, some BME therapists felt they were treading on a thin line when working with some one from the same background taking into account issues of over-identifying with the patient. In these situations, the dilemma for the therapist could be that they easily get caught up in the patient's negative experiences and perceptions of the world and can end up focusing on a biased formulation. Cowdrill & Keeling (2007, June) emphasise that over-identification can occur in situations where there are unresolved issues on the part of the therapist. For example, unresolved personal issues of racism can impact on therapy leading to a therapist jumping to conclusions and making them a

focus of therapy when they might not be the key issue for the patient. Participants in this study emphasised the need for therapists to be cognisant of these issues and to assess what the individual values most, so that, BME and other practitioners do not make assumptions and over-generalisations of BME service users.

In contrast, the South Asian Muslim participants reported that they would prefer not to be seen in therapy by a practitioner from their ethnic background due to worries about confidentiality in the community. This resonates with worries about breaches from interpreters as well. These underlying worries were associated with stigma and shame of mental illness and its impact on marital prospects and family honour as discussed earlier in the report. Of importance to them was a therapist who understood their cultural background, norms and values and respected their religious beliefs and who would be willing to work not Eurocentric premises, but from the individual's cultural experiences. Gender issues within this group were also an influencing factor and needed to be addressed seriously, thus respecting an individual's choice of therapist.

### **5.13.5 Racism and it's effects**

A major theme consistent across all the groups was the avoidance of discussing or addressing anything that could be considered as 'racist'. Because of this, patients often felt dissatisfied and/or disengaged from therapy. Some therapists reported that talking about racism in therapy was an anxiety provoking process, some admitted to avoiding it for fear of political correctness or that they might say something that could easily be misinterpreted as racist. Therapists reported that they were not well prepared, that is, not trained to address racial issues in therapy. Some service users/patients preferred talking to someone of same colour or background about race issues as they felt they would be understood. Moreover, they argued that a therapist from their background and colour would relate better to their experiences. The following quotes illustrate this,

'...It's just the fact that um -racism ....can be very subtle....To talk about such things with another person who is White sometimes is difficult. That's all. I can't – um- put my finger on it. But when you are with friends from ethnic minority they understand what I am talking about. So I can talk about it more freely with them.'

[**PAC52**, interview with African Caribbean service user]

'You don't know the half of it mate....I am glad I got a chance to speak now. I can speak to you because you are a man of my colour and I can explain - so that I don't feel no shame.' [**PAC72**, interview with African Caribbean service user]

Use of clear case formulations that can be evaluated as therapy progresses should be considered to explore and understand patients' experiences of racism.

### **5.13.6 Characteristics of an ideal therapist**

Characteristics of an ideal therapist were identified by the respondents as someone who is empathic, honest, a good listener, understanding of culture, background and family dynamics, willing to learn, articulate, experienced, has time, sensitive, straightforward, non-judgemental, trustworthy and willing to discuss issues of racism.

## 5.14 Theoretical modifications

### 5.14.1 Validation

This therapy strategy is not novel to standard CBT. However, in CBT for borderline disorders such as Dialectic Behavioural Therapy<sup>8</sup>, validation as well as acceptance and non-judgemental strategies have been noted to form a crucial part in therapy (Linehan, 1993). Furthermore, their fundamental application in helping patients to fully accept 'themselves and their world' as they are 'in the moment,' is emphasised (Linehan, 1993). Validation goes beyond empathy in that the therapist attempts to make sense of the patients' thoughts and assumptions within the context and function (Ivanoff, et al., 2001).

The basic tenet in validation is to help the patient learn to trust and validate themselves. Through validation, therapeutic relationships can be strengthened especially, in situations where a patient feels they are not being blamed or judged. In this study, CBT therapists with experience in mindfulness-based approaches reported that utilising these strategies (validation, acceptance and non-judgemental) in therapy could strengthen therapist-patient relationship especially in situations where patients might feel they are not being blamed or judged. A common theme by a majority of BME patients was that of being labelled as a number. Through validation a therapist takes a genuine stance of treating patients as people with equal status rather than just a mental patient. Acknowledging that patients are experts (in relation to their life experiences, be it with hallucinations or delusions) may help address feelings of anger and frustration by patients who admitted to challenging their doctors as to whether they had ever experienced hallucinations when they felt invalidated.

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<sup>8</sup> DBT is 'a broad-based cognitive-behaviour therapy treatment developed specifically for Borderline personality disorder (Linehan, 1993)'.

In psychosis emphasis is on helping patients understand that their symptoms may occur as a result of a combination of vulnerabilities in the presence of stressful experiences (Kingdon & Turkington, 2005). Of importance is the validation of the feelings and allowing the patient to talk about their experiences without the therapist being judgemental.

### **5.14.2 Problems Solving**

The primary aim is to educate the patient to effectively problem solve by eliminating extreme behaviours and avoidance by developing a structured and methodological approach. It is about acquiring skills necessary for flexible life\*. In psychosis, problem solving deficits are often numerous and varied. Defining the problem at hand can be problematic for a person with hallucinations and delusions. Therefore, by exploring the pros and cons of behaving or think in a certain way, there is capacity to challenging and modifying dysfunctional assumptions, creating doubt and therefore consideration of alternative views. For BME communities these need to be in tune with their cultural beliefs and background.

### **5.14.3 Mindfulness Based Approaches**

Mindfulness is referred to as a way of 'paying attention'. This concept is derived from the Eastern meditation practices. Baer (2003) defines it as "the non-judgemental observation of the on going stream of internal and external stimuli as they arise" (p.125). It focuses on three primary states of the mind, namely the reasonable mind (logical, analytical problem solving) emotional mind (creative, passionate and dramatic) and wise mind (integration of both reasonable and emotion mind). A wise mind responds intuitively in a given situation. This helps develop self-trust and decision making skills\*. Although practitioners are using mindfulness in patients with psychosis, there is dearth in literature on its efficacy. Mindfulness based approaches may be appropriate in these communities as their origins

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\* Phiri, P. (2007). Functions of self-injury and how DBT addresses it. Unpublished manuscript, University of Southampton.

derive from Eastern practices-primarily Buddhism but also with Muslim, especially Sufist influences.

Rationalising does not always fit with particular communities. Introducing normal experiences from their cultures and shared experiences helps with normalisation. The mind and body model has proven more helpful and therefore therapy may need to start with behavioural and social tasks rather than cognitive models. Understanding of the desire for 'Pills' as a rapid solution to difficulties rather than therapy and emphasis on cure (as opposed to improving coping with on going symptoms) is important in Muslim clients. Use of culture specific metaphors has been helpful. Difficulties with interpreters need to be acknowledged and addressed. Use of clinical supervision has proven very important, preferably with a supervisor who has knowledge of the relevant culture.

The concept of self and collective ego impacts on therapy. Dynamics of the family are not only important in engagement but also in on going therapy. Expectations of the family and expressed emotions do impact on self-esteem.

## **5.15 Technical Adjustments**

### **5.15.1 Pre-engagement and Engagement phase**

In this section, modifications of techniques in order to engage patients from these communities will be discussed. The adjustments need to be made to the extent to which the client is aligned to minority culture. As members of these communities often trust their elders and priests more than services, education and information regarding available methods of treatment and collaborative working with these respected members of communities may help in engaging patients early. Creating a comfortable and safe environment that promotes relaxation is crucial. The initial assessment in ethnic minority

patients may need to be longer and at the pace that the patient is willing to accept.

Emphasis needs to be on listening and understanding.

'I mean they have got to simply have people in place who understand and make the people feel comfortable. So that the playing field is ready to be played on you know.' [ACL21, interview with African Caribbean service user]

The therapist needs more time to understand the patient's experience and allowing the patient to talk about their experience/beliefs helps with engagement process. Whilst this is no different to other patients, often therapy needs to start with the patient's experiences of migration, racism if these are more important to them etc. rather than an assessment of symptoms if the patient is not very keen to discuss these as this helps the process of engagement. "First impressions count" therefore therapists are judged by based these; this quote from a service user illustrates

'.. so it will help, seriously help because first impression counts. And if you blow it then you aren't getting back, you seriously aren't getting and then you end up wondering why that person is being aggressive towards you or whatever it is, - because of what you triggered off in the first place without even knowing it yourself...' [PAC21, interview with African Caribbean service user]

The transition from the consultative to collaborative model needs further adjustment as patients from the South Asian Muslim cultures respect and trust a paternalistic attitude from their therapist. A clear agreed summary of the first session is part of this, outlining

briefly the key issues and plans to deal with them. Tasks set collaboratively ('Homework') after this first and subsequent sessions to develop further understanding or test out beliefs expressed are important to endorse their feeling that 'something happened' and will continue to happen in therapy.

In the African Caribbean population, language becomes a barrier in situations where they feel misunderstood and therefore revert to speaking in Patios or Creole' just to express themselves. There are specific gender and race issues e.g. females may not be seen as authority figures by South Asian Muslim cultures and this can have an impact on engagement. First generation immigrants often prefer men who have such perceived authority. Second generation patients tend to be more adaptable. With some Pakistani clients there were noted to be issues about white female staff visiting Pakistani male patients. The family objected this, as they did not want their neighbours seeing white females due to possible impact on arranging marriages. In some black communities, women feel they need to be emotionally strong and cannot afford to show vulnerability. Sometimes the ethnic background of the therapist may have a role in engaging patients from these communities.

Perception of stigma is very important and needs to be dealt with at the outset.

Motivational interviewing with use of social and practical help is recommended where engagement is difficult. A seeing patient in own homes or near places of worship for therapy has been beneficial rather than hospitals or mental health centres.

From the outset the role of the family and extended community needs defining. Goals of therapy may need adjusting to the family values when family involvement is supportive & influential especially in the South Asian Muslim group.

'I think that with the young man I was working with ...had psychosis and really important part of that was also in engaging family. The care co-ordinator felt that dad was over-involved and because of this, the son felt that he didn't have any independence because dad was so worried about him and he couldn't do what he wanted to do. He was feeling quite frustrated and had more difficulties accepting the fact that he wanted to be able to do these western things. He wanted to be able to go out and drink with his mates...But his dad was quite traditional and found it quite hard to accept...His son had been ill and he really wanted to look after him the best way he could. And his understanding of the best way to do that was to keep a close eye on him all the time....The important part of that work was actually engaging dad in his son's recovery. Also, helping dad to understand that part of that might be helping his son to be more independent as well. But also acknowledging that part of their family culture particularly, the dad was about looking after the family and keeping them close.'[T11, Focus group interview with therapists].

This particular family valued its culture and norms in supporting each other and dad needed support dealing with issues of son 'flying the nest'. He found talking about this helpful. Moreover, the therapist allowed them to talk about their experiences in a non-judgemental way dispelling their expectations of being judged or told what they should do.

Similarities between the South Asian Muslim and Afro-Caribbean communities in relation to support of the family were evident. Where there was strong family support families tended to discuss and consult on the best possible way to help the patient. However, in some Black Caribbean communities where families are fragmented, their involvement would not be available although individual family members might still be able and willing to assist. They all can be prone to isolation and stress.

Drugs and alcohol problems in families in the Black Caribbean communities have an impact as in white communities, but seemingly less in South Asian Muslim groups. In the Black communities, issues of slavery and its psychological impact (colonial history) leading to feelings of discrimination and racism are important from the outset. Self-disclosure (this will be explored fully later) is more important with African Caribbean due to these perceptions and their thinking of 'them and us', 'I am just a number'. For instance, they may say "If I'm going to tell you about myself, I want to know something about you". How the therapist responds maybe as important as the content of the response. For these patients, small elements of self-disclosure and warmth build trust and the feeling of being respected as equals. Listening, validating and personalizing experiences have an important role and so does the discussion of the impact of migration early on in therapy. Fear of the system especially of 'being sectioned' needs allaying at an early stage for effective engagement. Therapy may be seen as an imposition of authority and control. Expressiveness with hands, gestures and tone of voice (high pitch voice) can be misinterpreted when it does not signify hostility or dangerousness.

In some instances dealing with practical issues will promote better engagement. These could include issues of assisting with transport or agreeing the venue for providing therapy. For some, the home environment may be unsuitable and a community centre

may be more convenient. Sometimes, therapy sessions may need to be associated with social activities.

### **5.15.2 Assessment and formulation**

Assessment and formulation of psychopathology needs to be in the light of cultural understanding of illness. In the case of BME patients, the cognitive model may need to start with culture. Use of formulation and use of diagrams to help understand formulation has proven to be a useful tool early in the therapeutic process. The use of formulations will not be different to working with any client; however there is a need to bring in cultural beliefs and experiences. In addition, an awareness of religious explanations for psychopathology and use of metaphors are important for the therapist. Religion is used as a way of coping with distress. Reciting Qur'an, and wearing armbands, use of charm lockets, talisman and *tavees* (armlets) to ward of evil spirits with Qur'an verses is used with enormous trust and confidence in South Asian Muslims. Addressing issues of religion and spirituality in therapy is fundamental for many individuals from these BME groups. Therapists admitted that when confronted with religion or spirituality in therapy they felt overwhelmed and tended to avoid dealing with this. In some cases, some felt they had limited knowledge and were untrained in supporting patients with religious issues due to faiths like Islam and Christianity being seen as complex and even bordering with psychotic belief. Distinguishing between psychotic and spiritual belief was seen as problematic although this was an area where understanding of the cultural background and communication with others from that background could help in clarifying such issues.

### **5.15.3 Work with Delusions and Hallucinations**

The experiential side of beliefs needs exploring. The explanations and systematization of delusions and hallucinations may be based on cultural beliefs. For example, delusions of possession by a ghost or spirit in African Caribbean patients can be based on a cultural

belief that ancestor's spirits are protective of native tribes. CBT with these delusions would need to rationalise and normalise using the cultural beliefs whilst addressing any distress that may be caused. Similarly, in South Asian Muslim patients, psychotic symptoms may be related to 'casting of evil eye/ spirits or magic'.

Addressing hallucinations and delusions in this instance will require therapists' cognisance of both cultural and religious background of patient involved. Validation of the distress is emphasised and with a focus on reducing distress. Developing shared formulations based on a model such as, Stress-Vulnerability (Zubin & Spring, 1977) has been useful in conceptualising and explaining this. In other cases therapists reported working collaboratively with the patient to test the client's idiosyncratic formulation of their presenting problem with a proposed cognitive hypothesis through reality testing and behavioural experiments where appropriate. Furthermore, use of mind and body models specific to person's culture is recommended.

The following case example describes how a BME therapist worked with a client who felt persecuted by a fellow client who she believed was a witch.

'....the formulation based on my cultural understanding helped in really dealing with the problem, by that I mean the challenges that we were facing because she had the delusion that there was another resident in the hostel ....She thought this resident; she didn't even use the word witch. But she was attributing so much to this woman that she was so scared of this woman. Nobody could understand why she was scared. But this is a tall black woman being afraid of this little white woman. She was so scared that even she wouldn't want to see her at a distance.

But eventually looking at how she described her, it gradually hit me. Because she looked at the white woman and the way she dresses. It was the image that an African child would actually give to a witch (laughter). Hair all about the place, I mean her makeup was all over red and bangles that way. And I just cracked it. Oh-oh “she is seeing a witch.” And that’s why she believed this woman could even influence her at a distance because they live in separate blocks. But she would say “she beat me in my room, she does that.” Nobody could make sense as to why this other woman would hit her. And then I could understand that she was actually “beating” meant doing witchcraft to this woman. So the lesson of the day was to work with the social workers to help...this other woman to dress down a bit because her makeup and everything was quite scary to everybody. They worked on the other woman’s’ self-image and I told them my understanding of the situation, how my client was attributing all those thoughts and beliefs to her. The staff was able to respond to her in a very positive way. When she came up with those ideas and I mean her intense anger towards this woman...so we managed to reduce the violence that this woman was directing towards this other person.’ [T, Focus group interview with therapists].

Here the therapist describes a patient attributing cause of distress to *jinn*’s, and how she explored with the patient cultural norm and the meaning to the individual.

‘I am just thinking about someone that is Iranian who lives here who has ‘*Jinns*, you know these ghosts that harm him in the night, kill him or something. I suppose you can work on the understanding that is a belief held by his culture ...how do other people (from his culture) cope with *jinn*’s? Why for him has it become distressing and obviously there is something psychologically based. Why for him it

has become more extreme and something about his beliefs, about them and other people's culture don't worry about, you know why has it become more distressing for him to have these experiences if they happen in his culture' [T, Focus group interview with therapists].

Further strategies include:

- Setting realistic goals so that progress can be evaluated is fundamental to maintaining focus throughout therapy.
- Modifying language to address terminology and concrete and abstract thinking.
- Non-judgemental approach to voices and use of acceptance
- Allowing patients to talk about their experiences.
- Appraisal of cognitive biases which may be culturally tuned and addressing prejudices.

#### **5.15.4 Relapse Prevention**

Identification of relapse symptoms known as the relapse signature is fundamental in therapy. Furthermore, drawing up a relapse prevention plan with the patient towards the end of therapy is crucial. This is normally done in collaboration with the patient. Therapists often offer patient's booster sessions and follow-up sessions.

#### **5.15.5 Blocks to therapy**

Managing blocks in therapy is an art. Therapists need to develop skills in handling blocks by discussing the issues with client, exploring any perceived dysfunctions in therapist and client behaviour and of its effects. These may be a result of lack of understanding of the client's culture. Emphasising impact of such behaviour outside of therapy and linking it to

relationships is important. Therapists need and should not react defensively and validating client's concerns helps. Validation of client's feelings and exploring pros and cons of behaving in a certain way need addressing. Therapists need to explore normative blocks, which reflect norms of client's culture rather than individual's idiosyncrasies (Cowdrill & Keeling, 2007). A typical example is were people just agree with figures of authority but do not do what was talked about or seemingly agreed or when moderators such as shame or guilt prevent some one from discussing their fear of dishonour or shame.

## **5.16 Summary and recommendations**

This dissertation has explored service users' and health professionals' views and opinions to describe understanding and beliefs around psychosis of clients from BME communities, their help seeking behaviours and more importantly attitudes towards CBT and recommends modifications to CBT with guidance for professionals so that the therapy delivered is culturally adapted and hence more acceptable. Some key findings and recommendations have emerged from this study are hereby presented in table 9.

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## Key findings and recommendations

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- Therapists to be mindful of pitfalls in therapy including over-identification/ Sameness, identifying with oppressor and colour blindness
- Mindfulness that therapist's own speech can reflect attitude and beliefs they hold about other cultures. Consider therapist with cultural expertise
- Offer choice/ preference-gender of therapist
- Address language issues from BME patients
- Avoid misinterpretation of patient behaviour/ not making cultural assumptions
- Awareness that patients are sensitive to stereotyping
- Use of techniques like Validating and being non-judgemental
- Introduce provider/service user forums
- Training clinicians in cultural sensitivity - Not reacting defensively to resistant clients
- Understanding culture of patient/ own as therapist
- Use of holistic approach e.g. Mind and body techniques are useful
- Use of Mindfulness based approaches which have oriental origins and concepts
- Awareness that core beliefs or schemas are strongly influenced by culture
- Listening carefully and considering ways in which a clients culture influences conceptualisation and treatment planning
- Understanding and being aware of alternative interventions or help seeking behaviour pathways specific to ethnic group
- Consulting with experts where appropriate and researching / updating self on cultures
- Awareness of use of religion as a coping mechanism
- Family in cultural context: Concept of self vs. collective e.g. Muslim – collective self
- Discuss race/ culture with patients and seek feedback on cultural assumptions of the therapy and its procedures
- Address illusions related to racial issues -Training interpreters (specifically in this area)
- Being straight forward and admitting own limitations and willing to learn from patients about cultural background
- Longer assessment time-relationship and involvement of interpreters
- Therapist needs to conceptualise thinking of client rather than correct them
- Behavioural tasks first before cognitive work
- Normalising and using culturally appropriate metaphors
- Questionnaires are sensitive to BME needs

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**Table 10: Summary of recommendations**



## Chapter 6 - Discussion

### 6.1 Introduction

The first part of this chapter presents a summary of the key findings and recommendations of this study. A section will follow this on the role of the researcher and an evaluation of his involvement in the study. Subsequently, limitations of the study together with methodological issues will be investigated. Brief comparisons with other work will be assessing whether CBT is acceptable if culturally adapted. This will lead to a discussion of practical implications of this study and consider impact of these on therapist and services equally. Finally, recommendations for future research in this area of study will be provided and will set the scene for the feasibility study.

### 6.2 Role of the researcher and participant experience

In the study a total of fifteen service user participants from African Caribbean, Black British and Pakistani ethnic groups participated in semi-structured in-depth interviews. The majority of service user participants in this study gave positive feedback with respect to their engagement in the project. For example:

‘I think it is a good interview to help people to improve the service. Not just for the BME (and) community as a whole.... I think something like this is useful throughout the community.’ **PAC52**

From the perspective of some of the Afro Caribbean community, the background, gender and skills of the researcher were crucial and raise debate as to whether a White interviewer would have gained similar data. These issues are well documented in the literature (Adamson & Donovan, 2002; Crozier, 2003; Douglas, 1998; Rehman & Walker,

1995). Furthermore, the role of the interview in providing 'advocacy' for the participants was also evident.

'You understand and are of same colour. I would love to see you again. I enjoyed the interview and you asked the right questions.'**PAC31**

'I am glad I got a chance to speak now sometimes because I can speak to you. Because you are a man of my colour and I can explain so that I don't feel no shame. If I want to say 'yea- I am the Black Messiah'...and I believed that at the time- that's the way I was feeling.'**PAC71**

'I said, 'yea why not explain myself if it is going to help other people'. And help whoever has got to read it to understand that black people need to be heard.'**PAC72**

There were no negative comments by the South Asian Muslim group about the researcher's ethnic background and it did not appear to have a detrimental effect but it is possible that this influenced the interviews and outcomes from them.

A positive emotional response was noted from lay participants who participated in the study, for example, some of the benefits of taking part included gaining an awareness of mental illness and psychosis, understanding what cognitive behavioural therapy was and that should a member of their family suffer with mental illness they would seek help and request CBT were appropriate. Furthermore, the lay participants took information on schizophrenia, depression and CBT in Urdu and Bengali provided by the researcher.

African Caribbean lay participants expressed their concerns about psychiatric research in general, stating that they were being over-researched and not seeing the benefits of the studies or being informed of the outcome/results of studies they have been involved in previously. The latter was given as one of the reasons why BME, in particular black people, show lack of interest in research. Another reason was that researchers were not genuinely interested in them (black people) but just wanted to obtain their PhDs or master's degrees. The above mentioned reasons may add to the assumptions that service users in psychiatric research do feel distressed as they may feel they are just being used as subjects by professionals for personal benefits. Clinicians expressed this view as well, as they expressed concerns about their service users being invited to take part in research. Common expressions used include, 'our patients are being over-researched, or they will refuse to take part, or it may destabilise them'.

In a recent systematic review by Jorm et al. (2007) on participant distress in psychiatric research, the authors concluded that ethical concern that participants in psychiatric research will become distressed and therefore worsen their mental state was not borne out of evidence. However, they acknowledged that a minority of research participants in the studies they had reviewed had experienced distress, although short-term in duration. This study supports Jorms' findings in this regard. Clearly stating the aims of the study, the impact on service users and policy and clinical implications; the response to participation in this study improved.

### **6.3 Evaluation by the researcher**

Through conducting this qualitative study I have gained an increased understanding of the literature, concepts and theories involved in working with specific ethnic groups under

study. I have also acquired a greater comprehension of the issues related to race, culture, ethnicity and psychosis in the context of ethnic groups and how current treatment interventions although effective for predominantly white populations were not meeting the needs of BME patients. As a cognitive behavioural therapist belonging to a BME group, understanding one's cultural background, being aware of my own culture and prejudices and how these can influence attitudes, it was crucial for therapists to be cognizant of culturally derived behaviours.

My heritage is of African origin, I was born in Zimbabwe where I spent my childhood and early adulthood then moving to England in early 1998. I was therefore able to relate to some of the experiences of the groups involved in the study, for instance the impact of immigration and related stresses. Moreover, my shared beliefs with the ethnic groups in particular the African Caribbean group ensured the inclusion of themes, which might have otherwise been considered meaningless by non-African Caribbean members of the research review team.

In my role as a researcher, belonging to the same BME group as the participants in the qualitative study may have influenced interactions and engagement during the interviews. Some participants perceived issues of having a researcher from their own background (thereby highlighting issues of 'sameness') as a positive factor that allowed them to feel relaxed and understood when relating their life experiences as illustrated by the extracts from individual interviews discussed earlier in chapter?

This raises issues of bias, however, I was aware of this and bias was bracketed (Giorgi, 1985). Regular supervision with a qualitative expert helped address these issues. This ensured that my therapist stance did not interfere with the interview process.

In situations where data had conjectures on my part; through supervision, analysis ensured themes were grounded in the transcripts, hence, analysis of transcripts by two to three members of the research team to check for validity and authenticity of coding and reducing interpreter bias (Elliot et al., 1999). Furthermore, the authors postulate that use of excerpts from original data allows the reader to assess lucidity of analysis and therefore can agree or disagree with interpretation given.

Working with BME groups in this study has allowed me to appreciate the richness of diverse cultures and the underlying premise of preserving ones' culture. Nevertheless, it elucidated the challenges of working across-cultures and assumptions that cognitive behaviour therapy fits in all cultures. Indeed, one size does not fit all, thus by making necessary adaptations and theoretical modifications to current CBT philosophies and accommodating the findings of this study it is hoped that some of these measures could improve BME patient experience in therapy.

## **6.4 Methodological issues**

### **6.4.1 Limitations of the study**

The major limitation of this study was the difficulty in recruiting service user participants for individual interviews. A number of difficulties in recruiting participants from mental health services are noted for instance: eleven potential participants were identified from an early intervention service with 35% BME service users. Only one respondent was interviewed, the majority of service users from this particular team were reported to be unwilling to take part. Three service users who had experience of CBT had agreed to take part, however, one left the area, the second one became unwell prior to interview appointment and the third did not respond to invitations to interview appointments. A similar trend was noted in those teams that had identified suitable individuals.

Focus group discussions for service user participants did not materialise, as the researcher felt it was impractical and would have been time consuming to arrange, given some of the delays in obtaining Trust approval in the London and Portsmouth site. Therefore, individual interviews were more suitable. Consequently, the quality of data that would have been obtained from focus group interviews with service user participants may have been missed. Discussions allow for debate but also challenging ideas. On the contrary, given the sensitive nature of the research, and the issues of fear and mistrust of both services and professionals by the BME groups, use of individual interviews rather than focus group discussions with service users allowed participants feel safe and willing to disclose sensitive personal experiences and beliefs as discussed in the results section.

A few Bangladeshi service users who had been identified as suitable declined the offer to take part. One particular service user stated that he was only interested in talking to someone who would assist him with getting accommodation. The majority of London teams reported that clients were either unwilling to take part and/ or did not meet the inclusion criteria. It is likely that accessing the Portsmouth Site earlier, where there is a significant Bangladeshi population, would have improved recruitment of service users from this group.

Therefore, whilst a substantial number of interviews and focus groups from the different communities were conducted, limited number of South Asian Muslim patients participated in comparison to the African Caribbean. Accordingly, it can be argued that a bigger South Asian Muslim service user participant sample may have produced a different data set.

Nevertheless, the lay member participants from this ethnic group were well represented in this study as discussed in the lay participant recruitment section.

While the recommendations were drawn after data was saturated, this will be further tested through the feasibility study which will take into account the above mentioned limitations and include a bigger South Asian service user sample as well as therapists researchers from the White and South Asian groups.

#### **6.4.2 Is culturally adapted CBT acceptable and suitable?**

Some small pilots have been conducted in this area however; they are limited systematic qualitative analysis and few small RCTs. There is a great need to explore this underdeveloped area. So far the evidence base for adapted CBT based therapies indicates success in low and middle-income countries.

CBT-based intervention provided by trained community health workers was reported to have effectively treated peri-natal depression and improved infant outcomes, according to a cluster-randomized trial conducted in rural Pakistan (Rahman et al, 2008). Other studies were conducted in Goa by Patel et al, (2007) aimed at treating depression and by Rojas et al, (2007) on cognitive therapy for depression in Chile.

A study in North America where adapted CBT has been used in African American groups has shown promising results. One such pilot study was conducted by Kohn et al. (2002) compared standard group CBT with Adapted CBT for African American women presenting with major depression (n=12) participants were recruited into the study and offered a choice of either group intervention. 10 out of 12 subjects chose AACBT and once standard CBT while another preferred individual therapy. Subsequently, the CBT group was retrospective (they chose participants who matched the AACBT and had completed CBT previously.) Treatment involved 90min of manualised group therapy. They were

group differences in that the AACBT group was a closed group. The results showed a significant drop in BDI scores post therapy for both groups. The AACBT with 12.3 points drop from baseline score of 34.6 pre-treatment in comparison to CBT with a 5.9-point drop from a baseline of 30.3. Methodological limitations in this pilot included a small sample size; thereby may not be generalisable to general African American population from low income and poor backgrounds (Kohn et al, 2002).

Literature from other cultural groups recommends the adaptation of cognitive-behavioural therapy for use with ethnic minority populations as necessary and possible (Deffenbacher, 1988; Hays, 1995). Group CBT for Seasonal affective disorder (SAD) has been acceptable and found to bring about a similar degree of symptom reduction among Japanese patients with SAD as among Western patients (Chen et al., 2007). Cognitive-behavioural approaches have received support for use in therapy with Hispanics (Casas, 1988; Runz & Casas, 1981), and despite the common perception that Chinese people may not benefit from western forms of psychotherapy, CBT was partially successful in assisting a client to understand the nature of her problem and guiding treatment to ameliorate some of her anxiety and depressive symptoms in a case report by Williams et al. (2006). Therefore, cognitive therapy must be modified to fit the values and belief systems of the given culture, as distorted cognitions in one culture may well become functional and adaptive ones in a different culture (Chung, 1996).

The findings in the study on attributions to psychosis echo McCabe's & Priebe's (2004) work on perceptions of causes of mental illness. Study participants highlighted similar causes of mental illness, particularly with respect to psychosis, namely, social factors (family stresses, economic and environmental), supernatural including spiritual and previous wrongdoing. Another key finding in this study was the suggestion by some of the

Afro-Caribbean respondents that mental illness was attributed to being arrested by a police officer. This resonated from the reports of being misunderstood and misinterpreted by the arresting officer. McCabe & Priebe (2004) concluded that Caucasians rather than Afro-Caribbean and West Africans frequently cited biological explanations. In contrast, the BME participants in this study, although acknowledging biological vulnerability as a cause for illness strongly leaned towards and frequently cited previous wrong doing and supernatural beliefs as causative. This is further resonated in the BME groups help seeking pathways.

The findings of the study endorse previous work on communicating with clients from BME communities (Bhui & Bhugra, 2004). The authors in this paper emphasize that explanatory models represent the position from which patients may express distress; and they can govern how patients interpret a psychiatric explanation of their problems. Even if patients unconditionally accept the medical perspective, there is still scope for explanatory models to influence adherence to treatment, especially if family, community and some personal explanations are at variance with the medical model as discussed earlier. CBT therapists working with clients from these communities face the same challenges and need to be aware of the cultural beliefs influencing explanatory models.

The majority of participants in this study reported that, of paramount importance was an understanding of their cultural background by practitioners regardless of practitioner ethnicity. Greater emphasis was on preserving their culture no matter how bizarre it may be. The notion that western concepts are preferred over non-western concepts that are perceived primitive was highlighted by Katz (1985) who contends that individuals are socialized to believe that western norms are preferred over non-western norms. Consequently, patients are more likely to disengage and terminate therapeutic relationship.

A number of findings and recommendations for CBT emerging in this study, for instance, the concept of self in the collectivist culture versus the individualist culture impacting on therapy, dynamics and expectations of the family endorse previous literature for instance, (Mason & Sawyer, 2002; Tseng et al., 2005) work on Asian culture and psychotherapy. Similarly, like the South Asian Muslim participants in the study, Chinese people regard professionals as authority figures, knowledgeable, and to be respected. Therefore, when delivering therapy with Chinese patients, it has been recommended that an instructive and didactic style is used early in the therapeutic relationship, with less emphasis on collaborative empiricism and guided discovery in the initial stage of therapy (Williams, et al 2006).

Fear of services, specially fear of detention and the Police among the African Caribbean populations has been discussed in previous literature (Bhui 2002; Sainsbury Centre for Mental Health, 2002; Keating, 2004) and a recent Healthcare commission report revealed an increase in proportion of BME in-patients (Lombard, 2008; Count me in census, 2008). The survey highlighted a 23% increase of BME psychiatric inpatients in England and Wales since the 2001 census. The authors interpreted this increase in BME over-representation in psychiatric inpatient services as a continued failure by the mental health services in tackling BME issues.

In comparison to non-western countries the healthcare system in the UK is exceptional however, historical experiences of service users, in particular of African Caribbean origin relating to being misunderstood and subsequently discriminated against in the use of the mental health act (1983) compulsory powers has in most cases resulted in their fear and mistrust of statutory services subsequently, avoiding them. Of particular interest was the presentation of the majority of service user participants through the crisis teams or

presenting in crisis rather than utilising well-established services such as the early intervention in psychosis (EIP) teams and or primary care services. Participants in this study reported that general practice services were insensitive to BME needs. Given that general practitioner (GP) services in this country provide first point of contact are utilised by the majority of the population, however, BME participants highlighted some the barriers to accessing care including language, scrutiny by receptionists, limited consultation time by GPs and being offered medication as a first choice rather than considering alternative interventions such as talking therapies. Moreover, recent investment by the government in improving access to psychological therapies (IAPT) endorses need to provide such interventions (Turpin et al., 2008)

For the majority of participants the themes of stigma and shame played a crucial part as a moderator influencing their help-seeking pathways. This was further associated with stereotyping mental health service users by the public and in particular the media who tend to give a distorted view of them as dangerous (Beresford, 2005) consequently, politicians tend to respond to isolated cases by proposing more restricting measures to dispel public anxieties.

Given the current financial crisis, the healthcare services are not exempt from this global phenomenon, therefore implementing and training of staff will require working within current resource constraints. This fits well with CBT as demonstrated by the Turkington *et al.* (2002) insight study that utilised community nurses to provide brief CBT sessions to both patients and carers. Likewise, Rahman *et al.* (2008) study conducted in Pakistani on peri-natal depression by trained nurses, reported efficacy of adapted CBT. Moreover, the recent DOH investment in improving access to psychological therapies should be taken

advantage of in ensuring that its implementation and training programmes provide training on working cross-culturally.

BME groups in this study were multi-dimensional in their help seeking behaviours and pathways as discussed earlier in the findings; of paramount importance is acknowledgement by practitioners of their help seeking pathways and the notion that some treatments will be parallel to their traditional non scientific approaches. Literature review highlighted that CBT in conjunct to medication is superior to TAU, future studies may need to investigate collaboration with Faith healers to begin identifying and testing efficacy of these traditional approaches alongside scientific proven interventions. Such schemes already exist in developing countries such as Zimbabwe where traditional healers belong to a credible association (Zimbabwe National Traditional Healers Association: ZINATHA) that is recognised within the healthcare system of that country. On the contrary, family interventions have proven effective in reducing relapse and readmissions to hospital, maybe future investigations on modifying CBTp with family therapy should be considered.

Finally, the NICE guidelines should in the future recommend study designs to investigate more plausible interventions for BME groups for inclusion in the guidelines. Of concern was the very brief comment on ethnic groups and no recommendations from the 2009 draft guidelines for schizophrenia acknowledging paucity of evidence in this area. However, the final guidelines have highlighted this area as underdeveloped. There is much grey literature about BME research that needs to be considered in future consultations.

## **6.5 Practical Implications**

Based on the results of the study and other supporting literature as highlighted above, CBT is an acceptable approach for the communities involved in this study. Findings have face validity and make common sense i.e. they are not radical developments of CBT. They provide an emphasis on specific issues as being particularly important to the different communities. Collaboration and individualization of therapy is reinforced as a principle but in practice an understanding of the issues that have been raised by the communities is needed to inform therapy and optimize it. For example when a therapist is working with a African Caribbean man, they can expect that self-disclosure (discussed in detail in the next chapter seven) may be an important issue and they might want to prepare in advance how exactly to respond to this. Similarly, for an individual from a Muslim community, ensuring that family views are elicited and responded to needs to be specifically addressed.

Specific issues required to adapt treatment based on findings on the study will be evaluated in order to provide written training materials that can be incorporated into training and practice.

### **6.5.1 Implications for therapists**

The study highlights important implications for therapists/ professionals who work with BME clients. The onus remains on the therapist to build a relationship with the patient and to earn their trust given that majority of BME groups mistrust services. Trust can be viewed in two ways, namely involving practitioners such as therapist –patient relationship and healthcare institutions such as the National Health Service. BME trust of the healthcare system in particular, mental health services have previously been reported to be low (Thornicroft et al., 1998). This may be based on lower BME public and patient satisfaction surveys evaluating services. There might be an association between lack of

trust of services and lower patient satisfaction; a hypothetical assumption is that patient dissatisfaction will lead to disengagement with services.

Here a therapist highlights the dilemma relating to trust or mistrust in therapy

'It can be very difficult, especially with the particular guy I was talking about, he, it was through our service that he was admitted in the first place and so there was lots of mistrust in, well, what are you going to do and lots of anger, so it was very difficult ...trying to say well I am not a part of that, I'm here in the session for you and I am not colluding with anyone else, look at what we can do' **T24**

Often people with psychosis have issues with engagement due to mistrust and this can be made worse if they are seeing a practitioner from a different background as they may assume or jump to the conclusion that their experience will not be understood. Some African Caribbean service users admitted to testing out practitioners to see if they could trust them. This involved in some cases asking them personal questions or disclosing something.

There is a need to recruit bi-lingual therapists in provision of therapy to these groups. The findings have implications and highlight issues pertinent to the BME therapists and practitioners working with the predominantly White population. It is of paramount importance for therapist self-awareness and also understanding how their own cultural background can influence their treatment of White patients or indeed other ethnic groups. They too may need to be cognisant of culturally derived behaviours and beliefs within the

White population. A typical illustration here is where a White patient presents with low mood following lose of her pet cat. Given the value of animals in the western societies, the BME practitioner will may need to intervene with sensitivity using western concepts that are in tune with the patient's culture and norms rather than their own.

### **6.5.2 Implications for services**

Whilst the findings of this study need further evaluating, they have implications for the adaptation of clinical or public health practice in improving psychoeducation in these communities, especially regarding treatment options available. In relation to primary care settings, gaining access will imply provision of culture awareness and competence training including reception staff, this is crucial given that the majority of patients with mental health problems are seen in primary care settings (Goldber & Huxley, 1992).

Engagement, education and collaboration with community and spiritual leaders of these communities needs further developing in order to engage patients from these communities. Recruitment of bi-lingual practitioners, supporting and training of staff to be culturally competent in working with BME groups is vital to ensuring issues raised earlier on in literature and in the findings are addressed.

Within mainstream mental health services practical implications may include flexibility in delivering psychological interventions. Where appropriate acknowledging BME help-seeking pathways and working in collaboration with BME groups not only in service provision but also in designing and developing services. The culture of service user involvement should extended to these communities at large. In addressing and campaigning against stigma and discrimination of mental illness, individual and involvement of families and the communities is a prerequisite if this is to work. When targeting health promotion to BME communities issues of acculturarion should be taken

into account. Improving interpreter services and training in specialist areas such as mental health is recommended.

A training manual to guide therapists using culturally-sensitive CBT for psychosis is being prepared. The recommendations from the project and training manual need to be evaluated and refined through a feasibility study which has been funded, and granted ethical approval. This study is now underway and will be discussed in the next chapter. If the feasibility study is successful, further investigations in the form of a definitive randomised controlled trial will be the way forward.

## **6.6 Summary**

This chapter presented a succinct summary of the key findings and recommendations of this study, and has acknowledged the strengths and limitations of the methodological approaches and techniques used in this research. It has highlighted implications for cognitive behavioural therapists and other healthcare professionals working in a multi-cultural society in particular with patients experiencing psychosis. Similarly, implications for policy makers were noted. The next chapter explores therapist self-disclosure a theme that emerged from the study. The function of this theme when working with BME groups is discussed in detail, and followed by implications for clinical practice. Chapter eight introduces the second study 'feasibility study of culturally adapted CBT for psychosis for ethnic groups'. It aims to assess the feasibility and fidelity of culturally adapted CBT for psychosis (CaCBTp) for use with the African Caribbean and South Asian Muslim groups. Based on further results from this trial, implications for policy makers will include the training of staff and dissemination of guidance on therapy.

## **Chapter 7 - Culture and Therapist Self-disclosure**

Prepared for submission

## **Abstract**

**Objective:** This chapter critically discusses the extent to which therapist self-disclosure impacts upon the early stages of therapeutic relationship. Particular reference is made to the importance of self-disclosure with Black and Asian minority ethnic groups.

**Method:** Our group recently conducted a qualitative study aimed at developing culturally sensitive cognitive behavioural therapy for psychosis for ethnic minority patients by exploration and incorporation of service users and health professionals' views and opinions, funded by the Delivering Race Equality (DRE). This two-centre study consisted of individual in-depth face-to-face interviews and focus groups on a total data set of 114 participants comprising of service users with schizophrenia, therapists and mental health practitioners and lay member participants from the minority ethnic groups in the UK.

**Results:** The results had face validity that CBT would be acceptable if culturally adapted. Several themes emerged relating to the need for therapist awareness of culturally derived behaviours, beliefs and attitudes that can influence client response and participation in therapy. Therapist self-disclosure is one such theme. This issue is contentious and has challenged previous thinking regarding disclosure of personal issues. Implications for clinical practice and practical guidance are discussed.

**Conclusion:** In conclusion, client initiated self-disclosure by the therapist has significant relevance to multi-cultural psychological practice today. It requires therapists' cognizance and sensitive response to nurture trust and promote rapport. Further investigation in this area is recommended.

**Keywords:** Culture, cognitive behaviour therapy, self-disclosure, psychotherapy, ethnic minority

## 7.1 Introduction

Traditionally, the attitude towards self-disclosure in psychotherapy has been based on the Freudian concept that psychoanalysts should be “*impenetrable to the patient...reflect nothing but what is shown to him*” (Freud, 1912/1958, p.118).

In therapist – client relationship, it is the client who discloses their personal issues. But occasionally, especially where counselling or cognitive therapy is the modality of treatment offered, a therapist will decide whether to disclose something personal or not. Luft and Ingham (1955) described a *Johari* window which may be useful in shedding light on the aspects of the self that therapists might reasonably be prepared to disclose, that is, those aspects that are known to self and others e.g. professional background or experience (Hill & Knox, 2001). In contrast any aspects that are not known to *others* (our emphasis: in this case the client) the authors postulate that the *individual* (our emphasis: a therapist) maintains a façade. Therapist disclosure about things known to others may not be the issue here. Of interest in our study was client initiated therapist self disclosure; this concerned those aspects which therapists would usually keep in their private space and may choose to share with those that they are close to but not automatically to a client.

Surprisingly, the Freudian culture of psychoanalysts being *impenetrable* is widespread across professional disciplines including cognitive behavioural therapy (CBT). To date clinicians have differing views and opinions about addressing self-disclosure issues despite evidence that therapist self-disclosure has a vital role in therapy (Strong & Claiborn, 1982; Anderson & Mandell, 1989; Goldstein, 1994; Corrigan & Lundin, 2001).

The studies that have investigated therapist self-disclosure have all assumed that the therapist initiated disclosure and thus the advocates of this (Patterson, 1985; Beutler, 1978; Derlega, Lovell & Chaiken, 1976) report positive effects of self-disclosure.

Conversely, the opponents of its efficacy conclude that no relationship was found between individual client improvement and therapist disclosure (Dickenson, 1969; Strong, 1978).

There are mixed views in psychotherapy about therapist disclosure with a majority of therapist traditionally not keen to disclose personal issues to their clients (Hill & Knox, 2001; Barrett & Berman, 2001). The bulk of literature in this area has been polemical about the therapist disclosing or initiating disclosure (e.g. Patterson, 1985; Delega et al., 1976; Strong & Claibom, 1982). However, in our study it was the clients who triggered this form of seeking self-disclosure from the therapist by using direct and even trick questions so that they could ascertain when the therapist was genuine and would disclose something personally about themselves (Rathod et al., 2010).

The type of communication used, questions and content of information-seeking concerned generally personal nature. For instance, the client might say "*what music do you like... how many children do you have....., where do you live?*"

## 7.2 Self-disclosure

Self-disclosure is a purposeful expression or a bridge to understanding a client's state at a particular moment. It is a way of engaging clients in treatment and can be reciprocal in a therapeutic relationship (Barrett & Berman, 2001). According to Simone, McCarthy & Skay (1998, p.174) self-disclosure is defined as "*a conscious, intentional technique in which clinicians share information about their lives outside the counselling relationship.*"

Hill and Knox (2002) support the above definition. Similarly, Myers and Hayes (2007) implement it for their study. Conversely, Hyman (2008) quotes a verbatim from one of his participants who argued that self-disclosure presupposes that people in the mental health community may choose to keep some things secret or private and that if known, something undesirable will be done to them. This implies the significance of boundaries for the safety of both professionals and clients. Consequently, therapists need to consider the costs and benefits of self-disclosure in order to determine whether this would be helpful to their clients.

### 7.3 Problem with self-disclosure

*“If I’m going to tell you about myself, I want to know something about you” [Interview with African Caribbean participant]*

The above excerpt from an interview indicates that issues of self-disclosure can be problematic. Most practitioners will be familiar with the concept of self-disclosure. The most common form involves voluntary disclosure of one’s personal situation or illness to another in this case a patient or client. It is assumed that the role of disclosure will be to instil hope (Fisher, 1994) to clients and hopefully nurture a process of openness and self-disclosure on their part, concurrently reducing any form of stigma and shame resulting from suffering with mental illness (Hyman, 2008). However, in our recent study pertinent to the engagement process, was a theme of therapist self-disclosure, as initiated by clients? (Rathod et al., 2010) The impact of this theme on the therapeutic process will be discussed in more detail.

Patterson and Hidore (1997) definition of therapist self-disclosure postulates that disclosure is facilitated by the therapist and that most clients will be willing to talk about themselves and their problems when they come to therapy (Farber, 2006). Although this may be the case for the predominantly white population, working across cultures indicates that this may not be the case. For instance, African Caribbean people are secretive and reluctant to disclose (Anderson, Elam, Solarin, Gerver, Fenton & Easterbrook, 2009) thus they tend to be cautious when talking to outsiders about their personal problems and this impacts their help-seeking behaviours and pathways (Rathod et al., 2010) consequently, presenting in crisis. In United States, similar observations have been noted amongst people of colour by Arthur (2000).

Similarly, Corrigan & Lundin (2001) identify two levels of self-disclosure, namely *selective* and *indiscriminate* disclosure. The authors’ standpoint describes disclosure as a choice by an individual to tell about their mental illness, and deciding when to disclose. The

assumption by Patterson and Hidore (1997) that most clients 'expect to talk about themselves' is challenged here when relating to Black and Minority Ethnic (BME) clients; literature indicates that they fear being misinterpreted and misunderstood and therefore incarcerated (Fernando, 1998). Furthermore, African Caribbean patients have elevated issues of mistrust and dissatisfaction with mainstream statutory services (this is where they are likely to access or be offered psychological therapies) impacting on help seeking behaviours and pathways. In addition, literature reports poor access to psychological therapies for minority ethnic groups in the UK (IAPT: Turpin, Richards, Hope, Duffy, 2008). Therefore, this minority ethnic group with an overrepresentation in psychiatric services ('Count me in', 2008) and with the vast majority of its client group admitted to hospital involuntarily under detention of the Mental Health Act 1983 (Singh, Greenwood, White & Churchill, 2007) also presenting through the criminal justice system (Keating, 2007; Lelliot & Audini, 2003; Lombard, 2008) may not talk freely about themselves.

The authors' assumption that towards the end of therapy most clients will focus less on themselves and more on the therapist as a person, therefore asking the therapist personal questions, as illustrated by this quote: '*... its an indication that therapy is nearing, or is at its end*'. (Patterson, 1985, p.81) may not apply to some BME clients. Patterson's notion does not apply in cross-cultural psychotherapy, thus requires therapists to be cautious before assuming that when their clients ask them personal questions therapy is drawing to an end. Dialectical behaviour therapy (DBT) a third wave therapy developed by Linehan (1993) for individuals with complex personality traits advocates use of therapist self-disclosure. Interestingly, a recent New York Times article described patient initiated therapist self-disclosure when one of Linehan's patients asked her "are you one of us?" Subsequently, Linehan decided it was time to publicly disclose her history of mental illness and reiterated the benefits of disclosing to patients (Carey, 2011). Corrigan (2003) purports this form of self-disclosure.

## **7.4 Our qualitative study**

In a recent study (Rathod et al., 2010) the authors found that BME clients will ask the therapist personal questions throughout therapy, more so in the beginning stages of therapy. The following sections will explore the findings on self-disclosure and discuss the rationale, implications and future considerations on this theme.

## 7.5 Findings

### 7.5.1 Rationale for self-disclosure: the why?

The reason for this was twofold; first, it signified that the therapist or clinician was treating the client as a human being and “*not just another number.*” This means that the client is judging and using this process as a vehicle to establishing a rapport with the therapist.

Secondly, by not being hesitant and answering the question at hand the client assumed they could trust this therapist and therefore, took the therapeutic rapport to another level. This level of seeking to establish trust by the BME client was over and above that which clients generally sort. The client will be seeking a degree of spontaneity and determines the manner and speed with which response is given. When therapists are assessing their clients they need to be aware that the client is also assessing them. Clients tend to come to a conclusion earlier than the therapist. Here they are eliciting the degree of trust.

However, some of the therapists reported that when they were defensive in their response and/or declined to answer the posed question on self-disclosure, the BME client revealed minimal information or was less responsive in therapy (Rathod et al., 2010).

Some African Caribbean service user participants reported that they intentionally used subtle questions on clinicians and/or therapists. We therefore, asked cognitive behaviour therapists in focus group interviews how they dealt with self-disclosure as initiated by clients. A few therapist participants in response, reported that they felt secure in themselves and did not find disclosing a personal issue a problem as long as this was appropriate and within therapeutic boundaries. It was not clear how these boundaries were determined. In contrast, those therapists who had responded in a defensive manner to questions of self-disclosure in particular with the African Caribbean patients reportedly found it difficult to engage their clients (Rathod et al., 2010).

This theme of self-disclosure although consistent in the African Caribbean and South Asian Muslim groups in our study was explicit in the African Caribbean group owing to their perceptions and assumptions of being portrayed as *'them and us, I am seen as just a number'*. The following narrative typifies this:

*If I'm going to tell you about myself, I want to know something about you.* [AC1, African Caribbean service user interview]

Some service user participants in this study who admitted to testing professionals by asking them personal questions in order to ascertain whether they could trust them confirmed this. BME clients are wary of clinicians fearing they might be misunderstood and misinterpreted. There maybe a link between this client-initiated therapist self-disclosure and mistrust for statutory services and dissatisfaction (Bhugra, 1997; Bhui, 1998).

Interestingly this 'testing' was done to all clinicians regardless of their race and ethnicity. First impressions count and can be a litmus test as to whether the client engages with the therapist or clinician. Furthermore, the level of engagement maybe dependent on whether the therapist passes that test.

Pertinent to the African Caribbean participants was the issue of trust and its association with assessing the therapist if they were trustworthy, genuine and would relate to them as a person. The study showed that African Caribbean communities were sensitive to issues relating to trust. Mistrust stems from years of dissatisfaction with the mainstream services and their previous experiences and encounters with services.

African Caribbean service user participants admitted to asking therapists tricky questions just to see how they would respond to them. For instance, they would ask questions such

as, “*Do you have children... or where do you live?*” Some questions were so subtle such that the therapist was unaware they were being tested.

The fear of feeling misunderstood and misinterpreted was identified as an influencing moderator that contributed to this ethnic group feeling vulnerable and therefore testing practitioners at onset. It is important to note that therapists are not singled out when it comes to seeking self-disclosure, the African Caribbean participants reported that they would do this to their friends as well.

### **7.5.2 Therapists’ experience of self-disclosure**

Where therapists felt secure about themselves they did not have problems about self-disclosure and some reported that this did promote engagement in treatment. One narrative outlines this:

*I don’t have issues with disclosure provided you don’t breach any basic safety, so I will not disclose where I live...what bus I take. But that’s just personal common sense. That’s just our code of practice as well. I think disclosure can have a very therapeutic use and I certainly use it very often. [F2, CBT therapist focus group interview]*

In response to the quote “*If I’m going to tell you about myself, I want to know something about you.*” The respondent further states:

*And I think yes they are right, very often we do ask lots of questions and when people ask you, ‘where are you from’ ...and some people say, ‘why do you want to know that?’...well you know, I don’t have an issue with telling people that I am Spanish. ...I think I do certainly use a lot of self-disclosure, I guess therapeutically within guidelines. [F4, CBT therapist focus group interview]*

## 7.6 Discussion

### 7.6.1 Should a therapist self-disclose?

**“Does my experience match that of the patient or am I being indulgent”?** (C. Pritchard, personal communication, November 23, 2008)

There are situations where a therapist’s experience although similar to a clients’ experience may not match in many respects, for instance; a client may state that his or her mother has died. The therapist may empathize by disclosing that they do understand because they too lost a parent a while go, and can relate to what the client may be experiencing. To play the devil’s advocate here, what happens to that form of therapist self- disclosure when supposedly a client then replies, *“I m glad the old nag is gone, I hated her”?*

Therapist disclosure of similar experiences as their clients (Patterson, 1985) purport the disadvantages may lead clients to query the expertise or competence of the therapist. In particular the perception those problems may not be taken seriously or will be undermined. For instance; *“look at me I got through that problem, you too should be able to get over this soon,”* could result in the client perceiving the therapist as having unrealistic expectations of them. Consequently, the client may feel unmotivated.

Furthermore, there is a danger that the therapist may over-identify with a client’s problems and thus lose focus on the actual presenting problem by focusing on a less pertinent issue. Conversely, clients may be motivated that they have something in common and assume that the therapist will be able to relate to their problem (Carey, 2011). Similarly, Gondim (2006) provides a counselling viewpoint on self-disclosure and argues that when used appropriately this technique can be helpful in the therapeutic process. This is echoed by Beck (2007) she relates using self-disclosure with specific clients she believes would benefit from it. One example she notes in her blog relates to a client with perfectionist

standards and discloses the standards she applies to herself and her children. The unknown area in the *Johari* window in Beck's scenario appears to be when she talks about her son with severe learning disabilities to a client with inferiority issues. She then explores with the client how her self-disclosure might apply to them. Here is an extract from her blog:

*I don't use self-disclosure with every patient but I do with most. .... often gives them a different way of thinking about their problems. .... goes a long way in strengthening our relationship when patients recognize ... I am a human being ... willing to share something of herself to help them (Beck, 2007).*

For some it may harness hope that they will get better, while for others this form of therapist disclosure may normalize their distress and be less stigmatizing. These variables will require investigating in future studies to test their effectiveness.

Therapists should air on the side of caution when matching their experiences to the client's and consider whether this is relevant and would act as a bridge rather than a barrier to engagement in the therapeutic process. Consequently, their disclosure might not be mistaken for indulgence.

Therapists' responses to client-initiated self-disclosure should be sensitive and take into account their cultural background. It is not the content but the context with which the response focuses on. So if a therapist tactfully responded to the client without divulging anything personally but was sensitive in their response, the client felt reassured. The other reason raised by the participants questioned the way clinicians expect to know much about the clients, when they themselves do not want to self-disclose. It is imperative to develop therapeutic rapport based on reciprocity when dealing with self-disclosure issues.

Similar tactics of “testing” therapists existed within the South Asian Muslim participants. Of particular importance was the subject of social class and cast of the therapist if they belonged to the South Asian group, the following narrative illustrates this:

*.....so they asked me whether I was from India or from Sri Lanka...because they are saying confidential things....it's more of a security issue.....for Asians it's very tricky because the caste system is there and I see it from the nurses that they dread the question of which caste are you from ..... it can be very difficult if you are from a lower caste... [F4, CBT Therapist focus group interview]*

Therapists who have worked with refugees, asylum seekers and interpreters also reported this. They would also want to know the therapist's religious beliefs. In some cases the age, marital status and the number of children the therapist had was important in particular to some 1<sup>st</sup> generation lay participants. They related that talking to someone who had for instance, the same number or more children than them was perceived as experienced, credible and an expert. Therefore, they assumed that such a practitioner would be able to relate to their needs more than a practitioner who was not a parent. The following narrative details this:

*...one psychologist recently told me that she was confronted by a woman ... 'do you have children? .... and clearly it was coming from one-upmanship. I have three children,' the psychologist happened to have four, so she had credibility, is what she said, yes I have four children.' If she had said, no and hadn't disclosed, she was gone, there wouldn't have been a relationship. ...clearly this was a big status symbol and very important... [F4, CBT Therapist focus group interview]*

## 7.7 Risks of therapist self-disclosure

Areas to be mindful of relate to therapist –client boundaries these are there to protect both. Risk in self-disclosure and client initiated therapist self-disclosure as highlighted earlier where the therapist's experiences don't match the clients' needs assessing. When working with individuals who have difficult personality traits or presenting with psychosis, therapists need to be aware that in some cases their personal experiences may be used against them and therefore, should balance disclosure with genuineness. Interestingly, Rowan (2008) provides the following commentary on therapist self-disclosure when working with paranoid or delusional patients:

*Self-disclosure is almost obligatory with patients with serious difficulties in decentering, for example those suffering from delusions or paranoid ideation... If a therapist does not disclose what he or she thinks, patients will, in case of doubt, imagine, as the default option, that the therapist wants to trick them. Self-disclosure here is... almost the only action able to preserve the alliance.*

Therapists should weigh the cost and benefits of self-disclosure in such instances. Use of validation of emotions is emphasized here.

### 7.7.1 Tips for therapists

First impressions count, therefore, when asked a personal issue, such behaviours, as hesitation and time taken to respond and the defensive stance sometimes taken by some therapists are likely to result in a client deciding not to engage.

When you are assessing your client, be aware that they are also assessing you and they usually complete their assessment of you before you complete yours. It is therefore, important to respect your client and be cognizant of cultural background so that culturally derived behaviours relating to being secretive, mistrust, need to find out whether the therapist is genuine and would treat the client as human being not just another number

are dealt with appropriately and with sensitivity. When working with refugees or asylum seekers, they may be wary of you and therefore may ask you personal questions to ascertain that you are genuine and would not jeopardize their immigration status. It is worth considering and discussing in clinical supervision those pertinent issues therapists may find difficult to disclose when asked trick questions by clients. Use of role-play in supervision may prove useful.

Self-disclosure has its strengths and limitations; therefore therapist cognizance is of essence to avoid pitfalls such as mismatching your experience with that of the client, over-identification with client problem, and sameness. Use of observational and listening skills is emphasized here to ensure therapists understand clients' experiences and relevance of self-disclosure. In relation to client initiated therapist self-disclosure it is worth adopting a sensitive approach when working across cultures. Where trust is an issue, it might help to pre-empt this at offset, that the therapist does not assume that trust 'is a given right' but will have to be earned as the relationship develops.

## **7.8 Summary**

In conclusion, basic values should be maintained such as treating clients with respect and dignity. Sometimes getting into 'the other's shoes (metaphorically speaking) and treating your client as you would like them to treat you if you were in a similar situation' is fundamental in developing a trusting relationship. How the therapist responds to client initiated self-disclosure maybe as important as the content of the response. For these clients, small elements of self-disclosure and warmth build trust and the feeling of being respected as equals. After all the therapist – client relationship in cognitive behaviour therapy should be the meeting of two experts, the expert client and the expert practitioner who work collaboratively with the aim of helping the client to understand the development of their problems and develop alternative strategies of reducing distress. Given that this theme on client initiated self-disclosure discussed here was limited to the Rathod et al. (2010) qualitative study it is hoped that this article will stimulate a debate on this subject area and encourage researchers to investigate client initiated therapist self-disclosure and its impact on engagement and outcomes in therapy.



**Chapter 8 - A Randomised Controlled Trial of Culturally Adapted Cognitive Behaviour Therapy for Psychosis for Ethnic groups (CaCBTp)**

## 8.1 Introduction

There were an estimated 4.6 million people in England from black and minority ethnic groups according to the 2001 census; however this figure is expected to increase significantly following the recent 2011 census. The relationship between ethnicity and mental health has been the focus of much debate and dispute in this country for several years now. Psychological therapies as currently delivered are grounded in an ineluctably Western version of a person. Socio-demographic factors and cultural background influence perception of symptoms of mental illness and hence, engagement with services. Cultural adaptations and understanding of ethnic, cultural and religious interpretations is an area, which currently remains underdeveloped.

Recent studies in schizophrenia have shown cognitive behavioural therapy (CBT) to be of benefit in the treatment of positive symptoms (Tarrier et al., 1998) and negative symptoms (Sensky et al., 2000). Medication adherence has been improved by a brief CBT intervention in patients with schizophrenia (Kemp et al., 1996) and the intervention has been found to be cost effective (Knapp & Healey, 1998). Other brief interventions (e.g. Turkington et al., 2002) have led to a statistically significant improvement in overall insight and symptoms of depression at post therapy assessment. This was achieved with a brief insight oriented CBT intervention delivered by trained nurses to patients with schizophrenia in the community. The intervention had an impact on time to hospitalisation (Turkington, et al 2006). However, in this study, the African Caribbean group at three months and the Black African group at one year follow up analysis showed higher dropout rates and significantly poorer change in insight compared with the White group (Rathod et al, 2005).

## 8.2 Cognitive behavioural therapy for Psychosis for Ethnic minority groups

There is a paucity of studies on CaCBTp specifically for BME groups. Our empirical data on efficacy of CBTp is mainly based on a generic predominantly western population with very limited BME sample presentation in most RCTs (see table 1). This has raised questions on the efficacy of this intervention for this group following significant dropout rates and poor outcomes in previous trials. Few studies on CBT with BME have to date indicated acceptability. To date two meta-analyses have been conducted on Culturally adapted evidenced based interventions in comparison to traditional treatments by Griner and Smith (2006) with a total of 76 studies and reported efficacy of adapted intervention with an effect size  $d = 0.45$  ( $SE = 0.04$ ,  $p < 0.0001$ ; CI 95% confidence interval of  $d = 0.36$  to  $d = 0.53$ ). When compared with the Wykes et al. (2008) meta analysis of 34 trials assessed using the Clinical Trial Assessment Measure (CTAM) reported a modest effect size  $d = 0.35 - 0.44$ .

In contrast, Huey & Polo (2008) meta-analysis was inconclusive. The authors argued that there was no evidence to suggest that culturally adapted interventions were effective and therefore findings from studies should be taken with caution. As with all meta-analyses methodological rigor has to be taken into consideration, an immediate disparity between the Griner and Smith (2006) and Huey and Polo (2008) meta-analyses was the targeted populations and age group; the later (Huey & Polo) was solely on youth and adolescents whereas Griner & Smith studies were pooled from the adult population.

A recent RCT to evaluate the efficacy of cognitive therapy for low-functioning patients with schizophrenia conducted by Grant, Huh, Perivoliotis, Stolar and Beck (2011) found that CBT was superior to TAU, with clinical significant mean improvements in global functioning (Cohen  $d$ , 1.36 vs. 0.06;  $p = 0.3$ ; similar improvements were observed in negative symptoms (avolition-apathy;  $p < .01$ ; between group  $d = -0.66$ ) and positive symptoms)  $p = .04$ ; between group  $d = -$

0.46) at 18 months follow-up period. Of particular interest in this trial was the ethnic diversity of the sample, of whom 68 % were from minority groups (African American, 31 (65%); Asian American 1 (3 %); Biracial 1 (3%). Attrition rates were low

In light of these recent developments in adaptations of CBT for minority groups, development and modification of culturally adapted CBT for psychosis is justified in order to bridge the gap and improve treatment outcomes. Rathod et al. (2010) recently conducted a qualitative study using semi-structured individual interviews and focus groups to develop culturally sensitive Cognitive Behaviour Therapy for Psychosis for Ethnic minority patients by exploration and incorporation of service users' and health professionals' views and opinions. The project was funded by Delivering Race Equality (DRE: DOH), a Clinical trailblazers group. It has resulted in a culturally adapted CBT for psychosis manual with guidance for health professionals. This present study has been designed to both address the limitations of standard CBTp by taking into account relevant cultural factors and incorporating these within the CBT framework; for instance therapist cognisance of patients' cultural background, beliefs and norms; eliciting whether patient is from an individualistic or collectivist culture will inform direction of adaptations. An often-neglected factor has been acculturation to host culture and acculturation stresses; Impact of emotional expression and limitations language can have if patient's first language is not English, needs to be taken into consideration. The hypotheses tested were that CaCBTp is acceptable and superior to standard treatment as usual (TAU) in symptom reduction as measured by the CPRS in this BME population. It is anticipated that the benefits will be maintained 6 months post-treatment. The CaCBTp randomised clinical trial therefore aimed to:

- a) To assess the feasibility of culturally-adapted CBT for psychosis (CaCBTp) for use in specified Black and minority ethnic (BME) groups.
- b) Assess fidelity of culturally-adapted CBT for psychosis.

- c) To further modify CaCBTp in accordance with findings of pilot.
- d) To design a trainee training package for dissemination.

## **8.3 Methodology**

### **8.3.1 Study design**

This was a single blind multi-site, randomised trial with a 6 month follow-up period of CaCBTp for psychosis for ethnic minority patients compared to TAU.

### **8.3.2 Participants**

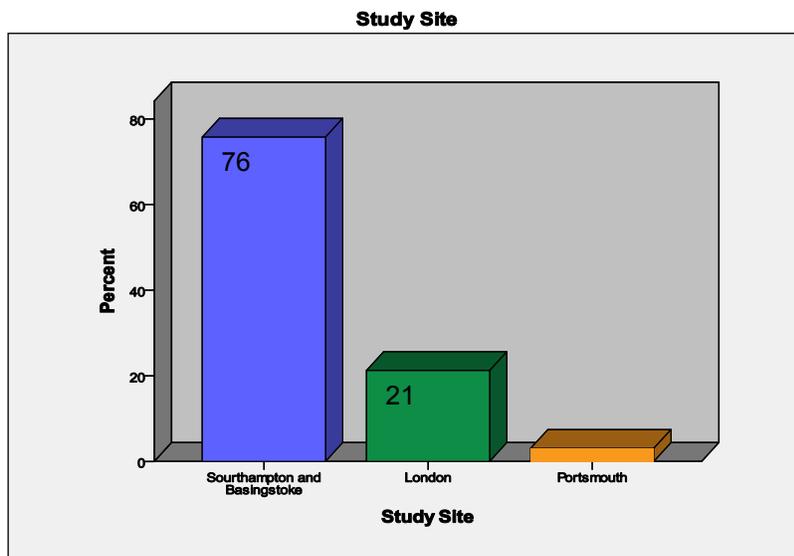
Participants were recruited from the following BME populations:

- Black British, Black Caribbean or African Caribbean (all three terms usually refer to people of Caribbean origin with Caribbean origin parents and heritage, even if they are born in the UK themselves),
- Pakistani or Bangladeshi.

Eligible participants were randomly assigned to either CaCBTp intervention and treatment as usual; or treatment-as-usual alone (TAU). We aimed to recruit a total of forty participants into the trial . This would ensure that, even after loss to follow-up, there would be at least 12 subjects per group for analysis (FDA guidance <http://www.fda.gov/cder/guidance/5356f1.pdf>). Randomisation was stratified by ethnic group as stated above.

### 8.3.3 Study centres

A three centre study conducted in the UK, namely: Hampshire (Southampton/ Portsmouth sites), London (Central and North West London Mental Health Trust) and Manchester (Penine Trust in Lancashire and Greater Manchester sites, although this site was excluded in the early stages of the trial due to delays in setting up study). The centres provided a good mix of urban inner city and suburban population which it was hoped would allow for generalisability of findings to a wider UK population. The Manchester centre was going to provide the majority of the South Asian Muslim participants given its geographic location and concentration of this group in the Midlands, however, we utilised the Southampton site for this group. Graph 7 below shows distribution of participants by site.

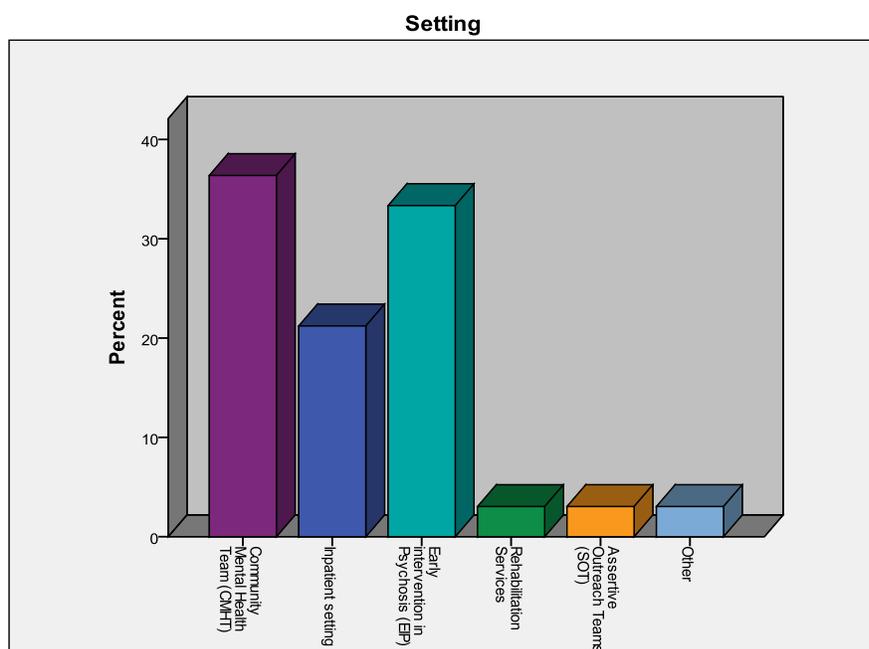


Graph 7: Study site

## 8.4 Recruitment of participants

Recruitment of individuals with a diagnosis of schizophrenia, schizo-affective disorder, psychosis and or delusional disorders was conducted from May 2009 to December 2010 by the author (PP) firstly, by approaching the local mental health teams (CMHTs), specialist services including Early Intervention in Psychosis (EIP), Assertive Outreach Teams (AOT) and Rehab

services and Forensic inpatient services; permission to approach suitable potential participants was obtained from the responsible medical officers (RMO) or clinical team. Suitability of potential participants was determined by the Consultant and/or Care co-ordinators from the respective services. Patient information sheets (Appendix 12) were given by the Consultant and Care co-ordinators who explained the study in detail. The author (PP) did not approach potential participants until they had indicated interest in taking part to their clinical team member. Written informed consent (Appendix 9 ) was obtained before recruitment from all participants.



**Graph 8: Settings**

### **8.4.1 Assessment and recording of patient’s capacity**

This was a requirement by the Ethics committee given the vulnerability of this client group.

Assessment of capacity was based on the 5 core principles of the Mental Capacity Act (2005)

Section 3. Capacity to consent was specific to the research study.

Section 3 of the Mental Capacity Act (2005) states that:

- *if a person is unable to make a decision for himself i.e. he is unable to:*

- *understand the information relevant to the decision*
- *retain the information use or weigh the information*
- *communicate his decision (by any means)*

It was not assumed that a person could not make any decision because of their diagnosis or age or behaviour. The Consultant and/or Care co-ordinator was encouraged to take necessary steps to helping patients make decisions. These steps included recognising language and cultural differences, giving right amount of detail and pacing the information, checking for understanding and repeating if necessary and/or involving an advocate. The Consultant and/or Care co-ordinator were asked to record a summary of capacity assessment in the patient's clinical notes.

The researchers approached potential participants only if they indicated their interest to take part in the study to their clinical team member (e.g. Consultant and/or Care co-ordinator).

#### **8.4.2 Loss of capacity during research**

In case of loss of capacity during the trial, participation would be withdrawn and the data collected up to that point would be anonymised.

#### **8.4.3 Inclusion criteria**

1. Individuals between ages 18 and 65 with a diagnosis of schizophrenia using ICD-10 criteria
2. Belong to an ethnic minority community :

Black British, Black Caribbean or African Caribbean (all three terms usually refer to people of Caribbean origin with Caribbean origin parents and heritage, even if they are born in the UK themselves),

South Asian Muslim (Pakistani and Bangladeshi)

3. Willingness to participate in the interview and have notes made and/or be tape recorded.

Reasons for non participation may be explored in further interviews.

4. Have capacity to consent and understand the interview. If capacity present, decision making process around psychotherapy may be recorded.

5. At this stage we will include only those who can speak English or are willing to participate with the assistance of interpreters.

Patients detained under the mental health act (1983) in hospital or under a community treatment order (CTO) were deemed eligible for participation, this was in line with the literature review on this population, as it demonstrated that they remain over-presented in inpatient services and under detention. In total (n = 2) were under section 37/41 of the mental health act; (n = 5) under section 3; (n = 1) Community treatment order; (n = 3) had informal status when recruited to the study.

#### **8.4.4 Exclusion criteria**

1. Severe illness which may affect capacity or markedly affect their ability to participate in interview, e.g. very thought disordered or distressed by symptoms.

2. Lacks capacity or not agreeing to consent

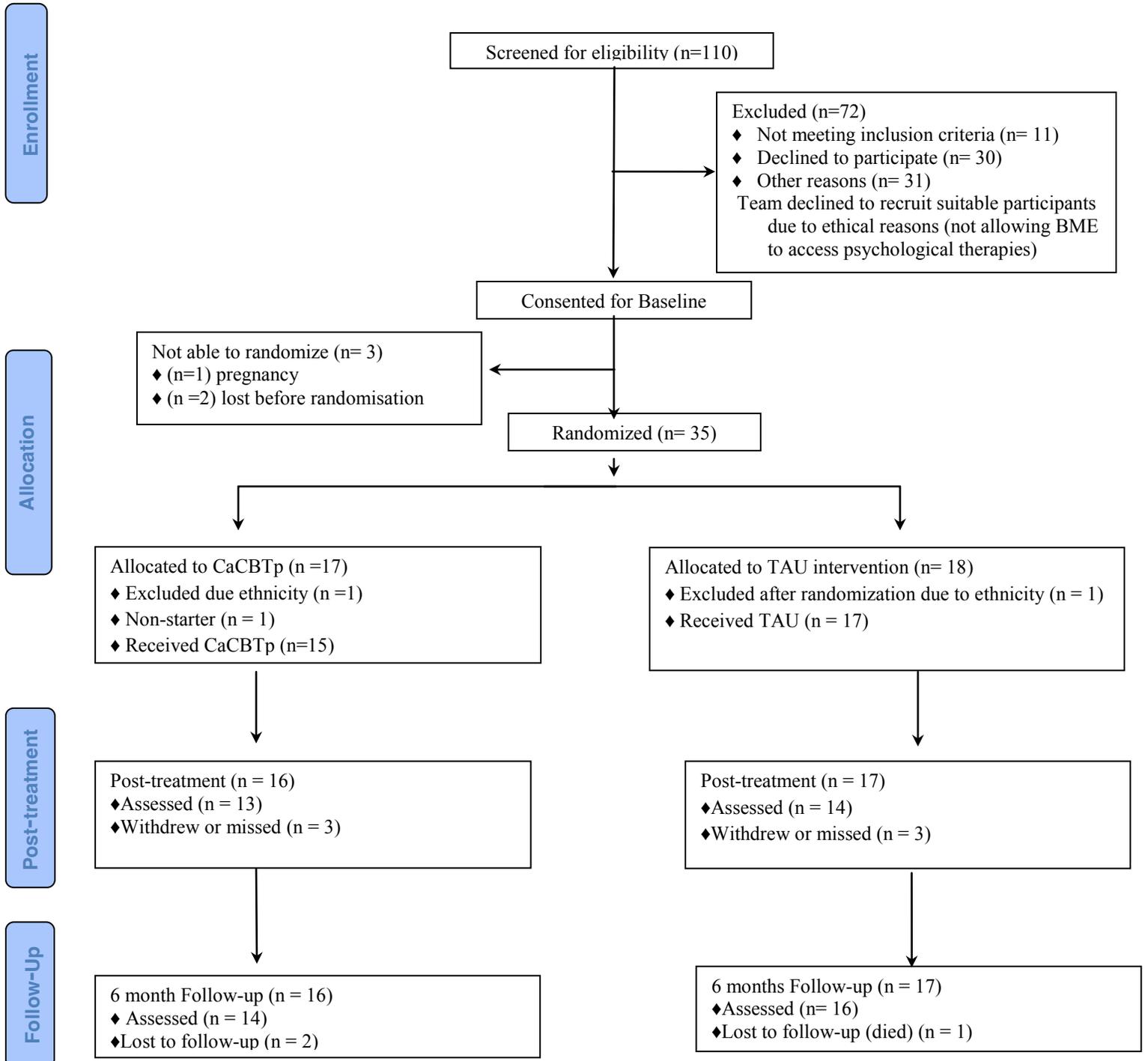
3. Those patients who in the opinion of the Care Co-ordinator would be thought to be distressed by the interview due to low insight.

#### **8.4.5 Randomisation process**

Once written consent was obtained participants were contacted by the assessors for baseline assessment. This was followed by randomisation process conducted at a remote place in Winchester by an independent administrative secretary who was contacted by the researcher to open an envelope from the specific site. Block randomisation also known as random permuted blocks was used in this trial to ensure that similar numbers of participants were allocated to each arm of the trial (Altman & Bland, 1999).

Figure 8: Study consort diagram

### CaCBTp CONSORT Flow Diagram





## **8.5 Treatment and Control procedures**

The treatment arm group was offered 16 sessions of CaCBTp over a period of 16 to 20 weeks from the author (PP) and two London based trial therapists (LW & AS) who were trained CaCBTp. All therapists were accredited by the British Association for Behavioural and Cognitive Psychotherapies (BABCP). Two were clinical psychologists and the lead researcher (PP) a nurse therapist. For participants in the TAU group details of how to access the therapy were provided at the end of the trial. Non-English speakers were not excluded in the trial and therapy was provided through an interpreter.

Prior to the trial therapists attended a one day training workshop led by (DK, PP & SR). During the study all therapists received ongoing CaCBTp supervision through teleconference lasting an 1hr and a half.

THERAPY PHASE	BLACK AFRICAN & AFRICAN CARRIBEAN	SOUTH ASIAN MUSLIM
Pre-engagement/ Engagement	<ul style="list-style-type: none"> <li>• Pathways to care: <ul style="list-style-type: none"> <li>○ Not usually through own community</li> <li>○ Avoid contact with services causing delay so tending to present in crisis</li> <li>○ Use of police – by community or own family or arrest</li> </ul> </li> <li>• Fear of people thinking I'm losing my mind – shame – lead to denial</li> <li>• Self-disclosure by therapist facilitates</li> <li>• Patients sent home to C</li> <li>• Religion/superstition <ul style="list-style-type: none"> <li>○ 'Obeahmen' &amp; traditional remedies also.</li> <li>○ African - witchcraft</li> <li>○ AC – voodoo practice</li> <li>○ Tradition of wearing clothes inside out – 6<sup>th</sup> Jan Feeding of ancestors – ward off spirits (like All Saints day)</li> </ul> </li> <li>• Racism <ul style="list-style-type: none"> <li>○ Slavery – big issue – linked to racism, especially if made to feel inferior</li> <li>○ Family still living in plantation areas in Caribbean – acknowledgement/validation</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Pathways to care: <ul style="list-style-type: none"> <li>○ Through own community – advantages and/or delays</li> <li>○ Crisis presentation may occur</li> </ul> </li> <li>• Gender an issue – less if 1<sup>st</sup> gen. or married to white person</li> <li>• Shame – women and impact on marriage/divorce</li> <li>• Community grapevine influences – talking therapies new concept</li> <li>• Patients may be sent 'home' to Asia</li> <li>• Religious issues <ul style="list-style-type: none"> <li>○ Also work with healers – needs acknowledging</li> <li>○ Islamic festivals – awareness because of relevant customs</li> <li>○ Praying as normal or exaggerated activity</li> </ul> </li> <li>• Expectations: <ul style="list-style-type: none"> <li>○ Of medication</li> <li>○ Instructive cfd to collaboration</li> </ul> </li> <li>• Effect of racism less pronounced</li> </ul>
Assessment	<ul style="list-style-type: none"> <li>• Cultural identity</li> <li>• Loss &amp; uncertainty of culture is an issue – not knowing esp. when educated/born here</li> <li>• Cannabis use – also illegal in C. but may be seen as part of 'my' culture</li> </ul>	<ul style="list-style-type: none"> <li>• Cultural identity</li> <li>• Movement of traditions, values, etc. from country of origin</li> <li>• Local community norms – increase in religious standards</li> </ul>

	<ul style="list-style-type: none"> <li>• Fragmentation of family</li> <li>• Attributions – calibrating psychosis</li> <li>• Spiritual (Christian) &amp; religious <ul style="list-style-type: none"> <li>○ Evils, devils, black magic, evil eye</li> </ul> </li> <li>• Police</li> <li>• Language: patois or Creole: not say what mean – check out</li> <li>• Sigh, click lips – not necessarily mean anger/annoyance</li> <li>• Expressiveness</li> <li>• ‘Yeh ... man’ – reflecting – needs to be genuine: their own language</li> <li>• Talking to God &amp; voices, baptised in spirit especially common – ‘spirit came over me’</li> </ul>	<ul style="list-style-type: none"> <li>• Integration of country of origin</li> <li>• Attributions</li> <li>• Spiritual &amp; religious <ul style="list-style-type: none"> <li>○ Evils, devils, black magic, evil eye</li> </ul> </li> <li>• Language: Urdu, etc.</li> <li>• Bow as sign of respect – no response may lead to issues</li> <li>• Superficially trying to please – so impairs communication of concerns/anger</li> <li>• Not maintain eye contact – not sign of schiz – esp. men to women therapist</li> <li>• Body language may be a clue where particularly compliant</li> <li>• ‘Echoing responses – mm... Etc.’</li> <li>• Thank you – <i>shukria</i> (Urdu for thank you) – acknowledge identity</li> </ul>
Formulation	<ul style="list-style-type: none"> <li>• Attributions &amp; culture</li> <li>• Cultural formulation</li> <li>• Diagrams OK may be especially useful</li> <li>• Somatic symptoms – supernatural attribution</li> </ul>	<ul style="list-style-type: none"> <li>• Attributions &amp; culture</li> <li>• Diagrams – OK – may be especially useful</li> <li>• Draw from cultural philosophers – beliefs re Koran; man disrespecting wife</li> <li>• Somatic symptoms may start as ‘physical’ move to ‘emotions’ when reframing accepted – attributed to illness as well as religion.</li> </ul>
Delusions	<ul style="list-style-type: none"> <li>• Cultural attributions to take into account – calibrating</li> <li>• Reasoning approach – use guided discovery/imagery – questioning style: more direct style once culture understood</li> </ul>	<ul style="list-style-type: none"> <li>• Cultural attributions</li> <li>• Reasoning approaches – ‘my fate’ - draw in from religion. ‘My <i>jinn</i>’ – acknowledge – why you not others – curiosity.</li> </ul>

	<ul style="list-style-type: none"> <li>• Conversational style – may divert from agenda – how to handle: questioning may be particularly challenging, ‘why are you analysing me’</li> <li>• Questionnaires need considering.</li> <li>• Worry – Christian: don’t worry – leave it to Christ.</li> <li>• Dominance of father in AC families where present – disrespect to challenge them</li> </ul>	<ul style="list-style-type: none"> <li>• Worry – ‘Will of Allah’</li> <li>• Decision-making/assertiveness – especially in women – especially toward family. ? Preamble, etc. needed.</li> </ul>
Voices	<ul style="list-style-type: none"> <li>• Religious – Christian</li> <li>• Normalising.</li> <li>• Coping – praying</li> </ul>	<ul style="list-style-type: none"> <li>• Religious – linked to <i>jinn</i>.</li> <li>• Normalising</li> <li>• Coping – praying, use of Quran verses</li> <li>• What does Allah say? set as task</li> </ul>
Negative	<ul style="list-style-type: none"> <li>• Maintain AC energy – ‘self-fulfilling prophesy’ of avoiding contact</li> <li>• Cultural context ‘motivators’ – excitability</li> <li>• Fear of cycle – expectations</li> <li>• Reinforce stigma/racism – effects on relationships</li> </ul>	<ul style="list-style-type: none"> <li>• Work expectations – family pressures high – but support of family/family businesses</li> </ul>
Presentation: Sub-groups	<ul style="list-style-type: none"> <li>• Stress-sensitivity – late presentations</li> <li>• Drug-related - police, stigma, violence – part of my culture – use of cannabis/alcohol [legal/illegal]</li> <li>• Trauma - ?possibly low - ?equate to differing prevalence of BPD in different cultures</li> <li>• Anxiety – perhaps perpetuated by racist incidents</li> </ul>	<ul style="list-style-type: none"> <li>• Stress-sensitivity – also present late as emerge slowly</li> <li>• Drug-related -- low</li> <li>• Trauma – physical/emotional abuse (rare sexual)</li> <li>• Anxiety – racism, etc.</li> </ul>

Table 11 Treatment overview

CaCBTp intervention was delivered by first author (PP) and (LW and AS, London site trial therapists). Treatment consisted of 16 sessions of CaCBTp. Like standard CBTp sessions were held on a weekly basis and varied in duration from 40min to one and half hours. The settings varied (see graph 8) and accommodated patient preferences. The above table displays the different phases of the adapted intervention. Therapists had access of the Kingdon & Turkington, 2005 Manual and a supplement booklet of culturally adapted CBT. Therapy was audiotaped where consent was obtained.

**Case examples:**

a) Assessment phase: British South Asian Muslim participant (Appendix 20).

b) Relapse Prevention Plan: –Safiya (Appendix 21).

c) Addressing self-harm: British African Caribbean participant (Appendix 22).

**8.5.1 Inter-rater reliability**

The blind assessors were trained in conducting the CPRS and Insight scale by the authors (DK, PP).

Correlations			Rater1	Rater2
Kendall's tau_b	Rater1	Correlation Coefficient	1.000	.456**
		Sig. (2-tailed)	.	.000
		N	68	68
	Rater2	Correlation Coefficient	.456**	1.000
		Sig. (2-tailed)	.000	.
		N	68	68
Spearman's rho	Rater1	Correlation Coefficient	1.000	.481**
		Sig. (2-tailed)	.	.000
		N	68	68
	Rater2	Correlation Coefficient	.481**	1.000
		Sig. (2-tailed)	.000	.
		N	68	68

\*\* . Correlation is significant at the 0.01 level (2-tailed).

**Table 12: Correlations (Inter-rater reliability)**

## 8.5.2 Treatment as Usual

Definitions of TAU vary according to services and across the nation. Generic TAU within the NHS in mental health services involves pharmacotherapy, regular monitoring by a multi-disciplinary team (as per care programme approach: CPA level) including outpatient clinic appointments with a Consultant Psychiatrist, Specialist registrar, or Senior Housing Officer; care co-ordinator and support worker input with social activities; occupational therapist (Foster, Startup, Potts and Freeman, 2010) or attendance at day centre for meaningful activities such as art, drama, voices group etc. It is worth noting that some specialist services such as Early Intervention in Psychosis (EIP) would have psychological interventions as standard treatment as usual; as was the case in Manchester and London sites, therefore making it difficult to recruit participants from these sites.

### **8.5.3 Monitoring medication during the trial period**

Medication was recorded at baseline for all the participants. The assessors recorded any changes of medication during the course of the trial. Where data was missing from the assessment the researcher (PP) liaised with key workers and or checked participant electronic records (RIO system). Antipsychotic medication was calculated as chlorpromazine equivalents (mg/day) using the formulae recommended by (Atkins, Burgess, Bottomley, Riccio, 1997).

## **8.6 Outcome measures**

Independent assessors blind to the treatment allocation conducted the following outcome measures. They were trainee psychiatrists (SS, CU, UP, MT) level of qualification ranged from ST4 to Specialist Registrar.

### **8.6.1 Comprehensive Psychopathological Rating Scale (CPRS: Asberg, Montgomery, Perris, Shalling, Sedvall, 1978)**

The Comprehensive Psychopathological Rating Scale (CPRS) a well validated scale comprising 67 items scale developed in England and Sweden, covers a range of psychopathology sensitive to change in the severity of acute schizophrenia (Asberg et al., 1978). Following its modification by Montgomery et al (1978) it was deemed applicable and reliable for use cross-culturally. Each items was scored on a 4 point likert scale with discriptors rating intensity, duration and frequency ranging from 0 (not present) to 3 (severe). It can be administered by a trained mental health practitioner. Items 1- 40 provide subjective responses by the pateint . Items 40- 65 are observer rated by the administering interviewer with the last two items (66 and 67) measuring global view of illness and rater reliability respectively (Kastrup and Bech, 1985). Reduction in overall CPRS scores post therapy was primary outcome.

Several subscales were derived from the CPRS namely;

### **8.6.2 The Montgomery-Asberg Depression Rating Scale (MADRAS: Montgomery & Asberg, 1979)**

This 10 items subscale measures symptoms of depression.

### **8.6.3 The Schizophrenia change scale (Montgomery, Taylor and Montgomery, 1978)**

Montgomery, Taylor and Montgomery (1978) abstracted 12 items from the CPRS that were sensitive to change in schizophrenia symptoms and tested them against another widely scale the Brief Psychiatric Rating Scale (BPRS: Overall & Gorham, 1962).

### **8.6.4 Brief Anxiety rating scale (Tyrer, Owen, Cicchetti, 1984)**

A 10 item subscale abstracted from the the CPRS measuring anxiety symptoms

### **8.6.5 Brief Assessment of Negative Symptoms Scale (BRAINS: Hansen, Turkington, Kingdon & Smith, 2003)**

Hansen et al. (2003) developed a new brief rating scale sensitive to measuring change in negative symptoms of schizophrenia based on 10 items selected from the CPRS. These 10 CPRS items had a correlation ranging from 0.56 at baseline to 0.87 at follow up with the validated scales such as the Scale for Assessment of Negative Symptoms (SANS: Andreasen, 1983) and the Positive and Negative Symptoms in Schizophrenia scale (PANSS: Kay, 1991).

### **8.6.6 Insight in Psychosis scale (David, 1990)**

David (1990) developed the insight scale to rate with three domains namely; compliance with treatment; awareness of illness and Relabelling of psychotic experiences correctly. The schedule for assessing these three domains of insight have items ranging on a descending scale from 2 (being often); 1 sometimes and 0 ( being never: indicating lack of insightful). These ratings are based on a clinical interview and scored following subjective responses from the patient. The total score is 14.

### **8.6.7 Patient Experience Questionnaire – post treatment (PEQ; IAPT, 2008)**

Satisfaction with the therapy was assessed by a questionnaire designed for this purpose. The Post –treatment Patient Experience Questionnaire (PEQ) designed and used in the IAPT services for assessing patient experience and evaluation of the quality of therapy, choice and their overall satisfaction was adopted for use in the trial for participants in the intervention group (CaCBTp) at the end of therapy.

The PEQ is composed of 11 items scale. Items 1-10 ask respondents to indicate whether needs were met on a two point scale 1 'being yes and 2 being no'. Questions are on a 5 point scale ranging from 0 not satisfied to 5 very satisfied with services. This scale is administered to the treatment group at the of therapy intervention. Item 11 captures qualitative data on any recommendations for improvement. Acceptability of the intervention as assessed by satisfaction, number of sessions attended and drop-out rates.

Fidelity was measured by review of therapy audio tapes, only (PP) was able to record sessions. Author (PP) had tape excerpts listened to regularly at supervision by supervisor (DK) during individual supervision. Regular teleconference supervision groups were held between (PP, LW, AS and DK).

### **8.6.8 Blinding**

The assessors (CU, SS, MT, UP) were blind<sup>9</sup> to allocation for the duration of the trial. They were all trainee Psychiatric doctors and were trained to administer the outcome measures by authors (PP and DK). They were independent from the therapists (PP, LW, AS) and blind to the randomisation status of the participants. The therapists were blind to treatment allocation and only became aware once patients were assigned to them for treatment in

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<sup>9</sup> Blinding is a procedure used to conceal or mask the assessors, i.e. keeping them ignorant as to the treatment arm the participants received (Earl & Slater, 2002, p44)

the CaCBTp arm. The rationale for blinding was to reduce selection bias and outcome bias. During training on the use of measures the assessors were encouraged to adopt a conversational style interview schedule that was culturally sensitive when administering the outcome measures CPRS and Insight in Psychosis scale. These measures were completed simultaneously at three time points, that is, at baseline, post-treatment and at 6 months follow-up. Consent to access participants was sought (detailed in section 1.4 and 1.4.1)

### **8.6.9 Ethical considerations**

Ethics approval for the trial was obtained from Southampton Committee (B); REC: 08/0504/5. Trial number: ISRCTN95603741. Research and Governance approval was granted at all sites. Confidentiality was protected by anonymisation of data, and only where written informed consent was unambiguously given then patients were enrolled in the trial. Data was collected in a non-coercive manner.

The research team that was involved with the project were all registered mental health practitioners (PP, SR, DK, CU). The author (PP) was an accredited therapist by the British Association of Behavioural and Cognitive Psychotherapies (BABCP) body. The researchers (PP, CU) also had obtained enhanced CRB checks and explicit permissions for access to participants in the three UK sites Hampshire (Southampton; Basingstoke), West London and Portsmouth.

## **8.7 Statistical Analysis strategy**

This exploratory trial will provide estimates of effect size that may inform a fully powered RCT of the intervention. Intention to treat (ITT) analysis was performed on the primary outcome measure of reduction in overall CPRS scores post-treatment. ITT principle posits inclusion of all participants randomised to the trial to their assigned arm regardless of intervention assigned being completed or not (Altman et al, 2001) therefore complete

case analysis which violates this principle was considered not suitable (Hollis & Campbell, 1999) however, given the nature of 'missingness', that is, data missing not at random (MNAR) assumption performing a complete case analysis with sensitivity analysis was appropriate for imputation of missing data. The outcome of the two groups was evaluated using analysis of covariance post-treatment and 6 months follow-up. Secondary continuous outcomes were also analysed using analysis of covariance. Binary outcomes were analysed using logistic regression. All continuous outcome variables were checked for the assumption of normality. If the assumption was not met, data transformations or equivalent non-parametric tests were conducted. Pearson's' correlation coefficients were used to examine the relationships in the PEQ items with outcomes. Analysis will estimate main effects for change in the three time points from baseline to post-treatment and at 6months follow-up in the new intervention; taking account differences at baseline. The following adjusted analysis of the relevant covariates was conducted to assess for confounding factors: age, medication and gender.

These analyses were compared to unadjusted analyses to adjust for confounding variables (for example, I may adjust for medication (CPZequivalent dosage), age, gender and duration of illness) that may differ by chance between the two groups. One way repeated measures ANOVA analyses were conducted on baseline covariates following observations of imbalances between the two groups in order to test whether baseline imbalance between the treatment groups was related to outcomes. PEQ analysis involved descriptive data on each item relating to patient satisfaction of the treatment group only. Comparison of mean satisfaction scores involved t-test on gender and ethnicity. Analysis of variance was employed to test if there was any significant difference in participant satisfaction according to therapist /centre. Dichotomous items are presented in pie charts. Nonparametric tests were used to explore associations between variables. Relationship between continuous variables was assessed through correlation. Pearson's  $r$  and Spearman's rank correlation coefficients were used where appropriate. P -values of less

than .05 levels were considered significant. IBM Statistical Package for the Social Sciences version 19 for Windows (SPSS Inc., Chicago) was the statistical package of choice. The study was reported in accordance with the CONSORT (Consolidated Standards of Reporting Trials: Moher et al., 2001) statement and ICH Guidelines for Good Clinical Practice.

### **8.7.1 Power analysis**

Power calculations were informed by previous pilot studies (e.g. Turkington and Kingdon, 2000).

## Chapter 9 - Results

### 9.1.1 Preliminary Analysis

Demographic data was collected and coded between May 2009 to December 2011. Table 16 displays the demographic characteristics of the participants. A total of 35 participants were randomly allocated to either CaCBTp group (n = 16) or TAU group (n = 17). The mean (SD) age was 33.55 (11.60) years. Gender breakdown was composed of 20 (61%) male and 13 (39%) female. African Caribbean were 9 (27%); Black British 5 (15%); Mixed Race 10 (30%); South Asian Muslim 9 (27%); (Pakistani 6 (18%); Bangladesh 2 (6%) and Iranian 1 (3%). Duration of illness: mean (SD) was 10.39 (8.63).

The consort diagram figure 8 displays the recruitment of allocation of participants into the trial. A total of 110 participants were identified and screened for eligibility. Of those screened 72 were excluded for the following reasons: (n = 30) declined to participate; 11 service users did not meet the inclusion criterion. A total of 31 participants from an Early intervention in Psychosis service who met the criteria for inclusion were declined participation by their team apparently due to ethical reasons, the team was concerned that their participation in a randomised trial may deny them (BME) access psychological therapy should they be randomised to TAU. In total (n = 38) participants consented for baseline assessment, however two were lost before randomisation and one participant who was pregnant decided to withdraw her consent. Consequently, 35 participants were randomised to the CaCBTp study. Two participants randomised to either group were excluded from the study and analysis following randomisation when it was discovered that their ethnicity met the exclusion criteria (both were of Indian origin) and had their ethnicity recorded as Pakistani. In line with literature that BME groups are over-presented and admitted to hospital under mental health act; from our total sample of (n = 33), those detained under the mental health Act made up 18% of the total sample ( 15% were in forensic settings, n= 3 under section 37/41). The CaCBTp group was allocated (n = 16)

and TAU group (n = 17). Post-treatment assessment was (n = 13) in the CaCBTp group and (n = 14) in the TAU.

In order to assess the Gaussian distribution (to determine assumptions of normality and homogeneity of variance) of the data following allocation of participants to either treatment group or control group, graphical displays of histograms were generated. The following examples of normal and skewed distribution are displayed below (figure 9) and the rest are in the appendices. Data was normally distributed; the bell shape had a peak in the middle and showed symmetrical tails for variables such as age, total insight.

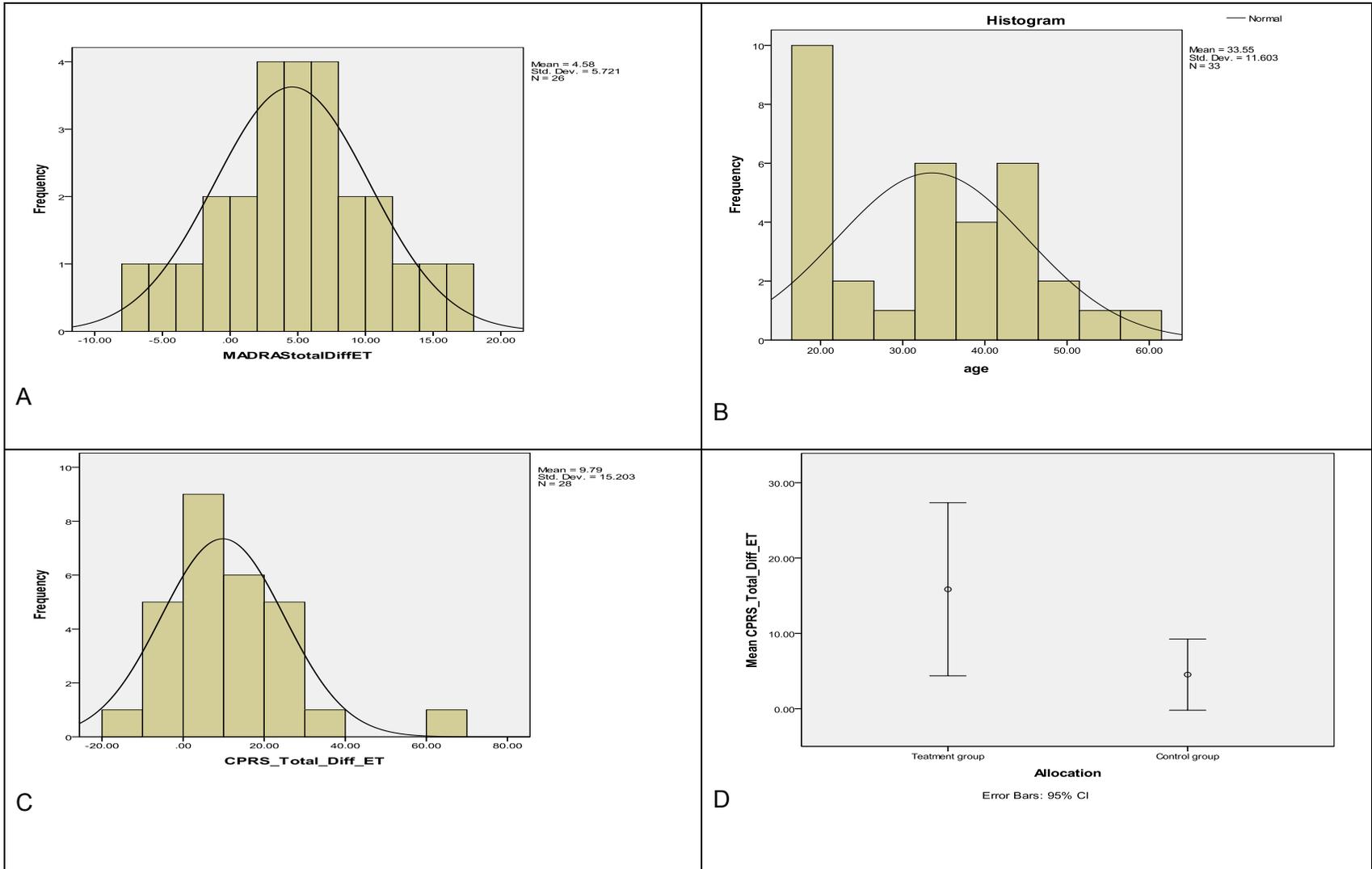


Figure 9 Histograms

A: MADRAS displays normal distribution

B: Age histogram

C: CPRS Total diff end of treatment

D: Mean CPRS Total diff ET: above displays a standard error bar chart summarising the results of the mean CPRS Total difference post-treatment. The treatment gains at 6 months follow-up were significantly sustained in the CaCBTp group, whereas the TAU did not maintain its gains (see main results in section 9.2 table 17).

Attrition rates between baseline and post-treatment were similar in both groups 9% withdrew/ missing. Two participants in the TAU were seen by psychologists for psychological input, therefore violating their group allocation however, their data was included in the analysis.

### 9.1.2 CPRS Total difference scores post-treatment.

The CaCBTp group outperformed TAU group post-treatment. Group standard deviations were significantly different, moving away from the assumption of homogeneity of variance.

The mean CPRS total difference post-treatment: CaCBTp group (M = 15.84; SD = 19.00) and TAU group (M = 4.53; SD = 8.51) respectively, the one way ANOVA showed a significant effect:  $F(1, 26) = 4.33$ ;  $p = 0.04$ , Partial eta squared = 0.14, a large effect (Cohen, 1988). This result confirms the hypothesis that the new intervention was effective in reducing CPRS total scores in the CaCBTp group.

On the contrary, repeated measures MANOVA tests of between-subjects effects had a significant effect on CPRS Total adjusting for baseline:  $F(1, 23) = 9.73$ ;  $p = 0.05$ , Partial Eta squared = 0.29, a large effect.

### 9.1.3 Managing Missing data

Missing data methods commonly used in literature are displayed in **table 13** below, they have been considered in this present study to inform choice of best fit method.



**Table 13** Summary of missing data approaches drawn from literature

<b>Missing data methods</b>				
<b>Methodology</b>	<b>Assumption</b>	<b>Strengths</b>	<b>Limitations</b>	<b>Fit for trial</b>
Regression substitution	Utilises a regression substitution estimate to replace a missing data point	Superior to LOCF & Mean Substitution	Bias in correlation and overestimation of precision due to replacement of missing data with values with minimal variability	Maybe not
*Mixed effects Regression model (MRM)	Laird & Ware (1982) Assumes that data are ignorable; MAR assumption	Utilises all observed data	Holds assumption that data is missing at random	Best fit
Sensitivity analysis	Compares the results of two analyses; one with the worst possible outcome and the best possible outcome to all missing data from both groups	Strengthens robustness of primary analysis and justifies choice of approach, if results are consistent and lead to similar estimates of treatment effect	Can be time consuming; also may obscure overall findings if not clearly presented	Best fit
	Uses participants last observation as an estimate of their missing observation	Where measurements are expected to be relatively constant over a period of time	LOCF assumptions may not hold true	No
		Respects ITT principle	Inflates degrees of freedom and increases likelihood of type 1 error	
		Is conservative	May underestimate improvement in the treatment arm	
Last Observation Carried Forward		Ideal for use only where assumptions are plausible	Treats imputed and observed values on an equal level and does not account for any realistic trajectory	

Mean substitution	Known to reduce the effect of correlation between the measures		Mean substitution does not preserve relationships among other variables in the data	No
MLM/E-M	No qualitative difference between dropouts and completers		Computes estimates of missing data based on the observed sample data	Maybe
Single Imputation	Involves replacing missing values with plausible values	Replacing missing value with one made up value Reduces bias	Overestimates precision	No
Multiple Imputation	Involves creating two or more imputations for each missing value	Can hold true if MCAR; MAR; imputation model can incorporate a variety of variables to help the prediction	Does not distinguish between observed and imputed values Loss of information Biased parameter estimates	Maybe
Complete case analysis (list wise deletion)			Loss to power resulting from used partial data (non-completers)	No

## Missing data at two time points

	Post- treatment		Follow-up	
	CaCBTp (n=16)	TAU (n=17)	CaCBTp (n=16)	TAU (n=17)
Missing outcome	9%	9%	6%	3%
Mean of observed outcome	16.23	18.6	19.57	17.56
SD of observed outcomes	10.77	14.84	12.94	14.57

**Table 14: Missing data at two time points**

Pattern of missingness in the CaCBTp trial			
CPRS outcomes recorded	CaCBTp	TAU	Total n
Baseline missing	0	0	0
Post-treatment missing	3	3	6
6 Follow-up missing	2	1	3
Completed Post-treatment & Follow-up (no missing data)	11	13	24
Total	16	17	33

**Table 15: Pattern of missingness in the CaCBTp trial**

Attrition rates were low when compared with similar CBTp studies. However, it was vital to conduct conservative analysis on missing data (table16) on the primary outcome CPRS and Insight in Psychosis scale. The overall strategy of the sensitivity analysis followed a range of two parameters. In this model 1 used the maximum and minimum values of the CPRS scores. Sensitivity analysis was conducted for each parameter individually using the parameter values (worst and best values: 69 and 0) on the main outcome measures as described before. Unresponsive parameters were then excluded from further analysis. The responsive parameters were then considered for correlation with each other. Sensitivity analysis tested the nature of missingness of data under two assumptions. The first assumption hypothesised that missing values on the TAU group had the best value 0, meaning that the group had the best result, in contrast to the CaCBTp group which under this assumption was awarded the worst value 69, meaning that, this group's missing values had the worst result. The second assumption hypothesised that the CaCBTp group's missing data had the best values 0, meaning that the group had the best result, whereas, the TAU under this assumption was imputed with the worst values 69. This

meant that this group's missing values had the worst result. Separate data sets were created on SPSS and labelled as sensitivity high (maximum values) and sensitivity low (minimum values) and analysed accordingly under both assumptions.

### **Statistical analysis strategy (see section 8.7)**

- Preliminary analyses tested for normality distribution of study variables and for between group comparability on demographic variables (age, gender, medication and duration of illness) and other potential confounding factors.
- Analysis was on ITT basis.
- Treatment impact was assessed utilising repeated measures ANOVA (testing for effect of Time, group and Time X Group interactions).
- Missing data was considered and therefore secondary conservative sensitivity analysis were conducted
- Unadjusted analysis & Adjusted analysis will be presented accordingly.
- Pearson's correlation and Spearman's rank were used on PEQ

## 9.2 Main analysis

Demographic data was collected and coded between May 2009 to December 2011.

Baseline demographics characteristics are detailed in the table below.

### Baseline Demographic Characteristics of the participants

	Total sample (n= 33)	CaCBTp (n= 16)	TAU (n= 17)
Gender n (%)			
Male	20 (61%)	10 (63%)	10 (59%)
Female	13 (39%)	6 (37%)	7 (41%)
Age			
Mean age at trial entry (years)	33.55	31.37	35.58
Standard deviation	11.60	12.43	10.72
Ethnicity n (%)			
African Caribbean	9 (27%)	5 (31%)	4 (24%)
Black African	5 (15%)	1(6%)	4 (23%)
Mixed Race	10 (30%)	4 (25%)	6 (35%)
Pakistani	6 (18%)	3 (19%)	3 (18%)
Bangladesh	2 (6%)	2 (13%)	0
Other (Iranian)	1 (3%)	1 (6%)	
Duration of illness			
years (mean)	10.39	8.56	12.33
Standard deviation	8.63	8.24	8.88
CPZ equivalents			
Mean (mg/day)	456.36	407.30	502.54
Standard deviation	(472.10)	(392.62)	(544.59)
Marital status, n (%)			
Single	26 (79%)	14 (87%)	12 (71%)
Married	5 (15%)	2 (13%)	3 (17%)
Divorced	2 (6%)	0	2 (12%)
Employment status, n (%)			
Unemployed	28 (85%)	13 (81%)	15 (88%)
Student	3 (9%)	2 (13%)	1 (6%)
Employed	2 (6%)	1 (6%)	1 (6%)
Setting			
Inpatient Forensic services	7 (21%)	3 (19%)	4 (24%)
Rehabilitation	1 (3%)	1 (6%)	0
Assertive Outreach Team	1 (3%)	1 (6%)	0
Early Intervention in Psychosis (EIP)	11 (33%)	7 (44%)	4 (23%)
CMHTs	12 (37%)	4 (25%)	8 (47%)
Other (Immigration centre)	1 (3%)	0	1 (6%)
Centre			
Southampton	25 (76%)	11 (69%)	14 (82%)
London (NWC)	7 (21%)	4 (25%)	3 (18%)
Portsmouth	1 (3%)	1 (6%)	0

**Table 16 Baseline demographic characteristics of participants**

Frequencies are displayed with percentages in parentheses with the exception of age, Duration of illness, CPZ equivalent are displayed with means and standard deviations

The demographic characteristic table above does not include any p values, the rationale for this is that at this stage we are not testing baseline as participants were randomly allocated. The differences seen if any are entirely due to chance alone. A quick look at the data reveals that medication was higher in the TAU compared to the CaCBTp group by 100mg per day (chropromazine equavalents calculations). Similarly, duration of illness varied by a 4 year difference with the TAU group having more years than the CaCBTp group. The differences observed at baseline maybe clinically important. They have been treated for longer and this may justify slightly higher doses. Therefore we may have an imbalance between groups, which will be addressed in the analysis by treating these two factors as covariates and adjusting for this in the analysis. They may probably be interrelated. Unadjusted (crude) analysis may pick up this difference. Therefore analysis will be adjusted for medication, duration of illness and standard factors in CBTp studies such as age, gender and ethnicity.

### Summary of clinical assessments at three time points

Outcome measures	Time point	CaCBTp			Treatment as Usual				
		N	Mean	SD	N	Mean	SD	Crude	Adjusted
<b>CPRS Total score</b>	Baseline	16	32.25	20.86	17	24.70	17.06		
	Post-treatment	13	16.23	10.77	14	18.60	14.84	**	*
	6 months FU	14	19.57	12.94	16	17.56	14.57		*
<b>CPRS Global Score (Item 65)</b>	Baseline	16	1.75	0.44	17	1.65	0.70		
	Post-treatment	13	1.15	0.80	14	1.29	0.72	*	
	6 months FU	14	1.50	0.65	16	1.25	0.77		
CPRS Subscales:									
<b>MADRAS</b>	Baseline	16	10.62	6.85	17	7.11	5.29		
	Post-treatment	13	4.92	3.06	14	4.85	4.94	**	.11
	6 months FU	14	4.78	4.94	16	4.50	4.97	**	.07
<b>Schizophrenia change</b>	Baseline	16	9.25	7.02	17	6.11	5.36		
	Post-treatment	13	3.46	3.07	14	4.78	5.33	**	*
	6 months FU	14	4.00	3.44	16	3.37	3.05		.26
<b>Brief Anxiety scale</b>	Baseline	16	7.18	5.17	17	6.00	5.27		
	Post-treatment	13	3.76	2.71	14	5.00	4.00	**	.19
	6 months FU	14	4.21	3.33	16	4.25	3.89	*	.28
<b>BRAINS</b>	Baseline	16	5.43	3.75	17	4.00	2.59		
	Post-treatment	13	3.30	2.59	14	3.28	2.36	*	.19
	6 months FU	14	3.71	3.38	16	3.56	3.61		.32
<b>Insight in Psychosis Scale ≠</b>	Baseline	16	8.81	3.74	17	9.38	3.72		
	Post-treatment	13	10.23	3.49	14	11.07	3.70	**	.71
	6 months FU	14	10.14	3.32	16	11.06	2.90	*	.44
<b>Psychopathology (CPRS items)</b>									
<b>Delusions †</b>	Baseline	16	2.37	2.18	17	1.76	1.88		
	Post-treatment	13	.46	.96	14	1.35	1.82	*	*
	6 months FU	14	.69	1.03	16	.56	.72		.24
<b>Hallucinations ‡</b>	Baseline	16	3.25	3.17	17	1.52	1.69		
	Post-treatment	13	1.84	2.33	14	2.28	3.17	**	*
	6 months FU	14	2.07	2.01	16	1.25	1.69	**	**
<b>PEQ-Post treatment</b>	post-treatment	14	4.36	1.08	.....	.....	.....	**	

**Table 17: Summary of clinical assessments at three time-points**

CaCBTp: Culturally adapted Cognitive Behavioural Therapy for Psychosis; TAU: Treatment as Usual; CPRS:

Comprehensive Psychopathological Rating Scale; MADRAS: Montgomery-Asberg Depression Rating Scale;

BRAINS: Brief Assessment of Negative Symptoms Scale; PEQ: Patient Experience Questionnaire

≠Lower values are significant in all measures except for the Insight scale where higher values are significant.

statistically significant \*p = 0.05; \*\* p < 0.01

† Measured using CPRS items 31, 33, 36. ‡ Measured using CPRS items 37, 38, 39, 40.



Parameter Estimates for the main effects on the outcome measures

Outcome Measure	Parameters	$\beta$	95% Confidence Interval		p-value
			Lower Bound	Upper Bound	
	Intercept	23.908	4.653	43.163	.01
	TAU group	-9.582	-20.555	1.392	.08
	CaCBTp	0a			
	Male	11.726	-22.745	-0.706	.03*
	Female	0a			
CPRS Total Diff ET	Age	-0.057	-0.577	0.464	.82
Post-treatment	CPZeq.	-11.62	-23.065	-0.186	.04*
	Age & Gender	-7.4	-21.864	7.057	.30
	Male	14.11	-28.577	0.345	.05*
	Female	0a			
Follow-up Schizophrenia Change total diff	Intercept	-4.805	-8.666	-0.9444	.01
Post-treatment	TAU group	4.9	0.282	9.529	.03*
	CaCBTp	0a			
	Age	4.09	-0.663	8.861	.08
Follow-up	CPZeq.	-2.661	-7.419	2.097	.26
BRAINS					
Post-treatment	CPZeq.	-1.824	-4.614	0.966	.19
Follow-up	CPZeq	-1.86	-5.623	1.903	.32
Delusions					
Post-treatment	TAU group	1.707	0.169	3.245	.03*
	CaCBTp	0a			
Follow-up	TAU group	0.886	-0.644	2.416	.24
Hallucinations					
Post-treatment	Intercept	-5.122	-9.061	-1.184	.01
	TAU group	1.235	-0.928	3.398	.24
	CaCBTp	0a			
	Male	3.045	0.777	5.314	.01**
	Female	0a			
	CPZeq.	2.05	-0.236	4.336	.77
Follow-up	TAU group	0.568	-0.657	1.792	.34
	Male	1.664	0.427	2.901	.01**
	Female	0a			
Insight total					
Post-treatment	CPZeq.	0.47	-2.539	3.484	.74
	Age & Gender	.57	-2.58	3.72	.71
Follow-up	Intercept	10.11	8.104	12.127	.01
	TAU group	0.912	0.441	-1.481	.44
	CaCBTp	0a			
Brief Anxiety scale					
Post-treatment	CPZeq.	-1.92	-4.873	1.022	.19
Follow-up	TAU group	-1.87	-5.37	1.627	.28
	CaCBTp	0a			
MADRAS					
Post-treatment	TAU group	-3.725	-8.472	1.022	.11
	CaCBTp	0a			
Follow-up	Intercept	0.72	-7.689	9.129	.86
	TAU group	-4.249	-8.942	0.444	.07
	CaCBTp	0a			

CPZeq.	-3.554	-8.418	1.309	.14
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**Table 18: Parameter estimates**

Statistical significant: \*p = 0.05; \*\*p = 0.01  $\beta$ : indicates beta (main effect size)

CPZeq: indicates Chlorpromazine equivalent dosage; TAU: Treatment as Usual; CaCBTp: Culturally adapted Cognitive Behavioural Therapy for Psychosis;

- a. This parameter is set to zero because it is redundant.

### 9.3 Primary outcome measure

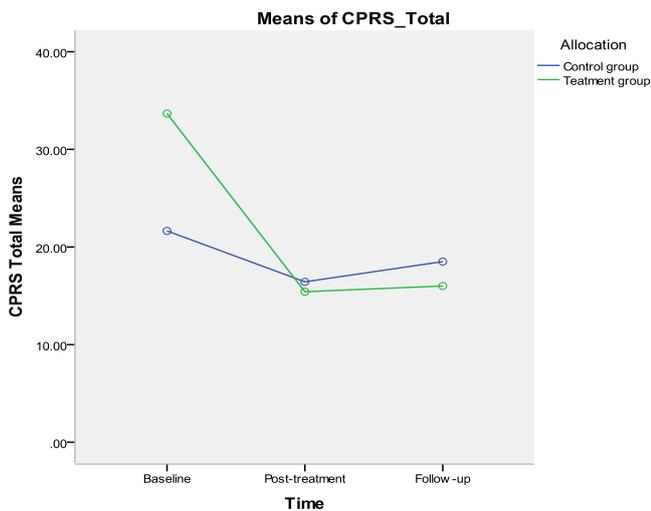
**Table 16** displays the demographic characteristics of the sample at baseline; i.e., what the participants looked like; they were some similarities and differences in baseline means, which will be discussed in-depth later.

CPRS baseline means levels in the CaCBTp group (M= 32.25, SD 20.86) were higher than the TAU (M = 24.50, SD = 16.58) therefore it was assumed that the post-treatment levels would be higher in CaCBTp group. Gender and age factors were adjusted using one way repeated Analysis of Variance (ANOVA).

#### 9.3.1 CPRS Total Scores

The CPRS total mean difference post-treatment for TAU was M = 4.53 (SD = 8.51) and for the CaCBTp group was M = 15.84 (19.00). One-way repeated measures ANOVA showed F to be significant beyond the 0.01 level:  $F(1, 26) = 4.33$ ;  $p = 0.04$ . Partial eta squared = .14, which according to Cohen's (1988) classification is a large effect. The magnitude of the effect change is on average 11 units higher in the CaCBTp group than it is in comparison to standard treatment as usual. The mean scores for the three time points of CPRS total scores differed significantly at the 5% level:  $F(2, 48) = 4.24$ ;  $p = 0.02$ . Partial eta squared = 0.15, which is a large effect. However, tests of between-subjects effects at follow-up (FU) were not significant:  $F(1, 28) = 0.67$ ;  $p = 0.41$  *ns*. The magnitude of change was 6 units bigger in the CaCBTp group than in the TAU. (95% CI, -9.04 to 21.17).

Results of the MANOVA are in agreement with the ANOVA; there is a significant main effect of time factor, Wilks' Lambda = 0.55,  $F(2, 23) = 9.41$ ;  $p < 0.01$ . The main effect of time X randomisation  $F(2, 23) = 3.15$ ;  $p = 0.06$ , approaching statistical significance.



**Graph 9: Means of CPRS Total scores**

### 9.3.2 CPRS Schizophrenia change

Mauchly's Test of Sphericity, a test for homogeneity of covariance had a p-value less than 0.05; therefore the null hypothesis of covariance is rejected. The chi-square value is 9.77 and it's significant associated within subject  $p < 0.01$ .

The means and standard deviations of the two conditions in relation to the CPRS

Schizophrenia change subscale at 6 months follow-up were: TAU (M = 3.07, SD = 3.01);

CaCBTp (M = 3.25, SD = 2.73). The mean scores for the three time points of CPRS

Schizophrenia change differed significantly at the 5% level:  $F(1.4, 33.85) = 13.70$ ;  $p < 0.01$ .

Partial Eta Squared = 0.37, 'a large effect'. There was a statistically significant effect for time

x randomisation,  $F(1.47, 33.85) = 3.90$ ;  $p = 0.04$ . Partial eta squared = 0.145 'a large effect'.

A one-way repeated measures ANOVA for Total Schizophrenia difference post-treatment

had a statistically significant effect for randomisation,  $F(1, 25) = 4.38$ ;  $p = 0.04$ . The new

intervention showed a 4.62 unit improvement post treatment when compared to standard

treatment with CI (95% -9.17 - .068) and a 2.43 unit improvement at 6 months follow-up CI

(95% -2.25 7.13). Between-subject effect was not significant,  $F(1, 23) = .64$ ;  $p = .42$

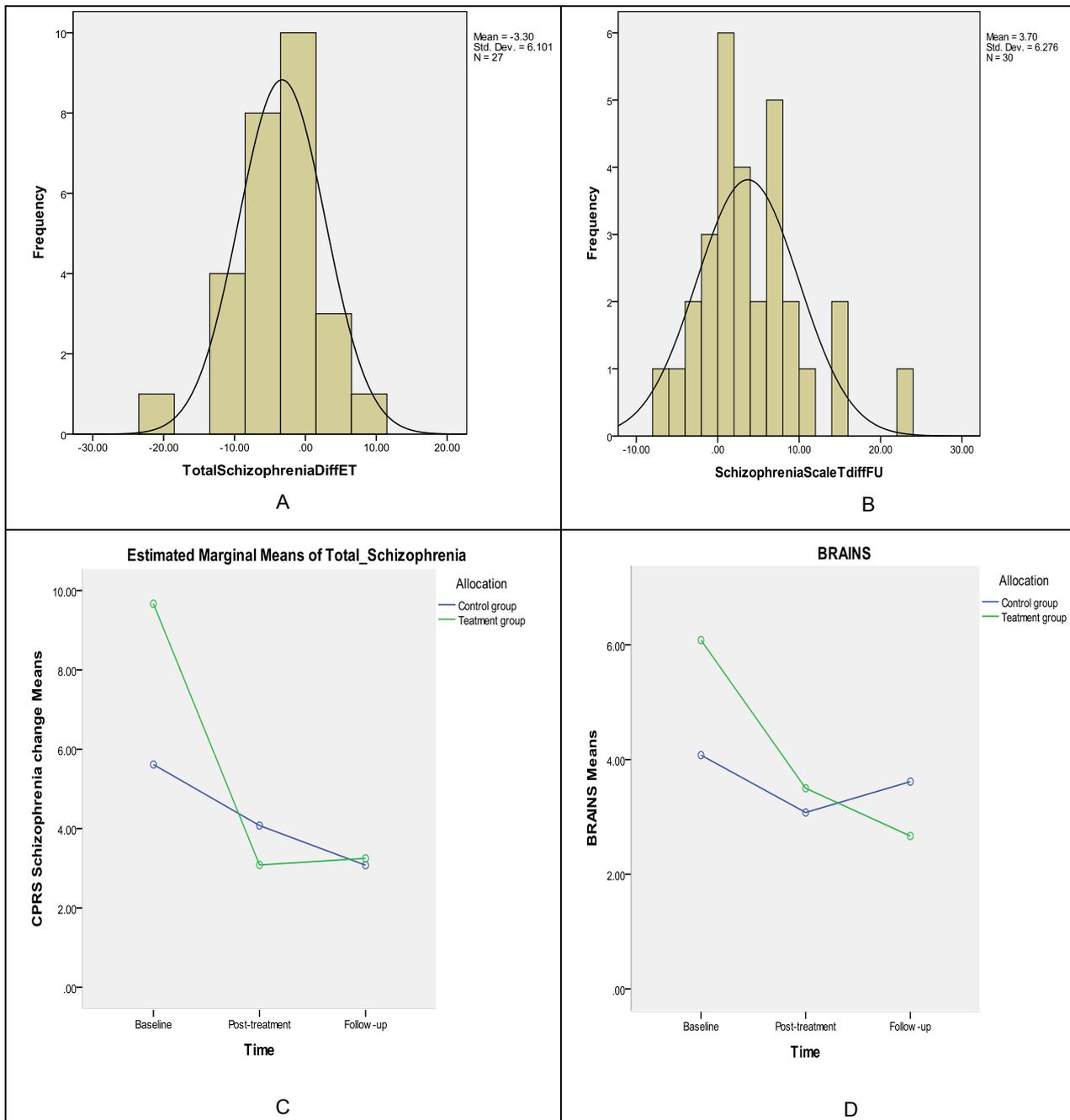


Figure 10: (A) Total SchizophreniaDiff ET; (B), Schizophrenia Tdiff FU  
(C) CPRS Schizophrenia change means; (D) BRAINS

### 9.3.3 BRAINS

Mauchly's Test of Sphericity, a test for homogeneity of covariance had a p-value less than 0.05; therefore the null hypothesis of covariance is retained. The chi-square value is 2.91 and its  $p = 0.23$ .

The means and standard deviations of the two conditions in relation to the BRAINS subscale at 6 months follow-up were: TAU (M = 3.56, SD = 3.61); CaCBTp (M = 3.71, SD = 3.38).

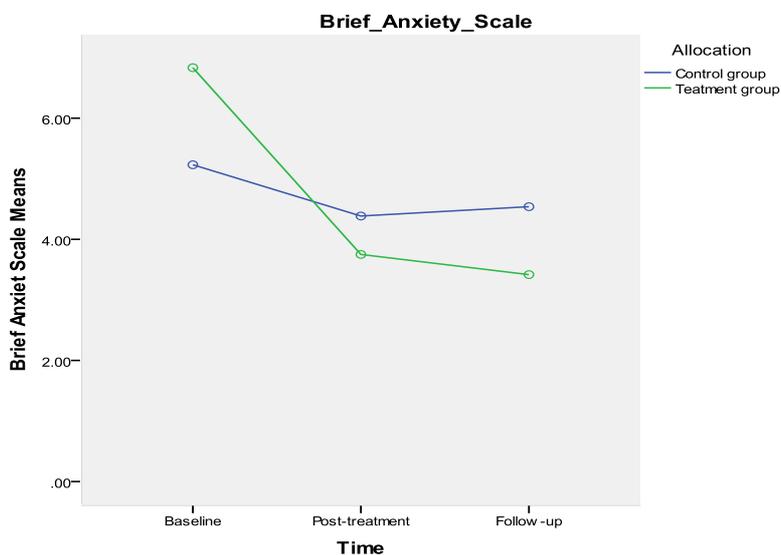
BRAINS subscale measuring negative symptoms had a statistically significant between subject effect on baseline adjustment,  $F(1, 24) = 30.69$ ;  $p < 0.01$  Partial eta squared = 0.56, a large effect. New intervention improved by 2.07 units in the CaCBTp group when compared to TAU. The mean scores for the three time points of CPRS BRAINS differed significantly at the 5% level: Given that the results of the Mauchly's test were insignificant the Sphericity Assumed  $F(2, 46) = 4.27$ ;  $p = 0.02$ ; Partial eta squared = .15, which is a large effect.

Between subject effect was not statistically significant,  $F(1, 23) = 0.374$ ;  $p = 0.54$ . The magnitude for change is on average 0.49 units higher in the treatment group than it is in comparison to the control group (CI, 95%, 11.17 to 2.16).

### 9.3.4 Brief Anxiety Scale

The means and standard deviations of the two conditions in relation to the CPRS Brief Anxiety subscale at 6 months follow-up were: TAU (M = 4.25, SD = 3.89); CaCBTp (M = 4.21, SD = 3.33). One way repeated ANOVA had a significant effect with the baseline factor as a covariate:  $F(1, 27) = 28.09$ ;  $p < 0.01$ , Partial eta squared = 0.51, a large effect. The mean scores for the three time points of CPRS Brief Anxiety subscale were significant beyond the 1% level:  $F(2, 46) = 5.34$ ;  $p < 0.01$  Partial eta squared = 0.18, which is a large effect.

Test of between subjects effects had a statistically significant effect on baseline adjustment,  $F(1, 22) = 15.45$ ;  $p < 0.01$ . New intervention improved by 2.07 units in the CaCBTp group when compared to TAU.

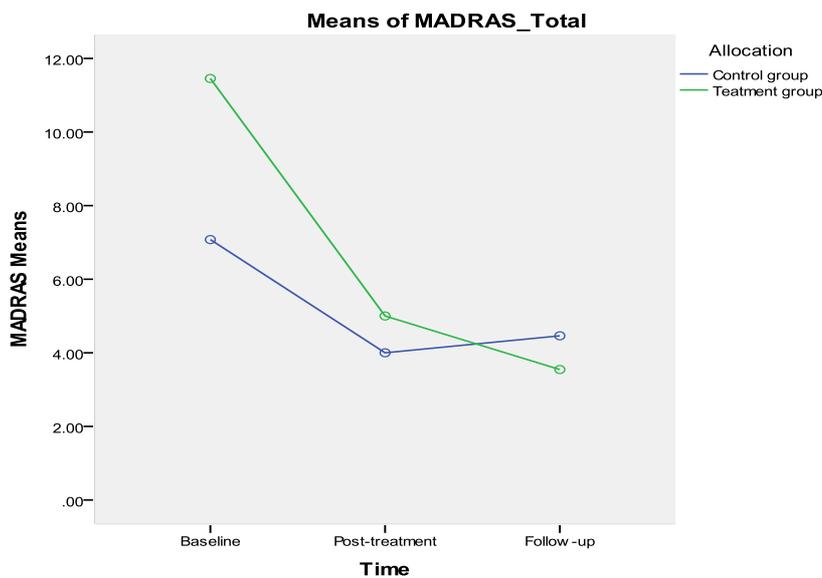


Graph 10: Brief Anxiety Scale means

### 9.3.5 MADRAS

The means and standard deviations of the two conditions on the MADRAS subscale at 6 months follow-up were: TAU (M = 4.46, SD = 5.23); CaCBTp (M = 3.54, SD = 2.94). The mean scores for the three time points of CPRS MADRAS subscale differed significantly at the 5% level:  $F(2, 44) = 20.62$ ;  $p < 0.01$  Partial eta squared = 0.48, which is a large effect. The mean difference scores between the three time points were statistically significant. CaCBTp group had a 3.35 unit improvement at FU when compared to TAU.

Time and randomisation effects were statistically significant, Wilk's Lambda, 0.69,  $F(2, 22) = 4.83$ ;  $p = 0.01$ . Between subject effect MADRAS adjusted for baseline had a significant effect,  $F(1, 22) = 13.08$ ;  $p < 0.01$



Graph 11: Means of MADRAS Total scores

## Delusions

Independent samples test of the delusions total difference scores post-treatment were conducted. The mean score of the CaCBTp group ( $M = 2.37$ ;  $SD = 2.18$ ) was significantly higher than that of the TAU group ( $M = 1.76$ ;  $SD = 1.88$ ). One-way repeated measures ANOVA showed a significant effect on randomisation factor  $F(1, 24) = 4.41$ ;  $p = 0.04$  Partial  $\eta^2 = 0.15$ , a large effect. Similarly, one way ANOVA test of between-subject effects on the delusion symptoms post-treatment adjusted for baseline score revealed a significant effect:  $F(1, 24) = 24.13$ ;  $p < 0.01$  Partial  $\eta^2 = 0.50$ . CaCBTp showed a -1.12 unit improvement compared to TAU.

However at follow-up, the main effect remained statistically significant with baseline controlled for:  $F(1, 26) = 107.04$ ;  $p = 0.01$  Partial  $\eta^2 = 0.80$ , a large effect. The randomisation factor had no significant effect:  $F(1, 26) = 0.014$ ;  $p = 0.90$  *ns*.

There was a significant effect for time x randomisation, Wilk's Lambda = 0.76,  $F(2, 22) = 3.44$ ;  $p = 0.05$ .

Figure 11 below displays histograms of Delusions Total Difference (End point and at follow-up) and Hallucinations (End point and at follow-up).

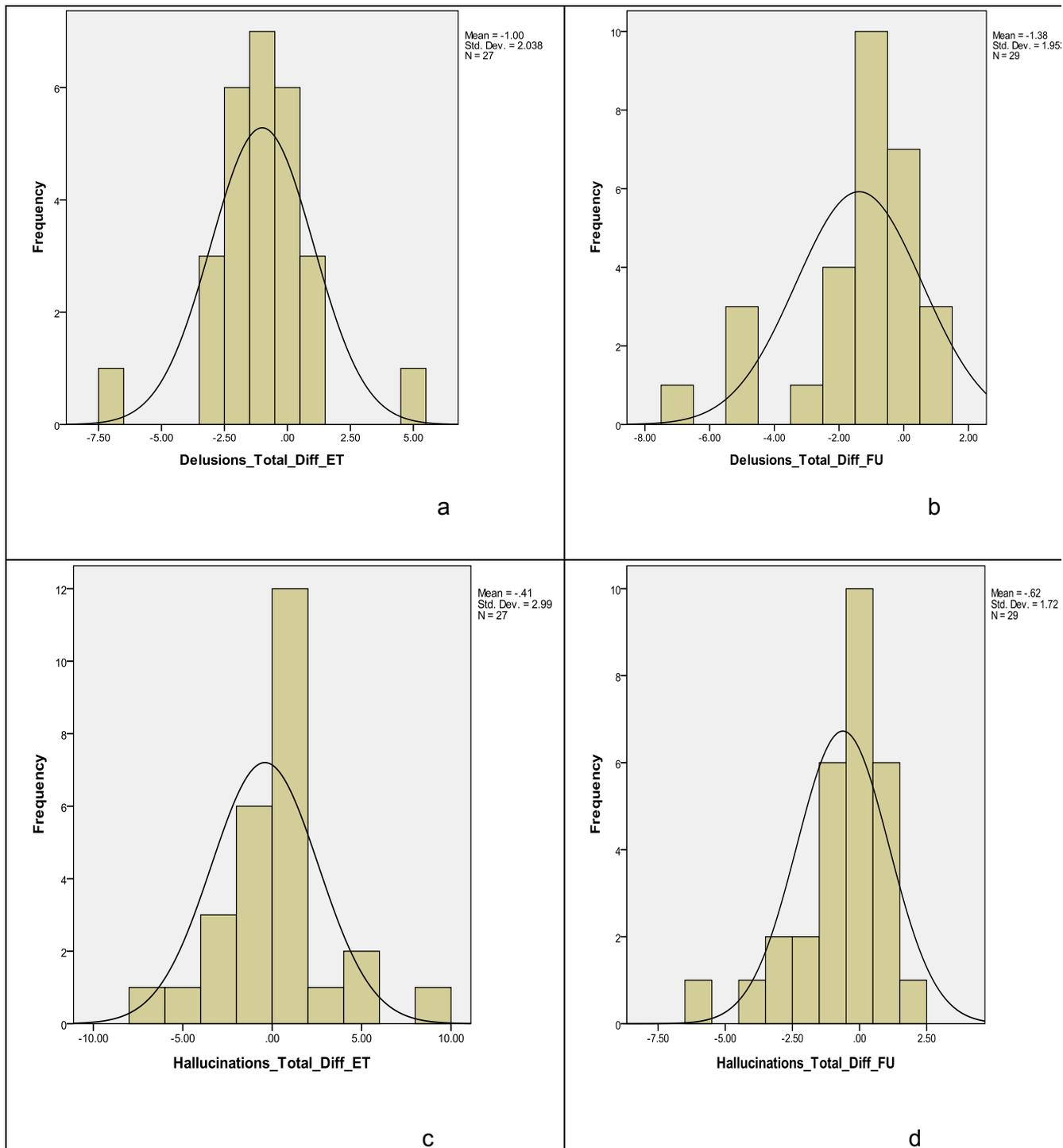


Figure 11: Histogram -Delusions and Hallucination Total mean differences at two time points

a: Delusions Total Diff ET

b: Delusions Total Diff FU

c: Hallucinations Total Diff: End of treatment histogram, normal distribution, with one outlier. At Follow-up the histogram is nearly positively skewed.

d: Hallucinations Total Diff FU

Hallucinations mean total difference scores post-treatment were: CaCBTp group (M = 1.84; SD = 2.33) compared to TAU group (M = 2.28; SD = 3.17). CaCBTp group had a statistically significant effect beyond 1% level when adjusted for baseline scores:  $F(1, 24) = 5.71$ ;  $p = 0.02$  Partial eta squared = 0.19, a large effect. The randomisation factor resulted in  $F(1, 24) = 1.45$ ;  $p = 0.24$  *ns*. However the CaCBTp group had a -2.18 unit improvement when compared to TAU. When adjusted for duration of illness, there was no statistical significance,  $F(1, 23) = 2.12$ ;  $p = 0.15$  *ns*.

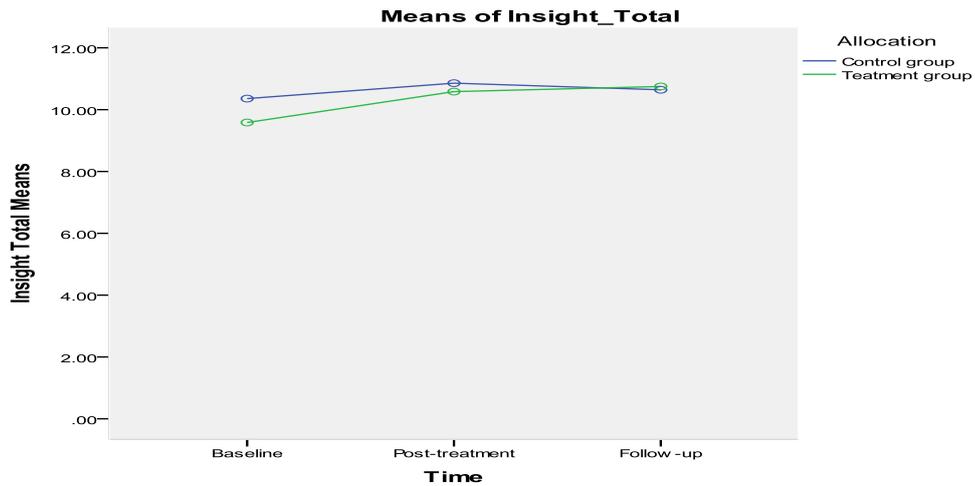
### 9.3.6 CPRS Global illness item

Repeated measures ANOVA was statistically significant for CPRS global rating score,  $F(1, 22) = 5.71$ ;  $p = 0.02$  Partial eta squared = 0.20, a large effect.

Randomisation effect was not significant;  $F(1, 22) = 0.04$ ;  $p = 0.83$  ns. Neither was the duration of mental illness significant. CaCBTp group had a -0.44 unit improvement when compared to standard treatment.

### 9.3.7 Secondary Outcome Measure: Insight Scale

The mean Insight total score at follow up for the TAU group was  $M = 11.06$  ( $SD = 1.83$ ) and for CaCBTp group  $M = 9.84$  ( $SD = 3.26$ ). One-way ANOVA showed  $F$  to be significant beyond the .01 level:  $F(1, 25) = 5.58$ ;  $p = 0.02$ . Eta is 0.18, a large effect (Cohen, 1988) when adjusted for baseline scores. Tests of within-subject contrasts showed a statistically significant effect on the time effect,  $F(1, 23) = 4.79$ ;  $p = 0.03$ . However, allocation (randomisation) factor showed  $F(1, 25) = 0.52$ ;  $p = 0.47$ , ns. One-way repeated ANOVA at follow-up adjusted for baseline had a significant effect:  $F(1, 27) = 6.82$ ;  $p = 0.01$ . Partial eta squared = 0.20, a large effect. There was no significant difference in insight improvement between the two groups:  $F(1, 23) = 0.50$ ;  $p = 0.48$  ns. There was no statistical significant main effect when adjusted for duration of illness covariate,  $F(1, 23) = 1.61$ ;  $p = 0.21$ , ns. Post-treatment the CaCBTp group showed a -0.16 unit improvement when compared to TAU. The CaCBTp group had a -0.79 unit improvement at Follow-up when compared to TAU group.



**Graph 12: Insight Total mean scores**

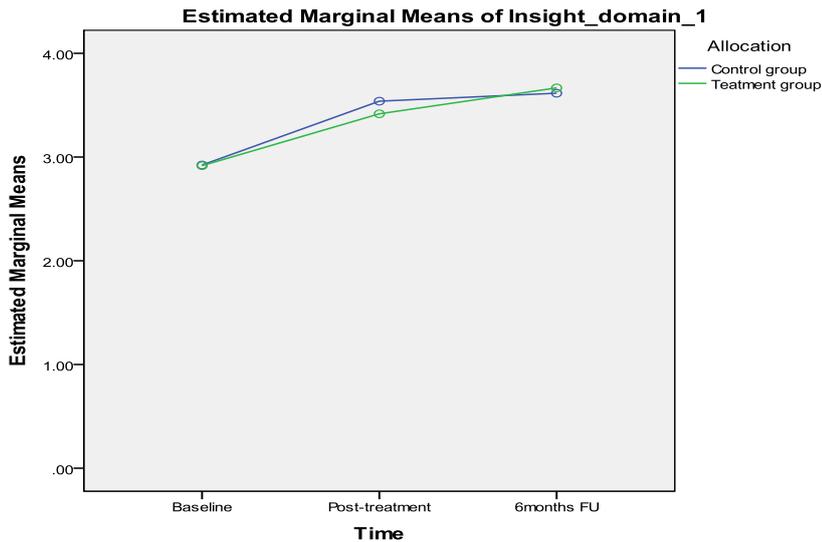
This section will look at the results of insight domains at three time points.

### 9.3.8 Insight domain 1: Treatment Adherence

Tests of within subject effects showed that the time effect was significant beyond the 0.01 level:  $F(2, 46) = 7.21$ ;  $p < 0.01$ . Partial eta squared = 0.23, a large effect (Cohen, 1988).

However, there was no significant interaction between Time x Randomisation:  $F(2, 46) = 0.09$ ;  $p = 0.90$ . There was no significant difference in between the two groups.

**Graph 13** below shows estimated marginal means of the treatment adherence domain 1 at three time points for both groups.



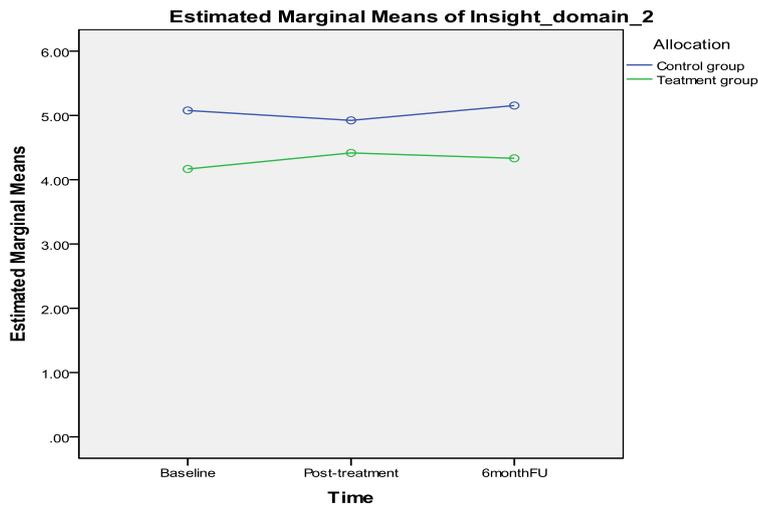
**Graph 13: Estimated marginal means of Insight domain 1**

### 9.3.9 Insight Domain 2: Acceptance of Illness

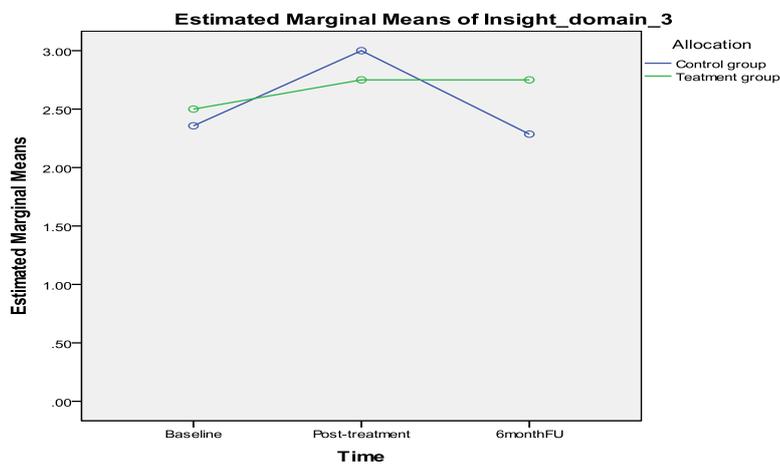
There was no significant effect of the randomisation factor:  $F(1, 24) = 0.02$ ;  $p = 0.96$  *ns*.

Adjusting for baseline score had a main effect that was significant beyond the 1% level:  $F(1, 24) = 6.27$ ;  $p < 0.01$ . Partial eta squared = 0.20, a large effect. Graph 14 below shows between group differences. These two groups started off at different levels at baseline.

The CaCBTp group had a slight improvement post-treatment but this was not maintained at follow-up. In contrast, the TAU had a slight drop post-treatment but this improved slightly at follow-up. Time factor was significant:  $F(1, 25) = 63.96$ ;  $p < 0.01$ , however, time x randomisation was not significant:  $F(1, 25) = 3.18$ ;  $p = 0.08$ .



Graph 14 displays Domain 2 comparisons by allocation at three time points



Graph 15 shows Domain 3 comparison by allocation at three time points.

### 9.3.10 Insight Domain 3 Re-labelling of psychotic experiences

Similarly, there was no statistically significant difference between the two groups in this domain:  $F(2, 48) = 0.55$ ;  $p = 0.57$ .

One way repeated measures ANOVA tests of between subjects effects adjusted for baseline scores had significant effect:  $F(1, 27) = 8.79$ ;  $p < 0.01$ . Partial eta squared = 0.24, a large effect. CaCBTp group had a 0.11 unit improvement when compared to the TAU group.

The means and standard deviation for change in insight domain scores at three time points are displayed in the table 19 below.

Summary of Insight subscale Total at three time points							
Outcome measures	Time point	CaCBTp			Treatment as Usual		
		N	Mean	SD	N	Mean	SD
<b>Subscales Domains</b>							
<b>1. Treatment Adherence</b>	Baseline	16	2.87	1.08	17	2.82	0.95
	Post-treatment	13	3.46	0.87	14	3.57	0.75
	6 months FU	14	3.5	0.75	16	3.5	0.81
<b>2. Acceptance of illness</b>	Baseline	16	3.87	2.12	17	4.76	1.67
	Post-treatment	13	*4.23	1.96	14	4.64	2.16
	6 months FU	14	4.21	2.15	16	4.93	1.84
<b>3. Re-labelling psychotic symptoms</b>	Baseline	16	2.12	1.5	17	2.29	1.49
	Post-treatment	13	*2.53	1.45	15	2.8	1.47
	6 months FU	14	2.42	1.28	16	2.5	1.46

**Table 19: Summary of Insight subscale total scores at three time points**

Insight domain 2: post-treatment revealed a non-significant group difference between groups  $\beta = 0.04$ ;  $p = 0.95$ , *ns*. However when adjusted for baseline the effect was significant:  $\beta = 0.55$ ;  $p = 0.02$ . At follow-up this significant effect disappears:  $\beta = 0.22$ ;  $p = 0.24$ , *ns*.

## 9.4 Adjusted Analysis results:

A series of one way repeated measures ANOVA were conducted on all variables that were showing an imbalance between groups on observation of baseline characteristics. These variables were then included as covariates in the ANOVA analysis and controlled for. Unadjusted analysis will pick up any differences which may be due to these variables:

- \*Medication
- \*Duration of illness
- \*Age
- Ethnicity
- \*Centre
- Setting
- \*Gender (sex)

\*Controlled for as standard in CBTp studies

When the comparisons between groups were repeated controlling for the above - mentioned covariates the following results were obtained: these are described according to the specific outcome measure or subscale. The reported results will exclude the following covariates; duration of illness, ethnicity, centre and settings as these were not found to be confounding factors.

### 9.4.1 Comprehensive psychopathological rating scale

One way repeated ANOVA analysis was conducted on the main outcome measure CPRS total difference post-treatment on two covariates gender and age x randomisation, parameter estimates were also computed. The following results were obtained: Once adjusted for age and gender the differences between the two groups were not significant. However, a positive trend was seen. The difference in change of score was -9.5 units

(95% CI, -20.55 to 1.39). Meaning that the TAU group is changing by 9.5 units less than the CaCBTp group which has changed by 9.5 units a bigger improvement:  $p = 0.08$  approaching significance.  $\beta = 9.5$ .

With regards to differences between gender, there was a big difference between females and males, in that females showed a greater improvement when compared to males:  $\beta = 11.7$ ;  $p = 0.03$ ; (95% CI, -22.74 to -.70). The effect of age, given that age is continuous, for every increase in age, their change is slightly less, i.e., the older they are, the less treatment effect they get. On the contrary, the younger they are, the more benefit they get regardless of which treatment group they are in. In conclusion, these results suggest that the patients most likely to respond and benefit from the new treatment would be young and female.

Due to baseline imbalance in the chlorpromazine equivalents (CPZeq) dosage (purely by chance) of 100mg/day) all the analyses were therefore controlled to investigate whether this variable was associated with outcomes. There was no statistically significant difference between the groups. Maybe the difference was explained more by gender than medication. When adjusted for baseline CPZeq (medication) dosage we are still showing significance between the two groups  $\beta = -11.62$ ;  $p = 0.04$ .

At 6 months follow up, when adjusted for age and gender, the two groups do not sustain their therapeutic gains:  $\beta = -7.40$ ;  $p = 0.30$ , *ns*. However, the gender variable indicates that females retain a marginal effect:  $\beta = -14.11$ ;  $p = 0.05$ .

#### **9.4.2 Insight in Psychosis scale**

Insight scores post-treatment (ET) adjusted by baseline CPZeq dosage showed that there was no statistical significant difference between the two groups:  $\beta = 0.47$ ;  $p = 0.74$  *ns*. At

follow-up the effect increased slightly in the CaCBTp group by 0.91 units better than TAU group.  $\beta = .91$ ;  $p = 0.44$ , *ns*. Estimates of randomisation x gender and age obtained a non-significant effect  $\beta = 0.57$ ;  $p = 0.71$ , *ns*.

### **9.4.3 MADRAS**

MADRAS post-treatment: Age, gender and medication x randomisation was insignificant:  $p = 0.11$ , *ns*.  $\beta = -3.55$ ;  $p = 0.14$ , *ns*. At follow-up (FU):  $\beta = -4.24$ ;  $p = 0.07$ , *ns*.

### **9.4.4 Brief Anxiety Scale**

Brief Anxiety ET between group difference after adjusting for medication  $\beta = -1.92$ ;  $p = 0.19$ , *ns*. At FU: All three variables adjusted for resulted in  $\beta = -1.87$ ;  $p = 0.28$ , *ns*. No gender differences were found  $\beta = -3.72$ ;  $p = 0.11$ ; and Age:  $\beta = -4.24$ ;  $p = 0.07$  respectively.

### **9.4.5 Schizophrenia change scale**

Schizophrenia change total difference ET: there was a significant group difference when estimates of randomisation x CPZeq interaction were analysed:  $\beta = 4.90$ ;  $p = 0.03$  in favour of CaCBTp group. There was a 4.35 unit difference between the TAU and the CaCBTp groups when adjusted for gender x age x CPZeq, meaning the CaCBTp performed 4.35 units better than the control group.  $\beta = 4.35$ ;  $p = 0.08$ , approaching significance. The difference between groups at follow-up disappears:  $\beta = -2.66$ ;  $p = 0.26$ , *ns*.

### **9.4.6 BRAINS**

BRAINS post-treatment was not significant with a  $\beta = -1.82$ ;  $p = 0.19$ , *ns*. At follow-up there was no significant group difference (see table 18).

### 9.4.7 Delusions

Delusions total difference ET indicated a significant group difference when adjusted for medication:  $\beta = 1.70$ ;  $p = 0.03$ . However, this was not sustained at follow-up  $\beta = 0.88$ ;  $p = 0.24$ , *ns*.

### 9.4.8 Hallucinations

Hallucinations total ET was not significant on all factors together  $\beta = 1.23$ ;  $p = 0.24$ , *ns*.

There was however a difference between males and females:  $\beta = 3.04$ ;  $p = 0.01$  in favour of females. FU results maintained significance in gender differences  $\beta = 1.66$ ;  $p < 0.01$ .

Group differences were not significant:  $p = 0.348$ , *ns*. When adjusted for medication alone ET the result was approaching significance:  $\beta = 0.56$ ;  $p = 0.07$ .

### 9.4.9 Insight Domain 2

Insight domain 2, post-treatment revealed a non-significant group difference between

groups  $\beta = 0.04$ ;  $p = 0.95$ , *ns*. However, when adjusted for baseline the effect was

significant:  $\beta = 0.55$ ;  $p = 0.02$ . At follow-up this significant effect disappears:  $\beta = 0.22$ ;  $p = 0.24$ , *ns*.

## 9.5 Medication

Anti-psychotic medication were recorded at baseline and converted to CPZ equivalent doses, analysis revealed mean dosage: CaCBTp group M (S.D) = 407.30 (392.62); TAU group M (S.D) = 502.54 (544.59). The difference was not that significant between groups. Descriptive statistics revealed that: 6% were on 1<sup>st</sup> generation antipsychotics; 85% were on 2<sup>nd</sup> generation antipsychotics; 6% were on a combination of both and 3% on antimanic (see figure 8). A total of 6 participants increased their medication during the trial in comparison (n = 3) that had a reduction. There was no change in 60% (20) participants. One stopped medication and two commenced new medication. Comparisons revealed that there was a significant effect beyond the 1% level between group difference in change of medication \*randomisation: Control M (S.D) = 2.29 (1.10) compared to CaCBTp group M (S.D) = 3.13 (0.619):  $p < 0.01$ .

Participants on Clozapine constituted only 18% of the sample size compared to 82% of participants not taking clozapine (see figure 12 below). The mean medication change for the TAU group was M (S.D) = 2.29 (1.10) and CaCBTp group M(S.D) = 3.13 (0.61). There was a statistical significant difference between the two groups:  $\beta = -0.83$ ;  $p < 0.01$ .

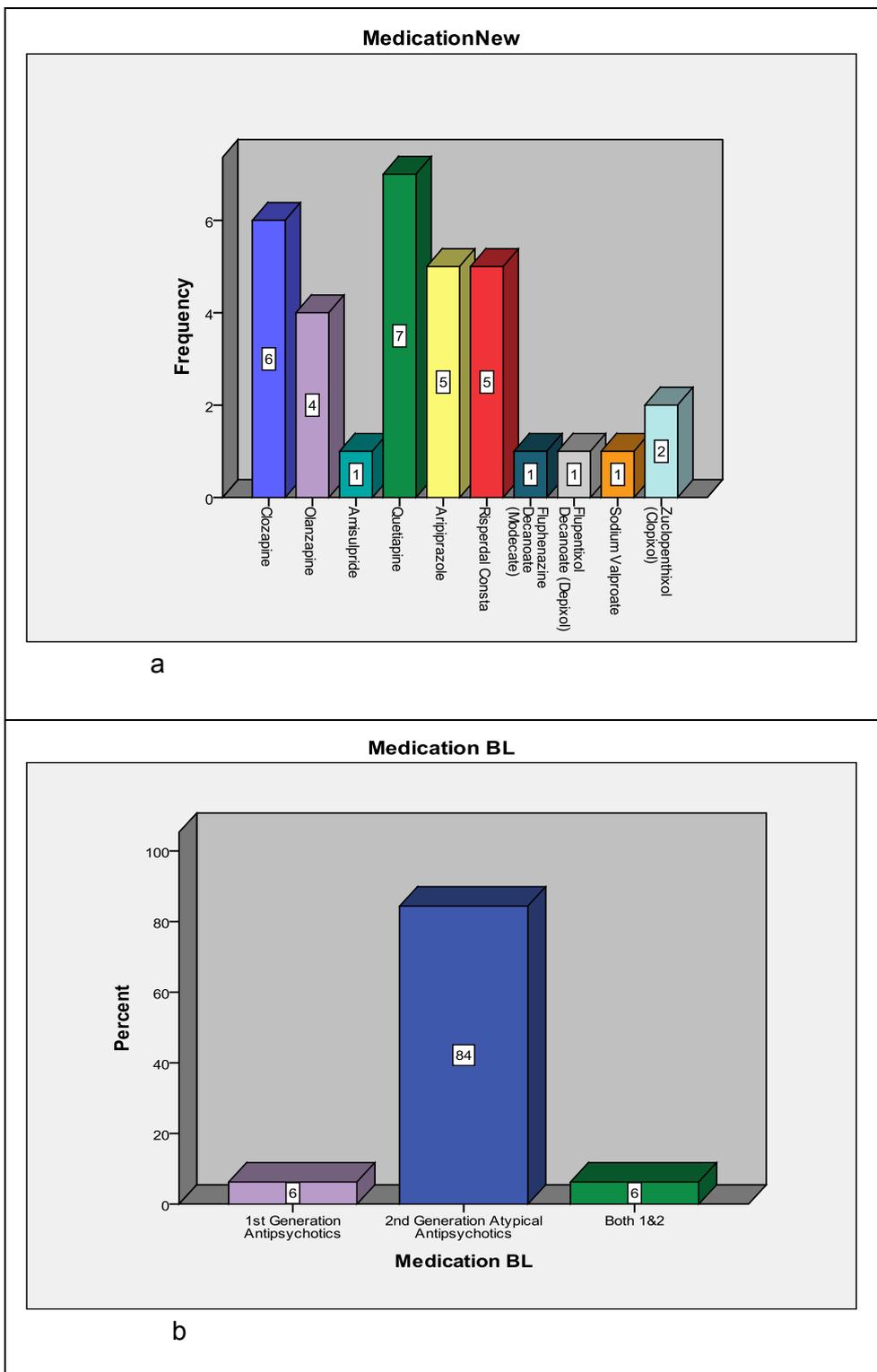


Figure 12: Medication is a graphical display of participants on first and second generation anti-psychotics medication.

## 9.6 CaCBTp sessions

The mean (SD) number of CaCBTp sessions for the 15 participants in the treatment group was 13.6 (4.9). One patient allocated to CaCBTp did not attend any treatment sessions.

Three trial therapists each treated: (N = 13) PP; (n = 2) LW and (n = 1) AS. This disproportionate distribution will be discussed later.

### **CaCBTp Case example1: Pre-engagement**

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Safiya is an 18 year old, British born South Asian Muslim young lady with Pakistani background. She entered the CaCBTp trial while under Early Intervention in Psychosis Services following a presentation with a psychotic episode and deliberate self-harm behaviours. Although Safiya initially agreed to participate in the trial we had to seek consent also from her family. A joint home visit was arranged with her key worker, a mental health practitioner. She was seen at home with her parents, she was relying on her mother for responses to questions asked. Initially, Safiya's mother expressed her concern about the randomization process and the likelihood that should her daughter be allocated to the control arm, she may not engage in other psychological input for the duration of the trial. The researcher validated her emotions and gave clear information and rationale for the study, also reiterating that the allocation would not affect her current treatment, which involved medication, and regular monitoring and support by the EIP services. The researcher gave family a summary of the findings of a recent qualitative study in particular emphasised the recommendations from South Asian Muslim groups (e.g. health seeking behaviours and pathways to care; attribution beliefs to causes mental illness. By demonstrating understanding of South Asian Muslim cultural background the researcher was able to engage the family in this process. Safiya's father responded by disclosing how he had taken her daughter to Pakistani to seek help from traditional healers. He related spending over £3000 to various healers with no success until he was advised to seek help from the UK health service. Consequently he returned and referred her to her local General Practitioner who subsequently involved the EIP services. Following a narrative of presenting problem from her parents and their consenting to Safiya taking part in the study, she gave both her verbal and written consent.

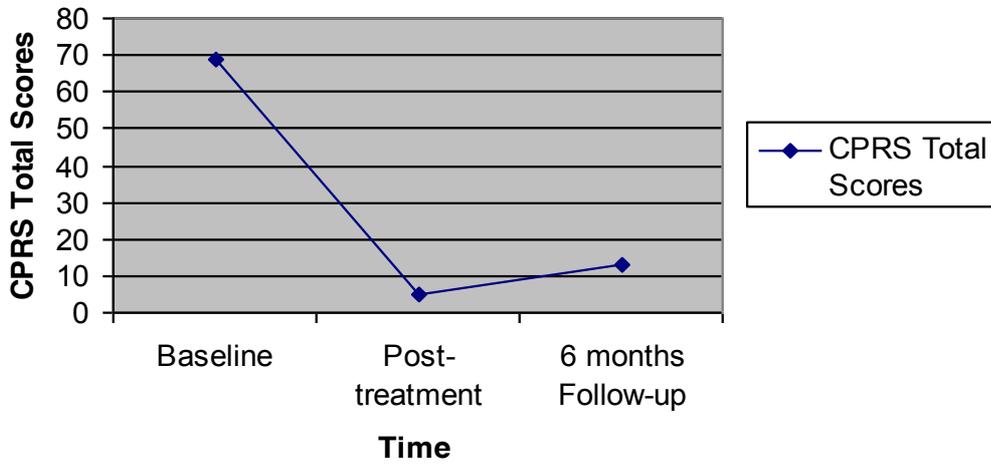
It is worth noting that the information disclosed by Safiya's father to the researcher (their cultural beliefs about causes of mental illness and help-seeking behaviours, had not been disclosed before to their EIP team or key-worker. Safiya's father felt able to talk about this once

the researcher had shown his understanding of their culture and beliefs about mental illness. This excerpt above illustrates the importance of cultural sensitivity and normalizing of cultural beliefs. When the researcher pre-empted his understanding of South Asian Muslim group and findings from his study, Safiya's father felt able to talk about those issues he initially felt embarrassed to talk about.

How relevant is this in the pre-engagement phase of therapy? Within South Asian groups engaging a patient in treatment may also involve family members who will sit in your assessment session and or subsequent therapy sessions. It is vital for therapists to understand the collectivist culture when working with individuals from this group. This meeting with the family enabled their valued input and support for Safiya during the trial. Her mother took on the role of co-therapist and would encourage her to complete her voices diary and use the strategies she was learning in therapy. When Safiya visited her husband in Pakistani she took with her a relapse prevention plan (see appendix 21) she had developed with her trial therapist. Her mother prompted her to use this while abroad and upon return both reported how useful this was. Safiya completed 16 sessions of CaCBTp intervention. The following graphs show her baseline, post-treatment and 6-month follow-up scores from the primary outcome measures.

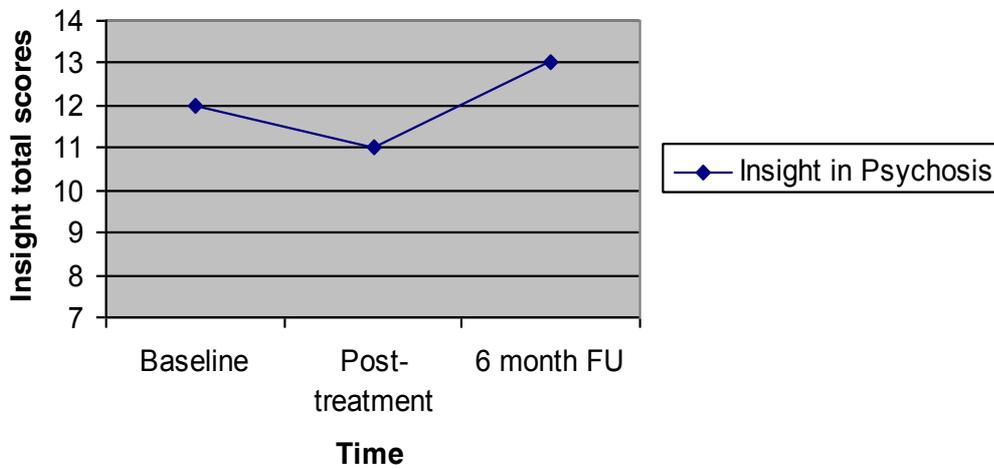
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### Safiya CPRS Total Scores



a

### Safiya's Insight in Psychosis scale



b

Figure 13: display total scores for Safiya, following her completion of the CaCBTp trial. Both a and b demonstrate significant improvement in the outcome measures.

## **9.7 Loss to follow-up**

In order to minimise missing data, attempts were made to follow-up all randomised participants even those that dropped off the trial as recommended by White et al (2011). This led to obtaining end point measures on (n = 2) participants; first discontinued therapy after six sessions and the second one was a non-starter in the CaCBTp arm. One of the participants in the TAU arm died prior to follow-up assessment ratings due to deterioration in mental state. The participant was reported to have committed suicide.

## 9.8 Results from the CPRS and subscales

Just to recap, the overall strategy of the sensitivity analysis as described before followed a range of two parameters. In this model I used the maximum and minimum values of the CPRS scores. Sensitivity analysis was conducted for each parameter individually using two parameter values (worst and best values: 69 and 0) on the main outcome measures. Unresponsive parameters were then excluded from further analysis. The responsive parameters were then considered for correlation with each other. The results of this analysis are reported in this section and will be compared with the main complete case analysis as displayed in **table 20** below. The comparison will show the extent of deviation from the main parameters.

**Summary of clinical assessments at two time points comparing 4 analyses**

Outcome measures	Time point	CaCBTp			Treatment as Usual						
		N	Mean	SD	N	Mean	SD	Crude	Adjusted	SA-Max	SA-Min
<b>CPRS</b>											
<b>Total score</b>	Post-treatment	13	16.23	10.77	14	18.60	14.84	**	*	*.04	* **<.01
	6 months FU	14	19.57	12.94	16	17.56	14.57	.41	*	.41	.16
CPRS Subscales:											
<b>MADRAS</b>	Post-treatment	13	4.92	3.06	14	4.85	4.94	**	.11	.15	.06
	6 months FU	14	4.78	4.94	16	4.50	4.97	**	.07	.16	*.05
<b>Schizophrenia change</b>	Post-treatment	13	3.46	3.07	14	4.78	5.33	**	*	*.04	**<.01
	6 months FU	14	4.00	3.44	16	3.37	3.05	.29	.26	.29	.12
<b>Brief Anxiety scale</b>	Post-treatment	13	3.76	2.71	14	5.00	4.00	**	.19	.19	*.02
	6 months FU	14	4.21	3.33	16	4.25	3.89	*	.28	.44	.22
<b>BRAINS</b>	Post-treatment	13	3.30	2.59	14	3.28	2.36	*	.19	.31	.12
	6 months FU	14	3.71	3.38	16	3.56	3.61	.38	.32	.38	.27
<b>Insight in Psychosis Scale ≠</b>	Post-treatment	13	10.23	3.49	14	11.07	3.70	**	.71	.92	.35
	6 months FU	14	10.14	3.32	16	11.06	2.90	*	.44	.97	.41
<b>Psychopathology (CPRS)</b>											
<b>Delusions †</b>	Post-treatment	13	.46	.96	14	1.35	1.82	*	*	*.03	*.03
	6 months FU	14	.69	1.03	16	.56	.72	.25	.24	.25	.25
<b>Hallucinations ‡</b>	Post-treatment	13	1.84	2.33	14	2.28	3.17	**	*	*.05	*.05
	6 months FU	14	2.07	2.01	16	1.25	1.69	**	**	.29	.29
<b>PEQ-Post treatment</b>	post-treatment	14	4.36	1.08	....	.....	.....	**			

**Table 20: Summary of clinical assessments at two time points comparing 4 analyses**

Crude: Unadjusted Analysis; Adjusted; Adjusted Analysis for covariates (Gender, Age, Medication)

SA-Max: Sensitivity Analysis Maximum (high values [e.g. CPRS total 69] are imputed to CaCBTp group and low values [0] in the TAU group.

SA-Min: Sensitivity Analysis Minimum (low values [e.g. CPRS total 0] are imputed group to the CaCBTp group and high values [69] in the TAU group.

CaCBTp: Culturally adapted Cognitive Behavioural Therapy for Psychosis; TAU: Treatment as Usual; CPRS: Comprehensive Psychopathological Rating Scale; MADRAS:

Montgomery-Asberg Depression Rating Scale; BRAINS: Brief Assessment of Negative Symptoms Scale; PEQ: Patient Experience Questionnaire

≠Lower values are significant in all measures except for the Insight scale where higher values are significant.

statistically significant \*p = 0.05; \*\* p < 0.01

† Measured using CPRS items 31, 33, 36. ‡ Measured using CPRS items 37, 38, 39, 40.

Table 20 shows the distribution of the p-values obtained from the CaCBTp trial: main analysis (complete case analysis); adjusted analysis and the sensitivity analysis.

### **Sensitivity Analysis**

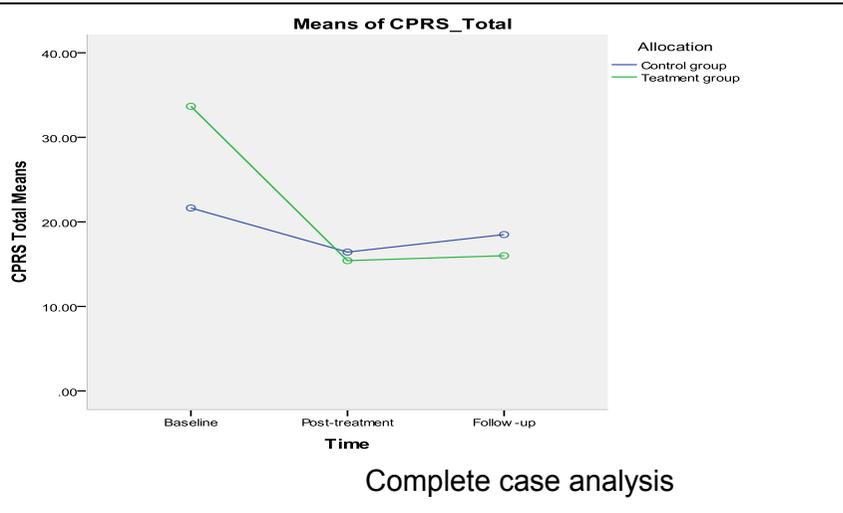
**Figure 14 (A, B, C)** shows the CPRS at three time points based on the worst case scenario values imputed on the CaCBTp group post-treatment and at follow-up. This CaCBTp group retained the statistical significant effect despite having high values added to its missing data. This result suggests the main analysis was robust and maintains its effect.

As shown in table 20 above, If maximum parameters are considered on the CaCBTp group change away from the complete case analysis p values was retained a significant effect:  $p = 0.04$ .

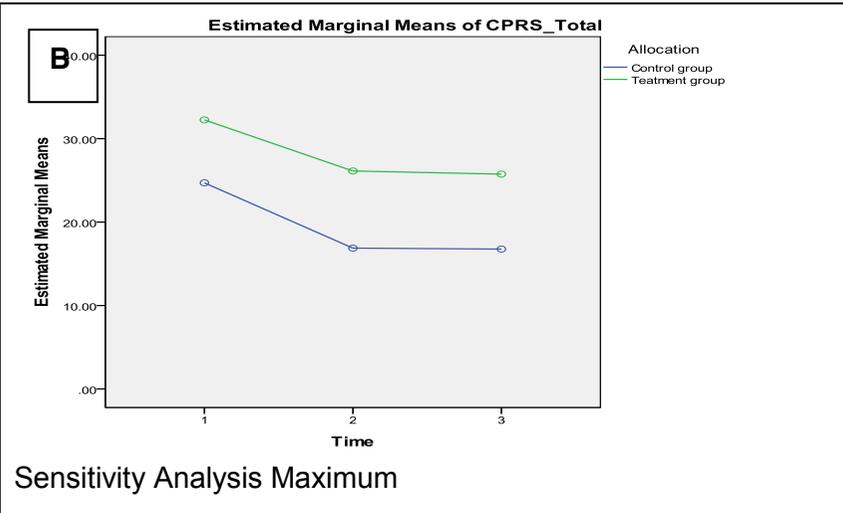
If minimum parameters are considered on the CaCBTp the effect was retained as indicated by a significant p-value  $p < 0.01$ .

**Figure 14** is a graphical presentation of summaries of all the results, i.e., what we get, if we make assumptions of missing data.

**A**



**B**



**C**

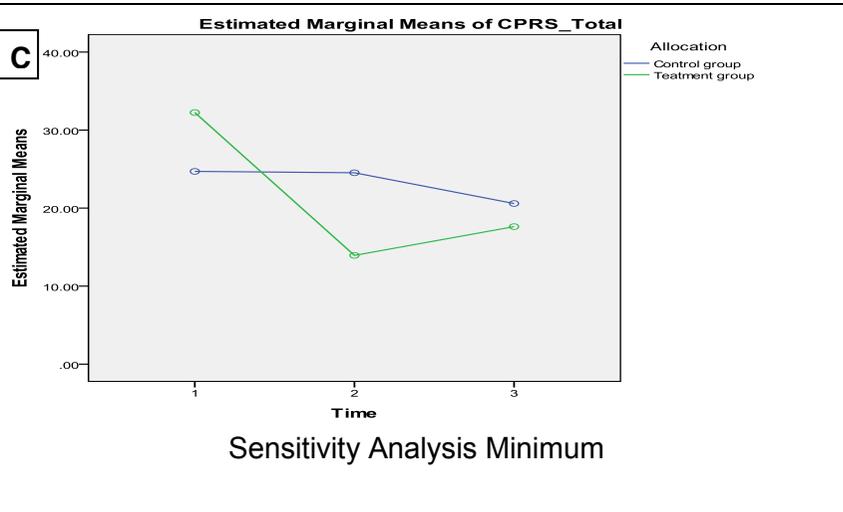
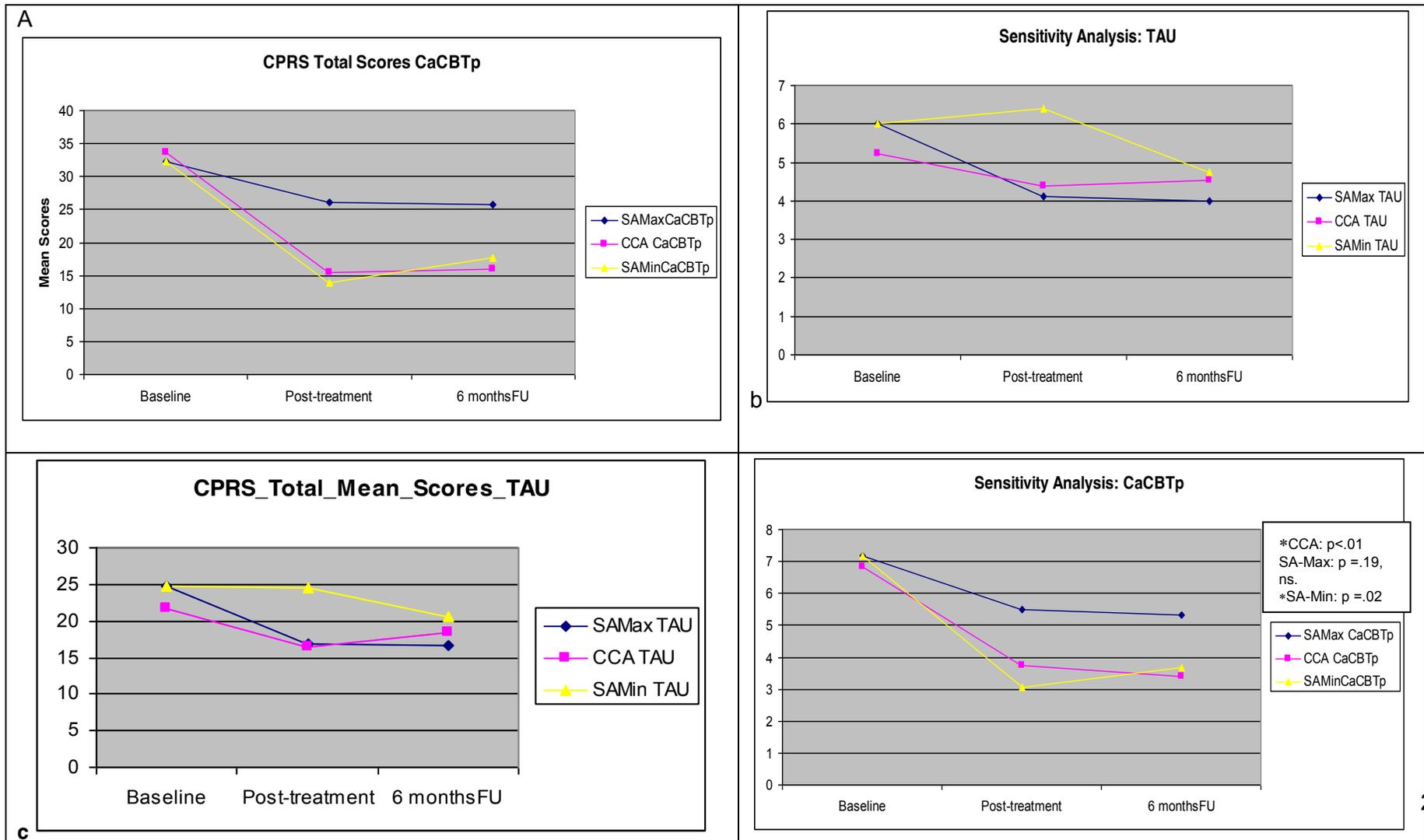


Figure 14: Summary of Sensitivity Analysis CPRS

Figure 15: Comparison of Sensitivity Analysis for CPRS scores



The figure shows Sensitivity Analysis (SA) results on changing TAU parameters (Maximum and Minimum levels) of CPRS total mean scores at three time points simultaneously to complete case analysis.

Figure 15 a: illustrates possible ways to impute outcome measures of the CPRS on drop out post-treatment (n = 5) and follow-up (n = 3). The main analysis Complete Case Analysis (CCA) and two sensitivity analyses (SA-Max CaCBTp assumes the CaCBTp group participants had the worst outcome; SA-Min CaCBTp assumes the CaCBTp group had the best outcome).

b: Displays the main analysis CCA TAU and two sensitivity analyses (SA-Max TAU assumes the TAU group participants had the worst outcome and SA-Min TAU group assumes that the TAU group had the best outcome).

c: Displays the main analysis CCA TAU and two sensitivity analyses of the Brief anxiety subscale outcome scores (SA-Max TAU assumes the TAU group participants had the best outcome and SA-Min TAU group assumes that the TAU group had the worst outcome).

d: illustrates the main analysis CCA and two sensitivity analyses of the Brief Anxiety subscale (SA-Max CaCBTp assumes the CaCBTp group participants had the worst outcome; SA-Min CaCBTp assumes the CaCBTp group had the best outcome).

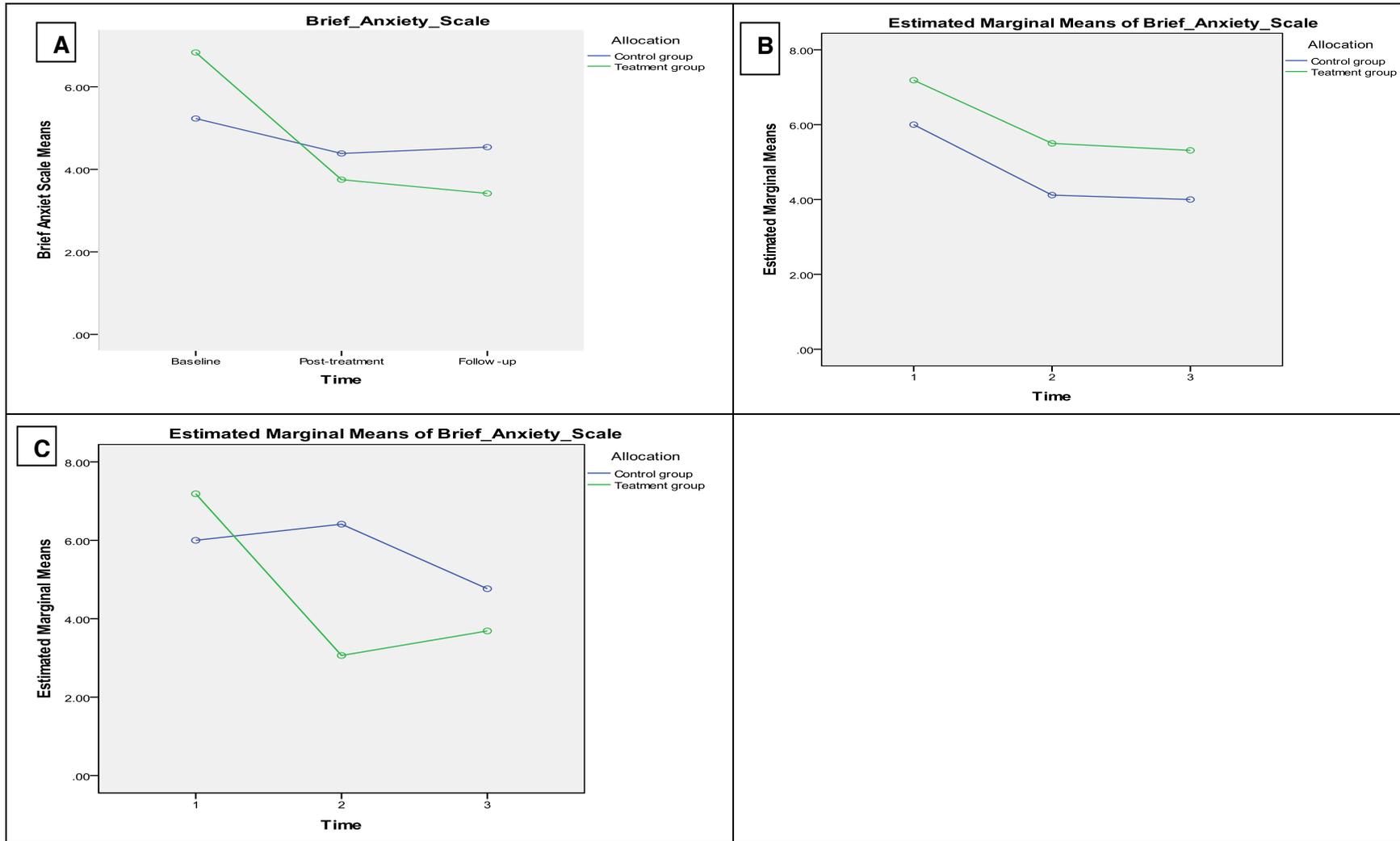


Figure 16: depict graphical displays of: A= complete case analysis; B= Sensitivity Analysis Maximum and C= Sensitivity Analysis Minimum.

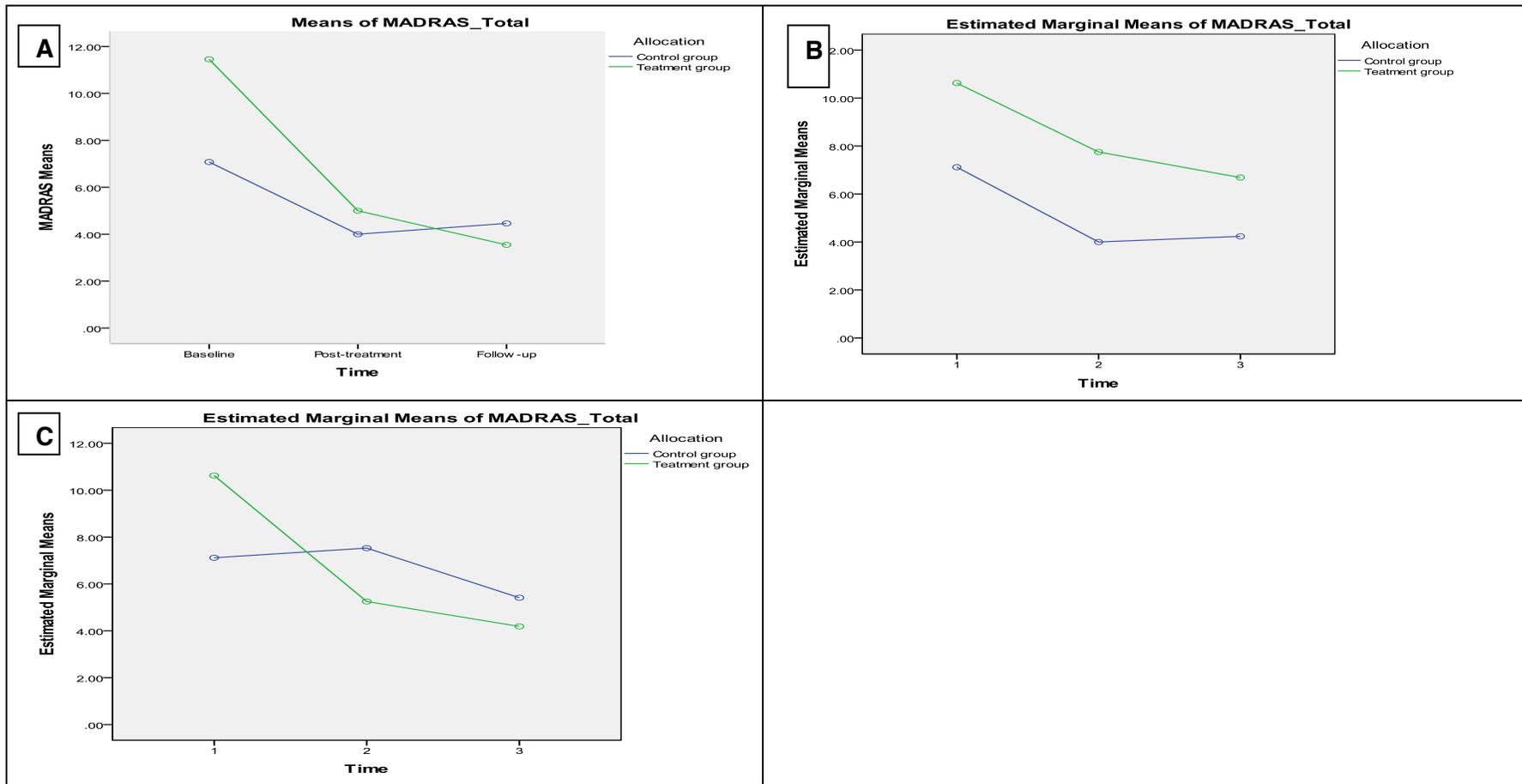
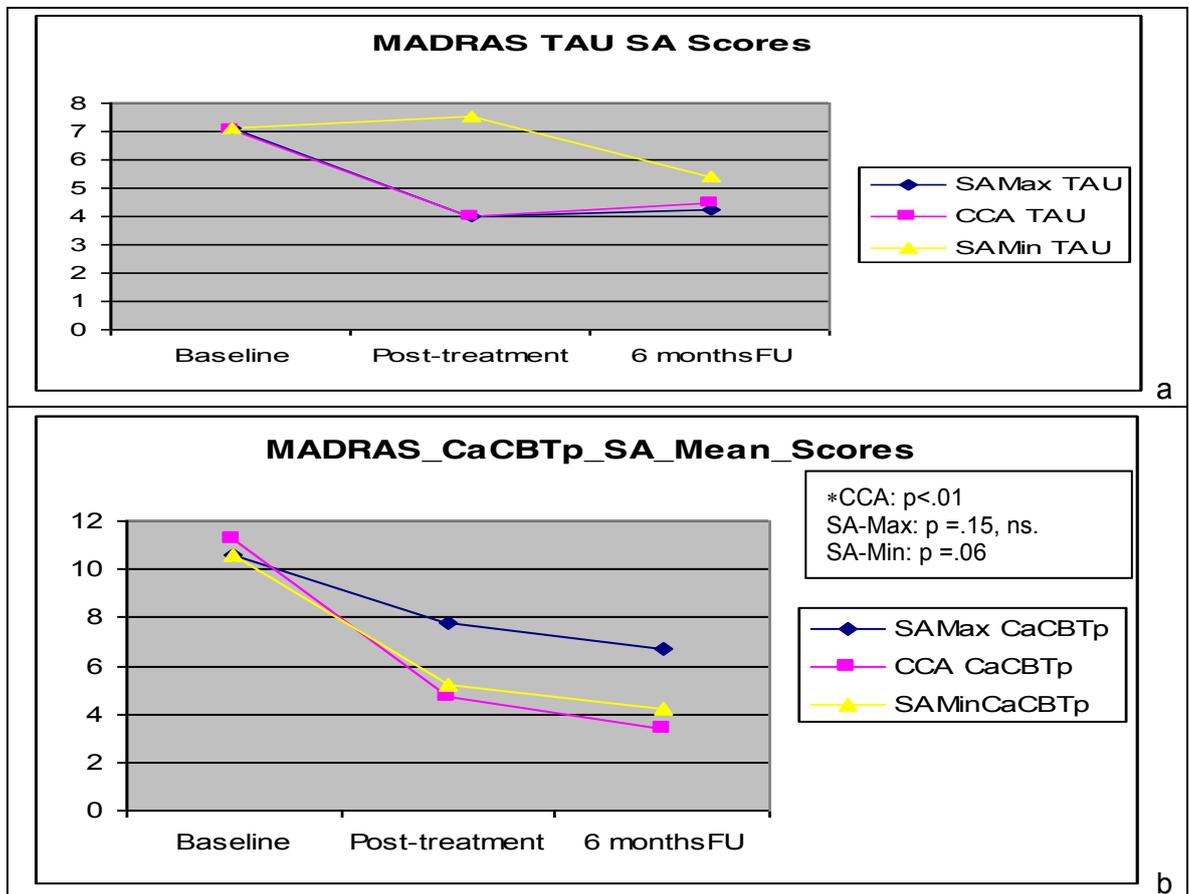


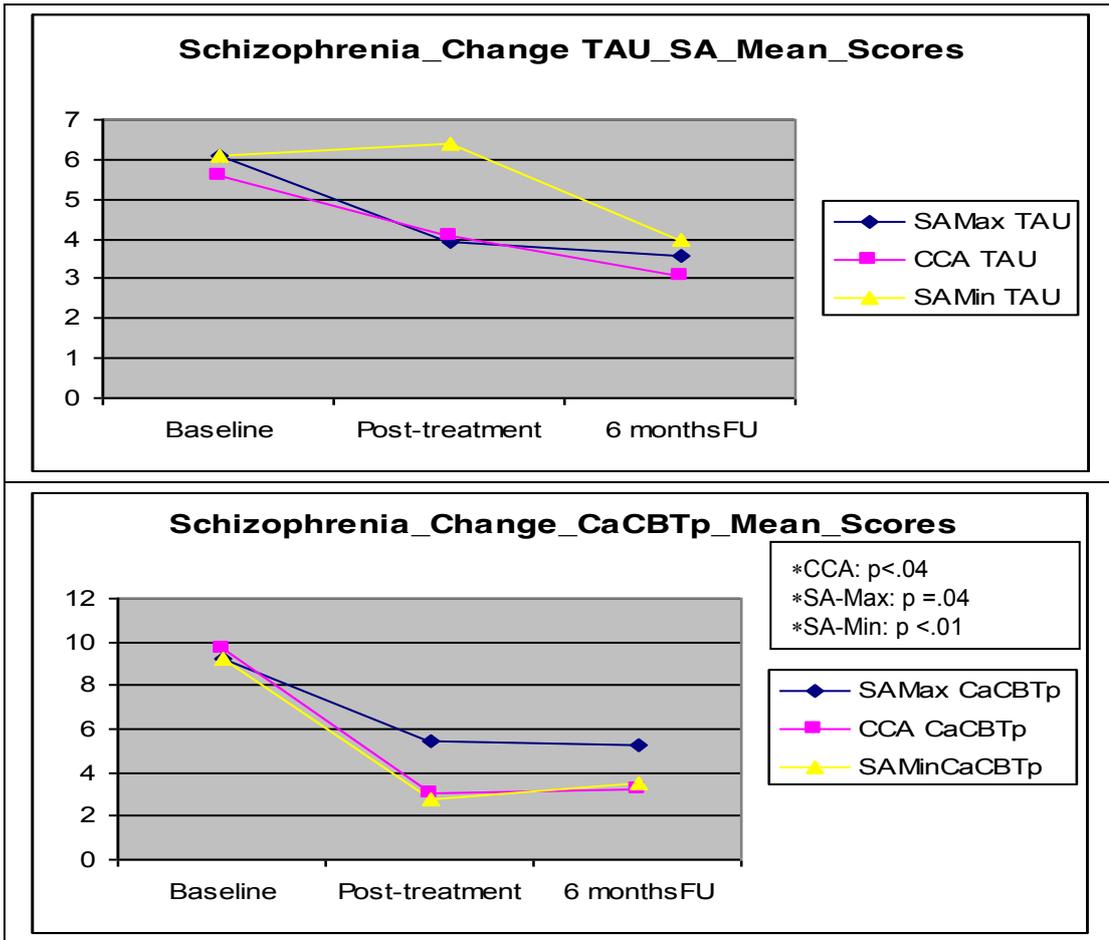
Figure 17: displays A= Complete Case Analysis; B= Sensitivity Analysis Maximum; C= Sensitivity Analysis Minimum

**Figure 18 a.** displays the main analysis CCA TAU and two sensitivity analyses for the MADRAS mean scores (SA-Max TAU assumes the group participants had the best outcome; SA-Min TAU assumes the group participants had the worst outcome).



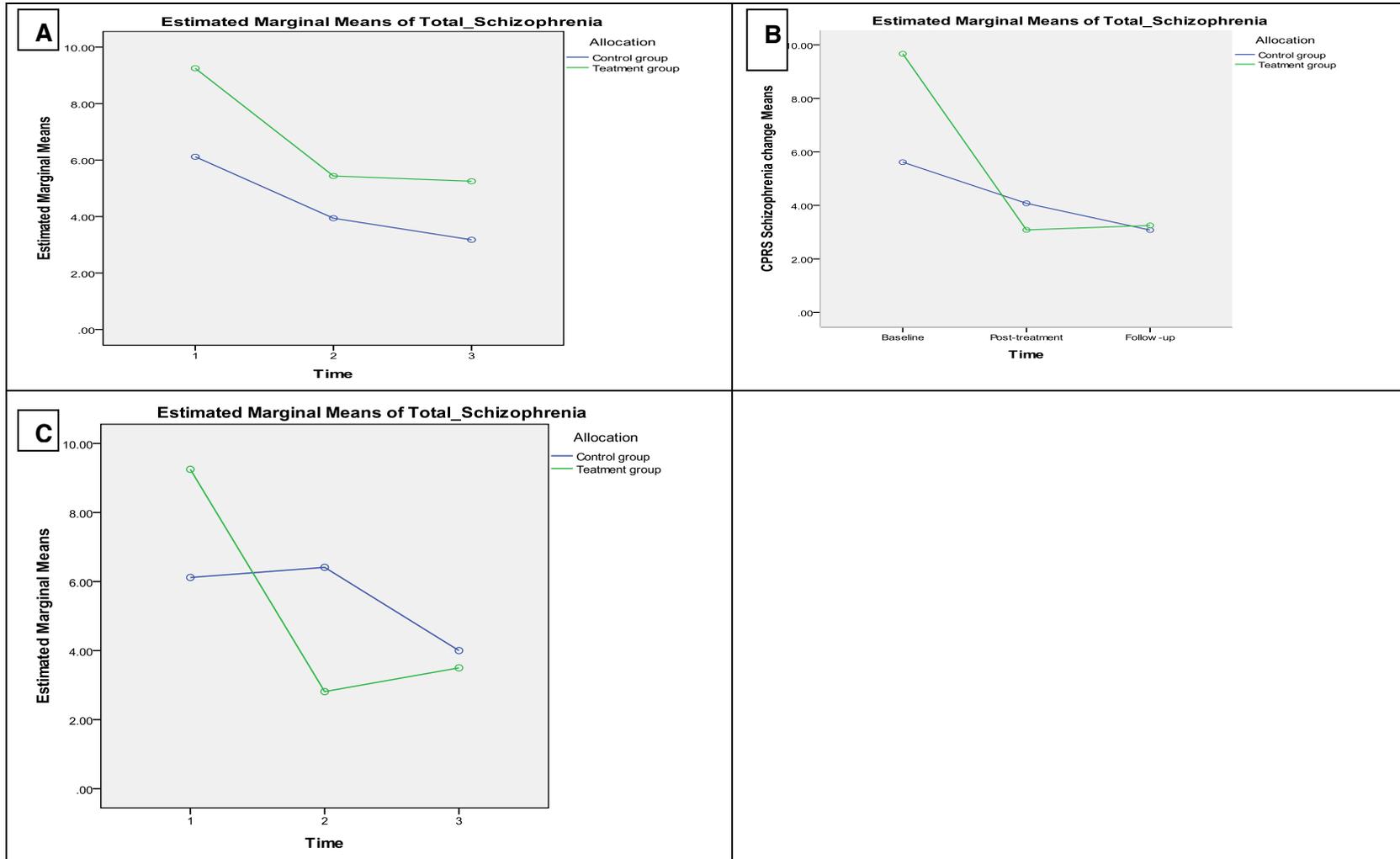
**Figure 18** illustrates the main analysis CCA CaCBTp and two sensitivity analyses for the MADRAS mean scores (SA-Max CaCBTp assumes the group participants has the worst outcome; SA-Min CaCBTp (assumes the group participants had the best outcome).

Figure 19, a below shows the schizophrenia change TAU mean scores for main analysis and two sensitivity analyses (SA-Max TAU assumes the group participants had the best outcome; SA-Min TAU assumes the group participants had the worst outcome).



**Figure 19:** b shows the schizophrenia change CaCBTp mean scores for main analysis CCA and two sensitivity analyses (SA-Max CaCBTp assumes the group participants has the worst outcome; SA-Min CaCBTp (assumes the group participants had the best outcome)).

**Figure 20, (A, B, C)** Graphical displays of: A= complete case analysis; B= Sensitivity Analysis Maximum; C= Sensitivity Analysis Minimum.



**Figure 20: Sensitivity Analysis- Schizophrenia Scale**

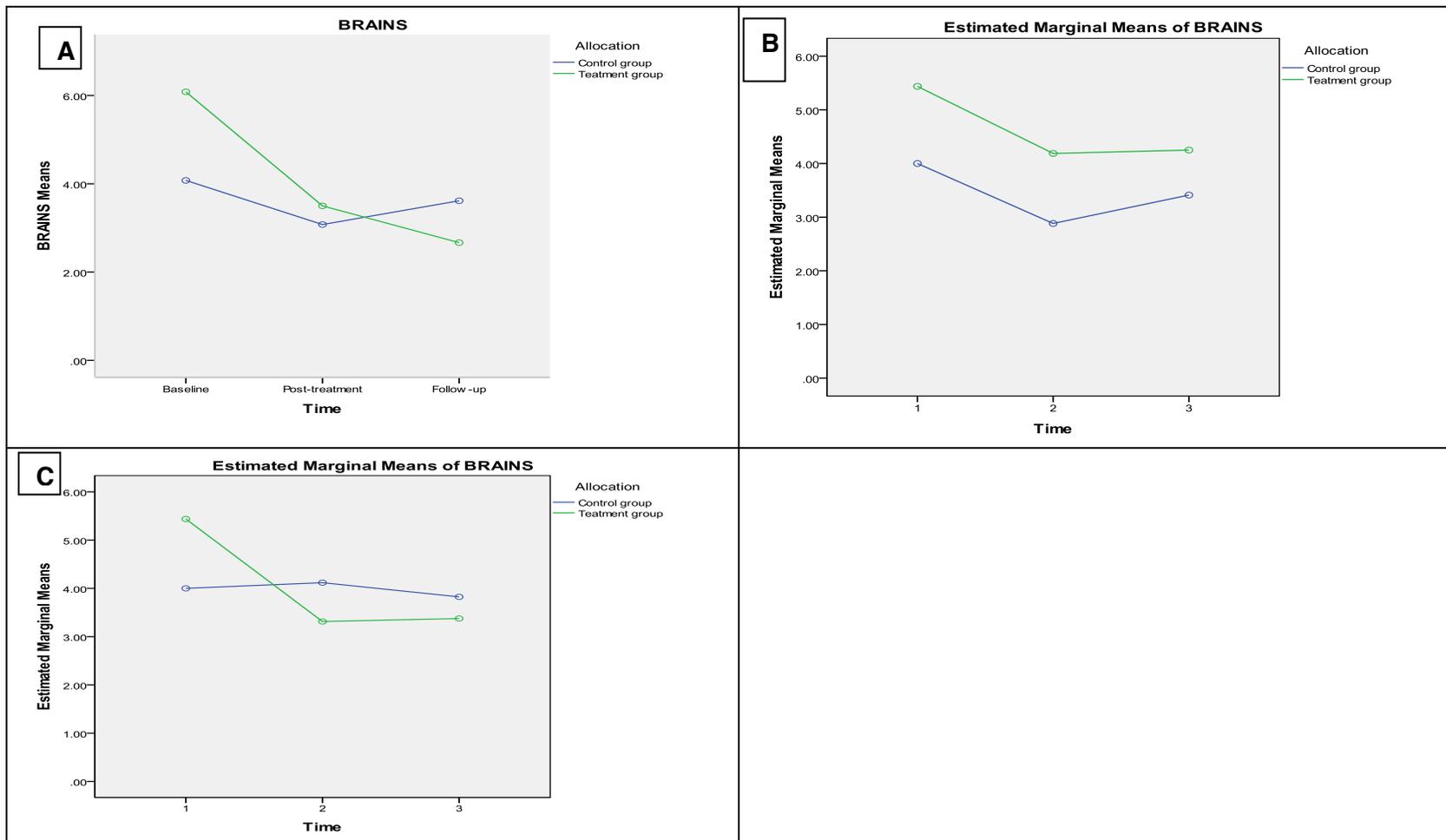
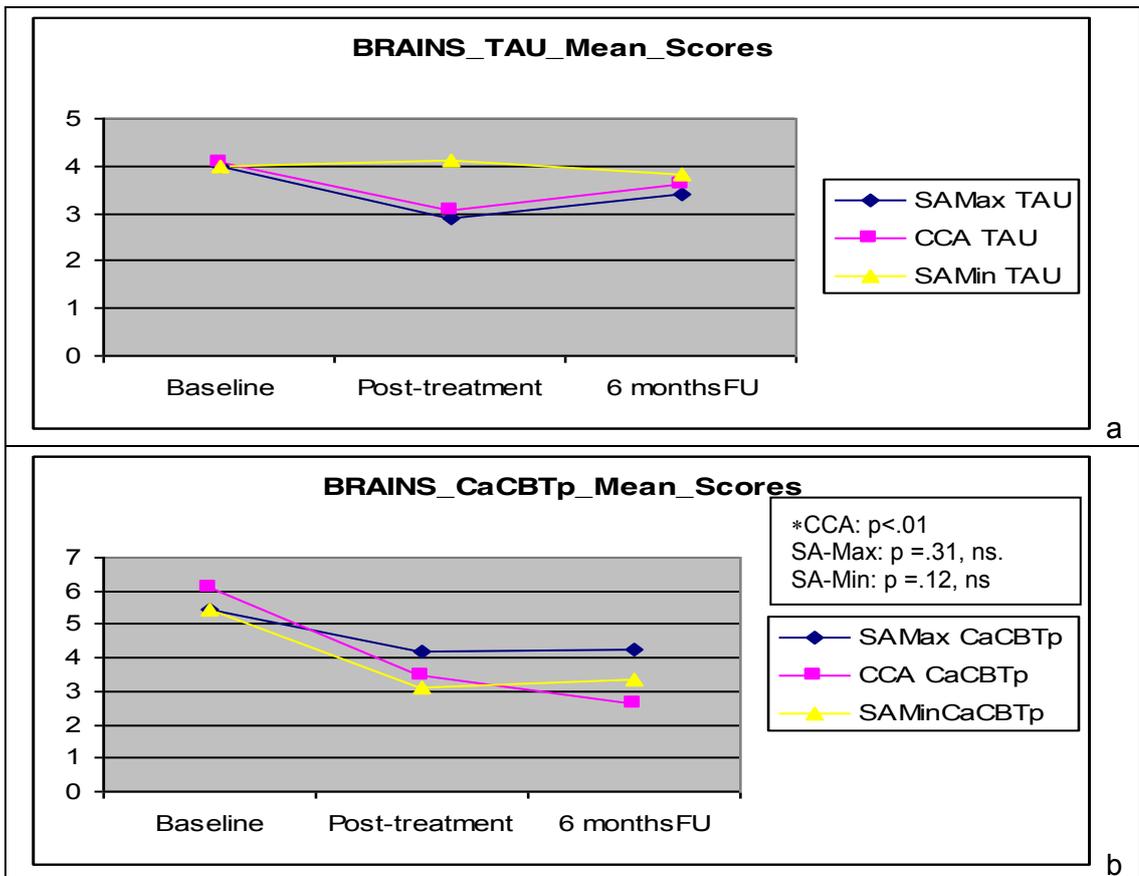
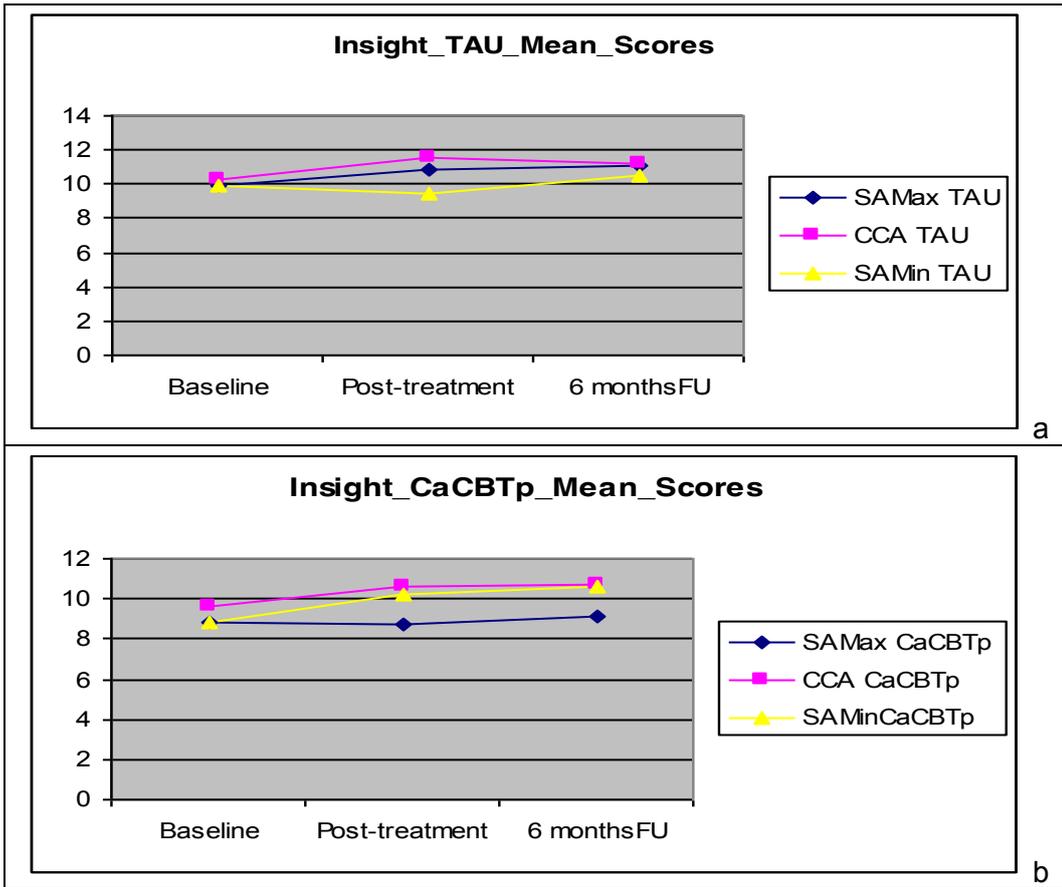


Figure 21: Sensitivity Analysis – BRAINS Scale



**Figure 22:** a shows the BRAINS TAU mean scores for the main analysis (CCA) and two sensitivity analyses (SA-Max TAU assumes the group participants had the best outcome; SA-Min TAU assumes the group participants had the worst outcome). b shows the BRAINS CaCBTp mean scores for the main analysis and two sensitivity analyses (SA-Max CaCBTp assumes the group participants has the worst outcome; SA-Min CaCBTp (assumes the group participants had the best outcome)).

**Figure 23** below depicts the Insight TAU mean scores for the CCA and two sensitivity analyses (SA-Max TAU assumes the group participants had the best outcome; SA-Min TAU assumes the group participants had the worst outcome).

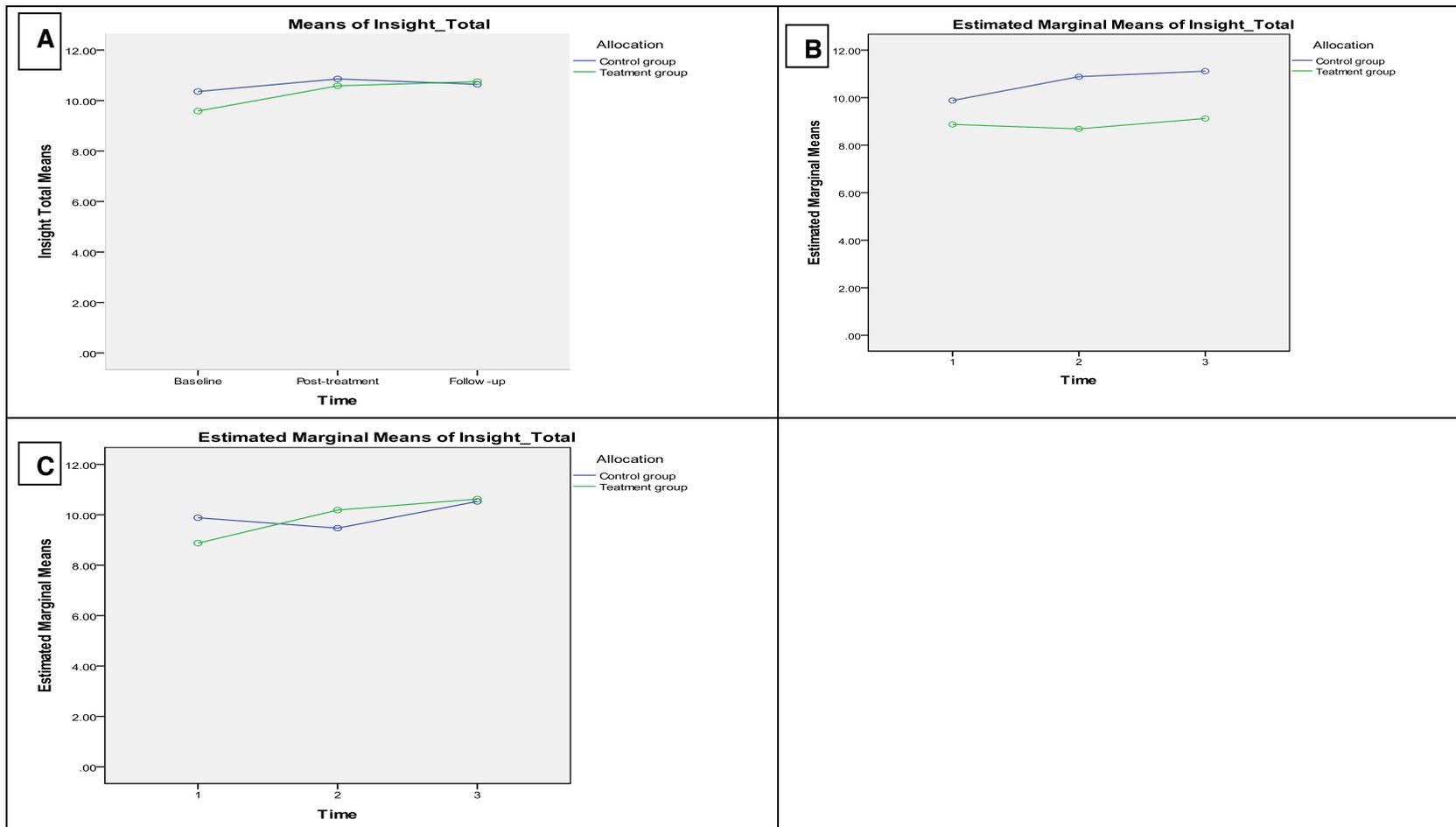


**Figure 23: Sensitivity Analysis –Insight scale**

Insight CaCBTp mean scores for CCA and two sensitivity analyses (SA-Max TAU

assumes the group participants had the worst outcome; SA-Min TAU assumes the group participants had the best outcome).

**Figure 24:** Graphical display of: A= complete case analysis; B= Sensitivity Analysis Maximum; C= Sensitivity Analysis Minimum.



**Figure 24: Insight scale –Sensitivity Analysis (complete case; Maximum and Minimum parameters)**

Overall the results produced a similar significance difference between the two groups on the CPRS scale, schizophrenia change subscale, hallucinations and delusions and therefore do support the conclusion that significant differences exist between the new intervention and the TAU group. The BRAINS, MADRAS and Insight scale did not retain their effect however the results were in the right direction. The fact that we are still getting a positive or even greater result (see table 14) strengthens credibility to our findings.

## 9.9 PEQ-post treatment results

PEQ analysis involved descriptive data on each item relating to patient satisfaction of the treatment group only. Comparison of mean satisfaction scores involved t-test on gender and ethnicity. Analysis of variance was employed to test if there was any significant difference in participant satisfaction according to therapist /centre. Dichotomous items are presented in pie charts. Of the (n=16) CaCBTp participants (n=2) did not complete the questionnaire due to loss at follow-up. Overall satisfaction with treatment experience was based on PEQ item 10 (PEQ) (n=14), M (S.D.) = 4.36 (1.082) S.E. = .28 (88.2% CI = 3.71, 4.71).

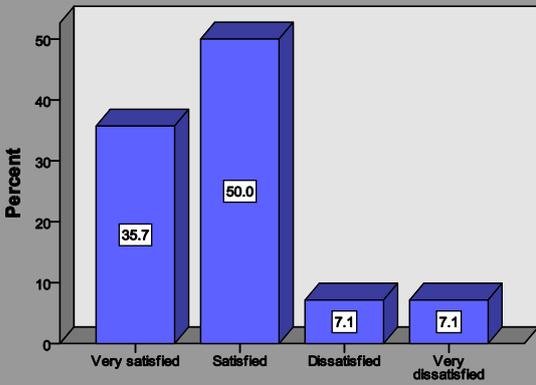
Non-parametric tests were used to explore associations between variables. Correlation was significant at: 0.05 level (2-tailed). Overall satisfaction was significantly correlated with the number of sessions attended ( $r = 0.563$ ;  $p = 0.03$ ). PEQ items 10 and 8 were significantly correlated ( $r = 0.563$ ;  $p = 0.03$ ).

There was a significant correlation at: 0.01 level (2-tailed) between PEQ items 10 and 5 ( $r = 0.78$ ;  $p < 0.01$ ). T-tests for comparison of means indicated that on average males had a slightly higher satisfaction than females ( $M = 4.50$  vs.  $M = 4.17$ )  $p = 0.58$ , not significant.

Furthermore, overall satisfaction was associated with accessibility, type of therapy, therapist and involvement in decision-making.

Figures 25-26 below, display graphical presentation of each of the PEQ post-treatment questionnaire item outcomes obtained from the CaCBTp group only.

**PEQ1**

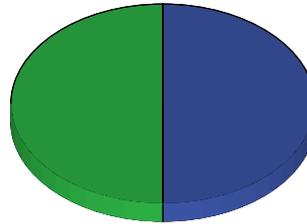


**Q1**How satisfied are you with the amount of time you had to wait for your first appointment?

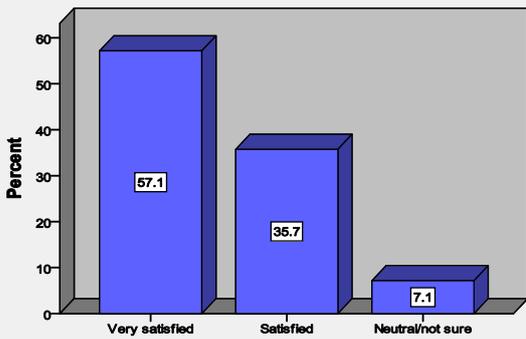
**Q2**Were you given the option of more than one form of therapy/treatment from which to choose?

■ Yes  
■ No

**PEQ 2**



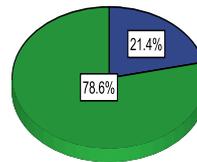
**PEQ 3**



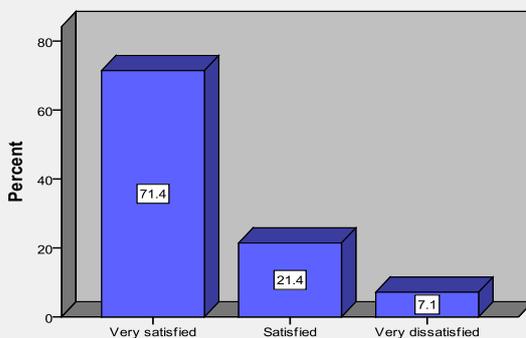
**Q3**How satisfied are you with the type of treatment that you received?

**Q4**Were you offered a choice of worker/therapist?

■ Yes  
■ No



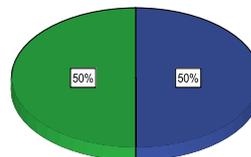
**Q5**How satisfied are you with the therapist that treated you?



**Q5**How satisfied are you with the therapist that treated you?

**Q6**Did you receive information from us in relation to other forms of help that may have been available to you?

■ Yes  
■ No



**Figure 25: PEQ items 1-6**

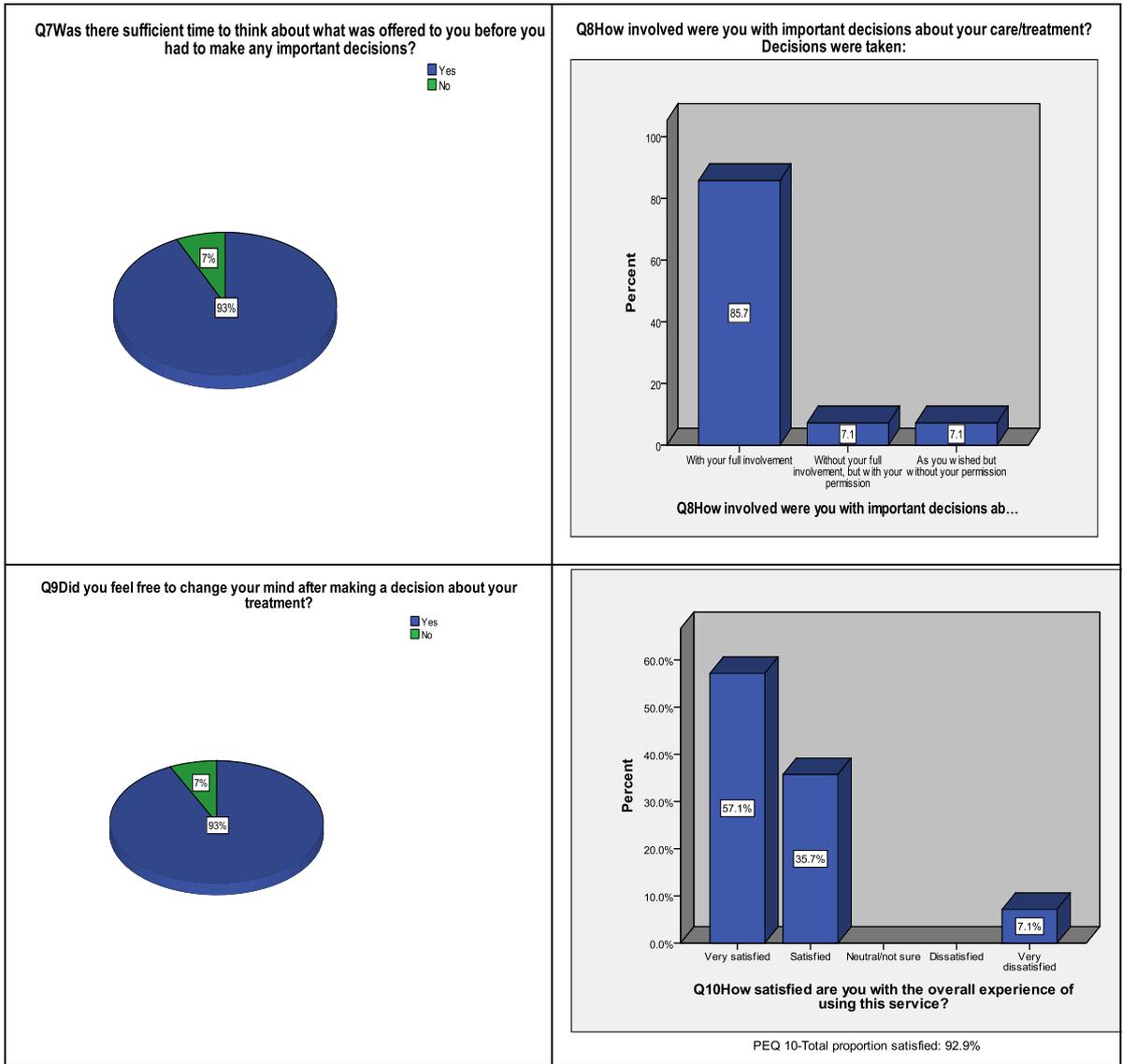


Figure 26: PEQ items 7-10

## 9.10 Qualitative analysis

Feedback obtained from respondents was analysed with emergent themes presented in a table below (PEQ 11).

### PEQ 11

---

#### Emergent Themes

---

- Therapy to involve going outdoors
- Sometimes every weekly session was a bit much for me, because I felt I couldn't cope and was not as good as the week before. Not contributing enough work for each session. I like the experiments.
- These are the things I found helpful, feelings of doing something worthwhile. Being able to live a normal life. Independence. Focusing on issues of employment
- To understand the concepts in CBT and also the perspectives used in CBT
- I discovered new techniques which were very helpful
- The things I found helpful? Everything. The things I did not find helpful? Nothing.
- Female therapist; Language- Hindi/Bengali
- Does not wish to have further CBT, as it did not help her. (Reported by key worker)

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**Table 21: PEQ item 11 – Emergent Themes**

## 9.11 The results of sensitivity analysis

From the base case model the initial optimal recommendation that is to form the standard for comparisons in the sensitivity analysis was the complete case analysis.

The maximum and minimum parameter values most affect the optimal recommendation. See figures above showing the values for a sensitivity index ranked according to their absolute values as recommended by Pannell (1997)

The results of the SA suggest that our CC was robust and retains the significance in that there is a trend towards a significant outcome, this will require a powered phase three trial to investigate the effect further that is, at follow-up.

The level of confidence that the recommendation is in fact optimal can be drawn from the comparison of confidence intervals from each SA. The results from the SA were comparable to the original analysis (complete case analysis).

Clinical Significance of Change is usually calculated following Jacobson and Truax's (1991) criterion for clinically meaningful and reliable change. There is however, on going debate on the appropriateness of this methodology, the following limitations lead to preference of calculating raw scores divided by baseline scores multiplied by 100 to get clinical significant change %. The cut off percentile on the CPRS scores was 20% and 50% improved as shown by table 22 below.

	Clinical significance	
	CPRS	
	Post-treatment	
	CaCBTp	TAU
Improved 20%	6	4
Improved 50%	5	4
Same %	0	1
Deteriorated %	1	5
Missing outcome	4	3

**Table 22: Clinical significance**



## Chapter 10 - Discussion

This is the first time that a culturally adapted CBT for psychosis study with a minority sample has been conducted in the UK showing statistical significant improvements and high levels of satisfaction and experience of intervention. The findings from the present study are timely given the on going attempts to reduce the disparities in the provision of psychological therapies for ethnic minorities. CaCBTp group achieved a significant improvement in the primary outcome measure. Despite the CaCBTp group being worse off at baseline than the TAU, they have shown massive improvement post-treatment, and were actually better than the TAU. Therefore there has been a bigger improvement in the treatment group than in the standard treatment group. Whether this is statistical significant or not is at this moment debatable. On the positive we have shown that there is an effect there. The effect on all the subscales is in the right direction with CaCBTp doing better than standard care. Size of potential future studies and health economic values for future high-powered trial will be considered. Global illness score, reduced moderately indicating initial good impact, however, this was not sustained at follow up in the CaCBTp.

Participants highly rated the therapy experience and satisfaction with the adapted intervention. CaCBTp has demonstrated sensitivity to cultural needs of the population and the adaptations were acceptable to BME groups. Attrition rates in the CaCBTp study when compared to similar trials were low. The new CaCBTp intervention was superior in the reduction of positive and negative symptoms in comparison to TAU. In order to gain obtain an effect size  $d = 0.33$ , a err probability = 0.05; power  $b = 0.80$ , the phase III CaCBTp trial would require a total sample size = 300 participants.

Results in this trial compare well with those of recently published trials, for instance Grant et al. (2011) reported significant benefits for CBT compared with TAU, this trial had a well represented minority sample of African American, and attrition rates were low in contrast to previous CBT trials (e.g. Morrison et al., 2004; Kuipers et al., 1997; TARRIER et al., 1998; Rector et al., 2003).

Insight outcomes in the present study were compared to previous published trials (Rathod et al. (2005). There was a positive trend towards the reduction of symptomatology in the subscales, although not statistically significant in between group comparisons, this maybe due to small sample size, or the fact that there maybe a need to develop culturally sensitive insight scales that will be able to capture awareness of illness in line with cultural beliefs.

The aim of this study was to test the feasibility of culturally adapted CBT for psychosis in BME groups in comparison to treatment as usual; to assess acceptability of this intervention and evaluate participant experience and satisfaction of intervention. When compared with the white groups in the Rathod et al. (2005) and Grant et al. (2011) studies, the baseline characteristics of this trial reveal similarities. Interestingly the differences are in duration of illness and age. Participants in present trial were mostly young with 32% of them drawn from the EIP services. Moreover, there was a reasonable forensic sample which previous trials have not included.

The main findings of this trial suggested that both interventions had a trend towards improvement, that is, a reduction in CPRS symptoms. The CaCBTp group engaged well as indicated by mean number of sessions attended and significantly high scores on the PEQ questionnaire. The present study was comparable to literature on CBT for schizophrenia with mean CBT sessions ranging from 19 sessions in the Sensky et al. (2000) with (n = 90) participants to 14.3 (SD=8.1); Edwards et al., 2001 with (n = 15) participants, the later was a culturally adapted CBT uncontrolled trial for depression with Hispanic participants.

The CRPS results were marginally significant in the CaCBTp group and remained significant when secondary conservative analyses were conducted, suggesting the robustness of the original findings. Moreover, the SA suggests the direction the results could take should the best or worst level of values be imputed on missing data.

Comparison of CPRS total mean scores with other published work suggests that CaCBTp

baseline mean scores (32.25) were comparable to previous CBT studies, for example (M = 35.6) in the Sensky et al. (2000). Similarly in the Turkington et al, five year follow-up trial they had mean baseline scores of 35.6 or greater. On the contrary, Rathod et al. (2005) study CPRS Mean (S.D.) = 23.23 (13.2) are lower than in the present CaCBTp study. In a trial comparing CBT with Befriending, post-treatment scores reported means M (S.D.) = 14 (9) CBT vs. BF M (S.D.) = 22 (12).

These findings suggest that there were bigger improvements post-treatment, although maintained in the CaCBTp there was a gradual decline in the gains in both groups at follow-up. This trend has been noted in the previous CBT for psychosis trials. The findings are also sensitive to the differing levels of entry into the trial, with the CaCBTp group with higher means at baseline predicted where they were going to be at the subsequent time points.

Insight findings were somewhat interesting in that although the mean scores were in the positive direction of significant effect; between group differences were marginal in all three domains; a speculation and conjecture here maybe the insensitivity of the insight schedule towards minority cultures. Furthermore, they may have been bias in the way question (3b) was rated by assessors. Subscale analyses of the three insight domains revealed domain two and three (acceptance of illness and re-labelling of psychotic symptoms) as statistically significant. Comparison with the Rathod et al. (2005) insight study which showed small changes in insight scores within the African Caribbean group and Black British lower in Black African had baseline; domain 1 mean scores were similar to the present study, however, their mean difference post-treatment had a 0.19 units increase, whereas the CaCBTp study has a 0.59 units. Domain 2 had a 0.48 unit increase in the insight study compared with 0.36 in CaCBTp trial post-treatment. Finally, domain 3 had a 0.41unit increase vs. CaCBTp with 0.36 units.

These findings suggest that CaCBTp intervention was marginally superior to TAU as indicated by the subscale analysis of the primary and secondary outcome measures. Although the improvements were maintained at follow-up this was not statistically significant and would require a highly powered trial to investigate this further. This study has provided promising results and challenges in adapting evidence-based interventions.

## 10.1 Comparison with other CBTp studies

When compared to the white groups the baseline characteristics of this trial reveal similarities. Interestingly the differences are noted in the duration of illness and age variables. Participants in the present trial were mostly young and drawn from the EIP services (32%). Moreover, there was a reasonable forensic sample which previous trials have not included.

Previous research has shown that CBTp can obtain a significant effect size as noted earlier in this thesis. Limitations of CBTp trials included small BME sample size to warrant accurate analysis of efficacy and generalisability to this group. There is an exception of a handful of recent trials with significant BME samples (Grant et al. 2011; Rathod et al., 2005) just to mention a few; the command trial at the time of writing this discussion had not published its preliminary results. The present study was designed to test the feasibility of culturally adapted CBT for psychosis with four specific ethnic grouped delivered by trained CaCBTp therapists over 16 weekly sessions in three centres. Our findings indicate that CaCBTp intervention attained a significant level of symptomatic reduction on the primary outcome measure CPRS as hypothesised in comparison to the TAU group. However, the benefits were only significant post-treatment.

BRAINS a subscale for assessing negative symptoms abstracted from the CPRS on analysis both groups did show a statistically significant effect post-treatment as would be the case in CBTp when targeting negative symptoms, however, the effect although a modest improvement, was not sustained at follow-up. The direction of the effect was positive towards significance.

Findings from this trial add to outcomes of trials on cultural adaptations in other mental health disorders other than psychosis. For example, there is evidence from small pilot studies suggesting locally adapted CBT with minority populations has been successful (Kubany et al., 2003; Carter et al., 2003; Hinton et al., 2004; Hinton et al., 2005; Patel et al., 2007; Rojas et al., 2007; Rahman et al., 2008).

In a recent trial by Grant et al. (2011) similar outcomes of efficacy of CBTp were reported, of interest here was the large ethnic minority group sample of (n = 39) from African American and (n= 1) Asian American background. Baseline demographic characteristics of the CaCBTp trial were compared to the Grant et al (2011) and Chinese CBT for schizophrenia trial Zayen et al. (in press) with the following outcomes; In terms of pharmacotherapy, antipsychotic medication converted to chlorpromazine equivalent dosage revealed means of 400mg or greater in the US and UK trials, in contrast to the Chinese trial with lower means of 300mg  $\pm$ . It would seem to confirm the beliefs that in western cultures high dosages of antipsychotics are prescribed to this population (Sensky et al. 2000; TARRIER et al. 2004 trials had even higher chlorpromazine dosage of 500 - 600mg) whereas in the east reasonably lower dosages seem preferential. Could the metabolic rates known to differ across cultures be having an impact here? Similarities were noted with regards to gender, where males tended to be more than females; age and duration of illness were constant across the three trials. Comparison with the Grant et al. (2011) trial; mean duration of illness differed slightly at 15.5 (12.18) vs. CaCBTp 10.39 (8.63). CPZ equivalents mean (SD) was 456.36 (472.10) this was indicative of a higher dosage of medication supporting the literature on ethnic disparities. Employment rates were higher in the Chinese cohort (49%) than in the UK CaCBTp trial (9%); with 2% in the Rathod et al. (2005) study; the US trial did not provide this information. This could be explained by taking into account differing healthcare systems; in China individuals self fund their healthcare bill, as is the case in the United States where individuals require health insurance or if from low-income threshold may qualify for Medicare. On the contrary, the UK NHS and the social welfare benefit system may indirectly influence this low employment rate. The results from our trial also provide predictions that the most likely group to have bigger benefits would be women of young age. Might this be associated with the level of acculturation to the host UK culture? Our previous qualitative study showed that second generation were more amenable to change and would depending on level of acculturation oscillate between the culture of the country of origin

and their host country. This would however, be dependent on the presenting problem and available moderators to inform help seeking behaviours and pathways.

The findings also demonstrate significant levels of patient satisfaction with the adapted intervention as indicated by the PEQ post-treatment scores. When compared to IAPT outcomes on the PEQ scores (Delgadillo, 2010) have similar or higher satisfaction levels in the CaCBTp study patient satisfaction. Moreover, the mean therapy sessions suggest acceptability of the culturally adapted intervention.

Presently there is paucity of literature on CBTp in secure settings; our findings suggest that CaCBTp can be delivered in varied settings including forensic settings. Of the (n = 7) forensic participants in the trial (n = 3) were allocated to the CaCBTp intervention, of these (n = 2) completed 16 sessions and (n= 1) following his discharge from the forensic setting to the community was a non-starter, numerous attempts to contact him were unsuccessful.

There were challenges in the delivery of the adapted intervention in particular therapy with a non-English speaking Bangladesh participant. Limitations included inconsistencies in interpreter and occasional reliance on husband to interpret. Interestingly, use of mindfulness techniques such as the “watching your thoughts drift by exercise” the transcript was translated into Bengali and used with the participant. Progress within healthcare in understanding cultural diversity remains elusive within the field of psychological therapies in particular cognitive behavioural therapy. Although across the pond (Sue et al, 1992 etc.) have made significant progress in cultural sensitive psychotherapy much work needs to be done in the UK to bridge this gap in particular within adult mental health population from ethnic minorities.

Patients with English as their second language or indeed those from bi- or multi-lingual backgrounds may have difficulties relaying or expressing themselves where professionals have limited or no understanding of this language phenomenon. Language barriers result in increase in healthcare costs (Bischoff & Denhaerynck, 2010). There is a tendency to expect patients from other backgrounds to be fluent or literate in the English language. Language has been identified as a barrier to seeking help and access to psychological therapies in minority groups as reported earlier in our qualitative study (Rathod et al., 2010).

It may be helpful to begin by defining terms of reference relating to first language (L1) and second language (L2). Monolingual refers to the ability to speak one language proficiently. In contrast, bilinguals speak two languages; subsequently multi-linguals have ability to speak several languages.

First language also known as “mother tongue” has been described by D’Acierno (1990) as an intrinsic component of a child’s social and cognitive development in contrast to L2. Accordingly, three types of bilingualism are noted by D’Acierno; namely compound bilingualism, co-ordinate bilingualism and sub-co-ordinate bilinguals. Of particular importance here is context in which language is learnt, for instance, where two languages are learnt in the same environment, the individuals are likely to acquire one notion with two verbal expressions (compound bilinguals). Acquisition of two languages in different contexts (host country and country of origin; this tends to be the case for some migrants to the west), D’Acierno argues that the two languages will belong to separate and independent systems (Khan, 2011). Within the sub-coordinate bi-lingual’s only one language dominates.

Often African Caribbean will revert to their mother tongue (Patois or Creole) if they felt they were not being listened to (Rathod et al. 2010). In some cultures where the culture of the country of origin is maintained at home subsequent generations will speak mother

tongue at home and revert to English when with peers or outside home. Language is used in social relationships and also to control cognitive processes (Khan, 2011).

In the African Caribbean population, language becomes a barrier in situations where they feel misunderstood and may revert to speaking in Patois or Creole to express themselves. Impact of language on emotions is emphasised here.

Observing baseline raw data it was apparent that two participants (P009 & P038) presented with low baseline scores in contrast to correspondence with clinical care team. At initial assessment it was apparent that both had a global symptom severity of 2. These observations suggested that baseline data were falsely low. This has implications on any therapeutic gains and may lower effect at follow-up analysis. Overall the findings are favourable to culturally adapted CBT for psychosis with this population. Although the sample size in this trial is small, given that this is the first study of its nature in the UK, the outcome is significant. Some snags along the way might have influenced the outcome and overall effect of the results, for example a number of participants in the control group were seen by psychologists for therapeutic interventions during the trial period (P006, P025) despite awareness that trial had not yet ended. A large sample could have been easily achieved had it not been impeded by London site team, which declined their participants participation in the trial fearing they might be allocated to the control group. Also fearing that it would be politically incorrect to withhold psychological treatment to a group that was seen as not having access to CBT.

Another factor involved the exclusion of the Manchester site, this had been earmarked to recruit South Asian Muslim participants to the trial; however, due to unforeseen circumstances this site was withdrawn from the study. Religion and spirituality relating to psychotic phenomenon addressed from a cultural standpoint was both sensitive and

acceptable by the participants as demonstrated by the case examples (see appendices 19 - 20).

Despite these hurdles clinically significant effects were found in this trial and most results were in the right direction, indicating a trend towards efficacy. Group analyses showed reduction in symptoms and improvement in insight. Patient satisfaction was rated highly.

Before considering the limitations of this trial, it is worth noting the strengths. This trial is timely given literature on disparities and high attrition rates on BME groups in CBT studies from literature and poor patient experience and satisfaction with treatment; and being the first culturally adapted CBTp trial in the UK. Most adaptations of evidence-based interventions have been successfully conducted in disorders other than psychosis (e.g. Kubany et al., 2003; Carter et al., 2003; Hinton et al., 2004; Hinton et al., 2005; Patel et al., 2007; Rojas et al., 2007; Rahman et al., 2008). The study design, a RCT is gold standard, with intent to treat analysis and conservative secondary sensitivity analysis to account for missing data albeit low attrition rates when compared with similar trials in literature. Assessors and therapists were blind to treatment allocation. Sensitivity to targeted ethnic groups was indicated by acceptability and high rates of satisfaction of CaCBTp (90%). Medication and changes was monitored for the duration of the trial.

## 10.2 Methodological limitations

A potential limitation was lack of choice of therapist gender and language matching as recommended by previous adapted studies (Griner & Smith, 2006) meta-analysis showed that language matching had good effect size. The present study had one non-English speaking participant (Bengali speaking). A Bengali speaking junior doctor (ST4) was involved as an interpreter. Evaluation of patient satisfaction was limited to the CaCBTp group; therefore its effect could not be compared with the TAU group; however, the findings of PEQ were comparable to the IAPT outcomes. Significant mean differences at baseline suggest that future designs of such trials may require robust screening assessments for severity with cut-off entry scores into the trials using such tools as the SCID interview assessment.

Addressing treatment as usual criteria will be a challenge as psychotherapy becomes more readily available as a standard routine treatment in the NHS.

In hindsight, Insight in psychosis scale may not have been sensitive to this population group and raises questions about a need for development of culturally sensitive outcome measures as adapting an intervention and using measures that might have been validated on predominantly western populations may defeat the objective of capturing the extent of gains resulting from the adaptations.

These findings provide a significant milestone in psychological interventions for minority populations and adaptations necessary for future interventions. This study was designed as a pilot trial and therefore would benefit from a bigger multi - centred trial replicating methodology and findings. It would have benefited from a more robust screening pre-treatment and reliability training of assessors. Unbalanced distribution of therapy between centres meant that the majority of therapy was delivered by the author (PP) and the other two London therapists each were allocated two participants due to recruitment problems

and commitment to trial in line with their clinical responsibilities; consequently these trial therapists could only see one participant at a time.

Some of the follow up data was conducted over the telephone (9%) due to participants moving out of area and being inaccessible. Teams not adhering to trial procedure, i.e. offering intervention to some participants in the control group, might have affected effects of CaCBTp.

Although our primary and secondary outcome measures are validated and robust instruments, comparison with similar CBT studies revealed the choice of measures was varied, with most studies preferring to use SANS, BPRS etc.

### 10.3 Randomisation process

The process of randomisation although scientifically robust and gold standard remains an issue for some groups who do not believe in chance and therefore refused to participate in the trial. Although scientifically plausible the process of randomisation in clinical trials is still seen by some participants as warranted but brutal (Tobias, 1992). During the recruitment phase, there was ambivalence from both clinicians and lay members (carers) in involving their patients in the trial, fearing that they would be randomised to control group and therefore spend duration of the trial receiving standard treatment as usual. Some expressed ethical concerns of not providing CBT to this population should they be allocated to TAU and opted not to involve their patients in the trial. One such service was an Early Intervention in Psychosis Team in the London site. The team had identified 100 potential participants with a diagnosis of who (n = 31) met the eligibility criteria. The service manager expressed concerns for those who might be allocated to the control group, consequently declined to invite participants to participate in the trial. This typical example echoes similar challenges trial researchers face and raises concerns as to the misunderstanding of the randomisation process in clinical trials. The notion of treatment being left to chance can be uncomfortable to those whose wellbeing may depend on a 1:1 chance. For some potential participants this was an incentive to participate in the trial with the hope that they may be allocated to the intervention group given that their services had long waiting lists for psychological therapies. Whilst the few that understood this process, accepted chance to decide their fate. Either way they reported that they were contributing to future evidence-based interventions. This was a form of goodwill gesture. Clinical trials are a novel concept for minority groups who in the past may not have participated in research. For some, explaining randomisation may require sensitivity, as belief in chance may not be culturally accepted. Providing clear training and information on randomisation and consenting in trials to both clinicians and members of the public will ensure increase in participation by those sceptical and not so keen to engage in research trials.

## 10.4 Report on missing data.

Missing data in this CaCBTp trial was small in comparison to previous published trials of CBTp. Both groups post-treatment had equal missing data ( $n = 3$ ) and at follow up the CaCBTp group had two lost to follow-up in comparison to TAU with one participant who died following suicide. This may suggest the severity of psychosis and its associated risk of self-harm.

Managing missing data in clinical trials can be challenging. There is ongoing debate amongst statisticians and researchers as to which methods are best fit for analysis where missing data is concerned. A recent online survey aimed at high impact medical journal editors and statistical reviewers investigated the frequency and critical statistical errors in submitted manuscripts (Fernandes-Taylor, Hyun, Reeder, Harris, 2011) and identified two main themes; namely statistical and sampling issues and inadequacies in reporting clarity. One of their sub-themes related to improper management of missing data. In particular failure to account for missing data including drop out rates. Moreover, they reported that most trials failed to describe their methods of imputation of missing data. The recommended approach to managing missing data is “not having any ” or limiting it (Siddiqui, Hung, O’Neill, 2009).

The impact of missing data to loss of power can be concerning in randomised trials when assumptions are made, the limitations can result in biased estimates, standard errors and wrong  $p >$  values and inflated Confidence intervals. Commonly advocated but less effective simple imputation methods such as last observation carried forward (LOCF: Canuso et al., 2009; Fernandes-Taylor et al., 2011) assume that participant responses remain constant after dropout and therefore impute the last observed values. On the contrary, White et al. (2011) suggests conducting sensitivity analysis (SA) for all randomised participants with the aim of exploring the effects of departures from the assumptions in the main analysis. Accordingly, Siddiqui et al. (2009) conducted a

comparison of regression and mixed models with LOCF on 48 clinical trials and concluded that MM/RM were superior in relation to minimising biases and controlling for type 1 error rates. Consequently, Mallinckrodt, Kaiser, Watkins, Molenberghs, Carroll (2004) vehemently dispute use of this method. Moreover, Wykes et al. (2008) meta-analysis refutes LOCF. Grant et al. (2011) in their CBT trial for schizophrenia used random effects regression model to analyse missing data and commend that it is superior to both LOCF and MI models. Similarly Miranda, Chung, Green et al. (2003) used MRM in their analysis of data. Taking the above into account, it was considered appropriate to evaluate the missing at random (MAR) assumption and conduct sensitive analysis as recommended (Graham, 2009). Although the preferred approach to missing data would have been the recommended Mixed effects Regression Model after statistical advice from the statistician and considering the missingness of assumption (i.e. Missing Not At Random: MNAR) as the MAR assumption did not hold, the following plan for analysing missing data was adopted.

First, to conduct a complete case analysis as befitting the nature of our trial being an exploratory study supplemented by secondary conservative sensitivity analysis to illustrate the robustness of our findings (White et al., 2011). As recommended in literature, use of sensitivity analysis was utilised to justify the primary statistical approach. It was assumed that sensitivity analysis would provide similar treatment estimates therefore render missing data to be of less effect on results of the study. The results of the full set were compared to the complete case analysis. Models of choice to explore missingness compared worst and best case scenarios. This involved assigning the best possible outcome to missing values in the control group and the worst possible outcome to the CaCBTp group and vis versa. Should the analysis be still favourable, it will be concluded that the results were robust to dealing with missing data, suffice to say that the parameter estimates in the models used to analyse missing data were most similar with a few

notable exceptions as shown previously by the graphical displays comparing sensitivity and complete case analysis.

Literature indicates that even small amounts of missing data may lead to inappropriate conclusions from complete case analysis with MNAR. Sensitivity analysis (SA) illustrating conclusions under a variety of alternative assumptions about the mechanism is necessary. The graphical displays described in the results section provided a full sensitivity analysis by showing the results under all possible allocations of the missing outcomes (Hollis, 2002). Although SA is recommended in MNAR data, it is seldom used in practice.

Data in the present study was MNAR therefore ruled out some of the recommended assumptions. I had to conduct secondary conservative analysis for robustness and to see how far the outcome would be. I therefore set this bar as high as possible; as demonstrated by table 29 the results show that our findings hold. We could have used a mid-point value rather than the worst/best value. We were able to find a difference that was clinically significant. It would have been helpful at offset to agree a cut-off point on the primary outcome measures for significant change. Given that our results hold, it is hoped that future trials will be able to replicate or demonstrate this effect.

## 10.5 Implications

Given that this is the first trial of its kind, the findings provide a benchmark on culturally adapted CBT for psychosis for ethnic minority population and the benefits this intervention has to patients and therapists working with diverse groups. Acceptability of CaCBTp suggests that patients will adhere to and engage with this intervention. Low attrition rates in the CaCBTp arm and high levels of satisfaction and patient experience suggest that this intervention was sensitive to the needs of individuals and families from BME groups and they would recommend this to others. The benefits of this project will be realised at different levels:

### **10.5.1 Power calculation**

As a randomised clinical pilot trial it will inform a fully powered PHASE III trial providing evidence of feasibility and acceptability by patients. It will also provide estimates of differences in outcome between the intervention and usual care groups;

### **10.5.2 Satisfaction**

An effective treatment based on cultural explanations will ensure better quality of care for this group of patients that they are more satisfied with and therefore will be more effective in this group as demonstrated by the outcome measures and the PEQ questionnaire. It will impact on the quality of care and lower distress through illness in this group. It will help engage patients, explain the illness and role of medication, treat early so that they can trust their caring teams, understand their illness and therefore prevent reoccurrence of

symptoms and sometimes admission especially when it is compulsory. Offering CBT to this group for psychosis offers choice and an evidence based alternative or adjunct to psychotropic medication (DRE, Inside, Outside). In summary it would mean better care for patients, which is least restrictive and according to choice agenda.

### **10.5.3 Policy makers**

Implications for policy makers will include the training of staff and dissemination of this therapy within resource constraints. CBT for psychosis is a well researched therapy with established benefits in patients with psychosis. However, currently this therapy is not widely available due to constraints on resources. Overall, provision of this therapy is a cost effective way of managing patients with psychosis in the community as the relapse rate is found to be low (Turkington, 2006) and therefore hospital admission, which is the most expensive aspect of patient care can be avoided.

### **10.5.4 Service development**

There are implications for further development of clinical or public health practice due to the role of this treatment in early intervention, relapse prevention and effective community care. On the organisational level the delivery of CaCBTp will require significant service change towards acknowledgement of equality and diversity coupled with resources and training provision in cultural competence within the NHS workforce. Recommendations from the qualitative study relating to help seeking behaviours and pathways including language barriers will require services to be modified in order to breach the gaps and promote a user friendly NHS to diverse cultures in the UK. Furthermore there are implications for increasing BME researchers in investigating such sensitive issues relating to culture. It is hoped that the significant outcomes in this study will influence policy makers to promote CaCBTp training and availability within NHS services.

### **10.5.5 Future research**

The work may highlight critical factors that need further research and development to maximise effectiveness of care such as culturally sensitive questionnaires for insight or awareness of illness.

This study has implications for how CBT trials conduct analysis on missing data. In the real world, avoiding missing data at all cost, is easier said than done; White et al., (2011) recommend trials to specify their primary and secondary analyses in the protocol before the unblended data is seen to prevent the bias of data driven changes to analysis. Such approaches, as LOCF should be avoided at all costs.

### **10.5.6 Clinical implications for Therapists**

Collaborative empiricism is a fundamental cognitive therapy principle that underpins teamwork and balanced contribution from both the therapist and patient. Some cultures are very paternalistic and will expect the clinician or therapist to be a figure of authority that will “solve their problems and tell them what to do”. Iwamasa (1993) also found that Asian patients might prefer a more structured (fits well with CBT principle) and prescriptive approach. This latter approach may conflict with cognitive therapy’s collaborative empiricism where the patient and the therapist work together to understand and develop alternative ways to address the patients’ difficulties. The expectation is that the therapist or others would solve their problems just like they would for instance, go to the Mosque to see a priest or Imam, who may give them *zum zum* (holy water), verses from the Qur’an to recite or *tavees* to ward off evil spirits. Furthermore, exploration of opinions about problems may lead to doubts about the clinician’s competences. The therapist therefore, needs to be creative and actively engage patient participation in his or her own recovery process.

The therapist can continue to maintain collaborative empiricism by working with the patient where they are e.g. somatisation (Literature suggests that attribution of symptoms of mental illness to external stressors is a common occurrence among individuals from different cultural groups: Cabassa et al., 2008; McCabe and Priebe, 2004; Krenawi et al., 2001). The transition from the consultative to collaborative empiricism is crucial in adapting CBT to this client group. Some patients from the South Asian Muslim cultures respect and trust a paternalistic attitude from their therapist but may expect a rapid and tangible return for their co-operation. A clear agreed summary of the first and subsequent sessions can be part of this process, i.e. outlining briefly the key issues and plans to deal with them. In-between session tasks set collaboratively after this first and subsequent sessions to develop further understanding or test out beliefs expressed are important to endorse their feeling that 'something happened' and will continue to happen in therapy. Contrary to paternalist cultures, some patients from African Caribbean backgrounds prefer the collaborative stance and would like the therapist-patient relationship to be viewed as equal. This re-enforces the notion that therapy is the meeting of two minds, the expert patient and the expert therapist working collaboratively to help ameliorate distress and teach skills to cope with their problems.

Issues of racism often avoided by therapists should be explored with curiosity and genuineness taking BME experiences at face value rather than avoiding or dismissing them for fear of political incorrectness. Awareness that trust is 'not a given' but will have to be earned can help put patients at ease. Issues of 'sameness' and matching should be considered on individual case basis. Therapists working with diverse cultures need to address their own attitudes about particular cultures they might have stereotypical assumptions about. Moreover, understanding ones own cultural beliefs, attitudes and norms may help identify or prevent therapist interfering behaviours, these can be discussed in clinical supervision. When conducting assessments, therapists will need to incorporate cultural assessments and formulations including attributions of illness that will differ according to cultural beliefs. In the CaCBTp study early involvement of family role

was crucial in supporting patient engagement with therapy. Therapist creativity when setting behavioural experiments collaboratively with patients is emphasised. In the CaCBTp study use of technology such as email correspondence when completing homework assignments for those patients who had access to computers improved homework adherence; mobile phone devices (see appendix 22) were used with patients who were isolating and avoiding social situations due to voices to engage in dialogue with voices.

Consideration of adaption models (such as: Bernal et al., 1995; Leong and Lee, 2006; Domenech-Rodriguez and Wieling, 2004; Hwang, 2006; Hays & Iwamasa, 2006; Barrera et al., 2006) and selection of Tseng's framework as model of choice allowed fidelity to the core principles of CBT with adequate flexibility for adapting the therapy to cultural beliefs, thereby preserving validity to the original treatment. It is acknowledged that in practice, even if desirable, it may not be feasible to develop a different CBT intervention for every cultural group and subgroup within them as every cultural group and subgroup may have their own uniqueness and could not be considered as one. Therefore, therapist choice of adaption models is crucial. Furthermore, choice of cognitive models that are sensitive to minority group needs should be considered when helping patients to make sense of their problems.

## 10.6 Conclusions

Our results are timely and raise the bar for culturally adapted CBT interventions not only for psychosis as the concepts of adapting evidence based interventions are applicable across the board and will impact any clinician working with diverse patients cross-culturally. Conservative analysis such as the sensitivity analysis are recommended in CBT trials where there is attrition be it high or low, the assumptions and the parameters imputed values take, can be vital for readers to make their own conclusions and interpretations of trial outcomes. They are and will be helpful for decision makers, policy makers and trainers as a predictor of clinical outcomes if the trial was for instance, replicated and either parameter was the outcome. Further research into the efficacy of the adapted treatment and prepared manual would be necessary and it is anticipated that this would take the form of a PHASE III randomised controlled trial. Future implications may involve a training package on the adapted intervention. The lead researcher (PP) already provides lectures on the adapted intervention to the Diploma in CBT for Severe Mental Health problems; IAPT Diploma in Depression and Anxiety and to the IAPT Low intensity programme with the University of Southampton and these sessions are well evaluated. It is anticipated that the training package will be available and used by clinicians working with diverse cultures.

The findings of this trial add to the developing body of knowledge on culturally adapted evidence based interventions and further demonstrate a trend towards significant effect on adapted treatments thereby supporting current literature on modified interventions as postulated by the Griner & Smith (2006) meta analysis.

Our study contributes to the growing evidence in the adaptation of evidenced based interventions and efficacy and acceptability of culturally adapted CBT for psychosis. When working with diverse cultures, therapist cognisance of culturally derived behaviours,

attitudes, beliefs, values and norms is vital for therapy to be sensitive to the individual's culture whether they have assimilated to the host country or stuck to the culture of the country of origin. Therapist awareness of individualist and collectivist concepts and incorporating these in the therapy process is highly recommended. Patient satisfaction and experience of the CaCBTp intervention was highly rated, therefore therapist understanding of patient's cultural background and sensitivity to cultural beliefs may have influenced this outcome. Indeed one size does not fit all; CBT can be effective when modified to specific cultural needs.



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## **Appendices**

### **Appendix 1: Interview Guide - Health Professionals (focus groups)**

Group discussion: ideally 6-8 in a group. Tape recorder required. Allow 1.5 hours to include preparation of room and equipment, introductions, tidying up etc. Interview itself no longer than 1 hour. Two researchers - 1 to lead and one to scribe, manage tape recorder, prompt etc.

Good morning/afternoon, thank you for coming.

Introduction – both of the researcher and the facilitator. Explain the purpose of the focus group and how it will be conducted

The researcher should give an explanation of the research giving the reason, procedures and outcome. Ask participants to say their name before speaking. This may be a pseudonym if preferred or sometimes it is beneficial to give participants a number to use before speaking.

#### **Consent**

For the focus groups mainly the participants will probably direct the discussion. However, the researcher should have questions to keep the discussion focused on the research aim. However, the participants must be allowed to introduce topics that are of importance to them.

The researcher will ask the questions and direct the focus group. If more than one person is speaking at the time the facilitator must help the researcher to try and get participants to speak individually. The facilitator should note who is speaking at any one time.

**General questions to follow up what someone has said:**

- 1) That is really interesting can you tell me more about that
- 2) Has anyone else got anything to say about that
- 3) What do you think would help?
- 4) Has anyone else found this?
- 5) How did you deal with this?

**Specific questions**

- 1) **Can anyone begin by telling me their experiences of conducting CBT with people from ethnic minorities – name them?**

**Prompts**

What did you find particularly useful?

What have you found particularly difficult?

Has anybody else experienced this?

**If there were problems** – did you find anything that made this easier?

Has anyone else found ways to deal with this?

**For good points** – would you recommend this as a way for dealing with people from ethnic minorities?

Difference and Similarities between the ethnic groups?

Have you any explanations or common themes for these similarities and differences?

- 2) Using the manual how did you find following the manual when working with people from ethnic minorities?**
  
- 3) If we take the manual a chapter at a time can you tell me about each chapter individually? Let's start with chapter 1 can anyone tell me what he or she think of these guidelines when dealing with ethnic minorities?**

## **Appendix 2: Interview Guide – Participants (face to face individual interviews)**

Thank you for agreeing to meet with me

I know that we have sent you some information and that your Dr has discussed the study with you but before we go ahead with the interview I would just like to go over exactly what is going to happen today and ask you to sign a consent form to say that you are willing to take part. You still do not have to take part and you may ask to stop at any time.

Explain the study – including taping the interview and the reasons why this is being done

Ask if everything is understood. Has the participant any questions?

Take consent.

### **Begin the interview**

Could you briefly describe how you first became aware that you needed to see a doctor about your problems?

### **Prompts;**

At the time, what did your family /friends think was happening to you?

What did you think was happening at the time?

At the time, what did you think was causing this problem?

Did you consider, or did anyone suggest that you should seek help from anyone apart from the doctor (e.g. spiritual healer)

Did anyone suggest any other ways of helping you with this problem? (who and what?)

Which explanations made you feel better?

Did you feel that the therapist/doctor did not understand your account of your problems?

(if yes.. explore further)

How do you now view things?

Throughout the interview use the phrases such as:

- 1) That is very interesting can you tell me more about that?
- 2) Really and how does that make you feel?
- 3) Going back to the point about ... what do you think might make it better for you?

### **More specific questions**

- 1) How do you feel about coming for the appointments?**
  
- 2) Can you tell me how you feel about your treatment?**
  
- 3) Have you been offered CBT and did you accept. If not- why not and what would have made it acceptable**
  
- 4) If you have received it did you find it helpful?**

### **Prompts**

Do you find it difficult to talk to the person who is treating you?

What do you find particularly good/bad?

- 5) Can you tell me what have you found particularly useful**
- 6) Can you tell me how you find your therapist?**
- 7) Did you find their explanations regarding your symptoms similar to those offered by family and friends?**

## **Prompts**

Can you tell me what kind of person you would prefer when choosing a therapist?

If someone from your community approached you because of similar experiences and they were wondering what to do, what advice regarding treatment would you give them?

## **Appendix 3: Interview Guide – Lay participants from ethnic minority background. (Focus groups)**

Good morning/afternoon, thank you for coming.

Introduction – both of the researcher and the facilitator. Explain the purpose of the focus group and how it will be conducted. Inform people again that they do not have to take part and may leave at any time

The researcher should give an explanation of the research giving the reason, procedures and outcome. Ask participants to say their name before speaking. This may be a pseudonym if preferred or sometimes it is beneficial to give participants a number to use before speaking.

### **Consent**

For the focus groups mainly the participants will probably direct the discussion. However, the researcher should have questions to keep the discussion focused on the research aim. However, the participants must be allowed to introduce topics that are of importance to them. Allowing the discussion to move away from the research aim at times is beneficial as it introduces new topics.

The researcher will ask the questions and direct the focus group. If more than one person is speaking at the time the facilitator must help the researcher to try and get participants to speak individually. The facilitator should note who is speaking at any one time.

### **General questions to follow up what someone has said:**

1. That is really interesting can you tell me more about that
2. Has anyone else got anything to say about that

3. What do you think would help?
4. Has anyone else found this?
5. How did you deal with this?

**Specific questions**

## Appendix 4: Patient information sheet



School of Medicine  
**Community Clinical  
Sciences Research Division**

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Prof. David Kingdon, MD  
MRCPsych

### PATIENT INFORMATION SHEET

1<sup>st</sup> April 2008

#### *1. Study Title: Developing Culturally Sensitive Cognitive Therapy For Psychosis*

**RESEARCHERS: Dr Rathod and Professor Kingdon**

**ETHICS NUMBER: 08/H0504/5**

**VERSION: 1**

#### **2. Invitation paragraph**

You are being asked if you would agree to take part in a research study. Before you decide 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 discuss it with others if you wish. 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.*

#### **3. What is the purpose of the study?**

Evidence from CBT research has shown that patients from Black and Minority Ethnic communities respond less favourably to cognitive behavioural therapy (CBT) than those from white communities. This project is designed to explore the reasons for this so that we can make therapy more culturally sensitive.

**4. What will I be asked about?**

You will be asked about your experiences when you were referred for CBT and how you got on with it. We will be using individual interviews to do this. You do not have to answer any questions that you don't want to and can stop the interview at any time. The interview will be recorded in order to accurately analyse your answers as part of this research study and will only be used for this purpose. The recordings will be kept in a locked cabinet in the Research & Development Department at the Royal South Hants Hospital and will be destroyed at the end of the project

**5. Why have I been chosen?**

We have asked your consultant if we can approach you to ask you to take part and they have given consent to this. We are now asking you if you agree to participate in an interview with the student doing this research.

**6. Do I have to agree?**

It is up to you to decide whether or not you take part. If you do decide to, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw that consent at any time and without giving a reason. If you do so, you will be asked if you consent to the information that you have already supplied being included in the study or not. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

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

The researcher will either meet you individually and ask you a number of questions **or** invite you to join a focus group. An individual interview will probably take up to 1 hour but you will be free to stop at any time and, if you agree, do the remainder of the interview later. The focus group involves a group discussion, this will probably last about an hour but you will be free to leave at any point.

If you agree, the interview or focus group will be audio taped for the purposes of this research study, which require that it be listened to, by another research psychiatrist. The audiotape will be destroyed at the end of the period specified by the Research Ethics Committee

**8. What do you have to do?**

This just involves answering questions and giving your views. If you don't want to answer any question, you do not have to do so. This would not affect your care in any way.

**9. What are the possible disadvantages and risks of taking part?**

This is an interview study so there are no significant risks or disadvantages of participating. If you should get distressed, tell the researcher who has instructions in how best to reduce this and who will contact his supervisor and make sure that your care coordinator, consultant and GP are made aware of this.

**10. What are the possible benefits of taking part?**

The information we get from this study may help us to treat future patients who do find that CBT is currently not sensitive enough to their needs.

**11. What if something goes wrong?**

If you should have any complaints about this study, these will be documented by the researcher and passed to the Complaints Officer, Hampshire Partnership Trust, Tatchbury Mount, Southampton or you can write to them directly yourself.

**12. Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you will have your name and address removed so that you cannot be recognised from it.

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

The results of the research will be submitted for publication to scientific journals and may be presented at conferences when the study is finished within the next two years. A copy of the published results will be available at that time from Professor Kingdon. You will not be identified in any report/publication.

**14. Who is organising and funding the research?**

Hampshire Partnership Trust are sponsoring and funding the research.

**15. Who has reviewed the study?**

Southampton & South West Hampshire Research Ethics Committee B Research Ethics Committee have reviewed the study.

**16. Contact for Further Information**

**If you would like more information now or in the future, please contact Professor Kingdon or Dr Rathod (023 80825045).**

**Thank you for your help: you will be given a copy of the information sheet and a signed consent form to keep.**

## Appendix 5: Patient Consent Form

Hampshire Partnership 

NHS Foundation Trust

**Research & Development**

1<sup>st</sup> Floor, Department of Psychiatry  
Royal South Hants Hospital  
Brintons Terrace  
Southampton  
SO14 0YG

Tel: 023 8082 5054

Fax: 023 80234243

www.hantspt.nhs.uk

### Patient Consent Form

**1 April 2008**

Study: **Developing Culturally Sensitive Cognitive Therapy for Psychosis**

**RESEARCHERS: Dr. Rathod, Prof. David Kingdon**

**ETHICS NUMBER: 08/H0504/5**

**Version: 1**

Please initial box:

(1) I confirm that I have read and understand the information sheet - dated 01/04/08 - for the above study and have had the opportunity to ask questions.

(2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, and without my medical care or rights being affected.

(3) I agree to take part in the above study.

(4) I agree to audio taping of the interview for the purposes of this research project.

\_\_\_\_\_  
**Name of Patient**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Signature**

\_\_\_\_\_  
**Researcher**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Signature**

**P.I.N. for this trial:** \_\_\_\_\_ 1 for patient, 1 for researcher, 1 to be kept with hospital notes

## Appendix 6: Consent form in Urdu

کیمیا پرٹیل 2008

اجازت نامہ برائے مریض

مطالعے کا عنوان۔ سائیکوس کیلئے ثقافتی حوالے سے موزوں سوچ قہرا پی کی تیاری

تحقیق کار۔ ڈاکٹر راجو ڈا اور پروفیسر گلگڈن

اخلاقی کمیٹی نمبر۔ 08/H0504/4

نسخہ نمبر۔ 1

مہربانی کر کے نیچے دیے گئے خانوں پر اپنے مختصر دستخط کریں

(1) میں اقرار کرتا ہوں کہ میں نے مورخہ 01/04/08 کی لکھی ہوئی معلومات پر ہمیں اور میں نے انہیں سمجھا۔ اوپر دیے گئے

مطالعے کیلئے میرے پاس مزید سوالات پوچھنے کا موقع بھی تھا۔

(2) میں جانتا ہوں کہ میری شمولیت ارادی ہے اور یہ کہ میں کسی بھی وقت شمولیت سے انکار کر سکتا ہوں، اور یہ کہ مجھے اس کیلئے کوئی

وجہ دینے کی ضرورت نہیں ہے اور یہ کہ اس سے میری طبی دیکھ بھال اور میرے حقوق پر کوئی اثر نہیں پڑے گا۔

(3) میں درج بالا مطالعے میں شریک ہونے پر رضامند ہوں۔

(4) میں اس تحقیقی منصوبے کیلئے ہونے والے اثر و یوز کی ریکارڈنگ پر اتفاق کرتا ہوں۔

مریض کا نام \_\_\_\_\_ تاریخ \_\_\_\_\_ دستخط \_\_\_\_\_

تحقیق کار \_\_\_\_\_ تاریخ \_\_\_\_\_ دستخط \_\_\_\_\_

1 کا پی مریض کے لئے، کا پی تحقیق کار کیلئے، اور 1 کا پی ہسپتال کے نوٹس کیلئے (P.I.N for this trial)

<sup>10</sup>Consent Form

<sup>10</sup> Urdu Consent Form for Pakistani participants

## Appendix 7: Glossary of terms

**Aamils/ Bush doctors or Faith healers** – has knowledge on religiosity or black magic.

**Desi**- traditionally conservative (tend to be village people)

**Dewana**- crazy

**Emancipation day** – 1<sup>st</sup> Aug (Jamaica)

**Feeding the ancestors**- 6<sup>th</sup> Jan (Jamaica)

**Grapevine**- informal news or knowledge from person to person

**Guru**-teacher

**Herbalist Imam**- ‘religious leader of prayer and interpreter of the law’ (arguably this function can be fulfilled by any qualified Muslim)

**Jinn**- ghost or spirit

**KalaJadoo**- black magic

**Kobiraz**-healers (Bangladeshi)

**Monhalf**-depressed or mind is bad (Bangladeshi)

**Matta dush**- head problem ‘someone who is mad’

**Manshi kruik**-mental health or depression

**Muslim**- ‘followers of Islam’.

**Mullah and/or Maulvis**- Priests (Muslim) religious leaders with some expertise in Islamic law

**Nazar lagana** - cast an evil eye or spells (Pakistani)

**Obeah**-someone has put (cast) an evil spirit on you (afro-Caribbean)

**Patois** or **Creole** Jamaican language

**Pirs**-holy man

**Paagal** -mad

**Pagal**-crazy (Urdu)

‘**Pagal-talaq-shuda**’- ‘mad-divorced label’

**Quacks**-unqualified individuals who provide medication (unlicensed pharmacy abroad – Pakistani and Bangladeshi)

**Sadye**

**Shari'a** -Islamic law

**Saints'or 'babas**- shrine leaders

**Shukria** (Urdu) thank you

**Tavees**-arm lockets

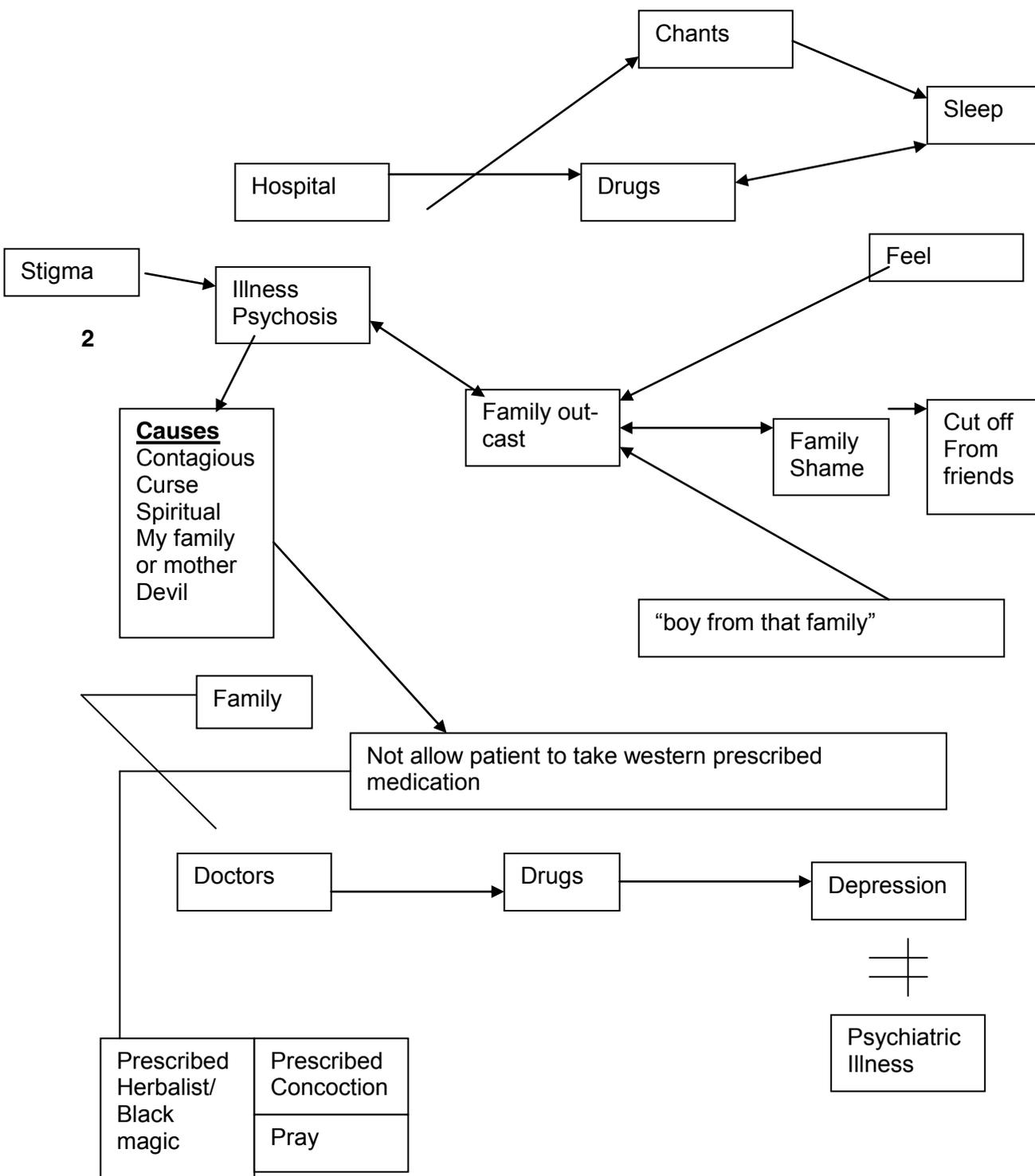
Pressure of the mind-mental illness

**Talaq**- divorce by husband

**Talaq-yafta**- divorced

**Voodoo**- practice common in the Caribbean

## Appendix 8: Concept Map



## Appendix 9: Patient Consent Form CaCBTp

Hampshire Partnership   
NHS Foundation Trust

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### PATIENT CONSENT FORM

9<sup>th</sup> December 2008

Study: *Feasibility Study of Culturally Adapted Cognitive Behaviour Therapy for Psychosis in Ethnic Minority groups*

**RESEARCHERS:** Dr. Rathod, Prof. David Kingdon, Peter Phiri

**ETHICS NUMBER:** 09/H0504/4

**Version:** 1

Please initial box:

(1) I confirm that I have read and understand the information sheet - dated 09/12/2008 - for the above study and have had the opportunity to ask questions.

(2) I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason, and without my medical care or rights being affected.

(3) I agree to take part in the above study.

(4) I agree to audio taping of the interview for the purposes of this research project.

\_\_\_\_\_  
**Name of Patient**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Signature**

\_\_\_\_\_  
**Researcher**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Signature**

**P.I.N. for this trial:** \_\_\_\_\_ 1 for patient, 1 for researcher, 1 to be kept with hospital notes

## Appendix 10: Consultant Information Sheet

# Hampshire Partnership

NHS Foundation Trust

**Research & Development**  
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### CONSULTANT INFORMATION SHEET

12<sup>th</sup> February 2009

**Study Title:** *Feasibility Study of Culturally Adapted Cognitive Behaviour Therapy for Psychosis in Ethnic Minority groups*

**RESEARCHERS:** Dr Shanaya Rathod, Professor David Kingdon, Peter Phiri

**ETHICS NUMBER:** 09/H0504/4

**VERSION:** 2

Dear Colleague,

We would like to invite patients under your care to join the above study.

Previous studies have demonstrated that cognitive therapy for psychosis is not as effective in Black and Minority Ethnic communities (BME) as in Caucasian populations.

Our research group has therefore recently conducted a qualitative study to develop culturally sensitive Cognitive Behaviour Therapy for Psychosis for Ethnic Minority patients by exploration and incorporation of service users' and health professionals' views and opinions. We have subsequently developed a Culturally-adapted Cognitive Behaviour Therapy for psychosis. The purpose of this study is to pilot this intervention – Culturally adapted Cognitive Behaviour Therapy for psychosis - in the following Black and Minority Ethnic populations:

Black British, Black Caribbean and African Caribbean

Pakistani and Bangladeshi

Your patient(s) has been chosen because they have at some stage been given a diagnosis of schizophrenia, schizoaffective disorder or delusional disorder and are from a Black and Minority Ethnic community. It is up to you to decide whether or not potential participants should be invited to take part. If you agree, arrangements will be made, in collaboration with their care co-ordinator, to discuss their participation in the study.

If your patient agrees to take part in the study a member of the research team will ask them to complete validated measures in order to assess their progress over the study period. The participants will continue with their usual treatment and in addition, following randomisation may also be offered the modified Cognitive Behaviour Therapy (Culturally adapted Cognitive Behaviour Therapy for psychosis).

If they are allocated to be offered Culturally adapted Cognitive Behaviour Therapy for psychosis, they will be offered up to 16 sessions by a trained therapist over a four-month period. The therapist will meet them individually on a regular basis for therapy. Each therapy session will last up to 50 minutes. However, participants will be free to withdraw at any point without giving any reason, or without their medical care or legal rights being affected.

If they are not offered the therapy, they will continue with their usual treatment. Details of how to access the adapted therapy will be provided to them at the end of the study.

If they agree, we would also like to audiotape the therapy sessions for the purposes of supervision. If they do not agree to audio taping, they will still be able to participate in the study. The recordings will be kept in a locked cabinet in the Research & Development Department at the Royal South Hants Hospital. The audiotapes will be destroyed at the end of the period specified by the local Research Ethics Committee.

No adverse effects of taking part in this study are anticipated. If the researcher (who will be a trained practitioner) notices deterioration in the mental status of any of the participants during the study they will inform you, their GP and Care Co-ordinator in the unlikely event that participants become unduly distressed.

If you or they should have any complaints about this study, these will be documented by the researcher and passed on to the Complaints Officer, Hampshire Partnership Trust, Tatchbury Mount, Southampton. Complaints can also be made directly.

The results of the research will be submitted for publication to scientific peer-reviewed journals and may be presented at conferences when the study is finished in the next two years. A copy of the published results will be available at that time from Professor Kingdon. Any personal information about you or the participants will not be disclosed in any report/publication.

This study is being sponsored by Hampshire Partnership Trust and funded by the Department of Health. Southampton & South West Hampshire Research Ethics Committee (B) has reviewed the study.

If you would like more information now or in the future, please contact by email or phone: [peter.phiri@hantspt-sw.nhs.uk](mailto:peter.phiri@hantspt-sw.nhs.uk) or **02380825762**

Yours sincerely,

Dr S Rathod, Professor D Kingdon & P Phiri

## Appendix 11: GP Information Sheet

Hampshire Partnership   
NHS Foundation Trust

**Research & Development**  
1<sup>st</sup> Floor, Department of Psychiatry  
Royal South Hants Hospital  
Brintons Terrace  
Southampton  
SO14 0YG

### INFORMATION FOR GENERAL PRACTITIONERS

Tel: 023 8082 5054  
Fax: 023 80234243  
www.hantspt.nhs.uk

9<sup>th</sup> December 08

*Dear Colleague*

Research project: *Feasibility Study of Culturally Adapted Cognitive Behaviour Therapy for Psychosis in Ethnic Minority groups*

**RESEARCHERS: Dr. Rathod, Prof. David Kingdon, Peter Phiri**

**ETHICS NUMBER: 09/H0504/4**

**VERSION: 1**

Patient name:.....D.o.b.....

We are conducting the above study to pilot an intervention - culturally adapted CBT for psychosis (CaCBTp) with patients who have diagnoses of schizophrenia, schizoaffective disorder or delusional disorder. Your patient has agreed to participate and the patient information sheet supplied to them is attached for your information. This letter is simply to inform you of their participation and we are not asking for any direct involvement from you or your primary health care team.

If you require further information, please contact me on 02380 825762.

Yours,

Professor David Kingdon, Dr S Rathod & P Phiri

# Appendix 12: CaCBTp Patient Information Sheet



**Research & Development**  
1<sup>st</sup> Floor, Department of Psychiatry  
Royal South Hants Hospital  
Brintons Terrace  
Southampton  
SO14 0YG

Tel: 023 8082 5054  
Fax: 023 80234243  
[www.hantspt.nhs.uk](http://www.hantspt.nhs.uk)

## **PATIENT INFORMATION SHEET**

**12<sup>th</sup> February 2009**

**1. Study Title: *Feasibility Study of Culturally Adapted Cognitive Behaviour Therapy for Psychosis in Ethnic Minority groups***

**RESEARCHERS: Dr Rathod, Professor Kingdon, Peter Phiri**

**ETHICS NUMBER: 09/H0504/4**

**VERSION: 2**

### **2. Invitation paragraph**

You are being asked if you would agree to take part in a research study which is entirely separate from the treatment you are currently receiving. Before you decide 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 discuss it with others if you wish. 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.

### **3. What is the purpose of the study?**

Our research group has recently adapted an established talking therapy - Cognitive Behaviour Therapy (CBT) for psychosis so that it is sensitive to cultural background of ethnic minority patients by exploration and incorporation of service users' and health

professionals' views and opinions. The purpose of this study is to test this modified therapy.

**4. Why have I been chosen?**

We have asked your consultant if we can approach you to ask you to take part and they have given consent to this. At some stage you have been given a diagnosis of psychosis and are from an ethnic minority community. We are now asking you if you agree to participate in this pilot study.

**5. Do I have to agree?**

It is up to you to decide whether or not you take part. If you do decide to, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw that consent at any time and without giving a reason. If you do so, you will be asked if you consent to the information that you have already supplied being included in the study or not. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

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

A member of the research team will meet you to ask about your problems and experiences using measures to assess progress over the study period. You will continue with your usual treatment and in addition, you may also be offered the modified talking therapy.

If you are allocated to be offered the talking treatment you will be offered up to 16 sessions by a trained therapist over a four months period. The therapist will meet you individually on a regular basis for therapy. Therapy sessions will last up to 50 minutes but you will be free to leave at any point. Whether you are offered therapy at this stage is determined by chance (random allocation).

If you are not offered the therapy, you will continue with your usual treatment. Details of how to access the adapted therapy will be provided at the end of the study.

If you agree, we would also like to audiotape the therapy sessions for the purposes of supervision. If you do not agree to audio taping, you can still participate in the study. The recordings will be kept in a locked cabinet in the Research & Development Department at the Royal South Hants Hospital. The audiotapes will be destroyed at the end of the period specified by the Research Ethics Committee.

**7. What do you have to do?**

If allocated to the therapy, you will work together with your therapist to understand and develop ways to address your difficulties and reduce levels of distress. Both you and the therapist will play an active role in therapy and you will be asked to practice some of the strategies learned in therapy outside of therapy. Your usual care would not be affected in any way by this.

**8. What are the possible disadvantages and risks of taking part?**

If you should get distressed, tell the person interviewing you who has instructions on how best to reduce this. They will make sure that your care coordinator, consultant and GP are made aware of this.

**9. What are the possible benefits of taking part?**

The information we get from this study may help us to treat future patients from Black and Minority Ethnic (BME) groups who find that CBT is currently not sensitive enough to their needs.

**10. What if something goes wrong?**

If you should have any complaints about this study, these will be documented by the researcher and passed to the Complaints Officer, Hampshire Partnership Trust, Tatchbury Mount, Southampton or you can write to them directly yourself.

**11. Will my taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you will have your name and address removed so that you cannot be recognised from it.

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

The results of the research will be submitted for publication to scientific journals and may be presented at conferences when the study is finished within the next two years. A copy of the published results will be available at that time from Professor Kingdon. You will not be identified in any report/publication.

**13. Who is organising and funding the research?**

Hampshire Partnership NHS Trust is sponsoring the research and the Department of Health is funding it.

**14. Who has reviewed the study?**

Southampton & South West Hampshire Research Ethics Committee (B) have reviewed the study.

**15. Contact for Further Information**

**If you would like more information now or in the future, please contact Peter Phiri, Professor Kingdon or Dr Rathod (023 80825762).**

You may obtain independent information or advice about your rights as a research participant or about being involved in this particular research study, by contacting The **Patient Advice and Liaison Service (PALS)** on:

Telephone: 023 8047 5265

Text/Minicom: 0238047 5297

Email: [hp-tr.hantsptPALS@nhs.net](mailto:hp-tr.hantsptPALS@nhs.net)

**Thank you for your help: you will be given a copy of the information sheet and a signed consent form to keep.**

# Appendix 13: CaCBTp Information Sheet

## Feasibility Study of Culturally adapted Cognitive Behavioural Therapy for Psychosis for Ethnic groups

Ethics number: 09/H0504/4

### Information Leaflet

#### What is cognitive behavioural therapy (CBT)?

**B**asically cognitive behavioural therapy involves talking to a therapist, nurse, doctor, psychologist or other trained person about the concerns and worries and trying to understand them better. This may mean:

- talking about how problems may have begun
- discussing how what was happening was interpreted
- understanding things that happen that seem strange
- finding out about the sorts of worries the person has

They may be hearing voices when nobody is about, or hear people referring to them as they walk past, or on the TV or radio. There are a variety of other things that can be helped by

discussion, e.g. feelings that somebody or some organisation is persecuting the person or knows what they are thinking. On the other hand they may have beliefs about themselves that others don't seem to understand or accept, for example, that they are a particularly special person in some way.

For some people, it may help to

- keep a diary of these thoughts
- identify particular problems
- find out more about the beliefs, and how they might be affecting them
- see if anything particularly makes them better or worse

Coping with troublesome beliefs can be difficult when others don't believe the person. Talking about them with a mental health worker may help them do so.

#### Can cognitive behavioural therapy help with 'voices' and strong beliefs?

Sometimes people with psychosis can hear someone, or a number of people, speaking or shouting, but nobody else seems to hear them. 'Voices' like these can be very distressing: they may say abusive things about the person or tell them to do unpleasant things. Cognitive behavioural therapy can help them understand these voices - that they are usually the person's own thoughts or memories sounding as if they are aloud - and then work out what causes them and what to do about them. Understanding them is important in reducing the fear and anxiety caused and there are also a variety of coping techniques which can help. Strong beliefs can often be understood through reviewing the way stress and vulnerability interact.

#### What about 'negative' symptoms?

When motivation seems very low and the person seems negative about everything, we describe this as having 'negative symptoms'. There may be a number of reasons for this, sometimes depression, sometimes voices and delusions which are not immediately apparent. Sometimes there is a fear of these symptoms coming back again and so all stress and stimulation is avoided. After an acute episode of illness, a period of convalescence and healing may be needed. Expectations need to be very realistic and sometimes this means a radical re-think; it may be an achievement to just answer a telephone call or watch a TV programme even in someone who was previously very capable. Small but readily achievable goals may be set to build confidence. The therapists may even advise that initially enduring a waiting period of just calm stability is appropriate, though not always easy to do. There is now good evidence that CBT helps patients by reducing pressure.

#### Doesn't it make voices and strong beliefs worse?

There is still a common belief amongst many doctors and nurses that talking about voices and strong beliefs makes them worse by focusing attention on them. Some psychiatric text books have advised against such discussion but there seems no direct evidence to support this. It is clearly wrong to force

Information adapted from Kingdon, D.G., & Turkington, D. (2005). *Cognitive Therapy of Schizophrenia*. Guildford Press

## Feasibility Study of Culturally adapted Cognitive Behavioural Therapy for Psychosis for Ethnic groups

Ethics number: 09/H0504/4

someone to talk about something if it distresses them but allowing them to talk, as occurs in cognitive therapy, seems humane and can be positive. If the person does become distressed, the conversation can be interrupted and then continue later, if appropriate. Where the discussion becomes repetitive, it probably is sensible to 'agree to differ' - a skilled cognitive behavioural therapist will then use techniques to overcome such blocks.

!

!

### Can you use cognitive therapy instead of medication?

All the studies which have shown cognitive behavioural therapy to be effective have used it in combination with medication - including using some studies in which clozapine and the newer drugs, like risperidone and olanzapine, have been used. Sometimes people will accept drugs but not cognitive therapy, and sometimes therapy but not drugs - but it seems that the combination is best.

### Summary

Like all therapies, Culturally adapted Cognitive Behavioural Therapy involves gaining an understanding of your problems and how they have developed. Therapy has been modified following a recent study (**Developing Culturally sensitive cognitive behavioural therapy for psychosis for Black and Minority Ethnic communities by incorporating Services Users' and Health Professionals' views and opinions**) and will take into account the relevant cultural issues raised by the specific ethnic groups. Therapy focuses on the *here and now*, on how current problems interfere with your day to day life and distress you.

Therapy is **collaborative**, that is, you and your therapist will work together to understand and develop strategies to address your difficulties and set **goals** for how this is to be achieved. The therapy is **structured**, and often uses exercises and homework activities to help test out new ideas in practice. Therapy sessions are aimed at equipping you with skills you can continue to use once therapy has finished to help you deal effectively with future problems should they arise.

The course of therapy will involve up to 16 sessions, initially on a weekly basis for duration of up to 50 minutes and gradually reduce to fortnightly or three weekly as necessary until completion.

CBT has been shown to be of benefit and proven to be an effective treatment for many conditions including psychosis. It is recommended by NICE (the National Institute of Clinical Excellence). More details can be found at the British Association for Behavioural and Cognitive Psychotherapies: <http://www.babcp.com> and [www.nice.org.uk](http://www.nice.org.uk).

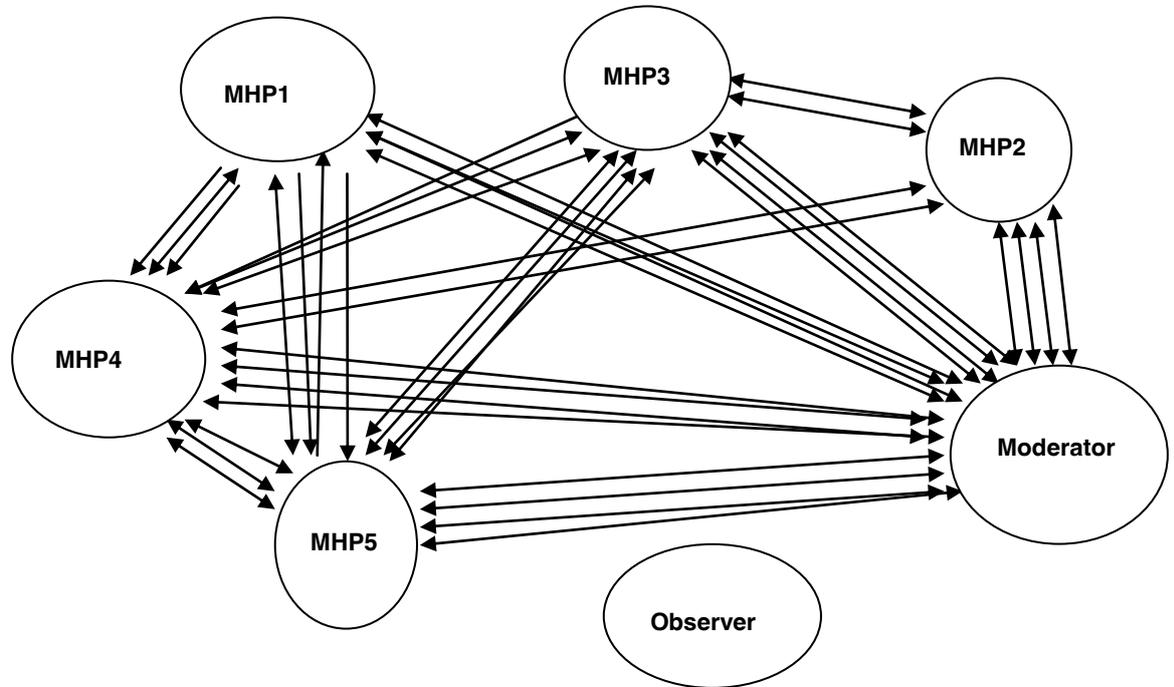
### Contact for Further Information

**If you would like more information now or in the future, please contact Peter Phiri, Professor Kingdon or Dr Rathod (023 80825762).**

Email: [peter.phiri@hantspsw.nhs.uk](mailto:peter.phiri@hantspsw.nhs.uk)

Information adapted from Kingdon, D.G., & Turkington, D. (2005). *Cognitive Therapy of Schizophrenia*. Guildford Press

## Appendix 14: Focus Group Sociogram





# Appendix 16: CPRS

## Comprehensive Psychopathological

### Rating Scale

#### 1. Sadness

Representing subjectively experienced mood, regardless of whether it is reflected in appearance or not. Includes depressed mood, low spirits, despondency, and the feeling of being beyond help and without hope. Rate according to intensity, duration and the extent to which the mood is influenced by events. Elated mood is scored zero on this item.

- 0 Occasional sadness may occur in the circumstances.
- 1 Predominant feelings of sadness, but brighter moments occur.
- 2 Pervasive feelings of sadness or gloominess. The mood is hardly influenced by external circumstances.
- 3 Continuous experience of misery or extreme despondency.

#### 2. Elation

Representing subjectively experienced mood - regardless of whether it is reflected in demeanour or not. Includes reports of well-being, high spirits and unvarying exuberance. Rate according to intensity, duration and the extent to which the mood is influenced by external circumstances. Distinguish from ecstatic experiences **(34)**. Depressed mood is scored zero.

- 0 Occasional cheerfulness may occur in the circumstances.
- 1 Predominant feelings of well-being and high-spirits but lower moods occur.
- 2 Pervasive feeling of well-being and high spirits. The mood is hardly influenced

by the

circumstances. Longer periods of abundant good humour.

- 3 Unvarying exuberance, supreme well-being, intense exhilaration.

### 3. Inner tension

Representing feelings of ill-defined discomfort, edginess, inner turmoil, mental tension mounting to panic, dread and anguish. Rate according to intensity, frequency, duration and the extent of reassurance called for. Distinguish from sadness **(1)**, worrying **(9)**, and muscular tension **(25)**.

- 0 Placid. Only fleeting inner tension
- 1 Occasional feelings of edginess and ill-defined discomfort.
- 2 Continuous feelings of inner tension or intermittent panic, which the patient can only master with some difficulty.
- 3 Unrelenting dread or anguish. Overwhelming panic.

### 4. Hostile feelings

Representing anger, hostility and aggressive feelings regardless of whether they are acted on or not. Rate according to intensity, frequency and the amount of provocation tolerated. Inability to feel angry is scored zero on this item. Cf. Inability to feel, **(5)**.

- 0 Not easily angered.
- 1 Easily angered. Reports hostile feelings, which are easily dissipated.
- 2 Reacts to provocation with excessive anger or hostility.
- 3 Persistent anger, rage, or intense hatred, which is difficult or impossible to control.

### 5. Inability to feel

Representing the subjective experience of reduced interest in the surroundings, or activities that normally give pleasure. The ability to react with adequate emotion to circumstances-or people is reduced. Distinguish from lassitude **(14)**.

- 0 Normal interest in the surroundings and in other people.
- 1 Reduced ability to enjoy usual interests. Reduced ability to feel anger.
- 2 Loss of interest in the surroundings. Loss of feelings for friends and acquaintances.
- 3 The experience of being emotionally paralysed, inability to feel anger or grief, and a  
complete or even painful failure to feel for close relatives and friends.

#### 6. Pessimistic thoughts

Representing feelings of guilt, inferiority, self-reproach, sinfulness, remorse and ruin.

- 0 No pessimistic thoughts.
- 1 Fluctuating ideas of failure, self-reproach or self-depreciation.
- 2 Persistent self-accusations or definite but still rational ideas of guilt or sin.  
Increasingly  
pessimistic about the future.
- 3 Delusions of ruin, remorse and unredeemable sin. Absurd self-accusations.

#### 7. Suicidal thoughts

Representing the feeling that life is not worth living, that a natural death would be welcome, suicidal thoughts, and preparations for suicide. Suicidal attempts should not in themselves influence the rating.

- 0 Enjoys life or takes it as it comes.
- 1 Weary of life. Only fleeting suicidal thoughts.

2 Much better off dead. Suicidal thoughts are common, and suicide is considered as a possible

solution, but without specific plans or intentions.

3 Explicit plans for suicide when there is an opportunity. Active preparations for suicide.

## 8. Hypochondriasis

Representing exaggerated preoccupation or unrealistic worrying about ill health or disease. Distinguish from worrying over trifles **(9)**, aches and pains **(24)**, and loss of sensation or movement **(26)**.

0 No particular preoccupation with ill health.

1 Reacting to minor bodily dysfunction with foreboding. Exaggerated fear of disease.

2 Convinced that there is some disease but can be reassured, if only briefly.

3 Incapacitating or absurd hypochondriacal convictions (body rotting away, bowels have not worked for months).

## 9. Worrying over trifles

Representing apprehension and undue concern over trifles, which is difficult to stop and out of proportion to the circumstances. Distinguish from inner tension **(3)**, pessimistic thoughts **(6)**, hypochondriasis **(8)**, compulsive thoughts **(10)**, phobias **(11)**, and indecision **(13)**.

0 No particular worries.

1 Undue concern, worrying that can be shaken off.

2 Apprehensive and bothered about trifles or minor daily routines.

3 Unrelenting and often painful worrying. Reassurance is ineffective.

## 10. Compulsive thoughts

Representing disturbing or frightening thoughts or doubts, which are experienced as silly or irrational, but keep coming back against one's will. Distinguish from hypochondriasis (8), worrying over trifles (9), and disrupted thoughts (30).

- 0 No repetitive thoughts.
- 1 Occasional compulsive thoughts, which are not disturbing.
- 2 Frequent disturbing compulsive thoughts.
- 3 Incapacitating or obnoxious obsessions, occupying one's entire mind.

## 11. Phobias

Representing feelings of unreasonable fear in specific situations (such as buses, supermarkets, crowds, feeling enclosed, being alone), which are avoided if possible.

- 0 No phobias.
- 1 Feelings of vague discomfort in particular situations which can be mastered without help or  
by taking simple precautions like avoiding rush hours when possible.
- 2 Certain situations consistently provoke marked discomfort, and are avoided without  
impairing social performance.
- 3 Incapacitating phobias which severely restrict activities, for example completely unable to  
leave home.

## 12. Rituals

Representing a compulsive repeating of particular acts or rituals that are regarded as unnecessary or absurd and resisted initially but cannot be suppressed without discomfort. The rating is based on the time spent on the rituals and the degree of social incapacity.

- 0 No compulsive behaviour.
- 1 Slight or occasional compulsive checking.
- 2 Clear-cut compulsive rituals, which do not interfere with social performance.
- 3 Extensive rituals or checking habits that are time-consuming and incapacitating.

### 13. Indecision

Representing vacillation and difficulty in choosing between simple alternatives. Distinguish from worrying over trifles **(9)**, and compulsive thoughts **(10)**.

- 0 No indecisiveness.
- 1 Some vacillation but can still make a decision when necessary.
- 2 Indecisiveness or vacillation that restricts or prevents action, makes it difficult to answer simple questions or make simple choices.
- 3 Extreme indecisiveness even in situations where conscious deliberation is not normally required, such as whether to sit or stand, enter or stay outside.

### 14. Lassitude

Representing a difficulty getting started or slowness initiating and performing everyday activities. Distinguish from indecision **(13)** and fatigability **(15)**.

- 0 Hardly any difficulty in getting started. No sluggishness.
- 1 Difficulties in starting activities.
- 2 Difficulties in starting simple routine activities which are carried out only with effort.
- 3 Complete inertia. Unable to start activity without help.

### 15. Fatiguability

Representing the experience of tiring more easily than usual. When lassitude **(14)** is extreme, this item is difficult to evaluate. If impossible do not rate. Distinguish from lassitude **(14)**.

- 0 Ordinary staying power. Not easily fatigued.
- 1 Tires easily but does not have to take a break more often than usual.
- 2 Easily wearied. Frequently forced to pause and rest.
- 3 Exhaustion interrupts almost all activities or even makes them impossible.

### 16. Concentration difficulties

Representing difficulties in collecting one's thoughts amounting to incapacitating lack of concentration. Rate according to intensity, frequency, and degree of incapacity produced. Distinguish from failing memory **(17)**, and disrupted thoughts **(30)**.

- 0 No difficulties in concentrating.
- 1 Occasional difficulties in collecting one's thoughts.
- 2 Difficulties in concentrating and sustaining thought, which interfere with reading or conversation.
- 3 Incapacitating lack of concentration.

### 17. Failing memory

Representing subjective disturbances of recall compared with previous ability. Distinguish from concentration difficulties **(16)**.

- 0 Memory as usual.
- 1 Occasional increased lapses of memory.

- 2 Reports of socially inconvenient or disturbing loss of memory.
- 3 Complaints of complete inability to remember.

### 18. Reduced appetite

Representing the feeling of a loss of appetite compared with when well.

- 0 Normal or increased appetite.
- 1 Slightly reduced appetite.
- 2 No appetite. Food is tasteless. Need to force oneself to eat.
- 3 Must be forced to eat. Food refusal.

### 19. Reduced sleep

Representing a subjective experience of reduced duration or depth of sleep compared to the subject's own normal pattern when well.

- 0 Sleeps as usual.
- 1 Slight difficulty dropping off to sleep or slightly reduced, light or fitful sleep.
- 2 Sleep reduced or broken by at least two hours.
- 3 Less than two or three hours' sleep.

### 20. Increased sleep

Representing a subjective experience of increased duration or depth of sleep, compared to the subject's own normal pattern when well.

- 0 No extra sleep.
- 1 Sleeps deeper or longer than usual.
- 2 Several hours extra sleep.

3 Spends a great deal of the day asleep in spite of normal or increased sleep at night.

## 21. Reduced sexual interest

Representing descriptions of a reduced sexual interest or a reduction of sexual activity (this should always be judged against the subject's usual sexual habits when well). Habitual impotence or frigidity should be ignored when assessing interest. Distinguish from inability to feel (S). Increased sexual interest is rated 0.

0 No reduction of sexual interest.

1 Sexual interest is admitted to be reduced, but activity is unimpaired.

2 Definite reduction of sexual interest. Ordinary sexual activities are reduced or non-existent.

3 Complete sexual indifference.

## 22. Increased sexual interest

Representing descriptions of a stronger sexual interest than usual, which may be reflected in an increase in sexual activities or fantasies. (This should always be judged against the subject's usual sexual habits when well).

0 No increase in sexual activities.

1 Increase in sexual interest or fantasies not reflected in activities.

2 Definite increase in sexual interest or activities, or intrusive sexual fantasies.

3 Totally preoccupied with sexual fantasies. Very marked increase in sexual activities.

## 23. Autonomic disturbances

Representing descriptions of palpitations, breathing difficulties, dizziness, increased sweating, cold hands and feet, dry mouth, indigestion, diarrhea, frequent micturition. Distinguish from inner tension (**3**), aches and pains (**24**), and loss of sensation or movement (**26**).

- 0 No autonomic disturbances.
- 1 Occasional autonomic symptoms, which occur under emotional stress.
- 2 Frequent or intense autonomic disturbances which are experienced as discomfoting or socially inconvenient.
- 3 Very frequent autonomic disturbances, which interrupt other activities.

#### 24. Aches and pains

Representing reports of bodily discomfort aches and pains. Rate according to intensity, frequency and duration, and also request for relief. Disregard any opinion of organic cause. Distinguish from hypochondriasis **(8)**, autonomic disturbance **(23)**, and muscular tension **(25)**.

- 0 Absent or transient aches.
- 1 Occasional definite aches and pains.
- 2 Prolonged and inconvenient aches and pains. Requests for effective analgesics.
- 3 Severely interfering or crippling pains.

#### 25. Muscular tension

Representing the description of increased tension in the muscles and a difficulty in relaxing physically. Distinguish from aches and pains **(24)**.

- 0 No increase in muscular tension.
- 1 Some occasional increase in muscular tension, more evident in demanding situations.
- 2 Considerable difficulty in finding a comfortable position when sitting or laying. Disturbing muscular tension.

- 3 Painful muscular tension. Completely incapable of relaxing physically.

3

## 26. Loss of sensation or movement

Representing impairment or loss of particular motor or sensory functions. Disregard any organic basis. Distinguish from hypochondriasis (8), autonomic disturbances **(23)**, and aches and pains **(24)**.

- 0 No impairment of sensory or motor functions.

- 1 Slight, and transient impairment which does not disturb ordinary activities.

- 2 Clear-cut impairment or loss of some function, but manages daily activities without help.

- 3 Severely incapacitating and persistent sensorimotor loss which necessitates help, such

as blindness, inability to walk or speak.

## 27. Derealisation

Representing a change in the quality of awareness of the surroundings, which may appear artificial. Also includes deja-vu, deja-vecu, and changed intensity of perceptions. Distinguish from depersonalisation (28).

- 0 No change in awareness.

- 1 Occasional episodes of deja-vu phenomena or derealisation.

- 2 Frequent episodes of derealisation.

- 3 Very frequent or persistent derealisation.

## 28. Depersonalisation

Representing a change in the quality of awareness of oneself combined with the feelings of unreality, bodily change, detachment, or radical change of person. Distinguish from inability to feel **(5)**, derealisation **(27)**, feeling controlled **(29)**.

- 0 No experience of change.
- 1 Occasional or vague feelings of change in oneself
- 2 Feelings of change of person which are intrusive.
- 3 Continuous experience of a radical change of one's person.

## 29. Feeling controlled

Representing the experience of being in the literal sense influenced or controlled from without, and the experience that feelings, impulses or volitions are imposed from without. Also rated under this heading is the experience of being able to control others in a similar manner. Distinguish from disrupted thoughts **(30)**, and ideas of persecution **(31)**.

- 0 Ordinary influence from social forces.
- 1 Vague or unconvincing report of being unnaturally influenced from without.
- 2 Occasional but clear experiences of being controlled from without, e.g. by means of hypnosis.
- 3 Continuous experiences that feelings or impulses do not derive from oneself but are forced into one, say by means of rays.

## 30. Disrupted thoughts

Representing the experience of a sudden stoppage of thoughts (thought blocking), or thoughts being put into one's head (insertion), or being taken out (withdrawal), or listened to or broadcast. Distinguish from compulsive thoughts **(10)**, and concentration difficulties **(16)**.

- 0 No thought interruptions.

- 1 Vague or unconvincing reports of episodes of interruptions to thought.
- 2 Occasional but clear thought blocking or occasional episodes of thought insertion or withdrawal. Feeling that thoughts are being read.
- 3 Disturbing or disabling thought interruptions. Thought broadcasting.

### 31. Thoughts of persecution

Representing suspiciousness, exaggerated self-consciousness, the conviction of being talked about or watched or persecuted with malicious intent.

- 0 No undue suspiciousness or self-consciousness.
- 1 Vague feelings of being observed. Occasional suspicions of malice.
- 2 Pervasive feelings of being talked about threatened or persecuted.
- 3 Unalterable conviction of being the victim of systematic persecution.

Delusional

misinterpretation of ordinary events or "cues". Conviction of being referred to beyond the realm of likelihood (for example on television or in newspapers).

### 32. Ideas of grandeur

Representing exaggerated opinion of self-importance, capabilities or good health. Distinguish from elation (2), and ecstatic experiences (34).

- 0 No ideas of grandeur.
- 1 Self assured with an inflated sense of one's own importance.
- 2 Clearly exaggerated opinion of self-importance and capabilities.

Grandiose, facile and

unrealistic plans for the future.

3 Absurd, delusional ideas of grandeur.

### 33. Delusional mood

Representing strong, unreasonable premonitions, the feeling of sudden conviction that trivial events of things have a profound and bizarre significance. Distinguish from derealisation **(27)** and ecstatic experiences **(34)**.

0 Vague ordinary superstitions. No delusional mood.

1 Vague premonitions that something personal and unknown is about to happen.

2 A strong feeling that generally trivial events have a special significance (delusional mood).

3 The sudden unshakeable conviction, appearing out of the blue, that a particular set of events has a profound and often bizarre meaning. (Autochronous delusions).

### 34 Ecstatic experiences

Representing experiences of mystic rapture. bliss or ecstatic happiness which may involve sudden illumination, insight into religious matters or union with God. Distinguish from elation (2) and ideas of grandeur **(32)**.

0 No ecstatic experiences.

1 Occasional inexplicable feelings of happiness with metaphysical overtones.

2 Frequent experiences of bliss rapture connected with feelings of sudden insight into metaphysical matters.

- 3        Marked, or continuous feelings of bliss or mystic rapture, "oceanic feelings",  
             mystical union with God.

### 35. Morbid jealousy

Representing an absorbing preoccupation with the possible unfaithfulness of a sexual partner.

- 0        No undue suspicions towards the partner.
- 1        Vague feelings of insecurity and suspicions about the partner's faithfulness.
- 2        Searches for and misinterprets "evidence" of unfaithfulness.
- 3        Morbid ideas of jealousy dominate life and actions. Threatens the partner and  
             tries to extract "confessions".

### 36. Other delusions

Representing any other delusions than those above. (Pessimistic thoughts **(6)**,  
hypochondriasis **(8)**, feeling controlled **(29)**, ideas of persecution **(31)**, ideas of grandeur  
**(32)**, delusional mood **(33)**, morbid jealousy **(35)**).

- 0        No other delusions.
- 1        Vague and unconvincing descriptions.
- 2        Definitely pathological ideas, approaching delusional strength.
- 3        Absurd delusions which may be reflected in behaviour.

### 37. Commenting voices

Representing the experience of hearing one's own thoughts spoken or repeated aloud, or  
hearing voices, commenting or arguing about one in the third person. Distinguish from  
other auditory hallucinations (38).

- 0        No hallucinated commenting voices.

- 1 Vague, or unconvincing report of commenting voices.
- 2 Definite, but not disabling hallucinated voices.
- 3 Frequent, disabling hallucinated voices.

### 38. Other auditory hallucinations

Representing all hallucinated sounds or voices except commenting voices **(37)**. Also includes auditory hallucinations in keeping with the predominant mood such as depression or elation.

- 0 No auditory hallucinations, except for hypnagogic phenomena (on going to sleep).
- 1 Misinterpretations of auditory stimuli. Vague or unconvincing reports of auditory hallucinations.
- 2 Definite hallucinations, which may be persistent but not intrusive.
- 3 Loud, or unpleasant hallucinations. Forceful commands.

### 39. Visual hallucinations

Representing a misinterpretation of a visual stimulus (illusion) or a false visual perception without any actual outside stimulus (hallucination),

- 0 No false visual experiences, except for possible hypnagogic phenomena.
- 1 Occasional illusions.
- 2 Frequent illusions, or occasional visual hallucinations.
- 3 Clear, frequent or persistent hallucinations.

### 40. Other hallucinations

Representing hallucinations of taste, smell or bodily sensation. Specify the senses and

base the rating on the most severe.

- 0 No hallucinations.
- 1 Vague or unconvincing reports of hallucinations.
- 2 Occasional but definite hallucinations.
- 3 Clear, frequent or persistent hallucinations.

## **OBSERVED PSYCHOPATHOLOGY**

### **41. Apparent sadness**

Representing despondency, gloom and despair, (more than just ordinary transient low spirits) reflected in speech, facial expression and posture. Rate by depth and inability to brighten up.

- 0 No sadness.
- 1 Looks dispirited but brightens up occasionally.
- 2 Appears sad and unhappy all the time.
- 3 Extreme and continuous gloom and despondency.

### **42. Elated mood**

Representing an elated and exuberant state (excludes ordinary transient high spirits). Includes evident increased well-being, self confidence, elation and hilarity shown in speech, choice of subject, facial expression, posture and activity. Rate according to intensity and inability to respond seriously when demanded.

- 0 Normal cheerfulness.
- 1 Self-confident and somewhat expansive but can change to seriousness when demanded.
- 2 Expansive hilarity with exaggerated self-confidence and mirth that is out of tune. Unable to respond seriously.
- 3 Displays persistent extreme exuberance, exhilaration and absurd hilarity.

### **43. Hostility**

Representing irritability, angry looks, words or actions. Rate by intensity and frequency and the small amount of provocation that elicits the response and the time taken to quieten.

- 0 No evident hostility.
- 1 Querulous, touchy and irritable on provocation. Occasional angry glances.
- 2 Pugnacious, quarrelsome, very aggressive gestures, but can be calmed down.
- 3 Threatening behaviour or actual physical violence.

### **44. Labile emotional responses**

Representing rapidly changing moods to sudden elation or sadness with a tendency to display intense emotional responses. Should not be confused with the preponderant mood. Rate by speed and frequency of change.

- 0 No sudden mood change.
- 1 Occasional and understandable rapid mood changes.
- 2 Frequent sudden or exaggerated mood changes.
- 3 Very rapid changes between intense opposite moods.

#### 45. Lack of appropriate emotion

Representing blunting of affects as shown by lack of emotional expression, or the occurrence of incongruous emotional displays, which are clearly out of keeping with the situation. Distinguish from apparent sadness **(41)** and elated mood **(42)**.

- 0      Appropriate affects in keeping with mood.
- 1      Apparent lack of concern, slightly odd displays of emotion.
- 2      Responds in a clearly inappropriate way on sensitive issues, or appears not to respond at all.
- 3      Only clearly bizarre emotional response, or total emotional indifference.

#### 46. Autonomic disturbances

Representing signs of autonomic dysfunction, hyperventilation or frequent sighing, blushing, sweating, cold hands, enlarged pupils and dry mouth, fainting.

- 0      No observed autonomic disturbances.
- 1      Occasional or slight autonomic disturbances such as blushing or blanching, or sweating under stress.
- 2      Obvious autonomic disturbance on several occasions even when not under stress.
- 3      Autonomic disturbances which disrupt the interview.

#### 47. Sleepiness

Representing evident diminished ability to stay awake as seen in facial expression, speech and posture. Distinguish from withdrawal **(49)**, perplexity **(50)** and slowness of movement **(60)**,

- 0 Fully awake.
- 1 looks sleepy. Yawns occasionally.
- 2 Tends to fall asleep when left in peace.
- 3 Falls asleep during interview or 1s difficult to wake.

#### 48. Distractibility

Representing attention easily diverted by irrelevant external stimuli. Distinguish from withdrawal **(49)**, perplexity **(50)**, blank spells **(51)**, flight of ideas **(56)** and hallucinatory behaviour **(65)**,

- 0 Adequately sustained attention.
- 1 Attention occasionally distracted by irrelevant stimuli (such as background  
Noises)
- 2 Easily distracted.
- 3 Continually distracted by incidental events and objects which makes  
interviewing difficult or impossible.

#### 49. Withdrawal

Representing grossly restricted attention and apparent unawareness of people or surroundings, Distinguish from sleepiness **(47)**, perplexity **(50)**, blank spells **(51)**, and reduced speech **(54)**.

- 0 Apparently well aware of the surroundings,
- 1 Occasional withdrawal, but attention can be brought back without difficulty.
- 2 Appears absent and withdrawn and is only brought back to the interview with  
difficulty.
- 3 Completely withdrawn. Appears not to react to words or touch.

## 50. Perplexity

Representing bewilderment, a difficulty in comprehending any situation and interpreting the context. Distinguish from sleepiness **(47)**, distractibility **(48)** and withdrawal **(49)**.

- 0 No perplexity.
- 1 Puzzled. Occasional difficulty understanding what should be simple questions.
- 2 Appears bewildered. Simple questions must be repeated to be understood.  
Occasional answers unrelated to the question.
- 3 Obviously perplexed and bewildered. Speech and behaviour clearly inappropriate, as if in a dream.

## 51. Blank spells

Representing sudden stoppages and inattention while speaking, which last for a few seconds or longer. It is often accompanied by immobility and apparent thought blocking. Distinguish from reduced speech **(54)**, specific speech defects **(55)**, incoherent speech **(57)**.

- 0 No blank spells.
- 1 Occasional lapses which could be interpreted as wandering of the mind.
- 2 Obvious blank spells even when not under particular stress.
- 3 Frequent or long blank spells which interfere with conversation.

## 52. Disorientation

Representing failure of orientation in time and place.

- 0 Fully orientated.

- 1 Minimal disorientation as to day or date.
- 2 Marked disorientation for date or some disorientation in time.
- 3 Markedly disoriented for time and place.

### 53. Pressure of speech

Representing pressure to talk, increased flow of speech and value loquaciousness. Reduced speech is scored zero on this item. Distinguish from flight of ideas **(56)** and incoherent speech **(57)**.

- 0 Ordinary speech without undue loquaciousness.
- 1 Rapid verbose speech. Gives detailed answers.
- 2 Garrulous and very difficult to interrupt.
- 3 Leads the interview. Words come tumbling out. Cannot be interrupted.

### 54. Reduced speech

Representing reticent or slowed speech with long delays or pauses. Pressure of speech is scored zero on this item. Distinguish from withdrawal **(49)**, perplexity **(50)**, blank spells **(51)**, specific speech defects **(55)**.

- 0 Ordinary speech without undue pauses.
- 1 Takes time to produce brief answers.
- 2 Extremely brief monosyllabic answers with long delays. Hardly any spontaneous comments and when they occur they are slow.
- 3 Monosyllabic answers are only produced with great effort. Almost or completely mute.

## 55. Specific speech defects

Representing for example stuttering, dysarthria and aphasia - specify the type and any obvious reason.

- 0 No specific difficulties with speech.
- 1 Occasional speech defects, especially when upset.
- 2 Very evident speech defects which are intrusive but do not interfere with communication.
- 3 Persistent and disturbing speech defects which markedly interfere with communication.

## 56. Flight of ideas

Representing a rapid flow of ideas shown in speech. There is a continuity of thought, even if it is difficult or even impossible to catch up, in contrast to incoherent speech (57).

- 0 Ordinary flow of ideas.
- 1 Free and lively associations with tendency to drift in the discussion.
- 2 Rapid flow of ideas which can be followed. Frequent changes of subject, which interfere with conversation.
- 4 The rapid changes of subject and the richness and speed of associations make conversation extremely difficult or impossible.

## 57. Incoherent speech

Representing circumlocutory disorganised or apparently illogical speech with inexplicable shifts from topic to topic, distortion and fragmenting of syntax and words. Distinguish from flight of ideas (56).

- 0 Coherent and understandable speech.
- 1 Pedantic and slightly circumlocutory speech. Some idiosyncratic but comprehensible use of words or phrases, especially under stress.
- 2 Illogical association between words or phrases even when not under stress, "Knights move" shifts.
- 3 Obviously disjointed and illogical speech. Fragmentation of phrases or words or bizarre neologisms, which seriously interfere with communication.

### 58. Perseveration

Representing a tendency to get stuck, to repeat sentences or actions such as repeating the answer to a previous question to subsequent questions and to constantly return to the same topic, or being unable to interrupt a thought or action.

- 0 No perseveration.
- 1 The same phrase is occasionally repeated. Returns to the same question several times.
- 2 Repeats the same phrase, but can be persuaded to give more adequate answers. Difficulties in interrupting a line of thought or an action once started.
- 3 Perseverating phrases or behaviour makes communication difficult or impossible.

### 59. Overactivity

Representing an increase in frequency and extent of voluntary movement (facial movements, gait, accompanying movements and gestures) and an increased speed in their initiation and completion. Distinguish from agitation **(61)**, and involuntary movements **(62)**.

- 0 Change between activity and rest.
- 1 Lively gestures and hurried gait, but can rest.
- 2 Obviously expansive and rapid movements and gestures. Abrupt reactions.  
Leaves the chair occasionally during the interview.
- 3 Continuous wildly exaggerated motor activity. Cannot be persuaded to sit or lie  
lie  
down.

#### 60. Slowness of movement

Representing a decrease in frequency and extent of voluntary movements. Facial movements, gait, accompanying movements and gestures retarded and sluggish.

- 0 Ordinary change between rest and activity.
- 1 Minimal gestured and facial movements.
- 2 Almost no spontaneous motor activity. Slow and laboured movement.
- 3 Has to be led to the interview. No spontaneous movements. Immobile face  
. Stupor.

#### 61. Agitation

Representing "purposeless" motor activity such as hand-wringing, picking at objects and clothes, inability to sit still. Distinguish from overactivity (59), involuntary movements (62) and mannerisms (64).

- 0 No agitation.
- 1 Difficult to keep hands still. Changes position several times during the interview.  
Fiddles with objects.

- 2 Obviously restless. Vacant and obtrusive picking up objects. Half-rises occasionally.
- 3 Cannot be persuaded to sit except for brief periods. Incessant purposeless wandering.

## 62. Involuntary movements

Representing the following involuntary movements – tics, tremor, choreoathetotic movements, dyskinesias, dystonias and torticollis. Specify the type.

Distinguish from overactivity (59), agitation (61) and mannerisms (64).

- 0 No involuntary movements
- 1 Occasional involuntary movements when under stress
- 2 Obvious and frequent involuntary movements, accentuated when under stress. Manages not to let them interfere with ordinary motor activity
- 3 Continuous involuntary movements which seriously interfere with ordinary activities.

## 63. Muscular tension

Represents observed muscular tension as shown in facial expression, posture and movements:

- 0 Appears relaxed
- 1 Slightly tense face and posture
- 2 Moderately tense posture and face (easily seen in jaw and neck muscles). Does not seem to find a relaxed position when sitting. Stiff and awkward movements.
- 3 Strikingly tense. Often sits hunched and crouched, or tense and rigidly upright at the edge of the chair

## 64. Mannerisms and postures

Representing repeated or stereotypic complex movements or postures, such as grimacing, stylized movements, odd postures, catalepsy. The rating is based on frequency, and degree of interference with other activities.

Distinguish from perseveration (**58**), agitation (**61**) and involuntary movements (**62**), especially tics.

- 0 No mannerisms
- 1 Occasional or doubtful grimaces or stylized movement
- 2 Mannerisms, grimaces or postures which are obvious but do not interfere.
- 3 Pronounced mannerisms or postures which take over from ordinary motor activity

#### **65. Hallucinatory behaviour**

Representing odd behaviour suggestive of hallucinations, for example turning around suddenly, shouting or apparently answering voices, retreating from presumed visual hallucinations. Should be rated regardless of whether hallucinations are admitted or not. Distinguish from involuntary movements (**62**), and mannerisms and posturing (**64**)

- 0 No hallucinatory behaviour
- 1 Odd behaviour like talking to oneself which might represent hallucinatory behaviour but is thought not to be
- 2 Convincing hallucinatory behaviour
- 3 Bizarre or frequent hallucinatory behaviour which interferes with the interview

#### **66. Global rating of illness**

- 0 None. Absence of illness
- 1 Minimal or doubtful illness which does not interfere
- 2 Moderate and definite illness
- 3 Severe or incapacitating illness

#### **67 Assumed reliability of the rating**

- 0 Very poor
- 1 Fair
- 2 Good
- 3 Very Good

## Appendix 17: Insight and Psychosis

**1 a.** Does patient accept (includes passive acceptance) treatment (medication and/or admission and/or other physical and psychological therapies)?

2 Often = (may rarely question need for treatment)

1 Sometimes = (may occasionally question need for treatment)

0 Never = (ask why)

If 1 or 2, proceed to 1b

**1 b.** Does patient ask for treatment unprompted?

2 Often = (excludes inappropriate requests for medication etc.)

1 Sometimes = (rate here if forgetfulness/disorganisation leads to occasional requests only)

0 Never = (accepts treatment after prompting)

**2a.** Ask patient: "Do you think you have an illness?" or "Do you think there is something wrong with you?" (Mental, physical, unspecified)

2 Often = present most of the day, most days)

1 Sometimes = (thought present occasionally)

0 Never = (ask why doctors/others think he/she does)

If 1 or 2 proceed to 2b

**2 b.** Ask patient: "Do you think you have a mental/psychiatric illness?"

2 Often = (thought present most of the day, most days)

1 Sometimes = (thought present occasionally, minimum once per day)

0 Never

If 1 or 2 proceed to 2c

**2c.** Ask patient: "How do you explain your illness?"

2 Reasonable account given based on plausible mechanisms (appropriate given

patient's social, cultural and educational background, e.g. excess stress, chemical imbalance, family history, etc.)

1 Confused account given, repetition of overheard explanation without adequate understanding or "don't know"

0 Delusional explanation

**3 a.** Ask patient: "Do you think the belief that ... [insert specific delusion] is not really true/happening?" or "Do you think that ... [insert specific hallucination] is not really there/happening?"

2 Often = (thought present most of the day, most days)

1 Sometimes = (thought present occasionally, minimum once per day)

0 Never

If 1 or 2 proceed to 3b

3 b. Ask patient: "How do you explain these phenomena [the belief that ... hearing that voice/seeing that image, etc.]?"

2 Part of my illness

1 Reaction to outside event/s (e.g. 'tiredness', 'stress', etc.)

0 Attributed to outside forces (may be delusional)

## Appendix 18: Patient Experience Questionnaire

(PEQ - Post-treatment)

Please help us improve our service by answering some questions about the service you have received. We are interested in your honest opinions, whether they are positive or negative. Please answer all of the questions. We also welcome your comments and suggestions. Thank you very much. We appreciate your help.

Please check  or tick  your answers. Please mark one answer per question.

1. How satisfied are you with the amount of time you had to wait for your first appointment?

*Very dissatisfied*      *Dissatisfied*      *Neutral/not sure*      *Satisfied*      *Very satisfied*  
                                                                                       

2. Were you given the option of more than one form of therapy/treatment from which to choose?

*Yes*                      *No*  
                     

3. How satisfied are you with the type of treatment (**CaCBTp**) that you received?

*Very dissatisfied*      *Dissatisfied*      *Neutral/not sure*      *Satisfied*      *Very satisfied*  
                                                                                       

4. Were you offered a choice of worker/therapist?

*Yes*                      *No*  
                     

5. How satisfied are you with the therapist that treated you?

*Very dissatisfied*      *Dissatisfied*      *Neutral/not sure*      *Satisfied*      *Very satisfied*  
                                                                                       

6. Did you receive information from us in relation to other forms of help that may have been available to you?

*Yes*                      *No*  
                     

7. Was there sufficient time to think about what was offered to you before you had to make any important decisions?

*Yes*                      *No*  
                     

**Continued overleaf....**

8. How **involved** were you with important decisions about your care/treatment?

Decisions were taken:

<i>Against your wishes</i>	<i>As you wished but without permission</i>	<i>Without your full involvement, but with your permission</i>	<i>With your full involvement</i>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. Did you feel free to change your mind after making a decision about your treatment?

<i>Yes</i>	<i>No</i>
<input type="checkbox"/>	<input type="checkbox"/>

10. How satisfied are you with the overall experience of using this service? **(CaCBTp)**

<i>Very dissatisfied</i>	<i>Dissatisfied</i>	<i>Neutral/not sure</i>	<i>Satisfied</i>	<i>Very satisfied</i>
<input type="checkbox"/>				

11. Please tell us about anything that you think would improve this psychological therapies service. **(CaCBTp)**





## Appendix: 20: Assessment

### Assessment Case example: British South Asian Muslim

I am a British Asian Muslim from Bangladeshi background and that I believe in one god, that is, Allah and his holy prophet Mohammad is the last prophet and I pray five times a day and fast during the holy month of Ramadan. This is my religion and I offer charity and have 100% faith in God.

#### **Culture & Religion**

My culture is very different to my religion as it plays a big part of my life because it was what my parents had brought over from their country (of origin, Bangladesh). My whole family has been brought up with the same cultural beliefs since childhood. Although some people maybe confused about my culture and religion due to their being intertwined although they differ in how they relate to my life as I have already mentioned about my religion above and what I have to do for God, my parents and family and others that I love in the world.

My culture is refreshing, it is my first language I learnt when I was a child, it is called Bengali. My culture is from Bangladesh. I have visited this place twice in my life and I have been to Saudi Arabia for the religious purpose to engage in "Ummrah" for God, myself and my family.

At home (in the UK) I would wear traditional clothing (salwaremmize) so that I look respectful in front of elders. Most girls from an Asian background would wear traditional attire and speak in their mother tongue and help with house chores such as cleaning and cooking. Moreover, supporting the elderly and the poor as part of our duty to be passed on to future generations. People argue that the younger Asian generation has lost its culture and are more influenced by the British culture. For instance, interracial relationships which parents will disapprove of because "it's against their religion and culture; and is likely to bring disgrace and shame to their family in the community (patient's views)

#### **Family & support**

Now I am going to tell you about my family and how much they mean to me. They have supported me through everything in my life and I am grateful for that from the bottom of my heart. Apart from support I had moments where I would argue with them about silly things at home and the usual sibling rivalry in particular with my sisters. There were occasions where due to illness I would be left behind from family functions. When relatives came to see how I was getting on, I would react by being upset and flee to my room and mess up my room. My parents regularly attended to my hygienic needs. This was embarrassing, but it did happen. In all this my family continued giving me support and help during my illness.

#### **Stress and vulnerability**

My life was busy and confusing, hard and pressurising for a whole year I believed that I had brought this upon myself. Consequently, I would at times spend most of my time when home in my bedroom sleeping and crying myself to sleep. This was due to a stressful life and partly to being unorganised in general. My family had to step in and help me through my depression and psychotic episode and I would also experience trauma related to my bad childhood memories of being beaten by my dad with a belt together with my sisters and cousins. Both my uncle and dad thought it would be good way of discipline and respect and for us to listen to elders and our religion. Living with this "small trauma" in my life, as I grew up I saw life differently regarding my family and how my sister had to get married off to a man half her age [arranged marriage is part of tradition within this culture] who she did not like nor did my family at the end of their divorce. I learnt how men could be evil and controlling towards women. As result I am a feminist and believe in female dominance. Also I had to understand from an early age men get what they want and make others suffer because of their ill-mannered behaviours and attitudes towards women. X vividly describes traumatic childhood experiences, how at the age of 8 years old while attending school at a local mosque and also relates a history of abuse from the age of 12 years to 16 years. X describes these traumatic memories as the worst of experience in her life.

### Attribution beliefs

X still blames herself for the abuse and argues that “in a way maybe its god’s way of punishing me for all the bad things I have done in my life and that I may have been a victim in this case but “insallah” it will never happen to me again or any other person. Consequently, X is now keen to help Muslim girls who might need support coping with such experiences and has difficulties trusting others.

### How my problems got worse

I first started to get depressed and felt very lonely and stayed in my room most the time (day and night) crying and thinking to myself how life was so unfair to me and wondering why bad things always happen to me”. My family did notice a change in my personality and mood and would ask why I was isolating myself and looking sad. Things got worse, I let everything get to me, my work and studies; I didn’t know what I was doing and I lost myself in thoughts and resorted to expressing myself through emotions such as anger and keeping everything bottled up, not talking to any one as to why I was sad. I guess I just didn’t want to bother anyone about troubles in my life. I didn’t want people sticking their nose into my business, especially the doctors and nurses and the college asking me questions whether I am ok and why I am experiencing a breaking down at college; screaming and crying during my classes didn’t help, wanting to go home all the time without any reason. I was very depressed so my parents came to college and spoke to my teachers who suggested that I could take a break from college [period of convalescence]. Consequently I lost two months of college time due to my depressive and psychotic phenomenon.

### Help seeking pathways

My first contact with the Crisis Team (Crisis Resolution and Home Treatment Team) was through a visit at home. I never knew why they were in my home all the time and why they were there to see me. I got scared of them and would run to my bedroom or go hide in the other room until they had left. On the occasions that my dad (figure of authority) was at home I had to see them and they would ask me a lot of questions and I would sit quietly and stare at them and be like that every time they visited. Regular visits to the Psychiatrist [a man] I hated him and would run away from him into the car park and my dad would chase after me and I would scream and hit as I was led back to the outpatient room to see the doctor. A lot of things happened when I was ill, running outside screaming, breaking cutlery and refusing my medication, not sleeping and wanting to attend college. Consequently, Crisis team would deliver and monitor when I was taking my medication to make sure that I was compliant and that it would make be feel better and get well again.

My family thought I might need to see someone else like an Imam [Islamic religious leader] because they thought I might have been **possessed** [in line with cultural beliefs and attributions of mental illness in particular psychosis].

My parents decided to take me to this place [omitted for anonymity] where we visited this family or professional Imam who looked very scary “like they were going to kill me or my parents just had enough of me and wanted to sale me in the black market”. That was what went through my mind, consequently, I panicked and ran away; a man chased after me in the streets where I was asking people to help me and protect me from this “mad man” pursuing me. Eventually I was caught and dragged back to the house and questioned about my behaviour and attempt to run away. The Imam then came in with “knives in his hands” I was scared and screamed but my mother held me and told me that it was going to be okay. The Imam cut my hair with the knife [traditional ritual was being performed by the Imam], during this time I was screaming *helplessly* [my emphasis]

The Imam gave me a gift to wear for the rest of my life, *tavees* [a locket worn either on the waist or arm, to ward off evil spirits], one around my waist and the other on my wrist. I will never forget what happened to me that day [traumatic experience] I visited this place twice and hated it every time; it scared me and still to this day I have nightmares about that place and I have imagined “what if my family had left me there and how it would have been like to live there on my own and how scary it would have been for me.

## **Cultural Assessment**

### **Language**

Has access to more than one language for expressing her illness related experiences.  
Given that when with her family she would speak in Bengali, but when with clinicians and fellow services she would revert to English language. Literature indicates that language identifies a persons experience; however, when translated in a secondary language meaning can be distorted due to differences in emotional and cognitive expressions across cultures  
Use of English language was average and comprehensible. However, a limitation in her instance was that to date she had not been assessed or seen by a clinician from her cultural background or an interpreter. Literature suggests that is has significant impact in both emotional expression and eliciting meanings which otherwise would be lost to translation

### **Cultural factors in development**

Living with extended family and the stresses associated with this; disciplined by both dad and uncle in order to grow with respect for elders and responsibility to others first (that is, family and community: a collectivist concept) .  
Sibling rivalry [this is a common presentation across-cultures however they are differences based on the nature of the nuclear family and extended family dynamics.

### **Acculturation**

Culture of the country of origin  
Traditional attire, respect for elders, speaking in mother tongue and helping out at home. Looking after the elderly  
Bangladeshi traditional values and norms  
Culture of the host country (dishonour can bring disgrace to family)  
British Asian Muslim  
Has developed a deep connection with both cultures, but identifies herself strongly with the culture of the country of origin (Bangladesh).  
Gender issues (roles for women within her culture are emphasised)

### **Cultural identity**

British Asian Muslim with Bangladeshi heritage and background

## Religion

Maintains strong connections to her Islamic beliefs, that is, belief in 'One god' [Allah] and in the holy prophet [Muhammad]. Praying 5 times a day and fasting during the holy month of Ramadan. Engaging in charitable service and 'total commitment to god'.

She has visited Mecca for Ummrah. This is an important event for practicing Muslims, which they 'must' fulfill.

## Cultural attributions of illness

Parents believe her distress and illness were as a result of possession hence referral to the Imam for healing.

Believes in supernatural causation of her illness

## Help seeking behaviours and pathways

Support from immediate family; reciting the Quran and praying 5 times a day. Visiting Imam for religious and spiritual support following beliefs by parents that she maybe possessed by evil spirits.

Use of arm lockets [tavees] to ward off evil spirits

Regular contact and support from local Early Intervention in Psychosis Services.

This confirms the findings from the Rathod et al. (2010) study that South Asian Muslim help seeking behaviours and pathways are multi-dimensional and therefore will use both traditional and conventional pathways.

## Cultural elements of the therapist –patient relationship

### Formulation

Cultural identity is that of a second-generation migrant from Bangladesh heritage, with a reasonable knowledge base of English language and a strong cultural background. Problem solving and help seeking behaviours tend to oscillate between the culture of the county of origin (Bangladesh), and UK based culture and community or societal culture (keeping things secret from the rest of the community, in fear of stigmatisation and impact on potential suitors to siblings). Consequently, she preferred family to drive her to the team centre for therapy sessions rather than being seen at home.

**UNDERLYING CONCERNS** (*issues, beliefs, behaviours that may be behind some of current concerns*)

- Strongly believes she caused her sister's marriage to breakdown, and blames self.
- Others can not be trusted (in particular men) and hates men as a result of abuse
- The worldview: World is unsafe [in line with her past traumatic experiences]
- Belief that it may be god's way of punishing her for all bad things she has done in her life. [This sometimes can be challenging to address in therapy, given that from a religious stand point there is a belief in the "will of Allah" people tend not to challenge this belief and this might impact on engagement.

**Current Concerns** (*things that are bothering you in your day to day life now*)

1. Short temper
2. Depressed mood
3. Relational problems with family/ sister (\*\*awareness that therapy will focus on changing self rather than others)
4. Coping with stress
5. Shame and Guilt
6. Stopping self from being hyperactive (wants to be calmer)

**Predisposing Factors**

(*Issues that make a person more sensitive to stress and more vulnerable to developing mental health problems*)

- Strict and authoritative father and uncle.
- Bad childhood, hitting with belt by dad,
- 2<sup>nd</sup> generation migrant
- South Asian ethnic background, fighting with siblings,
- Childhood abuse at 8yrs old while at school by teacher.

**Precipitating Factors**

(*Events that happened just before a problem began or got worse*)

- Depression
- At 12-13yrs for a four year period was abused by her brother in law
- Marital breakdown of sister's marriage as a result of abuse precipitated feelings of guilt and self blame.
- Belief that she had caused breakdown of her sister's marriage.
- Became paranoid about my boyfriend stocking me

**Perpetuating factors**

(*Circumstances, beliefs, behaviours that make recovery harder or relapse prevention more likely*)

- Flashbacks? Isolation, withdrawal
- High expectations from family to get a degree like my siblings and cousins,

- Get married,
- Pressure from college and from home,
- Depression,
- Work load as a social secretary, family problems (fallout),
- Trauma being taken to Imam due to beliefs she was possessed, Crisis team

**Protective Factors**  
*(Strengths and resources which can aid recovery)*

- My faith, religion and culture background
- Family support (???)
- Use of *tavees* around waist and arm (to ward off evil spirits)
- Childcare course
- Friends

**Values directed Goals**

- Improve communication with family and sister
- Develop trusting relationships
- Developing ways of coping with stress
- Address low mood
- Address shame and guilt
- Return to college and pursue course in childcare

The conceptualisation diagram of the case taking into account the relevant information drawn from the assessment and narrative is included in the appendices.

## Appendix 21: RELAPSE PREVENTION Blue Print: Safiya

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**What have I learned? What has been useful to me?** (Ideas and strategies, facts, new techniques)

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- Self-monitoring using Voices Diary
  - Practice Mindfulness exercises on CD
  - Use Cost and Benefits Analysis to help me make informed decisions based on facts and not only on how I feel about things.
  - Play Music and use computer,
  - Talking about my feelings with someone; to mum and dad
  - Relaxation
  - Testing beliefs and assumptions to find out whether what is said is so (Using evidence for and against what the voices say).
  - Engaging in meaningful activities such as: Walks, Art group and hopefully join gym when I return from Pakistani.
  - Use Hot cross Bun to make sense of negative thoughts and the impact they have on my feelings and behaviour and consider alternative views or explanations.
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**How can I build on what I've learned?** (bringing skills into everyday life, enlisting others help; attend other groups/courses for specific skills- be specific with action plans)

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- Planning my day using the activity schedule sheet
  - Realise when voices appear and tackle them using the techniques and strategies I have learnt in therapy. (For example: test whether what the voices are saying is true or not as I have discovered in therapy when I have looked at the evidence for and against what they have said so far.
  - Talk to someone about my feelings and distress and consider alternative ways of coping.
  - Monitor my stress levels so that I can reduce them to tolerable levels
  - Keep practicing my skills and building my confidence
  - Keep practicing strategies I have learnt so far.
- 

**What will make it difficult for me to do this?** (Things in me e.g. motivation, hopelessness, things in the environment e.g. time pressures, lack of support)

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- Voices coming back (9/10 distressing and loud)
  - Lack of confidence
  - Lack of sleep
  - Demands from others and high levels of stress
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**How will I overcome these difficulties?** (Try to come up with specific strategies)

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- Use the notes that I have made during therapy sessions.
  - Write down what the voices say to do (voices diary) so that I have time to analyse and test whether this is true, then come up with alternative views and think about next step
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- Talk to others
  - Use strategies I have learned
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**What might lead to a setback for me?** (Future stresses, known areas of vulnerability, life problems)

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- Stress related to weight gain
  - More independence (less support from family)
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**If I had a setback what would I do about it?** (Specific skills, cheerleading statements, seek help)

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- Enlist support from mum and dad
  - Talk to the psychiatrist (in Pakistani)
  - Use a flash card: Rather than agreeing to or making promises that I can not keep, I will instead say “ **I WILL DO MY BEST**”
  - Use the techniques that I have learnt in therapy, testing what the voices are saying using evidence for and evidence against {EVIDENCE IS SOMETHING THAT CAN STAND IN THE COURT OF LAW}
  - Consider alternative views to situation
  - Practice mindfulness exercises and listen to relaxing music
  - Engage in meaningful activities
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## **Appendix 22: Addressing self-harm: British – African Caribbean participant**

### **Case example:**

Zandile was a 45-year-old mixed-race lady from who identified her cultural identity as African –Caribbean and British. She lived alone in a council flat and had regular input from the Assertive Outreach Services (aimed at working with those patients considered difficult to engage) With her diagnosis of schizophrenia, she was a high risk of deliberate self-harm and had presented to the Accident and Emergency department on numerous occasions following episodes of self-harm through overdoses. Severe depression and hopelessness, fear of therapy can make it difficult to address suicidality.

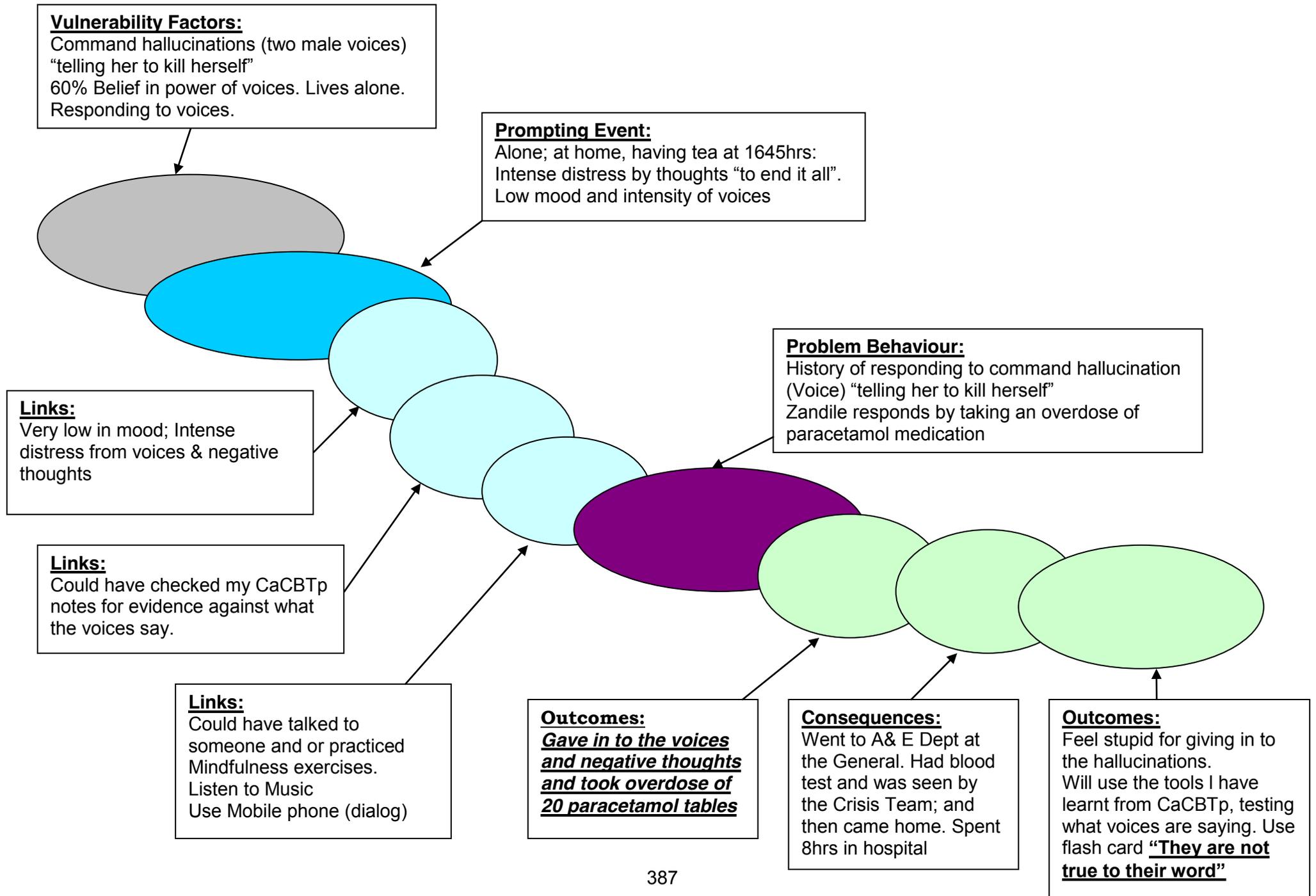
Following assessment and formulation it was paramount to address self-harm behavior as a priority. Zandile completed a voices diary which revealed the severity and frequency of voices, commanding in nature. She experienced two male voices (commenting voices) she could not identify who they were but they would tell her to “kill herself”. She would respond by taking her prescribed medication and ended up in hospital. In our assessment we considered the key beliefs about voices to address omnipotence and omniscience; we explored the meaning and purpose; power and control; compliance and identity of the voices.

Zandile was introduced to a chain analysis of problem behaviour below, adapted from the Linehan (1996) as an analytic tool to help address deliberate self-harm behaviour.

Zandile’s specific problem behaviour was self-harm behaviours. She was able to identify the prompting event and the subsequent precipitating events usually at home alone, feeling low in mood and experiencing high levels of distress from the voices. She identified her vulnerability factors as omnipotence of command hallucinations. This was followed by a detailed description of events or actions that lead to self-harm behaviour and the consequences thereof. We then explored the immediate effects of her behaviours on self and others. She realized the amount of time she was spending at the hospital, the services and staff involved. We elicited key emotions and cognitions and was keen to consider alternative helpful behaviours. We returned to the links and discussed where she could have broken the link and intervened or sort help; she was able to identify coping strategies she could use to prevent

maladaptive behaviour and outcome. Encouraged to use and practice techniques to deal with voices. She developed a flash card that we printed and laminated so she could use and keep in her bag. **[The voices are not true to their word]**.

# Chain Analysis of problems behavior (Linehan, 1996)



She tended to comply with the voices and would carry out their commands without questioning them. She was also appeasing them as she feared that as in the past when she refused to carry out their commands the voices got worse and distress increased. One of the strategies we used was “having a dialogue with the voices”. Zandile initially found this difficult as they did not respond to her. However, as she kept on practicing the technique she was able to maintain a dialogue, this gave her a voice to challenge them and through some of our reality test behavioural experiments such as challenging the voices to turn off digital recorder in session, or move a cup of tea; to open the consult room or force the therapist to leave the room. In all these experiments the voices failed to carry out these task, gradually Zandile began to develop statements that her voices where not true to their word and they had failed several experiments. Given that she used to isolate and avoid social situations fearing the voices might talk to her and embarrass her in a public place; we introduced use of a mobile phone. The therapist asked whether Zandile could distinguish a person hearing voices and speaking (responding to them) in a public place to a person talking on a mobile phone or smart phone device (concealed or not). She reported that most people appear to be talking when they are walking on a closer look, they maybe holding a mobile phone device or using a blue tooth. We considered a way of normalising her dialogue with voices without fearing that she would look odd and bizarre talking to herself. In our session I role played talking on a mobile phone and then asked her to comment whether she could tell that I was actually talking to someone else or just engaged in a monologue. She was agreeable to try using her mobile phone as an experiment and report back the following session. She gave positive feedback on how she was able to respond to the voices (being assertive) on the bus and used her mobile phone. She observed that other passengers where minding their own business and did not pay any attention to her.

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