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**APPLYING PSYCHOSOCIAL**  
**MODELS OF PSYCHOSIS**  
**AND WORKING WITH**  
**CULTURAL DIVERSITY**

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*March, 2005*

Thesis submitted in partial fulfilment of the requirements of a degree of Doctor of Psychology at City University. Research conducted in a NHS Trust.

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## **Declaration**

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# **SECTION A INTRODUCTION**

## **Background**

Counselling psychologists provide a service to a diverse population in terms of the range of problems individuals present with and the myriad of ethnic groups and cultures service users align themselves with. As researchers, clinicians and/or trainees, a degree of reflexivity is required as we interact with the complexities of the human mind and behaviour. It is often necessary for psychologists to consider the impact of their own attitudes, behaviour and physical appearance within the socio-political/cultural context that this interaction occurs. There are a number of currently topical issues that this thesis examines. Namely, access to psychosocial interventions for people presenting with some forms of psychosis, how one of those approaches is applied clinically and working with and beyond culture and ethnicity.

This introduction outlines Sections B, C and D within the thesis. It begins with a synopsis of Section B the Empirical Research, “Barriers to Access of Cognitive-Behavioural Therapy and Family Interventions for People with Medication-Non-Responsive Schizophrenia/Schizoaffective Disorder: The Views of Service Users, Carers and Mental Health Professionals”. Then a summary of Section C, which offers an example of Professional Practice where a Case Study highlights the use of a Cognitive Behavioural Therapy approach to working with someone with schizophrenia. This is followed by a consideration of Section D the Extended Essay, “Issues and Practice of Transcultural Counselling: A Brief Guide for Trainees”.

## **Summary of Sections B, C and D**

Section B Empirical Research focused on barriers to accessing psychosocial treatments for schizophrenia and schizoaffective disorder for service users and carers. The two treatments discussed were Cognitive-Behavioural Therapy (CBT) and Family Interventions (FI). The literature review stated that both types of treatment had been shown to be effective with people suffering from schizophrenia. Participants in the study included service users suffering from schizophrenia/schizoaffective disorder, carers and mental health professionals who had contact with this client group. This study was, in part, an opportunity for service users and carers to discuss their experiences of mental health services. It was also a chance for them to share narratives they had accumulated throughout their journeys as mental health service

users/carers in terms of access to psychosocial treatments. This research promotes the importance of examining the accessibility, acceptability and quality of the services offered to service users and their carers in the mental health NHS Trust. Mental health professionals were also given the opportunity to comment on what they perceived as barriers to service users and carers accessing CBT and FIs as treatments for schizophrenia and schizoaffective disorder.

Using qualitative methods, the research aimed to explore, describe and provide explanations for barriers to accessing CBT and FIs. It did this using Grounded Theory to collate and analyse focus group discussion and data from individual semi-structured interviews. Among other themes emerging from the analysis, the therapeutic relationship was identified as being a key factor in terms of engagement with the service and access to psychosocial treatments. The results highlighted six main themes or categories under which the data could be organised, these were as follows:

Dominance of the medical model; Mistrust between service users and professionals; Service hostility; Perception of services as 'elitist'; Information and communication; and Overcoming barriers.

Whilst in the process of conducting the research presented I was mindful of the need to ensure the quality of the research. The qualitative researcher's, responsibility is to, "develop an understanding of the phenomena under study based as much as possible on the perspective of those being studied" (Elliot, Fischer and Rennie (1999: p.216). Therefore, as a researcher one's involvement in the process of interpreting the research necessitates that, among other important considerations, one engage in a reflexive process of acknowledging one's own perspective. I was aware that assumptions based on my own experience would impact the research. Anecdotally, my clinical experience as a counselling psychologist led me to believe that although many people with schizophrenia/schizoaffective disorder seemed to value talking treatments, they had been known to mental health services for a number of years with no documentation suggesting that evidence-based psychosocial treatments had been offered. In this study particular attention was given to ensure the quality of the research against emerging standards in qualitative methods and make explicit how my own assumptions impacted the findings. The discussion presented the various clinical

implications of the study and ideas for future research. As a result of interacting with the participants and the data they produced, my curiosity regarding how service users, carers and mental health professionals spoke about barriers to accessing psychosocial interventions continued to develop throughout the process of carrying out the research.

Section C Professional Practice presents two case studies that describe the use of a Cognitive Behavioural Therapy (CBT) approach to working with people with schizophrenia. I have developed an interest in utilising cognitive behavioural therapy with service users suffering from positive symptoms of schizophrenia. I was particularly attracted to this approach by the normalising rationale (Johns and van Os, 2001) that makes symptoms that have historically been described as “abnormal”, quite understandable within the context of the individual’s prior vulnerability and certain key triggering factors. According to Johns and van Os, (2001) although marginalised and stigmatised in society due to a having a mental health problem, people who attract a diagnosis of schizophrenia, are in fact not so different from everyone else.

I chose to use the process of writing a case study to facilitate further in-depth reflection on the application of theory to practice, in particular to consider the impact of my approach and choice of interventions on the service user I worked with. With, “I Heard it on the Grapevine” I was able to use the guiding principles of a CBT for psychosis approach to work with RH to assist him with developing a view of his condition that enabled him to improve his quality of life. Through this case I learned that CBT for psychosis is by necessity an individualised approach. It requires the clinician to be flexible in selecting and applying techniques. This study demonstrates CBT for psychosis being applied with someone from a minority ethnic group.

The diverse population that psychologists provide a service to is also represented in terms of the range of ethnic groups and cultures service users identify with.

Reflexivity is required as we interact with individuals from diverse cultural groups. It is suggested that it is fundamental that psychologists consider the impact of their own culturally informed beliefs, values, verbal- and non-behaviour as well as their physical appearance in the socio-political/cultural context within which interaction with service users occurs. This postulate is discussed in the essay on, “Issues and Practice of

Transcultural Counselling: A Brief Guide for Trainees". It is argued that, for example, the process of reflection on the impact one's own cultural identity has on the therapeutic alliance can be essential to maintaining the integrity of that relationship. It is suggested that only once the therapist acknowledges his/her own cultural identity can one become aware of the responsibility one has within the relationship in terms of working with and beyond difference. For example, trainees are invited to consider that they have a responsibility to establish credibility with the service user and use a framework for discussing the presenting concerns that is sensitive and responsive to the service user's culture.

The Extended Essay offers an introduction to some of the issues in transcultural counselling. It discusses theory relating to transcultural counselling and considers how trainees might apply some of the literature outlined to their own clinical practice. Part one positions transcultural counselling within a historical context. Definitions of race, culture and ethnicity are expounded. It also raises the question, 'Why think about issues and practice of transcultural counselling?' In part two an outline of how models of racial identity might be used to examine an individual's developmental processes is discussed. Part three centres on the issue of managing difference in therapy. It provides an opportunity for the trainee to reflect on his/her own cultural identity and how this might impact the therapeutic alliance. Lastly, part four utilises case material from the author's own practice to highlight the process of transcultural counselling.

Conceptualising this guide required an examination of my own cultural identity and in-depth reflection on how it impacted my clinical work. I also considered how my training had prepared me to work with difference and how my clinical experience could be used to inform trainees. Clearly, there is no simple solution to working with, through and beyond the difference that culture and ethnicity present. However, the literature discussed in the essay attempts to raise awareness of some of the issues and suggest how they might be addressed.

## **Conclusions**

In summary, this introduction has highlighted the importance of reflexivity as a counselling psychologist whether one is a researcher, clinician and/or trainee. Each person with whom one interacts presents with a unique constellation of concerns and comes from a background particular to him- herself. I have provided an overview of Sections B, C, and D. This thesis juxtaposes the following: empirical research exploring barriers to accessing CBT and FIs for people with schizophrenia/schizoaffective disorder and their carers; a professional practice case study where CBT for psychosis was applied with someone from a minority ethnic group; alongside an extended essay discussing transcultural issues in counselling psychology.

In conclusion, this thesis uses the process of delineating categories whether of service users, carers, mental health professionals or people from majority- or minority ethnic groups to highlight differences between groups. It does this whilst having the fundamental aim of giving a voice to those who might otherwise not be heard due to the socio- cultural, political context. It is suggested that it is possible to build empathic relationships with people who might look or behave differently from ourselves and to negotiate with the systems we interact within in order to facilitate this. However, it is also argued that building empathic relationships requires acknowledging one's own standpoint, beliefs and values and sometimes being prepared to suspend one's own perspective high and long enough to be in a position to hear and value another's.

**SECTION B EMPIRICAL RESEARCH:**  
**BARRIERS TO ACCESS OF COGNITIVE-**  
**BEHAVIOURAL THERAPY AND FAMILY**  
**INTERVENTIONS FOR PEOPLE WITH**  
**MEDICATION-NON-RESPONSIVE**  
**SCHIZOPHRENIA/SCHIZOAFFECTIVE**  
**DISORDER: THE VIEWS OF SERVICE**  
**USERS, CARERS AND MENTAL HEALTH**  
**PROFESSIONALS**

## **Reflexive Preface**

This study arose from a strong desire to enable service users and carers to have their say about the quality of the mental health Trust I worked in. It was essential to explore their perception of the services provided, examining what they thought was useful and what could be improved. It was important to get a sense of some of the difficult issues that service users and carers were confronted with as they attempted to interface with the service. I hoped to explore their notions of the treatments available to them, their beliefs and values in terms of those treatments and how they perceived accessing psychosocial interventions.

My clinical practice as a counselling psychologist with people with schizophrenia/schizoaffective disorder, prior knowledge of research and discussions with service users, carers and other mental health professionals informed my thinking about this topic. This led me to postulate that there were a number of people with persistent and distressing symptoms of schizophrenia/schizoaffective disorder and their carers who might never have had the opportunity to experience how psychosocial models could be used to assist them. This research was designed to develop a theory about any barriers that emerged in terms of the implications for service users and carers. It was essential to use a qualitative method to elicit depth of meaning. Utilising focus groups and semi-structured interviews as methods of data collection and Grounded Theory to analyse the data seemed to fit this purpose well. My guiding principle was that it was important for every effort to be made for consumers of mental health services to have an opportunity to view those services as capable of being sensitive and responsive to their diverse needs.

Carrying out this research challenged me on every level. I was confronted with my own vulnerability in terms of maintaining a state of well being. My hopes for professional development were that the process of conducting this research would directly impact my clinical practice enabling me to become more sensitive to opportunities for service user/carer involvement. Whilst conducting the research I had a real sense that the service users and carers involved in sharing and developing their narratives around this topic found it rewarding. My feeling was that we had achieved

some form of emancipation. I hope that the views of the service users and carers who participated will be heard and appreciated far and wide.

## **Abstract**

Specific psychosocial treatments have been shown to be effective with people suffering from severe mental illness. Access to psychosocial treatments: cognitive-behavioural therapy (CBT) and family interventions (FIs) is considered paramount for every mental health service user with a diagnosis of schizophrenia/schizoaffective disorder and their carers (NHS Executive, 2000). This study aimed to explore and describe the views of service users, carers and mental health professionals regarding barriers to accessing CBT and FIs for people with medication-non-responsive schizophrenia/schizoaffective disorder and their carers.

The following were target groups for this research: service users; carers and mental health professionals. In order to meet inclusion criteria, service users were required to have at least one positive symptom of psychosis which had been unremitting for 6 months. Carers were required to be 18 years or older and caring for someone suffering from schizophrenia/schizoaffective disorder. Carers were also required to have a minimum of 10 hours of direct contact with the service user per week. It was requisite that mental health professionals were working within the particular mental health Trust under study. The design involved collating data from focus group discussions and individual semi-structured interviews. Focus group questions were constructed to elicit descriptions of the following: how participants viewed the treatments available in the Trust; their beliefs about the barriers service users and carers faced in terms of accessing CBT and FIs; and views on how things might be improved. The semi-structured interview questions addressed the following topics: Awareness; Skill mix; Culture and ethnicity; Religion; Age; Gender; Sexuality; Resources; Mental health diagnosis; and Physical disability. Grounded Theory analysis of the data led to the emergence of five barriers, namely: Dominance of the medical model; Mistrust; Service hostility; Perception of the service as 'elitist'; and Information and communication. There were also methods of Overcoming barriers that emerged. The accounts of barriers differed for service users, carers and mental health professionals in terms of their complexity and impact. This research contributes to illuminating the multiplicity of barriers to accessing CBT and FIs for service users and their carers.

## **Chapter 1: Literature Review**

### *1.1 Introduction*

This research study aimed to explore how barriers to accessing cognitive behaviour therapy (CBT) and family interventions (FIs) for service users of a mental health NHS Trust with medication-non-responsive schizophrenia/schizoaffective disorder and their carers were perceived and experienced. The study was particularly interested in looking at whether accounts from service users, carers and mental health professionals differed and where views were similar.

The relevant literature is presented below. This discussion begins with a consideration of psychosocial treatments for schizophrenia/schizoaffective disorder. This involves an in-depth look at vulnerability-stress models, family interventions (FIs) and cognitive behaviour therapy (CBT). The focus of discussion then turns to examining the barriers to accessing psychosocial interventions. This includes a brief consideration of the Mental Health Act (1983), a look at the medical model, discussion about social stigma, an exploration of professional anxieties about applying psychosocial interventions, an examination of the researcher-clinician divide and a brief review of the consumer movement.

### *1.2 The Concepts of Schizophrenia/schizoaffective disorder*

There has been much controversy about the concept of schizophrenia. Kraepelin (1856-1926) devised the categorical approach to psychiatric diagnosis. Boyle (2002) argues that referring to 'schizophrenia', as a scientific concept is problematic. Indeed, many authors have argued that the concept of schizophrenia is at best misleading and at its most offensive, detrimental (Drayton, 1995; Burbach 1996; Bentall, 1990; Bentall, 1993). Boyle (2002) suggests that the term does not refer to any particular medical pattern that can be described as a syndrome. Similarly, Bentall (2004) argues that population surveys show that psychotic symptoms are experienced widely within the general population. Hence, he suggests there is no discernible boundary between the 'well' and the 'sick'. Post-modern theorising informs us that mental illness is a social construction - giving and receiving a mental health diagnosis part of a social process (Fowler, Garety and Kuipers, 1995). Bentall (1993), states that there is disagreement about the symptoms of schizophrenia and proposes that the notion of a

unitary construct be abandoned in favour of a focus on particular symptoms individuals present with. Barrowclough and Tarrier (1997), argue that, since the term “schizophrenia” is used to refer to a reliably identifiable a group of symptoms (the most common being hallucinations, thought disorder and delusions (see also Hemsley, 1988), it has heuristic value. Yet, they point out that the disagreement about the validity of the concept maintains the debate’s momentum (Barrowclough and Tarrier, 1997). I have adopted the term ‘schizophrenia’ for the purpose of the study.

Schizophrenia is one of the most severe forms of psychiatric illness. It affects cognition, emotion and behaviour. Prevalence rates of schizophrenia range from 0.2 – 2% of the general population (Bentall, 1990; APA, 1995). Schizoaffective disorder appears to be less common (APA, 1995). According to the National Collaborating Centre (2002) prevalence rates are similar for men and women although onset of the illness for women occurs on average five years later than for men. A significant number of these people (40%) are severely distressed and disabled by persistent symptoms despite attempts to treat them with antipsychotic medication and periods of in-patient treatment (Sensky, Turkington, Kingdon, Scott, Scott, Siddle, O’Carroll and Barnes, 2000; Pilling, Bebbington, Kuipers, Garety, Geddes, Orback and Morgan, 2002a). In some cases, adherence to medication programmes is a particular area of contention for service users (Fowler, Garety and Kuipers, 1995). Unfortunately, non-adherence with medication regimes often precipitates readmission to noisy/over-stretched in-patient wards (Kuipers, Garety, Fowler, Dunn, Bebbington, Freeman and Hadley, 1997). As an intervention, medication alone is often inadequate to promote management of and recovery from the symptoms of schizophrenia/schizoaffective disorder (Tarrier, Barrowclough, Haddock and McGovern, 1999; Sensky, et al, 2000). The criteria for medication-non-responsive schizophrenia/schizoaffective disorder are at least one current positive psychotic symptom (within DSM IV criteria such as a hallucination or delusion). It is necessary that this symptom is distressing, unremitting (at least for the past six months) and has not responded to a previous trial of at least six months of appropriate neuroleptic medication (Kuipers, Garety, Fowler, Dunn, Bebbington, Freeman and Hadley, 1997).

Table 1.1 shows the Diagnostic and Statistical Manual of Mental Disorders, fourth edition criteria for schizophrenia (DSM IV, American Psychiatric Association, 1995). The DSM IV criteria for schizoaffective disorder are shown in Table 1.2 (DSM IV, American Psychiatric Association, 1995).

**Table 1.1 DSM IV Criteria for Schizophrenia**

|   |
|---|
| <p><i>Criterion A - Characteristic symptoms:</i> Two (or more) of the following, each present for a significant portion of time during a 1-month period (or less if successfully treated):</p> <ul style="list-style-type: none"> <li>◆ Delusions</li> <li>◆ Hallucinations</li> <li>◆ Disorganised speech (e.g., frequent derailment or incoherence)</li> <li>◆ Grossly disorganised or catatonic behaviour</li> <li>◆ Negative symptoms, i.e., affective flattening, alogia, or avolition</li> </ul> <p>Note: Only one Criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behaviour or thoughts, or two or more voices conversing with each other.</p> |
| <p><i>Criterion B - Social/occupational dysfunction:</i> For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning such as work, interpersonal relations, or self-care are markedly below the level achieved prior to the onset (or when onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).</p>   |
| <p><i>Criterion C - Duration:</i> Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meet Criterion A (i.e., active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).</p>   |
| <p><i>Criterion D - Schizoaffective and Mood Disorder exclusion:</i> Schizoaffective Disorder and Mood Disorder with Psychotic Features have been ruled out because either (1) no Major Depressive Episode, Manic Episode, or Mixed Episode have occurred concurrently with the active phase of the symptoms, their total duration has been brief relative to the duration of the active and residual periods.</p>  |
| <p><i>Criterion E - Substance/general medical condition exclusion:</i> The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.</p>  |
| <p><i>Criterion F - Relationship to a Pervasive Developmental Disorder:</i> If there is a history of Autistic Disorder or another Pervasive Developmental Disorder, the additional diagnosis of Schizophrenia is made only if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated).</p>  |

Mental health service users and their carers may find the labels of schizophrenia or schizoaffective disorder difficult to tolerate as a result of the social undesirability of

the terms. In such cases labelling may be a factor in service users and carers becoming withdrawn from mainstream society (Drayton, 1995; Fowler, Garety and Kuipers, 1995). Once diagnosed, people might find themselves increasingly marginalised by a socio-political/socio-cultural environment that is prejudicial and stigmatises against people with mental health needs, for example, perpetuating the view that people with mental health problems are, “abnormal” and/or “dangerous” (Mechanic, McAlpine, Rosenfield, Davis, 1994). Social stigma is a particular concern in some cultures and relatives might guard against members of their culture or subculture being informed about the service users’ condition.

**Table 1.2 DSM IV Criteria for Schizoaffective Disorder**

|  |
|--|
| A – An interrupted period of illness during which, at some time, there is either a Major Depressive Episode, a Manic Episode, a Manic Episode, or a Mixed Episode concurrent with symptoms that meet Criterion A for Schizophrenia.<br>Note: The Major Depressive Episode must include Criterion A1: depressed mood. |
| B. During the same period of illness, there have been delusions or hallucinations for at least 2 weeks in the absence of prominent mood symptoms.  |
| C. Symptoms that meet criteria for a mood episode are present for a substantial portion of the total duration of the active and residual periods of the illness.   |
| D. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.   |

Internally, labels can be self-defeating as individuals might have negative beliefs about themselves associated with being diagnosed as suffering from schizophrenia/schizoaffective disorder for example, “I’m going mad” - self-perceptions that have the potential to maintain an unhelpful state of emotional arousal. This then has the potential to exacerbate the experience of distressing psychotic symptoms (Fowler, Garety and Kuipers, 1995).

Alternatively, service users and carers may view receipt of the diagnoses of schizophrenia or schizoaffective disorder as a useful point from which to begin to make sense of their experience or the experience of the cared for person. In contrast with Kraepelin’s original ideas which suggest a mental decline with no prospect of recovery for people with schizophrenia, Ciompi (1980; 1994) suggests that long-term outcome is variable. There is also some evidence to suggest that acceptance of a diagnosis and awareness of symptoms is associated with a better clinical outcome

(Fowler, Garety and Kuipers, 1995). Further, illness metaphors can be empathic and clinically beneficial (Fowler, Garety and Kuipers, 1995). Hence, some approaches to psychotherapy aim to assist the service user with arriving at an understanding of their condition which suggests that there are opportunities to gain control, that there is hope for the future and to promote the service user's active engagement in adaptive behaviour (Kuipers, Garety, Fowler, Dunn, Bebbington, Freeman and Hadley, 1997). Therefore, in order to circumnavigate the limitations of contemporary classification systems, it is argued that diagnosis may be used between professionals and where judged to be of clinical beneficence to service users and their carers.

### *1.3 Psychosocial treatments for Schizophrenia/Schizoaffective Disorder*

The Mental Health National Service Framework (NSF) is clear in detailing the commitment the NHS should have to treating people with serious mental health diagnoses such as schizophrenia/schizoaffective disorder (Department of Health, NHS Executive, 1999). Moreover, the focus of the government initiative "Clinical Governance" is on improving the quality of care from a service user/carer perspective (Department of Health, NHS Executive, 1999). In order to begin to promote the provision of health services nation-wide and ensure that there is consistency, the National Institute for Clinical Excellence (NICE) has developed standards regarding access to psychological treatment for people with persistent, distressing symptoms of psychosis (National Collaborating Centre, 2002).

#### *1.3.1 Vulnerability-Stress Models and the Concept of Illness*

Engel (1977) is often credited with coining the term "biopsychosocial" to describe a model that considers people in the context of multiple factors rather than a solely biological fashion (Barrowclough and Tarrier, 1997). Engel (1977) argued the necessity of examining symptoms in terms of the internal and external systems in which they occur, are influenced by and have an impact on. Similarly, as an alternative to exclusively biological models (Sellwood, Haddock, Tarrier and Yusupoff, 1994), the vulnerability-stress model proposed by Zubin and Spring (1977) suggested that there was an interrelationship between co-existing factors argued to be implicated in the development (aetiology and maintenance) of psychoses (Fowler, Garety and Kuipers, 1995).

Zubin and Spring's (1977) vulnerability-stress model (for discussions of other models see: Fowler, Garety and Kuipers, 1995; Barrowclough and Tarrier, 1997), links the genetic, biological, psychological, social, cultural and economic elements now widely agreed as intricately associated in the onset and course of schizophrenia and related conditions (National Collaborating Centre, 2002). It must be stated here that evidence for the causal role of the above factors remains tentative at present and findings supporting psychosocial implications for the course of the condition are still emerging (Hemsley, 1988). Nevertheless, it is argued that schizophrenia/schizoaffective disorder occurs in individuals with a "vulnerable predisposition" to develop the conditions and "onset often follows life events, adverse environments, illicit drug use, or periods of isolation" (Garety, Kuipers, Fowler, Freeman and Bebbington, 2001 p. 189).

Barrowclough and Tarrier, (1997) argue that if psychosocial factors are associated with the experience of symptoms of schizophrenia, this suggests that manipulation of these factors could be instrumental in the management of the condition. Clinically, discussing the model with someone who has been given the diagnosis of schizophrenia is often a useful method of assisting the person develop an understanding of the precipitating factors of their condition and the impact of the social environment on its course (Turkington and Kingdon, 1996). The vulnerability stress model places the experience of symptoms of schizophrenia on a continuum of responses to stressors (Fowler, Garety and Kuipers, 1995). This normalises the process of developing schizophrenia and related conditions, stating that given the same predisposing vulnerability and subsequent stressors, it is likely that others too would be in distress (Turkington and Kingdon, 1996). According to Tarrier, Barrowclough, Haddock and McGovern (1999), more recently there has been greater acceptance of vulnerability-stress models of schizophrenia.

### *1.3.2 Family Interventions*

Following the articulation of vulnerability-stress models of schizophrenia, psychological treatments which were developed involved the establishment of psychosocial techniques designed to be effective in the management of an individual's

symptoms (Yusupoff, et al 1996; Birchwood, Meaden, Trower, Gilbert and Plaistow, 2000; Pilling, et al 2002a). As outlined above, the vulnerability-stress model suggests that manipulation of the social environment is a key factor in managing the distress and disturbance inherent in the experience of schizophrenia/schizoaffective disorder (Barrowclough and Tarrier, 1997). Family interventions (FIs) are now considered “an accepted and established method of treatment” (Burck and Speed, 1995: p. 247). There are a vast number of, often conflicting, models within FI. However, these models can each be broadly described as belonging to one of two fields of enquiry. One theoretical domain related to FIs in schizophrenia/schizoaffective disorder is based on systemic explanatory frameworks and is referred to in the literature as family therapy this type of therapy will not be described here. The second, termed “family management” (Burbach, 1996), is largely based on cognitive and/or behavioural theory. The history of the development of the theoretical frameworks related to family management will be considered briefly in terms of their relevance to schizophrenia/schizoaffective disorder.

Early systemic theories asserted that families which included a person exhibiting psychotic symptoms could exacerbate symptoms in the index client as a result of their interaction (Burbach, 1996). Indeed, such theories argued that families had a role in the causation of schizophrenia (e.g. Bateson, Jackson, Haley and Weakland, 1956). Burbach (1996) notes that in the 1970s systemic theories were heavily criticised for blaming parents for the development of schizophrenia in offspring and as a result many of the early theories were rejected. Later, family management techniques began to gain wider acceptance (Goldenberg and Goldenberg, 2000). Pilling et al (2002a p. 765) define FIs as, “including family sessions with a specific supportive and treatment function, and a minimum of one of the following treatment components: Psycho-educational intervention; problem-solving/crisis management work; or, intervention with the identified service user (for at least 6 weeks)”.

There has amassed a body of literature on social environmental factors and schizophrenic symptoms. Expressed emotion (EE: in its most widely researched form) is the “affective attitude of criticism, hostility, and/or emotional over-involvement of a relative towards a service user with a psychiatric disorder such as

schizophrenia or another psychotic disorder...” (Humbeeck, Audenhove, De Hert, Peiters, Storms, Vertommen, Heyrman and Peuskens, 1999 p. 1). According to Barrowclough and Tarrier, (1997) pioneering work on EE began in the U.K. in the 1950s when antipsychotic medication became available and people were being discharged from large psychiatric institutions (Vaughn and Leff, 1976). Contrary to expectations, people suffering from schizophrenia were noted to have higher relapse and readmission rates if they went to live with their families than if they lived alone (Barrowclough and Tarrier, 1997). It was found that people being discharged to critical or emotionally over-involved families were three to seven times more likely to relapse within 1 year than people being discharged to families with a more positive affective climate (Nugter, Dingemans, Van der Does, Linszen and Gersons, 1997).

As measured by the Camberwell Family Interview (CFI; Brown and Rutter, 1966; Vaughn and Leff, 1976), EE is considered a reliable gauge of the family environment that research has repeatedly (with few exceptions) shown to be a robust predictor of relapse in schizophrenia after hospitalisation (Butzlaff and Hooley, 1998). People who suffer from symptoms of schizophrenia/schizoaffective disorder are sensitive to the amount of stimulation in the social environment (Barrowclough and Tarrier, 1997). Family members’ expression of negative emotion was reported to correlate with a deleterious process in the course of a person’s illness in which family members may unwillingly trigger an increase in the service user’s expression of psychotic phenomena (Kavanagh, 1992; Kuipers, 1992). As revised by Vaughn and Leff (1976), the CFI is a one - two hour semi-structured interview, which takes place with the relative of a mental health service user. The interview is audio-taped and scored to provide an indication of the family member’s attitudes toward the service user. Family members are either high or low EE depending on their scores on the interview (Hashemi and Cochrane, 1999). With the emergence of this research came FI programmes designed to change the social environment and enhance management of the distress and disability associated with schizophrenia and related conditions. Three of the main strands of family management programmes with models formulated by Leff, Kuipers, Berkowitz, Eberlein-Vries and Sturgeon (1982), Falloon and Liberman (1983), Tarrier, Barrowclough, Vaughn, Bamrah, Porceddu, Watts and Freeman (1988) are contrasted below.

Firstly, the FI model proposed by Leff, et al (1982) has three main facets: relatives are provided with psychoeducation regarding schizophrenia; they attend a coping skills group; and they are given supportive family sessions in their homes. Family work sessions are conducted in the home in order to aid the process of engagement of the family with the mental health professional (Leff, 2001). One of the aims of the intervention is to lower EE. An important outcome of this approach is to ensure that there is a reduction in the contact time between the index client and family members so that it is below 35 hours per week. This is the level of contact EE research had indicated was critical in order to facilitate the management of schizophrenia within the community (Barrowclough and Tarrier, 1997). The FI programme proposed by Leff, et al (1982) also involves: developing problem-solving techniques with the family; improving communication within the family; dealing with EE - particularly reducing emotional over-involvement of family members with the index client; expanding social networks of the index client; and lowering the expectations of the identified client and his/her family members relating to what he or she is likely to achieve depending on the phase of the illness (Leff, 2001). These pioneering interventions have been the subject of much investigation concerned with developing and refining family management programmes.

In contrast, Falloon and Liberman (1983), in the second strand of family management approaches to be considered here began to constitute a model of FIs in the U.S.A. The main interventions within this approach utilise behavioural methods designed to improve communication and enhance problem solving within the family (Barrowclough and Tarrier, 1997). This approach also emphasises the utility of education (Burbach, 1996). The model developed by Falloon and his colleagues (1983) is more inclusive than Leff et al's (1982) as it seeks to encourage the index client to be present during family sessions and suggests a process of negotiation and collaboration with the identified service user in terms of key decisions about his/her care.

The final of the three family management models to be considered here was developed by Tarrier, Barrowclough, Vaughn, et al (1988). This model is based on a

cognitive-behavioural theoretical framework. In comparison to the Leff, et al (1982) model, sessions are conducted at a clinic with homework assignments for the intervening period. The approach they outlined regarded the family as “rehabilitative agents” whom mental health professionals would train and encourage to take an increasing role in the care of their relatives with schizophrenia who were being discharged from large psychiatric institutions (Barrowclough and Tarrrier, 1997). Tarrrier et al’s (1988) intervention package had three main components. The first part of the programme provided families with instructional material on how to manage schizophrenia. The second aspect of the intervention was designed to teach the family how to cope with the stress of caring for someone with schizophrenia. The third part of the management package was an assessment of the needs within the family and a consideration of how those needs might be met by taking graded steps towards a goal. Their results showed that FI significantly lowered EE in the social environment (Barrowclough and Tarrrier, 1997). However, a criticism of this approach is that care in the community should not advocate that the responsibility for the management of schizophrenia is passed from statutory services to carers who may have needs of their own (Fadden, 1998).

Family intervention studies over the last 30 years have indicated that management of the social environment is more effective in reducing rates of relapse and readmission (Burbach, 1996; Garety, Kuipers, Fowler, Freeman and Bebbington, 2001; Pilling, Bebbington, Kuipers, Garety, Geddes, Orback and Morgan, 2002a) in comparison with social skills training and cognitive remediation which are not presently recommended for clinical practice (NHS Centre for Reviews and Dissemination, 2000; Pilling, Bebbington, Kuipers, Garety, Geddes, Martindale, Orback and Morgan, 2002b). Family interventions are also one means of meeting the needs of carers as stipulated in the Carer’s Act (1996). Burbach (1996), in his comparison between family therapy and family management approaches suggests that emergent theories concerned with FIs in schizophrenia are more likely to be based on systemic theories than to arise from a single understanding of a concept such as expressed emotion (see also Kuipers, Leff and Lam, 1992; Leff, Sharpley, Chisholm, Bell and Gamble, 2001). As a cautionary note, however, according to Pharoah, Rathbone, Mari and Streiner (2003) a review of available studies suggests that one cannot be confident of the

effects of family intervention although, they used particularly rigorous exclusion criteria. For example, they excluded studies that involved people who were in hospital and those where the intervention was less than five sessions. They suggested that family work might be less effective when administered by those who had learned the techniques rather than having been involved in initially developing it.

### *1.3.3 Cognitive Behaviour Therapy*

Cognitive behaviour therapy (CBT) is a psychosocial treatment devised by Beck (1970). It is a structured, goal oriented approach to psychological therapy which proposes that the meaning an event has for an individual will have implications for the person's affect, physiology and behaviour (Hawton, Salkovskis, Kirk and Clark, 1989). A recent definition operationalises cognitive behaviour therapy as having two main components which involve, "recipients {of treatment} establishing links between their thoughts, feelings or actions with respect to the target symptoms; and the correction of their misperception, irrational beliefs or reasoning biases related to the target symptoms" (Pilling, et al 2002a p. 765). The definition goes on to state that, "At least one of the following was also required: self-monitoring of the treated person's thoughts, feelings or behaviours with respect to the target symptoms" (Pilling, et al 2002a p. 765). Since the 1970s, the application of CBT with a number of debilitating conditions such as panic and obsessive-compulsive disorder has provided evidence of its clinical effectiveness in many areas of investigation (Hawton, Salkovskis, Kirk and Clark, 1989; Roth and Fonagy, 1996). Numerous researchers have taken on the challenge to develop and refine theory in order to widen the approach's application, attesting and enhancing its clinical efficacy (Durham, Swan, Fisher, 2000).

Historically, there was a myth that psychotic symptoms were not amenable to psychological intervention. Indeed the commonly held view was that interventions for people with schizophrenia/schizoaffective disorder based on psychological theory were contraindicated (reported in, Yusupoff, Haddock, Sellwood, and Tarrier, 1996; Birchwood, Meaden, Trower, Gilbert and Plaistow, 2000). However, over the last decade randomised controlled trials of CBT have begun to contribute to a growing body of evidence demonstrating its effectiveness with people suffering from persistent

and distressing symptoms of schizophrenia/schizoaffective disorder when used as an adjunct to pharmacological treatments (Garety, Kuipers, Fowler, Freeman and Bebbington, 2001; Pilling, Bebbington, Kuipers, Garety, Geddes, Orback and Morgan, 2002a). Rigorous randomised controlled trials are generally concerned with measuring relapse and readmission, mental state, treatment non-compliance and improvement in functioning as outcomes of CBT (Pilling et al, 2002a). In contrast with studies illustrating the effectiveness of CBT with psychosis, clinical trials of psychodynamic psychotherapy designed to treat psychoses have not demonstrated the effectiveness of a psychodynamic approach with this cohort (Sellwood, Haddock, Tarrier and Yusupoff, 1994; Drayton, 1995; Fowler, Garety and Kuipers, 1995; Fadden, 1998).

Within a cognitive behavioural theoretical framework psychotic symptoms are viewed as meaningful and assessed in the context of the individual's immediate presentation and history (Garety, 1991; Bentall, Haddock and Slade, 1994; Yusupoff, et al, 1996). According to Pilling, et al (2002a), used in conjunction with neuroleptics, CBT aims to bring about desired change by:

- ◆ Reducing the distress, emotional disturbance and disability caused by psychotic symptoms
- ◆ Helping the person arrive at an understanding of the psychotic cycle which promotes his/her active participation in the regulation of relapse and social disability

The approach is also concerned with working in collaboration with the individual to assist him/her with making sense of symptoms (Fowler, Garety and Kuipers, 1995). The treatment seldom comprises less than 10- and is usually between 20 and 25 sessions in total with between-session homework tasks which involve monitoring and challenging distressing appraisals (Fowler, Garety and Kuipers, 1995). Pilling et al, (2002a) note that the techniques involved in treatment are:

- ◆ Building and maintaining a therapeutic relationship
- ◆ Enhancing and developing strategies in order to cope with distressing symptoms and experiences (for example hallucinations)

- ◆ Normalising and destigmatising the psychotic experience
- ◆ Modification of psychotic symptoms (for example delusions and hallucinations)
- ◆ Promoting self-esteem
- ◆ Modification of anxiety and depression
- ◆ Relapse management

Research evidence suggests that CBT is effective at reducing distress for people suffering from schizophrenia/schizoaffective disorder (Garety, Kuipers, Fowler, Freeman and Bebbington, 2001). Moreover, gains made during a course of treatment have been found to be sustained, relative to comparison groups (Kuipers, Fowler, Garety, Chisholm, Freeman, Dunn, Bebbington and Hadley, 1997). In their review Pilling et al, (2002a) argue that improvements in mental state made with CBT were maintained at 18-month follow-up whereas those of comparison treatments were not. Evidence of CBT's effectiveness lasting more than two years post-treatment is weak (Pilling et al, 2002a). This may be due to the fact that as an intervention with schizophrenia, CBT is under evaluated, although promising (Jones, Cormac, Silvera da Mota Neto and Campbell, 2004).

#### *1.4 Barriers to Access*

The literature points to the following as potential barriers to access of CBT and FI: the Mental Health Act (1983), the medical model, social stigma, professionals' anxieties about applying psychosocial interventions, resources and finally the researcher-clinician divide. Many of the barriers outlined relate to both accessing CBT and FI although where the reasons for not accessing CBT and FI are different this is specified.

##### *1.4.1 The Mental Health Act (1983)*

There are two main issues to be discussed here: 1) Coercion per se and; 2) The high incidence of use of the provisions of the Mental Health Act 1983 with Black people. African-Caribbeans born in the U.K. develop psychosis at a rate 4 times higher than white-British people. The latter is considered to be related to social (isolation, alienation) and environmental factors rather than having a biological basis (Tarrier, Barrowclough, Haddock, McGovern, 1999; Burnett, Mallett, Bhugra, Hutchinson,

Der, Leff, 1999). Bentall, (2004) associates the higher incidence of schizophrenia among the Afro-Caribbean population in the U.K. with racial discrimination. He suggests that far from solely being a result of the overrepresentation of some minority ethnic groups in psychiatric hospitals, racism has been shown to be a precipitating factor in onset of schizophrenia (Bentall, 2004). Burnett, et al., (1999) argued that African-Caribbeans were more likely to be admitted involuntarily under the Mental Health Act, (1983) following their first admission than other ethnic groups (the same was true for men alone - see Commander, Sashidharan, Odell, Surtees, 1997).

Bentall (2004) asserts that conventional modern-day treatments such as ECT and neuroleptic medication often involve coercion. Understandably, coercion fuels a perception that one will be intentionally hurt by others and leads consumers to mistrust health care providers so that working collaboratively to engage service users in CBT or FIs becomes an almost impossible task (Corrigan, 2002). UK-born black people have been shown to be less satisfied with the service they receive than other ethnic group (Parkman, Davies, Leese, Phelan, Thornicroft, 1997). Clearly there is a need to promote cultural awareness within the organisation to prevent people from minority ethnic groups being caught in a cycle of relapse and readmission under the provisions of the Mental Health Act (1983). Reynolds, (2001) argues that it is of necessity that the philosophy of psychological therapies takes into account the multidimensionality of identities so that it acknowledges that individuals belong to more than one cultural group (e.g., ethnicity, gender, class, sexual orientation) and are impacted by their social identities.

#### *1.4.2 The Medical Model*

The pervasive, influential medical model -offering a reductionist view of the experience of mental distress has inhibited the consideration of the role of psychosocial factors and psychological interventions in the treatment and management of schizophrenia for service users and their carers (Ciompi, 1994; Barrowclough and Tarrier, 1997). Historically, people with schizophrenia/schizoaffective disorder were treated with ineffective and invasive procedures such as psychosurgery, insulin coma and, in more modern times with high doses of medication (Bentall, 2004).

Neuroleptics remain the mainstay treatment for schizophrenia/schizoaffective disorder

despite evidence to suggest that they are not as radically effective as first heralded. As many as 40% of service users have symptoms that persist despite relentless trials on anti-psychotic medication, leading to many survivors accumulating debilitating side effects such as sexual dysfunction along the way (Tarrier, Barrowclough, Haddock, McGovern, 1999; Tarrier, Yusupoff, Kinney, McCarthy, Gledhill, Haddock and Morris, 1998; Pilling et al 2002a; National Collaborating Centre, 2002; Bentall 2004).

As suggested above, dissatisfaction with the traditional medical model and the resulting clinical application of vulnerability-stress models with numerous scientific investigations into the effect of the social environment on relapse and readmission in schizophrenia provide utility to the concept of a multi-factorial cognisance of the aetiology and remission of schizophrenia and related disorders (Zubin and Spring, 1977). Previous authors have commented that in retrospect, it seems tragic that nurses were infected by psychiatry's *disease*, the legacy of which has meant that they often continue to work under the maxim that they are unable to speak to service users as it would exacerbate psychotic symptoms (Barrowclough and Tarrier, 1997). This is particularly disturbing when consumers are arguing that they require someone to listen to them and to present them with appropriate information so they are able to make informed choices about their care (NHS Centre for Reviews and Dissemination, 2000).

#### *1.4.3 Social Stigma*

Social stigma is considered to be a factor that prevents service users and carers accessing psychosocial interventions. According to the National Collaborating Centre, (2002) within society, indeed within the NHS, there is prejudice against people suffering from symptoms of schizophrenia. This results in inadequate numbers of people being referred for appropriate psychosocial treatments. Service users often report experiencing stigma although the consequences vary. For many people suffering from the disabling effects of schizophrenia, the ongoing process of recovery involves managing symptoms, coping with stigma, cultivating a positive self-concept and making contributions to society (Markowitz, 2001). Others have suggested that attributing one's difficulties to mental illness correlates with a reduced quality of life

(Mechanic, McAlpine, Rosenfield, Davis, 1994) whilst if attributed to a medical problem, people tend to report greater numbers of positive social encounters and a better quality of life. In their study, Mechanic et al. (1994) demonstrated that for a significant number of people a higher level of depressive symptomatology could be explained by the effect of stigma.

Consumers who experience themselves as the “stigmatised other” tend to conceal their illness and experience a deleterious effect on the process of their recovery (Mechanic, McAlpine, Rosenfield, Davis, 1994; Wahl, 1999). For some service users, related to the perception of social stigma is low self-esteem; poor employment prospects; lack of money and; altered behaviour from others (Thesen, 2001). Cross-cultural studies have shown that social stigma against mental illness in Eastern Asian societies, for example, Japan leads to a tendency to delay accessing services (Shimodera, Inoue, Tanaka and Mino, 1998). Other service users are able to preserve their self-concept and sense of social identity by rejecting unhelpful labels when they are perceived as denoting a negative stereotype, whilst acknowledging their own mental distress (Camp, Finlay and Lyons, 2002). Clearly, there are attributes of a culture or organisation that may prevent attitudinal change (Shepherd, Murray and Muijen, 1995; Tarrier, Barrowclough, Haddock, McGovern, 1999). However, it is suggested that as a fundamental measure mental health services consider raising awareness, at the very least within the organisation, of the impact of stigma on the mental health of their consumers and take steps to reduce the harm it causes. Perhaps awareness raising events could make use of the valuable experience of service users as trainers since some service users state that speaking out against stigma and advocating on the behalf of others are both useful coping strategies (Wahl, 1999).

#### *1.4.4 Professional Anxieties about Applying Psychosocial Interventions*

There are often conflicts in relationships between professionals and families, which are a barrier to the application of psychosocial treatment and management techniques for schizophrenia (Barrowclough and Tarrier, 1997). Once relatives have identified themselves as “stakeholders”, the responsibility and burden of caring for someone with a severe mental illness makes it difficult for them to get access to information and services. Quintessential to the implementation of CBT and FIs in routine clinical

practice is that community staff have training in such interventions (Leff, Sharpley, Chisholm, Bell and Gamble, 2001). For many, the prospect of working with families is daunting (Tarrier, Barrowclough, Haddock, McGovern, 1999). Mental health professionals should be informed about FIs as there is often a lack of basic information (Kuipers, 1998; Fadden, 1998), being equipped in this way will begin to enable more positive attitudes towards the involvement of carers. Further, information could be shared with carers to assist them with understanding client behaviour. Key professionals such as social workers, nurses and occupational therapists once qualified as such are required to engage in post-qualification training in order to be equipped to offer psychosocial interventions (Fadden, 1998). To meet part of this requirement national training centres have been set up in Manchester and London (Leff, Sharpley, Chisholm, Bell and Gamble, 2001). It is suggested that relatives could become trainers of family workers either by relaying their own experience in person or via a training video (Shepherd, Murray and Muijen, 1995; Fadden, 1998).

There are a number of additional issues regarding training in psychosocial interventions with schizophrenia. Tarrier, Barrowclough, Haddock, McGovern, (1999) have cautioned that the clinical techniques involved are more difficult to learn and implement than was initially anticipated. Thus, it is of necessity that workers are able to acquire skills within a supportive management context with adjustments made to caseloads where necessary and access to regular, specialist clinical supervision (Fadden 1997; Durham et al., 2000; Fadden, 1998). Clearly this has cost implications. Leff, et al., (2001) were able to demonstrate the cost of training compared favourably with that of in-patient care (see also Birchwood, Meaden, Trower, Gilbert and Plaistow, 2000). However, they argue that further such studies are required before the cost-effectiveness of FIs and associated training programmes can be made (Leff, et al., 2001).

#### *1.4.5 Resource Implications of Offering Psychosocial Interventions*

Limitations on resources are a barrier to service users and carers accessing psychosocial interventions for schizophrenia. The provision of CBT involves the investment of time of highly skilled professionals of which there are few (NHS Centre

for Reviews and Dissemination, 2000; Durham, Swan and Fisher, 2000). Time is a particular concern as it is suggested that CBT practitioners attempting to engage someone suffering from symptoms of schizophrenia are required to be flexible, offering long periods of assessment of between 4 and 6 sessions, as it is essential to build a collaborative relationship with the individual service user (Fowler, Garety and Kuipers, 1995; Corrigan, 2002; Durham, et al., 2000). Durham, Swan and Fisher, (2000) argue that brief contact with large numbers of clients dilutes the quality of the intervention. Whilst they suggest that longer-term interventions may leave the therapist with a waiting list - neither of these conditions is optimal in terms of meeting the needs of consumers. Service users may have particular anxieties about their symptoms, which make them difficult to discuss. Indeed, they may suffer from negative symptoms which inhibit their motivation to engage (Birchwood, Meaden, Trower, Gilbert and Plaistow, et al. 2000). Therefore, research is needed in order to develop and refine screening procedures with the ability to predict who would gain most from a course of CBT (NHS Centre for Reviews and Dissemination, 2000; Garety, Fowler, Kuipers, Freeman, Dunn, Bebbington, Hadley and Jones, 1997).

#### *1.4.6 The Researcher-Clinician Divide*

Research has been demonstrating the effectiveness of family interventions with schizophrenia for some time. Transferring knowledge gained from research conducted surrounding the clinical effectiveness of psychosocial treatments into service provision presents a challenge (Tarrrier and Bobes 2000, Yusupoff, Haddock, Sellwood and Tarrrier, 1996). Although training programmes which include both didactic teaching and clinical supervision imparting skills to staff other than psychologists have been produced to develop the quality of care in day hospitals and in the community (Durham, Swan and Fisher, 2000; NHS Centre for Reviews and Dissemination, 2000), “the provision of mental health services bears little relation to research....” (Tarrrier, Barrowclough, Haddock and McGovern, 1999 p.569). The task is for mental health organisations to unequivocally infiltrate all system levels with the message that psychological treatments for service users suffering from medication non-responsive schizophrenia/schizoaffective disorder and their carers are relevant and valued (Tarrrier, Barrowclough, Haddock, McGovern, 1999).

Research has highlighted a number of barriers within the framework of cognitive behaviour therapy that would need to be addressed if it is to be more widely applied. According to Birchwood, Meaden, Trower, Gilbert and Plaistow, (2000) in its present state, the limitations of cognitive therapy require clarification. For example, the U.K., similar to the U.S.A (Jeffrey, Ley, Bennun and McLaren, 2000), has an occurrence of substance misuse in people with severe mentally illness ranging from 15 to 60%. However, the majority of the literature to date has used co-occurring substance misuse as a criterion for exclusion from studies evaluating the clinical effectiveness of CBT with schizophrenia (Birchwood, Meaden, Trower, Gilbert and Plaistow, 2000). On a practical note, valuing the contribution of psychosocial treatments for working with people with psychosis might signify the necessity to take positive action in order to prioritise allocation of research grants to investigators committed to developing and refining psychological treatments to widen its clinical application (Kuipers, 1998; NHS Centre for Reviews and Dissemination, 2000).

#### *1.4.7 Consumer Movement*

Given the potential barriers to accessing psychosocial interventions stated above, this section now considers consumer perspectives on mental health services. The consumer movement has arisen against a background of discontent and angst with the provision of mental health services among service users. Over the last decade it has been accompanied by studies highlighting that services are consistently failing to meet the needs of service users and carers and that they continue to be rarely consulted about important aspects of their care (Shepherd, Murray and Muijen, 1995). Increasingly, there is a demand to contemplate consumers - the long-forgotten, indeed ultimately central, part of the mental health system (Deegan, 1993; Barrowclough and Tarrier, 1997) and to research their experience (Barker, Lavender and Morant, 2001). Where consumers are consulted on service delivery, their involvement ranges from examining levels of satisfaction with a service to their active involvement in decision-making about how services are provided and delivered (Barrowclough and Tarrier, 1997; Fadden, 1998). May, (2001) argues that services should engage in anti-discriminatory practice integrating user involvement on a wide scale via policies. Shepherd, Murray and Muijen, (1995) contend that the current lack of consistency across mental health trusts is not ethically defensible (see also Fadden, 1998).

There is a multiplicity of perspectives on mental health services, wherein lie discrepancies between how a clinician or manager might perceive the utility of a service and how consumers of that service might view it. In a study providing insight into some of those views, Shepherd, Murray and Muijen (1995) state that service users with severe mental illness emphasise the importance of practical help (e.g. housing, finance, occupation, physical health and counselling), whilst professionals highlight medication and symptom monitoring as essential. Their detailed qualitative study also demonstrated that carers argued that all aspects of care regarding service users were important, which meant that they placed more emphasis on professional input than did the service users. This suggests that carers may act as a channel between service users and mental health professionals where tension exists and professionals and service users find it challenging to work collaboratively. It is reported elsewhere that carers also find it helpful when they are assisted with practical matters such as benefits (Weinberg and Huxley, 2000) as this assistance aids to relieve burdens which are related to issues surrounding their own health and employment (Kuipers, 1998; National Collaborating Centre, 2002).

On some issues there appears to be consensus between service users, carers and mental health professionals, for example, the importance of sharing information, in particular relating to medication and its side effects, there was also agreement found on the usefulness of day care and the need for support at home (Shepherd, Murray and Muijen, 1995). Other authors have argued that information, although it does not reduce relapse in service users, is a useful tool to engage carers (Kuipers, 1998; Fadden, 1998). Since information is what carers are asking for and professionals agree it is important, priority should be given to ensuring that the dissemination of information about schizophrenia, its treatment and management is widespread (National Collaborating Centre, 2002). Carers involved in the Shepherd, et al. (1995) study mentioned that they often felt as though the caring role was devalued by staff, which left them feeling rejected. The nature of the caring role suggests that when presenting to a mental health service carers are likely to already have emotional responses to their relative's illness ranging from grief to a sense of hopelessness to cope with (Kuipers, 1998). According to (Barrowclough, Labbon, Hatton and Quinn,

2001) as many as 60% of carers suffer distress in relation to their care-giving role. Therefore, every action should be taken to ensure that the views of the carer are heard, their input valued and their emotional responses normalised. Some suggestions are that carers be encouraged to get involved in support groups which provide them with social support to reduce their distress (Fadden, 1998) and that they be provided with respite on occasion (Kuipers, 1998). Further, it is essential that mental health professionals and service users develop a shared understanding of service user and carer explanations of their experiences so that the utility of the treatments available can be presented in a way that is meaningful to the consumer (Barker, Lavender and Morant, 2001).

### *1.5 Rationale for the current study*

It is widely accepted that CBT and FIs are effective with schizophrenia/schizoaffective disorder. Although there is a wealth of research on psychosocial interventions for schizophrenia/schizoaffective disorder, few studies have examined the barriers to accessing those types of intervention from service user and carer perspectives and contrasted their views with those of mental health professionals (Corrigan, Markowitz, Watson, Rowan and Kubiak, 2003).

This study therefore endeavors to examine barriers to accessing psychosocial interventions for service users with schizophrenia/schizoaffective disorder and their carers. It was considered appropriate to use focus groups and semi-structured interviews with a qualitative Grounded Theory data collection and analytic procedure in order to explore barriers as perceived and experienced by service users, carers and mental health professionals (Krueger, 1994). Previous research has demonstrated that utilising qualitative methods with similar groups has been well suited to this purpose (Shepherd, Murray and Muijen, 1995). Therefore the present study aimed to illuminate barriers to accessing CBT and FIs that service users of a NHS mental health Trust with medication-non-responsive schizophrenia/schizoaffective disorder and their carers faced.

## **Chapter 2: Method**

### *2.1 Rationale for the methodology*

A review of the current literature indicated that previous studies had been concerned with psychosocial interventions for psychosis. Most studies of CBT and FIs have been concerned with the effectiveness of these interventions and have largely adopted quantitative methodology. The current study is endeavouring to provide an understanding of phenomena and as such lends itself to a more qualitative approach. Few studies have examined the barriers to accessing those types of intervention from service user and carer perspectives (Corrigan, Markowitz, Watson, Rowan and Kubiak, 2003). There are a number of qualitative research methods used within psychological research. Grounded theory is one particular type of qualitative research method. Utilising Grounded theory allows new theories to be generated from data using categories. Qualitative methods, in particular Grounded theory was used in the present study as this approach was more suited to address the broad research questions than tools associated with quantitative methods. The application of qualitative methods enabled useful information to be gleaned from semi-structured discussion with a relatively smaller number of respondents (Shepherd, Murray and Muijen, 1995). However this method of enquiry inevitably produces a considerable wealth of data and it can be difficult to select which aspects of a qualitative study to present. This study therefore focuses on the key themes that emerged from focus group discussion and semi-structured interviews, whilst acknowledging that the more minor themes may also contain information of interest. Examples of minor themes were as follows: being discharged from hospital with the uncertainty of follow-up in the community (SUG); how psychosocial treatments relate to getting to work (CG); women's affinity to talking treatments (CI); and the priority given to managing risk (MHPG).

#### 2.1.1 Research questions

- A. How might services users, carers and mental health professionals perceive & account for the barriers that service users and carers face in accessing CBT and family interventions?
- B. How do views of service users/carers and mental health professionals differ? If they converge, at what points does this happen?

C. How might answers to these questions be used to inform counselling psychology practice/research?

1

## *2.2 Participants*

Overall, there were five focus groups all consisting of volunteers. The focus groups each consisted of one 'type' of participant and in that sense were homogeneous. This accorded with the research questions, which aimed to explore how particular groups of people viewed barriers to accessing cognitive behavioural therapy and family interventions. Hence there were service user groups, a carers group and mental health professional groups. Recruitment of participants will be discussed under each participant-type sub-heading. Information documents were sent to participants one-month prior to the date when each of the focus groups were conducted (See Appendix 1 for 'Consent Form' and 'Information about the Study' documents). Participants were required to give written informed consent to be interviewed. Consent forms highlighted confidentiality issues and the requirements of the Data Protection Act (1998) were complied with. Participants were also required to speak English fluently. On all occasions the focus group moderator's assistant greeted the participants at the door of the venue and operated recording equipment. Since inclusion criteria for each type of participant was different, the following will provide a separate consideration of the requirements of each group of participants beginning with the service users, followed by the carers and ending with participants who were mental health professionals.

### *2.2.1 Service Users*

The inclusion criteria for service user participants stipulated that they were required to be current users of the NHS Trust's mental health services with a diagnosis of schizophrenia/schizoaffective disorder (according to DSM IV criteria as recorded in their medical notes). LG asked a community rehabilitation team to identify those who met the criteria. LG contacted those identified, informed them about the study and

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<sup>1</sup> The present study was in association with an investigation on Access to and Provision of CBT in the South London and Maudsley NHS Trust (Peregrine-Jones, Brown, Garety and Rhule, 2002: see Appendix 8).

asked them whether they would like to participate. Alongside this recruitment exercise, LG approached two rehabilitation in-patient units to ascertain which service users met criteria so that they could be informed about the study. The term “service user” is used throughout the thesis from this point on for the sake of brevity.

There were 12 service users in the present study who were divided in two groups each with six participants. One group comprised in-patients from two rehabilitation units and participants in the other group were users of a community rehabilitation team. Socio-demographics were recorded using a standard form showing the gender, age, occupation and ethnicity. Table 2.1 below shows the socio-demographics of the service user participants. It shows that 75% of participants were male. Most of the service user participants were unemployed. In terms of their ethnicity, the majority of participants either described themselves as black or white.

**Table 2.1 Socio-demographics of Current Service Users**

| <b>Participant</b> | <b>Gender</b> | <b>Occupation</b> | <b>Ethnicity</b><br>(See codes below) |
|--------------------|---------------|-------------------|---------------------------------------|
| 1.                 | Male          | Labourer          | M                                     |
| 2.                 | Male          | Unemployed        | PD                                    |
| 3.                 | Male          | Unemployed        | A                                     |
| 4.                 | Female        | Unemployed        | A                                     |
| 5.                 | Male          | Unemployed        | N                                     |
| 6.                 | Female        | Unemployed        | PC                                    |
| 7.                 | Male          | Unemployed        | PD                                    |
| 8.                 | Female        | Unemployed        | A                                     |
| 9.                 | Male          | Student           | PD                                    |
| 10.                | Male          | Labourer          | A                                     |
| 11.                | Male          | Labourer          | PD                                    |
| 12.                | Male          | Unemployed        | B                                     |

NHS Trust Ethnicity codes (see Appendix 6): M = Caribbean, PD = Black British, A = British, N = Other African, PC = Nigerian, B = Irish

Table 2.2 shows the number of participants with schizophrenia or schizoaffective disorder, their age and the length of the participant’s illness in years and summary statistics (See Table 2.2 for the Examination of Medical Records for Current Mental Health Service Users). The most frequently occurring mental health diagnosis among this group was schizophrenia. The average age was 43 years old (SD 11.98). The mean length of illness was 20.5 years. Copies of the consent forms, the statement

given to participants and study information document were sent to the service users' consultant psychiatrists to be retained in their medical records.

**Table 2.2 Examination of Medical Records for Current Mental Health Service Users**

| <b>Participant</b> | <b>Age<br/>(In years)</b> | <b>Diagnosis</b>         | <b>Length of<br/>Illness<br/>(In years)</b> |
|--------------------|---------------------------|--------------------------|---|
| 1.                 | 30                        | Schizophrenia            | 9   |
| 2.                 | 36                        | Schizoaffective disorder | 13  |
| 3.                 | 39                        | Schizophrenia            | 12  |
| 4.                 | 58                        | Schizophrenia            | 22  |
| 5.                 | 45                        | Schizophrenia            | 21  |
| 6.                 | 60                        | Schizoaffective disorder | 30  |
| 7.                 | 40                        | Schizophrenia            | 20  |
| 8.                 | 42                        | Schizophrenia            | 22  |
| 9.                 | 22                        | Schizophrenia            | 4   |
| 10.                | 51                        | Schizophrenia            | 21  |
| 11.                | 38                        | Schizophrenia            | 18  |
| 12.                | 60                        | Schizoaffective disorder | 43  |

### 2.2.2 Carers

The inclusion criteria for carers required all to be presently caring for a user of the NHS Trust with schizophrenia/schizoaffective disorder. Participating in the present research was a group of 4 carers. There was difficulty recruiting carers. Participants were volunteers from a list of 204 carers. Discussion with the co-ordinator of a carers group in a particular directorate enabled identification of those carers who would have regular contact with service users with schizophrenia/schizoaffective disorder. LG contacted those identified, informed them about the study and asked them whether they would like to participate. Table 2.3 below shows the socio-demographics of carers of current service users. It shows that 75% of participants were male, the average age was 59.5 years (SD 8.06). The most frequently occurring ethnicity was Irish. As carers included in the study were required to be in contact with current mental health service users within the Trust who experienced positive symptoms of psychosis, carers were assessed using the Relative Assessment Interview (Barrowclough and Tarrier, 1997: see Appendix for a copy of this measure). This

interview schedule was used to gather information on the contact time between the carers and services users they cared for, the service user's diagnosis, length of illness and current symptoms. The amount of contact time has been noted as an important indicator of how one might prioritise carers for family intervention (i.e. above 10 hours contact time per week is one factor in considering carers for this type of intervention - National Collaborating Centre, 2002). Table 2.4 below shows the Outcome of the Relative Assessment Interview.

**Table 2.3 Socio-demographics of Carers of Current Service Users**

| <b>Participant</b> | <b>Gender</b> | <b>Age (In years)</b> | <b>Ethnicity (See codes below)</b> |
|--------------------|---------------|-----------------------|------------------------------------|
| 13.                | Male          | 48                    | GC                                 |
| 14.                | Male          | 60                    | M                                  |
| 15.                | Female        | 64                    | B                                  |
| 16.                | Male          | 66                    | B                                  |

NHS Trust Ethnicity codes (see Appendix 6): GC = Black and White, M = Caribbean, B = Irish

**Table 2.4 Relative Assessment Interview Outcome for Carers of Current Mental Health Service Users**

| <b>Participant</b> | <b>Contact Time With Service User (hours/week)</b> | <b>Diagnosis of Service User</b> | <b>Length of Service User's illness (in years)</b> | <b>Service User's Current Problems/symptoms (incl.)</b> |
|--------------------|--|----------------------------------|--|---|
| 13.                | 30   | Schizophrenia                    | 14   | Hallucinations & Delusions                              |
| 14.                | 50   | Schizophrenia                    | 19   | Delusions   |
| 15.                | 168  | Schizophrenia                    | 8  | Hallucinations & Delusions                              |
| 16.                | 168  | Schizophrenia                    | 8  | Hallucinations & Delusions                              |

The median number of hours spent with service users was 109 per week. The most frequently occurring diagnosis service users they cared for had been given was schizophrenia with the mean length of the service user's illness in years being 11 years (ranging from 8 to 19 years). They frequently described the service users' most common problems or symptoms as hallucinations and delusions. Taken together, these factors indicate that the carers involved in the study would have been

appropriate for consideration of family intervention. As far as it was known, none of the carers were in any way related to the service user participants.

### 2.2.3 Mental Health Professionals

Participants in the present study included one group of 6 and another of 7 mental health professionals. One directorate was targeted for recruitment. LG liased with team leaders to ascertain which teams would have some involvement with service with a diagnosis of schizophrenia/schizoaffective disorder. Participants came from two teams and remained with their colleagues for the focus groups. Table 2.5 below shows the socio-demographics of mental health professionals. It shows that 92% of participants were female. The average age was 36 years (SD 10.13). The most frequently reported occupation was “nurse”. The most frequently occurring ethnicity was white.

**Table 2.5 Socio-demographics of Mental Health Professionals**

| Participant | Gender | Age<br>(In years) | Occupation             | Ethnicity<br>(See codes below) |
|-------------|--------|-------------------|------------------------|--------------------------------|
| 17.         | Female | 35                | Nurse                  | PD                             |
| 18.         | Female | 28                | Occupational therapist | C3                             |
| 19.         | Female | 54                | Psychiatrist           | CF                             |
| 20.         | Female | 35                | Social worker          | A                              |
| 21.         | Female | 49                | Nurse                  | B                              |
| 22.         | Female | 52                | Manager                | A                              |
| 23.         | Male   | 37                | Nurse                  | PB                             |
| 24.         | Female | 39                | Social worker          | N                              |
| 25.         | Female | 25                | Social worker          | C3                             |
| 26.         | Female | 28                | Nurse                  | A                              |
| 27.         | Female | 42                | Manager                | C3                             |
| 28.         | Female | 31                | Occupational therapist | A                              |
| 29.         | Female | 23                | Nurse                  | A                              |

NHS Trust Ethnicity codes (see Appendix 6): PD = Black British, C3 = White, CF = Greek, A = British, B = Irish, PB = Mixed Black, N = Other African

In summary, all participants were from 3 directorates across the NHS Trust and aged 18 years old or over. Service users and carers were given expenses for their involvement in the study funded by the Health Services Research Committee.

### *2.3 Ethical Considerations*

Information documents were sent to participants one month prior to the date when each of the focus groups were conducted (See Appendix 1 for 'Consent Form' and 'Information about the Study' documents). Participants were required to give written informed consent to be interviewed. Consent forms highlighted confidentiality issues and the requirements of the Data Protection Act (1998) were complied with. All focus groups and interviews were transcribed with all names and identifiers removed from the transcript to ensure confidentiality and anonymity. The ethical committee's code of practice on the use of audio-visual material was observed. Participants were given the opportunity to discuss any questions or concerns about the study itself or the topic area and a right to request a copy of the final report. Confidences of participants were respected as far as the law allowed (i.e. provided there was no immediate risk to themselves or others). Consultant psychiatrists were informed of service users' involvement in the study and given copies of consent forms and information sheets.

It was stated on the consent form completed by all participants that anyone who took part in the study was free to withdraw from it at anytime without giving a reason for this. Also, service users and carers were advised that withdrawing from the study would not in anyway affect their treatment/the services they received. Service users and carers involved in the study were given a modest sum as an expense payment. Further, it was not anticipated that participants would be distressed by their involvement in the study. Therefore, it was considered acceptable that service users detained under a section of the Mental Health Act (1983) could be included as participants. Ethical approval from the relevant NHS Trust research committees was gained for this study (see Appendix 1 for details of the research ethics application).

### *2.4 Design*

Participants in the study were invited to take part in order to explore their views on barriers to accessing cognitive behaviour therapy and family interventions for service users with medication non-responsive schizophrenia/schizoaffective disorder and their carers. The sample was therefore not a randomly selected statistical sample but a purposive one. This involved specifically targeting groups of people in order to illicit

their views on this subject. Being a qualitative study, the present investigation did not aim to use a representative sample (see Chapter 4 for a discussion on how this type of sampling affects the generalisability of the present findings). Data from focus group discussion and individual semi-structured interviews was analysed using a Grounded Theory qualitative method.

Here Grounded theory is briefly contrasted with other methods of qualitative analysis to further highlight the rationale for utilising Grounded theory in the present study. According to Willig (2001) Grounded Theory (- subjectivist version) has much in common with Interpretative Phenomenological Analysis. For example, both attempt to represent an individual or groups' "cognitive map". In contrast with Interpretative Phenomenological Analysis (IPA), Grounded theory is a historically more established approach that was initially designed to allow researchers to study contextualized processes (Willig, 2001). Content analysis was not suitable for the purposes of this research as it seeks primarily to provide a systematic description rather than develop a theory. Therefore, having examined the properties of IPA and content analysis and compared them with those of Grounded theory I found Grounded theory a more suitable tool for the purposes of this study.

The present study used a cross-sectional within-group design. This resulted in data from participants of each 'type' i.e. service user, carer and mental health professional being collated at distinct time points (focus groups and semi-structured interviews) to be compared and contrasted within and between each 'type'. This allowed for similarities, differences and recurring themes to evolve during discussions within groups and in the process of analysis between 'types' of participant. A cross-sectional within-group design enables rich data to emerge from each 'type' of participant whilst affording a consideration of the social context within which data is generated.

Although groups in which participants are homogenous in 'type' may facilitate discussion (Kitzinger, 1995), there may also be topics that are not mentioned due to the development of group norms. Therefore, semi-structured interviews with individual cases were used to allow for negative case analysis (see point 4 of Section 2.5 'Quality'). Participants for the individual interviews were selected following an initial reading of the focus group transcript that seemed to suggest their views

diverged from the group norm. This was particularly important as the abbreviated version of grounded theory was used. Using the abbreviated version of grounded theory resulted in limitations to theoretical saturation (i.e. the researcher did not return to the field for further data following the initial collation period). It was considered necessary to attain as much diversity of opinion as possible to enable the researcher to work towards theoretical saturation within the available data.

A method's epistemological stance is fundamental to its appraisal. A positivist position asserts that there is *an* identifiable underlying reality that can be studied. The stance taken by the researcher in the present investigation has been one of "subtle realism" where it is accepted that one can make *attempts to represent* an underlying "reality" (Mays and Pope, 2000). The researcher values a social constructionist approach that reflects on the active role of the researcher in the process of interacting with the data (Charmaz, 2000; Willig, 2001). The notion is that theory produced represents "one particular reading of the data rather than the only truth about the data" (Willig, 2001 p.44).

Data collection was conducted over one year, costs of the study were payment to service users and carers, room booking and equipment. There was input from a counselling psychologist (the author - LG), a trainee clinical psychologist and student nurses on placement within the NHS Trust.

### *2.5 Quality*

Elliot, Fischer and Rennie (1999) assert that qualitative research aims to "develop an understanding of the phenomena under study based as much as possible on the perspective of those being studied" (p.216). According to Mays and Pope (2000) the last decade has seen an increase in qualitative research in social science and medical fields. It is considered essential to be in a position to evaluate the quality of that research. A traditional positivist epistemological stance would be evaluated by criteria such as reliability, representativeness, validity, generalisability and objectivity. Social constructionist qualitative methodologies use the active involvement of the researcher in the interpretation process hence, traditional criteria are not entirely applicable to this type of research (Willig, 2001).

Mays and Pope (2000) assert that qualitative research may be judged in respect of validity and relevance. It is argued that concepts such as Triangulation, Respondent validation, Reflexivity, Attention to negative cases and Fair dealing are considered essential to judging the quality of qualitative research (Mays and Pope, 2000).

Elliot, Fischer and Rennie (1999) present, "Evolving guidelines" for assaying quality in qualitative research. They provide a contrast between quantitative and qualitative research expounding on their similarities and differences. Similarities are highlighted as overtly shared characteristics. They also highlight areas that they suggest may be more relevant to qualitative research. These are as follows: Owning one's own perspective, Situating the sample, Grounding in examples, Providing credibility checks, Coherence, Accomplishing general versus specific research tasks and Resonating with the reader (Elliot, Fischer and Rennie, 1999). Quality, as it relates to the present research will be discussed here under the following sub-headings taken from Elliot, et al (1999): Triangulation, Respondent validation, Accounts of methods of data collection and analysis, Attention to negative cases, Fair dealing, Owning one's own perspective, Situating the sample, Grounding in examples, Coherence, Accomplishing general versus specific research tasks and Resonating with the reader.

1. *Triangulation* – The researcher was mindful of the need to compare results from two or more methods of data collection or two or more data sources (Mays and Pope, 2000). To this end the design included both focus groups and semi-structured individual interviews with different "types" of participant (service users, carers and mental health professionals). However, it is acknowledged that potential problems with triangulation in this manner are that it assumes any weakness in one method of collection is compensated for by the other method (Mays and Pope, 2000). Further, that it may have led to a loss of the context-specific aspects of the data (Willig, 2001). Therefore, as described in the present study, triangulation merely ensures comprehensiveness and cannot be taken as a pure test of validity (Mays and Pope, 2000).
2. *Respondent validation* – This involves comparing the investigators account with those of the research participants to ascertain the level of correspondence between

the two (Mays and Pope, 2000). However, such “Credibility checks” have limitations as, for example, the account produced by the researcher will inevitably be different from that of the respondent due to the differing roles in the research process. Many researchers choose not to engage in this process as the informants may not be aware of the processes which have been identified during the analysis (Elliott, Fischer and Rennie, 1999). This is the position the present investigator has taken.

3. *Accounts of methods of data collection and analysis* – The researcher was aware that an account of the process of data collection and analysis was important (Mays and Pope, 2000). The researcher was mindful of producing comprehensive accounts of why phenomena had been labelled and categorised in particular ways. The researcher’s memos were also provided to clearly demonstrate the “*integration of theory*” and the rationale behind this (Henwood and Pidgeon, 1992). The “*abbreviated version*” of Grounded Theory was used to work with the original data only to produce a systematic representation of the participants’ accounts and an understanding of the barriers to accessing CBT and FIs for service users with medication non-responsive schizophrenia/schizoaffective disorder and their carers (Willig, 2001). Utilising the “*abbreviated version*” of Grounded Theory resulted in the *theoretical sensitivity* – where the researcher moves from a descriptive to an analytic level of interaction with the data being amenable to implementation solely within the texts that were being analysed (Willig, 2001).
4. *Attention to negative cases* – The researcher was aware of the importance of giving attention to negative cases (Mays and Pope, 2000) as a part of the process of *theoretical sampling* which involves collecting further data in view of categories that have been constructed during earlier phases of analysis (Willig, 2001). During analysis the researcher searched for elements in the data that appeared to contradict the emerging theory and discussed these in the Results section. Indeed, one of the main categories which was constructed considered overcoming barriers that participants discussed. The analyst carefully reviewed the data for discrepancies, overstatements and/or errors and made use of supervision with a clinical psychologist experienced in the field of mental health

in order to consider any corrections or elaboration to the original analysis (Elliott, Fischer and Rennie, 1999). Using the “abbreviated version” of Grounded Theory resulted in the process of *theoretical saturation* – where the researcher continues to sample and code the data until no new categories can be identified and negative case analysis being amenable only to implementation within the texts that were being analysed (Willig, 2001). Resources limited the researcher’s intention to achieve theoretical saturation by continuing data collection.

5. *Fair dealing* (Mays and Pope, 2000) The researcher was mindful of the need to ensure that the design of the study incorporated a range of perspectives enabling the views of a number of “types” of participant to be gathered. The types included in the investigation were: service users, carers and mental health professionals.
6. *Owning one’s own perspective* – Throughout the process of conducting the research the researcher was aware of her theoretical orientation, personal anticipations relating to relevant experiences and beliefs about the topic of research (refer to the section on Reflexivity above for a more in-depth discussion of the potential impact of the researcher on the research). The disclosure of the researcher’s own perspective on the research is designed to facilitate the reader’s consideration of possible alternatives (Elliott, Fischer and Rennie, 1999).
7. *Situating the sample* – The demographic characteristics of the research participants and their relevant life circumstances have been described in order to assist the reader with considering the range of people and situations for whom the findings might be relevant (Elliott, Fischer and Rennie, 1999).
8. *Grounding in examples* – Examples of the data taken from transcripts of both focus groups and individual interviews have been provided in Chapter 3 and in Appendix 5 in order to illustrate the analytical procedures used and the process of theory development (Elliott, Fischer and Rennie, 1999; Willig, 2001). The notion of “Grounding in examples” is similar to Henwood and Pidgeon’s (1992) term “*The importance of fit*” which is concerned with ensuring that analytic categories generated by the researcher fit the data well.

9. *Coherence* – Largely through supervision with an experienced clinical psychologist in the field of mental health steps were taken to enable the research to be represented in a way that achieved coherence and integration whilst maintaining nuances in the data (Elliott, Fischer and Rennie, 1999).
  
10. *Accomplishing general versus specific research tasks* – The aim of this investigation was to explore in-depth accounts of a small number of participants, rather than make more general and less detailed claims. This limits the ability to generalise from the findings of the research to other dissimilar persons or contexts. Theoretical sampling was used to ensure that an initial sample was drawn “to include as many of the possible factors that might affect variability” (Mays and Pope, 2000 p.52). The provision of demographic data and other information about participants’ lives enables readers and researchers to determine the extent to which the present findings might be considered similar to other groups or individuals. Research is considered “relevant” when it “adds to knowledge or increases the confidence with which existing knowledge is regarded.” (Mays and Pope, 2000 p.52). Their concept of relevance also incorporates a judgement on the extent to which findings can be generalised beyond the context they were constructed in.
  
11. *Resonating with the reader* – The researcher was mindful of presenting the material in such a way that the reader could judge it to accurately represent an account of the subject matter. The researcher aimed to clarify and expand the reader’s understanding and appreciation of the research area. This was assisted by discussion with both the research and field supervisors the former had extensive knowledge of the methods used and the latter, experience in the field of mental health (Elliott, Fischer and Rennie, 1999).

In sum, the above has listed eleven goals of qualitative research and stated how the present study was carried out with the intention of meeting those goals. The notion of quality is returned to in Chapter 4 as part of the discussion section.

Taken together, the criteria for assessing quality in qualitative research and the researchers epistemological stance clarify the status of the text and the position of the researcher.

## *2.6 Measures*

### *2.6.1 The Demographic Questionnaire*

Socio-demographic characteristics of participants were collated using a standard form. Participants were instructed to circle the answers that applied to them or fill out the dotted line. The goal of this demographic questionnaire was to enable the researcher to be alert to how the process of data collection and analysis were influenced by the demographic characteristics of the participants (see Tables 1, 3 and 5 above).

The pre-inclusion questionnaire that was administered was the Relative Assessment Interview (Barrowclough and Tarrier, 1997). For carers of service users the Relative Assessment Interview was used to establish contact time the carer had with the service user, the service user's diagnosis, current problems/symptoms and the length of the service user's illness. According to Barrowclough and Tarrier (1997) the Relative Assessment Interview has five main content areas, it can be used to obtain information about a patient's psychiatric history, symptoms and behaviours and social and role functioning. The five content areas are as follows: 1) Background information; 2) Psychiatric History of the Patient; 3) Current Problems/Symptoms; 4) Relationships Between Family Members and; 5) General Information About the Relative. For the purposes of the present study only questions relating to the first 3 content areas were posed. Following on from pre-inclusion questionnaires, focus groups for all participants and semi-structured interviews for one participant from each 'type' were conducted to constitute a form of triangulation.

There were five focus groups. The counselling psychologist (LG) moderated the focus groups with assistance from a trainee clinical psychologist or a student nurse (details of questions used in focus groups are provided in Appendix 4). The counselling psychologist also conducted 3 semi-structured interviews (see Appendix 2 for the interview schedule). The interview questions were constructed based on the researcher's previous knowledge of some of the issues facing service users and carers

regarding accessing psychosocial treatments. These measures were chosen in order to elicit views of people using mental health services with schizophrenia/schizoaffective disorder, carers of current service users with schizophrenia/schizoaffective disorder and mental health professionals.

### *2.7 Procedure*

Pre-inclusion, case notes of service users selected from two in-patient settings and from a community rehabilitation team were checked to ensure that they met DSM IV criteria for schizophrenia or schizoaffective disorder. Service users were given information sheets with details about the study. Carers were assessed prior to involvement in focus groups, this took place at a Social Action Centre (the focus group and semi-structured interview were carried out using the same venue). It was not considered necessary to ensure that the focus group moderator was blind to the carers' responses, as this information was not used in any systematic way for the purposes of the research. Therefore, it is unlikely the responses influenced the carer focus group/interview in any way. One month after receiving information sheets participants were approached and asked to give their written informed consent to participate in the study. All participants took part voluntarily. The interview and focus groups with service users took place either on an in-patient unit or at a community team base within the service they were using. Both the focus groups and the interview with the mental health professionals took place at their base site.

#### *2.7.1 Focus Groups*

According to Wilkinson (1998) a focus group is a discussion among selected participants regarding a specific topic. For all participants in the present study the procedure involved a 45-minute discussion where the moderator encouraged the focus group members to interact and extend each other's comments (Wilkinson, 1998). The questions were based on the following topic area of barriers to accessing cognitive behavioural therapy and family interventions for service users and their carers. This included questions on the treatments available for people using the NHS Trust who suffer from symptoms of schizophrenia/schizoaffective disorder, what prevents people suffering from such and their carers having cognitive behavioural therapy and/or family interventions in the NHS Trust and how participants might change things to

improve access to these types of treatment/intervention for these groups of people if they had the opportunity to do so (see Appendix 4 for a list of questions). Focus group schedules were designed to be economical in gaining the views of a number of people and provide opinions in the context of interaction. Participants sat in a circle in comfortable surroundings to help establish a facilitating atmosphere (Kitzinger, 1995). All focus groups were video recorded and transcribed with all names and identifiers removed from the transcript to ensure confidentiality and anonymity. Participants were given the opportunity to discuss any questions or concerns about the study itself or the topic area and a right to request a copy of the final report.

Statement given to participants in focus groups:

“Thank you for volunteering to be a part of this research into Barriers to Accessing Cognitive Behavioural Therapy and Family Interventions for Service Users suffering from symptoms of schizophrenia/schizoaffective disorder of the NHS Trust and Their Carers. For those of you who do not know me my name is LG.

As you can see we are recording this session. We are here today to explore views on barriers to accessing two psychosocial treatments: cognitive behavioural therapy and family interventions in the NHS Trust. We will have a group discussion for 45 minutes. You are free to withdraw at anytime during the discussion. There are five questions in all. After the first question, feel free to discuss your answers among yourselves. Do you have any questions?”

#### 2.7.2 Semi-structured Interviews

After focus groups with each type of participant had been conducted, an interviewee was selected to be involved in a 30-minute semi-structured interview. The interview schedule was based on the topic area of barriers to accessing cognitive behavioural therapy and family interventions for service users and their carers. This included questions about: Awareness, Skill Mix, Culture and Ethnicity, Religion, Age, Gender, Sexuality, Resources, Mental Health Diagnosis and Physical Disability (see Appendix 2 for the interview schedule). All interviews were audio-taped and transcribed with all names and identifiers removed from the transcript to ensure confidentiality and anonymity. As with the focus group discussions, participants were given the

opportunity to discuss any questions or concerns about the study itself or the topic area.

Statement given to participants in semi-structured interviews:

“Thank you for volunteering to be part of this research. As you may recall from the focus group you were involved in the aim of this study is explore views on barriers to accessing two psychosocial treatments: cognitive behavioural therapy and family interventions, in the NHS Trust. You have been chosen to be involved in a 30-minute individual interview. Do you have any questions?”

### *2.8 Data Collection and Analysis*

This section turns to a consideration of the procedure of data collection and analysis used during this investigation. The rich qualitative data gathered throughout the present study were analysed using a version of grounded theory. According to Willig, (2001) in essence, grounded theory is the progressive identification and integration of categories of meaning from data. In addition, the category identification which is characteristic of grounded theory is distinct from, for example, content analysis. It is acknowledged that it can be difficult to select which aspects of a qualitative study to present in a thesis. However, this study focuses on the key themes that emerged from focus group discussion and semi-structured interviews.

Grounded theory was originally developed by two sociologists Glaser and Strauss (1967) in order to create a method where researchers could move from data to theory so that new theories could emerge (Willig, 2001). It was designed to facilitate the process of discovery or theory generation. The underlying postulate was that these theories were considered to be specific to the context in which they were developed. Category labels are not derived from existing theoretical formulations. In this sense, theories were ‘grounded’ in the data they emerged from and were not dependent on analytical constructs. Theories evolved and were not mutually exclusive. Early versions of grounded theory have been the subject of much revision and refinement. In an attempt to further develop grounded theory, an Objectivist position taken by Strauss and Corbin (1990, 1998) aimed for unbiased data collection as it assumed an

objective external reality (Charmaz, 2000). Providing an alternative to the Objectivist stance, Constructivist grounded theory, “assumes the relativism of multiple social realities, recognises the mutual creation of knowledge by the viewer and the viewed and aims toward interpretative understanding of the participants’ meanings”(Charmaz, 2000 p. 510). Indeed, for the Constructivist in grounded theory an interviewer and interviewee co-construct a reality often with each other as reference points, the researcher’s task is to bring to the fore the subjectively determined essential qualities of that encounter. Further, in grounded theory analysis the data are “reconstructions” of experience, not the original experience itself (Charmaz, 2000 p. 514). Grounded theory is both the process of category identification and integration and its product. It provides guidelines about how to identify categories and how to make links between them. It also provides an explanatory framework with which to understand the phenomenon under investigation. However Charmaz (2000) cautions that new procedures using prescriptive analytic steps divert the researcher from the data and result in poorly integrated theoretical frameworks.

Coding is the process by which categories are identified. Charmaz (2000) demonstrated how codes might be kept “active” e.g. “considering the relationship” so they could then provide insight into what people were doing (see Appendix 5 for a Record of theory development). In their early stages codes are often descriptive. Labels are attached to discrete instances of phenomena. Ideally, category labels should be *in vivo* - utilise words and phrases used by the participants. Categories indicate the grouping of instances (of events, of processes, of occurrences) that share central features or characteristics. Descriptive categories inform higher level analytic categories. Both are based on the identification of relations of similarity and difference. Yet, they function at different levels of abstraction. Categories evolve throughout the research process.

Different versions of Grounded Theory subscribe to different coding paradigms. These include: Constant comparative analysis; Negative case analysis; Theoretical sensitivity; Theoretical sampling; Theoretical saturation; and Memo writing. Constant comparative analysis – having identified a common feature that unites instances of a phenomenon, the researcher needs to re-focus on differences within a category in

order to be able to identify any emerging subcategories. In this way, the full complexity and diversity of the data can be recognised. Dimensionalising takes place during initial coding 'to recognise and account for complexity beyond one meaning of a property or phenomenon' dimensions may lie on a continuum (Charmaz, p.516). Negative case analysis ensures that the researcher continues to develop the emerging theory in light of the evidence, where there are instances that do not fit. This allows the researcher to qualify and elaborate the emerging theory (Willig, 2001). The constant comparative method of grounded theory means: a) comparing different people (such as their views, situations, actions, accounts and experiences); b) comparing data from the same individuals with themselves at different points in time; c) comparing incident with incident; d) comparing data with category and; e) comparing category with other categories (Charmaz, 2000 p. 515). Axial coding is aimed at making connections between a category and its subcategories. These include conditions that give rise to the category, its context, the social interactions through which it is handled and its consequences (Charmaz, 2000 p.516).

Theoretical sensitivity moves the researcher from a descriptive to an analytic level. The researcher interacts with the data, asks questions of the data which are in turn modified by the answers. The therapist does this by making comparisons and looking for opposites. This may involve going back to the source to collect further data. Theoretical sampling involves the collection of further data in the light of categories that have emerged from earlier stages of data analysis. This means checking emerging theory against reality by sampling incidents that may challenge or elaborate its developing claims. Data collection and analysis ideally continues until theoretical saturation has been achieved. Memo-writing can help the researcher to define leads for collecting data both for further initial coding and later theoretical sampling (see Appendix 5 for an example of a memo from the present study). Through memo writing, it is possible to elaborate processes, assumptions and actions that are subsumed under our codes (Charmaz, 2000). It functions to focus the researcher on the analyses. Grounded theorists transport raw data into their memos in order to maintain those connections and examine them directly. Memo writing also helps researchers to: a) grapple with ideas about the data; b) to set an analytic course; c) to refine categories; d) to define the relationships among various categories and; e) to

gain a sense of confidence and competence in their ability to analyse data (Charmaz, 2000: see Appendix 5 for the Data Analysis Process used during the present investigation and a presentation of the Memos depicting the record of theory development).

### *2.9 Reflexivity*

Grounded theory is a dynamic analytic process whereby the researcher and the research construct the collected data and findings (Mays and Pope, 2000). The resulting account is a joint product of the reflection of both participant and researcher. Mays and Pope (2000) argue that it is important to be sensitive to the role of the researcher's "prior assumptions and experience" and provide an account of the researcher's impact. The data remain open to being re-interpreted using other research methods such as discourse analysis where a researcher might examine how the role of language has impacted the construction of the social reality of barriers to psychosocial interventions. This section is an attempt to own my perspective and balance the influence of my standpoint (Elliott, Fischer and Rennie, 1999). Firstly, I provide a brief summary of my demographics. This is as follows: I am a 29-year-old black British, Christian, female, heterosexual from a working class background now employed as a chartered counselling psychologist. I have worked in the NHS in London for five years with people who suffer from psychosis and their carers. I have no physical disability or mental health diagnosis. It is also essential to present in greater detail my reasons for investigating this topic and my own theoretical stance.

#### 2.9.1 Additional Reasons for the Investigation

According to the Commission for Health Improvement (2004) Clinical Governance is, "the system of steps and procedures adopted by the NHS to ensure that patients receive the highest possible quality of care, ensuring high standards, safety and improvement in patient services". In June 2000 I became Clinical Governance link worker for the clinical team I was part of. My role as link worker evolved and became focused on the following:

- ◆ Ensuring that members of the clinical team incorporated clinical governance into their everyday thinking and practice

- ◆ Taking a lead on actively developing, evaluating and reviewing local and Trust-wide standards
- ◆ Encouraging audit activity within the clinical team with a view to sharing good practice with others outside of the clinical team
- ◆ Taking a lead on locally co-ordinating pilot studies of innovations developed within the Trust

The aim was to do this by:

- ◆ Meeting regularly with a sub-group of members from the clinical team and service users to discuss current issues
- ◆ Bringing information from local audit presentations to meetings with members of the clinical team
- ◆ Liaison with other clinical governance link workers at bi-monthly borough-wide meetings and annual Trust-wide meetings
- ◆ Taking a lead on presenting information pertinent to clinical governance at team meetings

I attended a clinical governance conference organised by the Trust in 2001 where there was service user and carer representation. During the event, those in attendance were given the opportunity to vote for a topic that they wished to be pursued in terms of quality assurance from a service user/carer perspective. Talking treatments for people with psychosis was a topic that it was agreed would be useful to examine further. This was part of the impetus for conducting research in the area of barriers to accessing psychosocial treatments.

### 2.9.2 Theoretical Stance

As stated above, I am a counselling psychologist specialising in the treatment of people with psychosis. Lectures on 'Working with Psychosis' formed part of my undergraduate and post-graduate training leading to qualification as a counselling psychologist. Given the emergence of evidence demonstrating the effectiveness of psychosocial interventions such as CBT and FIs with psychosis I developed an interest

in those approaches. Since that time I have also engaged in post-qualification training in psychosocial interventions with psychosis. I was aware of my perspective that psychosocial models can be useful when working with people with persistent and distressing symptoms of psychosis, whilst carrying out the data analysis I remained alert to my stance. This belief did not prevent me hearing what service users, carers and mental health professionals stated were barriers to accessing those types of treatment. It was essential to me that an understanding of the perspectives of the participants was achieved. The process of supervision further increased my sensitivity to the impact of my own perceptions. Prior to conducting the research I anticipated that mental health professionals would argue that there was insufficient training in psychosocial approaches and that this was a barrier to service users and carers accessing those types of treatment. I also predicted that service users and carers might not be aware of how the treatments could be of use, which would be a potential barrier. During the research process I particularly found the overcoming barriers that emerged thought provoking. My initial assumption was that participants would find it challenging to find solutions to some of the difficulties they were discussing. However, given the opportunity to express perspectives on overcoming barriers participants demonstrated noteworthy creativity. For example, service users suggested that it was essential to ensure that the staffing was representative of the cultural diversity in the community. They also argued that an alternative to barriers would be to have service-user-tutors support other service users with accessing the interventions. Although I would usually take a collaborative approach to clinical work with service users, the process of conducting this research has challenged me to be more receptive to service user views on how the services being offered might be improved.

Having arranged the focus groups by 'type' of participant (i.e. service user, carer and mental health professional) one would expect that although the focus group questions were the same, the emerging themes would differ. However, it was considered essential as far as possible to confine each group to one type of participant in order to reduce the heterogeneity of the group and facilitate expression.

Being clinically trained and equipped with skills for facilitating group work and individual interviews I found that I was able to use those skills where appropriate to facilitate focus group and individual interview discussion. I used empathy, unconditional positive regard, warmth and respect to encourage participants to share their ideas. I offered a genuine interest in what participants were saying and I was congruent in my approach. I used the techniques of reflecting, summarising and paraphrasing informed by systemic theory. I also took a neutral stance making use of circularity, joining and mirroring where appropriate (see Chapter 1 for discussion regarding theoretical frameworks).

## **Chapter 3: Results**

### *3.1 Introduction*

The following is a consideration of interrelated categories of meaning constructed relative to the wealth of data on barriers to accessing psychosocial interventions Cognitive Behaviour Therapy and Family Interventions for service users with medication non-responsive schizophrenia/schizoaffective disorder and their carers. It should be noted that other categories were elicited that did not directly address the research questions and are therefore not presented. The research questions are listed as follows:

- D. How might services users, carers and mental health professionals perceive & account for the barriers that service users and carers face in accessing CBT and family interventions?
- E. How do views of service users/carers and mental health professionals differ? If they converge, at what points does this happen?
- F. How might answers to these questions be used to inform psychology practice/research?

A “core category” represents a topic that was constructed in relation to concepts/processes used frequently by participants that appeared to have shared meaning. The term “sub-category” has been used to refer to concepts subordinate to and subsumed by core categories (a “main sub-category” subsumes other sub-categories), which also relate to notions developed from the coding of the source data (see Appendix 5 for an example of a memo – which provide a record of theory development). The term “dimension” is used to describe the continua of descriptions relating to sub-categories. The researcher focused on 6 core categories which are presented in sections 3.2.1 – 3.2.6 namely: Dominance of the medical model; Mistrust; Service hostility; Perception of services as ‘elitist’; Information and Communication; and Overcoming barriers along with their sub-categories and dimensions (see Table 3.1 for core categories and main sub-categories around which participants’ statements about barriers to accessing CBT and FIs for service users and carers were organised). Figure 3.1 is a diagrammatic representation of the core categories of barriers to accessing CBT and FIs for service users and carers that were constructed in relation to focus group discussion and interviews with all participants, along with their main sub-categories and dimensions. It also shows overcoming

barriers. Core categories are in bold type in red boxes with the exception of the core category Overcoming Barriers, which is in a yellow box. Sub-categories are also in red boxes with the exception of the sub-categories for Overcoming Barriers, which are in yellow boxes. Some categories did not emerge within all sets of data.

**Table 3.1 Core- and main sub-categories around which participants' statements about barriers to accessing CBT and FIs for service users and carers were organised**

| <b>Categories</b>                                   | <b>Main Sub-categories</b>  |
|---|---|
| 1. Dominance of the medical model                   | 1.1 Medication and its side effects<br>1.2 Carers' burden<br>1.3 Diagnosis  |
| 2. Mistrust between service users and professionals | 2.1 Relationship between mental health professionals and service users<br>2.2 Timing of psychosocial interventions<br>2.3 Cultural sensitivity  |
| 3. Service hostility                                | 3.1 Exclusive, discriminatory boundaries<br>3.2 Anxieties about psychoses' amenability to treatment<br>3.3 Frustrated efforts<br>3.4 Defining one's role<br>3.5 What is perceived as 'good enough'?<br>3.6 Valuing psychosocial interventions |
| 4. Perception of services as 'elitist'              | 4.1 Needs of the local community<br>4.2 The researcher-clinician divide   |
| 5. Information and communication                    | 5.1 Relaying information<br>5.2 Identifying services<br>5.3 Engagement and acceptability<br>5.4 Carers' expectations<br>5.4 Clash of interests  |
| 6. Overcoming barriers                              | 6.1 Communication<br>6.2 Research, training and supervision<br>6.3 Service development<br>6.4 Valuing cultural diversity<br>6.5 Modes of delivery   |

Therefore, under each category, where appropriate, illustrations are provided for each "type" of participant affording a comparison between groups. Section 3.3 is concerned with examining the main relationships between core categories, the main sub-categories and their dimensions, Figure 3.3. focuses on demonstrating those relationships across four topics namely: Information, Culture, Role expectation and

Identifying needs. Excerpts from the transcript have been used to illustrate theory development. Statements were transcribed verbatim. The transcript is italicized and the following abbreviations have been used to identify the source of the data: SUI = Service user interview, CI = Carer's Interview, MHPI = Mental health professional interview, SUG = Service user group, CG = Carer's group and MHPG = Mental health professional's group, X is used to preserve the anonymity of the participants. A number is added to each abbreviation to identify the speaker, for example, 'SUG1' would indicate that service user 1 was speaking within the group. Speakers are numbered in order of appearance within the text below.

### 3.2 Presentation of the Core Categories

#### 3.2.1 Core Category Dominance of the medical model

Narratives portrayed the category of the Dominance of the medical model as a barrier to service users and their carers accessing CBT and FI. This category was used to organise discussion around medication and its side effects, carers' burden and diagnosis. This was so as it emerged that a particular 'domain' within mental health had a status that afforded its 'agenda' more credence than other domains. For example, mental health professionals, the medical model and treatments such as administering medication were viewed as privileged over service users/carers, holistic models and psychosocial treatments. Table 3.2.1.1 shows the core category "Dominance of the medical model", its sub-categories and their dimensions. Below, verbatim excerpts gathered from focus groups with service users, carers and mental health professionals are presented and analysed followed by analysis of extracts of data from the interviewees.

**Table 3.2.1.1 Core Category "Dominance of the medical model, Main Sub-categories and Dimensions**

| <b>Core Category</b>              | <b>Main Sub-categories</b>   | <b>Dimensions</b>                                 |
|-----------------------------------|--|---|
| 1. Dominance of the medical model | 1.1 Medication and its side effects<br>1.2 Carers' burden<br>1.3 Diagnosis | Deadly---bearable<br>High-----low<br>Good-----bad |

### 3.2.1.1 Medication and its side effects

Service users described a sense that medication was administered without a concerted effort to empower recipients to make decisions about their treatment. They discussed an apparent lack of a 'client-centred' approach. As demonstrated by the transcript, groups discussed how individuals' religious beliefs had been overlooked when considering prescribing and administering medication. There was a strong sense of the "unnatural" qualities of antipsychotic medication. Service users described a lack of collaborative working between themselves and mental health professionals. The clinician was positioned as writing out a prescription and giving it to the service user:

*'its just foolishness, medication's foolishness I weren't born with medication, I didn't see no part in the Bible or Qu'ran man taking medication.'* (SUG1)

*'They write a prescription, they give out the prescription, this and that medication, this and that injection, this and that tablet.'* (SUG1)

*'I don't think most of the drugs is working.'* (SUG1)

A result of an approach where the medical model was dominant was to produce a sense of powerlessness and abject hopelessness in service users. This particularly related to the expression of an expectation (fuelled by health professionals, carers and other service users) that there was no option save the need for service users to continue to take medication for the duration of their lives. There was discussion around the "offer" of medication that became imperative on refusal. The assumption was that mental health professionals possessed knowledge that was privileged over the experience of service users. The power imbalance between health professionals and service users was at its height when this occurred. The lack of hope for the future was deemed a barrier to accessing psychosocial interventions. There was a sense of the impossibility of the situation as though any attempts to recover would be in vain. There was also a sense that people became "stable" rather than "recovering" or becoming "well". Service users described a notion of "normality" and what it was like to "live a normal life":

*'If they offer it and you don't take it they restrain you and give you an injection.'* (SUG2)

*'The person said they live a normal life on medication but the problem is once you start on the medication is it very rare that you can actually come off of it.'*

(SUG2)

# Barriers to Accessing CBT and FIs

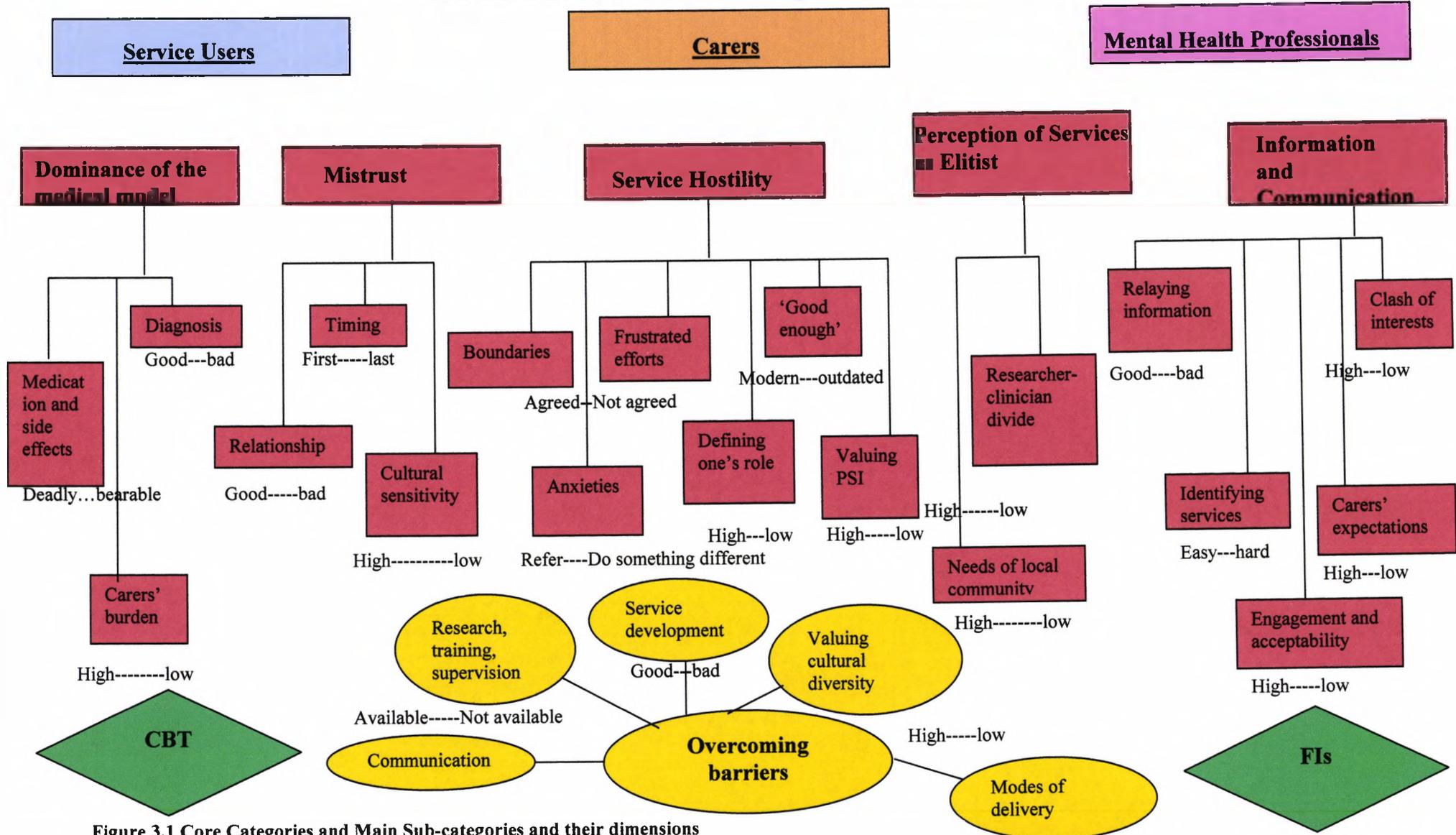


Figure 3.1 Core Categories and Main Sub-categories and their dimensions

*'You have to take them everyday'* (SUG2)

*'if we don't keep taking the medication we'll relapse ... so it's a vicious cycle'*  
(SUG3)

*'I'm stable someone keeps saying that you may relapse if you stop taking your medication'* (SUG2)

A particular concern for service users was the side effects of medication. They stated that its most debilitating consequences were that it affected the reproductive organs and even caused fatalities. The service users painted an alarming picture where people on antipsychotic medication lost control of their body movements, suffered from slurred speech and became incapacitated due to the side effects of the medication. Service users went on to suggest that once taking antipsychotic medication people would then become conspicuous by, for example, increased sweating, which would then contribute to a public perception of people suffering from mental illness leading to a detrimental effect on the self-esteem of the service user. There was a sense that on occasion, perhaps as a result of negligence, service users had been given the wrong dose of medication and this sense was associated with a deep fear of the same highlighting the powerlessness of the service user. Service users argued that one should be told the side effects of medication so that one would be in a position to make choices about what one wanted to take:

*'... {medication} stops your period straight away, dries up the sperm, medicine that brings death'* (SUG4)

*'... {side effects} some people get tired easily, some people foam at the mouth, some people shake, some people get beer gut'* (SUG1)

*'The only thing that backfires is the side effects.'* (SUG5)

Although some service users suggested that there were beneficial effects of medication others described a sense of physical treatments seemingly having little relationship with their experience. They suggested that they had not been listened to, therefore any attempts made to supply them with a service were misguided:

*'Oh yes, they think they have known the person, that is why they all phone and say that no, she doesn't do like that she does like this. You know, they think they know. So at this point I don't even know who knows better, whether it's the medical team or the family (laughs).'* (SUG4)

Service users described a fear of medication and its side effects. They suggested that this contributed to a sense of powerlessness, hopelessness and bewilderment about care for service users.

### 3.2.1.2 Carers' burden

Carers discussed the burden of the expectation that relatives and friends would be able to ensure that service users took their medication. They also mentioned the challenge of facing the consequences of a service user's relapse. There was a sense of helplessness and anxiety about what was realistically achievable and what was an unfair demand that prevented carers engaging with psychosocial interventions:

*'...not that I would expect a CPN to ensure that the user is actually taking his medication but how can the CPN or the psychiatrist expect the carer to deal with that because the carer is the one whose got to take the impact of the user not so this is what, you know there are some real concerns and issues about that.'* (CG1)

*'And you're talking about the medication well, nobody can make them take it that's the fight you know.'* (CG2)

*'...when I informed the CPN that my son is not taking his medication he insists he is taking his medication I know if I inform him he should listen to me as you said just now. They don't listen.'* (CG1)

It was suggested that mental health professionals did not listen to carers neither did they view their needs respectfully. Further, the mental health system and/or the general public appeared to be perpetuating the view that management of medication was of greater importance than psychosocial interventions. This was described as having the effect of heightening carer's anxieties about their competencies in medication management. Perhaps attempting to engage carers on this level reinforced the power imbalance between them and mental health professionals rather than providing a counterbalance to this perception. Carers mentioned that being a carer was burdensome as one had a "responsibility" and no "authority" to influence a care package:

*'You see it's really carers has a responsibility without authority.'* (CG3)

They spoke about the tension between having a sense of helplessness and the duty to act. They were contrasting training and experience and discussing the advantages and disadvantages of both:

*'I mean it would be difficult for you as a carer who has not had any training to try and relate that and there's nothing to say that that experience that you've identified is going to be in line with their textbook training anyway.'* (CG3)

Therefore, it was argued that issues that were significant to carers were devalued by mental health professionals clearly this was viewed as a barrier to engagement with services, thus could also be construed as a barrier to psychosocial interventions.

### 3.2.1.3 Diagnosis

Mental health professionals described a sense that people with a diagnosis of schizophrenia/schizoaffective disorder felt disadvantaged/disempowered. The suggestion was that often, as a result of their acquired poor social status, in response to labels they had been given, people within this group had little opportunity to impact change in the services they received:

*'There's also, I mean if you look at people with schizophrenia they're quite disempowered ...they're not the people who are going to be vocalising and organising themselves in groups to challenge and look for services as other more powerful groups would be'* (MHPG1)

*'If they were a powerful group lobbying parliament now I wonder how much treatment they would be getting. But they're not are they?'* (MHPG1)

Some mental health professionals expressed a sense of the limitations of the medical model in its historical form – dismissing it as reductionist. Mental health professionals stated that the medical model was not a panacea:

*'...they're going to need more than medication.'* (MHPG1)

Overall, whilst discussing issues related to the core category of the Dominance of the medical model between service users, carers and mental health professionals, service users appeared to be particularly concerned with medication and its side effects.

When medication and its side effects were described as “deadly” it was suggested that this was a major block to empowering service users to engage in a process where they

were negotiating with mental health professionals about aspects of their care. This was related to a lack of knowledge and a sense of hopelessness (see Fig. 3.2.1.1).

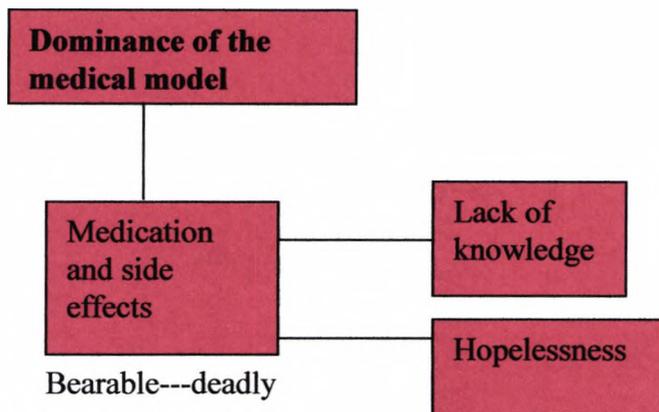


Fig. 3.2.1.1 Dominance of the medical model in the service users' account

It emerged that carers' concerns seemed to be the burden carers experienced which was related to helplessness, anxiety, a perceived lack of respect from mental health professionals, which was linked with the notions of responsibility and authority (see Fig. 3.2.1.2). When carers' burden was expressed as being "high" e.g. in relation to expectations that they would "manage medication" the suggestion was that attempting to engage carers on this level reinforced the power imbalance between them and mental health professionals – highlighting the dominance of the medical model.

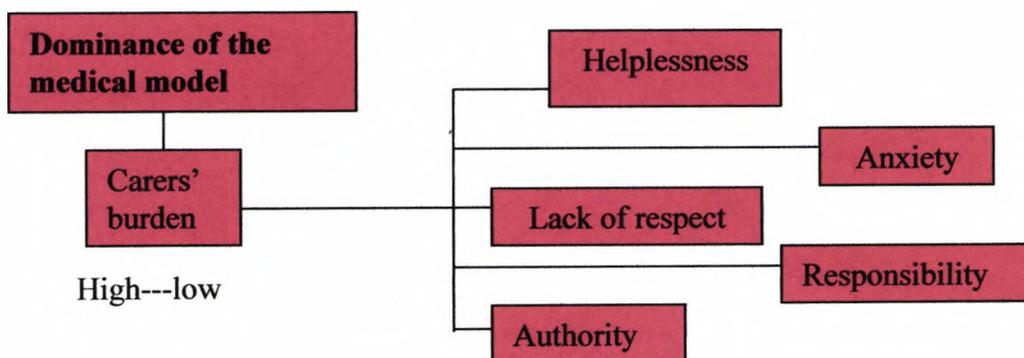


Fig. 3.2.1.2 Dominance of the medical model in the carers' account

In contrast, mental health professionals spoke mostly about the effects of diagnosis. They appeared to be suggesting that having a diagnosis could be problematic for service users as, for them, it seemed to mean that service users were labelled and disadvantaged (see Fig. 3.2.1.3).

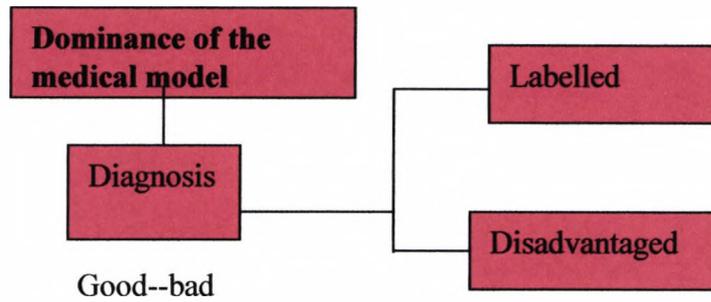


Fig. 3.2.1.3 Dominance of the medical model in the mental health professionals' account

In summary, the dominance of the medical model with its inherent assumption that medication was the most important (if not only) treatment meant that service users and carers felt that mental health professionals were in a more powerful position than themselves. The resulting sense of helplessness made it difficult for service users and carers to express their needs. This created a barrier to considering alternatives such as talking therapies.

### 3.2.2 Core Category 'Mistrust' Between Service Users and Professionals

Once again, issues around medication were prominent for service users. However, here the focus of discussion was on relationships between mental health professionals and services users, timing of psychosocial interventions, and cultural sensitivity. The term 'mistrust' was intended to capture a sense of the expectation that others would intentionally harm one. Participants in the study discussed this as a barrier to service users their carers accessing CBT and FI. Table 3.2.2.1 shows the core category "Mistrust", its main sub-categories and their dimensions. Data from focus groups with each type of participant (service user, carer and mental health professional) are presented and analysed followed by data from two of the interviewees.

**Table 3.2.2.1 Core Category “Mistrust”, Main Sub-categories and Dimensions**

| Core Category                                       | Main Sub-categories  | Dimensions     |
|---|--|----------------|
| 2. Mistrust between service users and professionals | 2.4 Relationship between mental health professionals and service users | Good-----bad   |
|   | 2.5 Timing of psychosocial Interventions                               | First-----last |
|   | 2.3 Cultural sensitivity   | High-----low   |

### 3.2.2.1 Relationship between mental health professionals and service users

Service users spoke of a poor alliance between the mental health professional involved in a service user’s care and the service user, which could be regarded a barrier to accessing CBT and FIs. Service users described a sense of “Mistrust” between service users and mental health professionals. They reported on the plight of service users with a desire to share their experience, which was hampered by their lack of confidence in the professionals involved in their care. Service users’ discussion suggested that the doctor-patient relationship had potential to interfere with a service user’s ability to focus on a consideration about treatments other than medication:

*‘There’s not enough of a relationship between the patient and the doctor. All the doctor does is come in once a week to prescribe medi pills to you while the staff are noting everything down. He won’t know any better will he, unless he’s taking the stuff himself’ (SUG6)*

*‘And then with the people we are talking to too we should have their confidence. That is very important.’ (SUG4)*

*‘...we do not want to be open, we hold it in inside and then the medicine comes on top and then you are suppressed like that. Whereas the real problem is still inside them.’ (SUG4)*

### 3.2.2.2 Timing of psychosocial interventions

Service users were clear in communicating that talking therapies such as CBT and FIs had face validity. They mentioned that they “broke down” because they were stressed. They discussed what appeared to be a service user’s aim of, making sense of his/her experience, which did not fit particularly well at times with being given medication and may have fit better with the timely provision of talking therapies. In addition to

the discussion about medication and its side effects in the “3.2.1 Dominance of the medical model” core category, the discussion about it described here focused on the mistrust that it induced between service users and mental health professionals. In particular, service users suggested that the primacy of their experience with medication had created the sense of mistrust they described between themselves and health professionals:

*‘The fact is that we break down because of stress and then I think that we should have more of counselling first of all.’ (SUG4)*

*‘This medicine is mashing everybody all up...Once the medicine starts coming we start with big tummy, we start developing beards and other things like that so there should be more of talking therapy.’ (SUG4)*

*‘I’d rather be on cognitive therapy before I take any medication’ (SUG6)*

There was a sense that mental health professionals were trying to do what they thought was best although this was often at odds with what service users believed was important. It was suggested that people were not treated as individuals instead they were given medication as a first line of treatment:

*‘Now I think that is why first of all they opt out for the medicine first. You know because they are thinking that ...the best way to cure you is to start with the medication’ (SUG4)*

They described a sense of mental health professionals using force and invasive treatment as a first option rather than humanely conversing with people:

*‘It would be better if someone come talk to you more than just hold you down, ram you, you know.’ (SUG1)*

Service users described a sense of only those who have used the system as being in a position to appreciate what it was like from this angle:

*‘You wouldn’t know unless you’ve been through the system’ (SUG2)*

Service users discussed a feeling that the NHS was attempting to rectify some of its past “wrongs” by carefully assessing needs and providing what is required in terms of psychosocial interventions:

*‘That’s why the NHS comes clear now. They support you. You know they give you, if you need a psychologist, if you need a care worker you are supported...’ (SUG4)*

Service users described the mental health system as a form of social control depriving people of their civil liberties:

*“it’s a load of rubbish because the peoples not sick. They just need their freedom.” (SUG1)*

Other service users described a perception that in order to be referred for psychosocial interventions one would need to have issues that one was able to articulate using the therapist’s language and they discussed this as a barrier to accessing psychosocial interventions as treatments for schizophrenia/schizoaffective disorder:

*‘Therapy is all very well but you’ve got to have something that fits, something to say.’ (SUG6)*

### 3.2.2.3 Cultural sensitivity

Service users stated that a lack of cultural sensitivity was a hindrance to engagement with people from diverse cultural backgrounds. They expressed that it was necessary to work with service users and carers from within their belief systems with a commitment to valuing diversity in order help them feel able to express themselves without fear of judgement:

*‘You know ...another thing is we should look at the cultural background. Yes you know when we are coming here, we all come from different cultural background. Maybe like for instance, if they are able to understand what we our beliefs or what we believe in maybe that would help us to be open to say I feel somebody cast a spell on me. You know so as you encourage the person.’ (SUG4)*

Service users suggested that mental health professionals should take into account the experiences of minority ethnic groups in Western culture. The notion was that for some people from minority ethnic groups there were a series of adverse events such as contact with the police and the judicial system and a sense of division in the community which contributed to suspicions regarding contact with mental health services:

*‘black people at the time who else was in the country ethnic minority things like that. Things like you had problems with the police picking you up if you were off school and all that suss law, them thing running you couldn’t go here, couldn’t go there because of racism things like that.’ (SUG1)*

During the mental health professional interview it was stated that the historical perspective was that service users from diverse ethnic groups were not engaged in psychosocial interventions as a result of racial discrimination and low socio-economic status:

*'I was talking thinking about people from different ethnic groups because I did, I do feel that, ... in like sort of early years and sort of like late eighties, I felt that this kind of therapy was for sort of white middle-class people who were extremely articulate and I actually saw evidence of that in psychological assessments when people would say well they haven't got the educational ability to actually take part in this because they couldn't they weren't articulate enough and so.'* (MHPI2)

Service users stated that it was difficult for doctors to understand the views of service users as they operated only according to "proven medicine" and did not appear to be in a position to entertain alternatives to this. They discussed implications this had for engagement with service users particularly those from diverse cultural backgrounds:

*'Then another thing is I do not know if the NHS can incorporate the alternative medicine. Because we've often heard before that they have things you know hypnotism, herbs, like herbal treatment. I think because they are not proven medicine. So that is why it is difficult for the doctor to understand because we do feel this problem of people casting spells on us and curses and things like that so.'* (SUG4)

Service users suggested that in general, clinicians were limited in their understanding in terms of considering treatments which may have greater validity for people from minority ethnic groups than some of the traditional medical treatments used in Western culture. Once people had been engaged in a culturally congruent manner they might then be offered psychosocial interventions. A carer felt that cultural diversity was a challenging issue. A sense of mistrust was identified that was particularly significant for people from diverse ethnic groups. Psychosocial interventions too needed to demonstrate a commitment to being culturally appropriate and acceptable to ethnic minority service users and carers. The carer suggested that Western ideology regarding mental health alienated ethnic minority service users. Further, there was the implication that the cultural diversity of therapists should be representative of minority ethnic groups within the communities they served:

*'Perhaps because yes I think it's a difficult area but I think perhaps it is because they don't always want to engage with white Europeans who would probably be in the main you know.'* (CI1)

The interview with a mental health professional yielded data suggesting that giving appropriate consideration to addressing diverse cultural needs was a mammoth task for mental health services. The mental health professional described a sense that there was discriminatory practice in terms of how people were referred for CBT or FIs based on their ethnicity and a lack of self-referrals among people for whom English was not a first language. This also resonated with the notion that minority ethnic groups were underrepresented by the people offering psychosocial interventions as suggested during the mental health professional's interview:

*'I think, I mean it's a very big question that, I think that people from various different ethnic backgrounds, its very hard to be very general about various different ethnic backgrounds but I would say perhaps people from black and Asian families or people who don't have English as a first language would be, wouldn't be the first people to be referred or refer themselves I would have thought because of the difficulties in communication but I, the reason why I mentioned about black and Asian people is that I think they're quite often discriminated against in terms of anyone even thinking about referring people so I think that's something which I'm sure they're underrepresented in the psychology services both as psychologists and also as people who service users.'* (MHPI2)

In sum, once again the lack of a client-centred approach meant that service users were unable to build trusting therapeutic alliances with mental health professionals. The lack of congruence for service users and carers led to a sense of Mistrust – here defined as the expectation that others would intentionally harm one. Service user discussion highlighted this as a multifaceted, complex issue for service users (see Fig. 3.2.2.1). They suggested that inadequate relationships could be a barrier to accessing CBT and FIs for service users and carers. They indicated that for service users the sharing of experience could be limited in response to Mistrust. They also spoke about the timing of the offer of psychosocial interventions suggesting that other treatments such as medication which, had usually been offered in the initial stages of engagement

with mental health services, did not always feel like the most helpful methods of treatment to begin with. This was a particular concern as medication was described as inhumane and a form of social control. Finally, in terms of Mistrust, service users spoke about the importance of cultural sensitivity – suggesting that listening to narratives about cultural identity from service users would encourage the service user to “be open” and engage in psychosocial interventions. They commented that it was essential for the mental health service to make an appropriate response to the historically established divisions between ethnic groups. It became clear that in essence, service users felt that there was not enough consideration given to building therapeutic relationships. Once again, medication was considered the primary treatment at the expense of psychosocial interventions and attempts to provide a culturally sensitive service, this led to Mistrust.

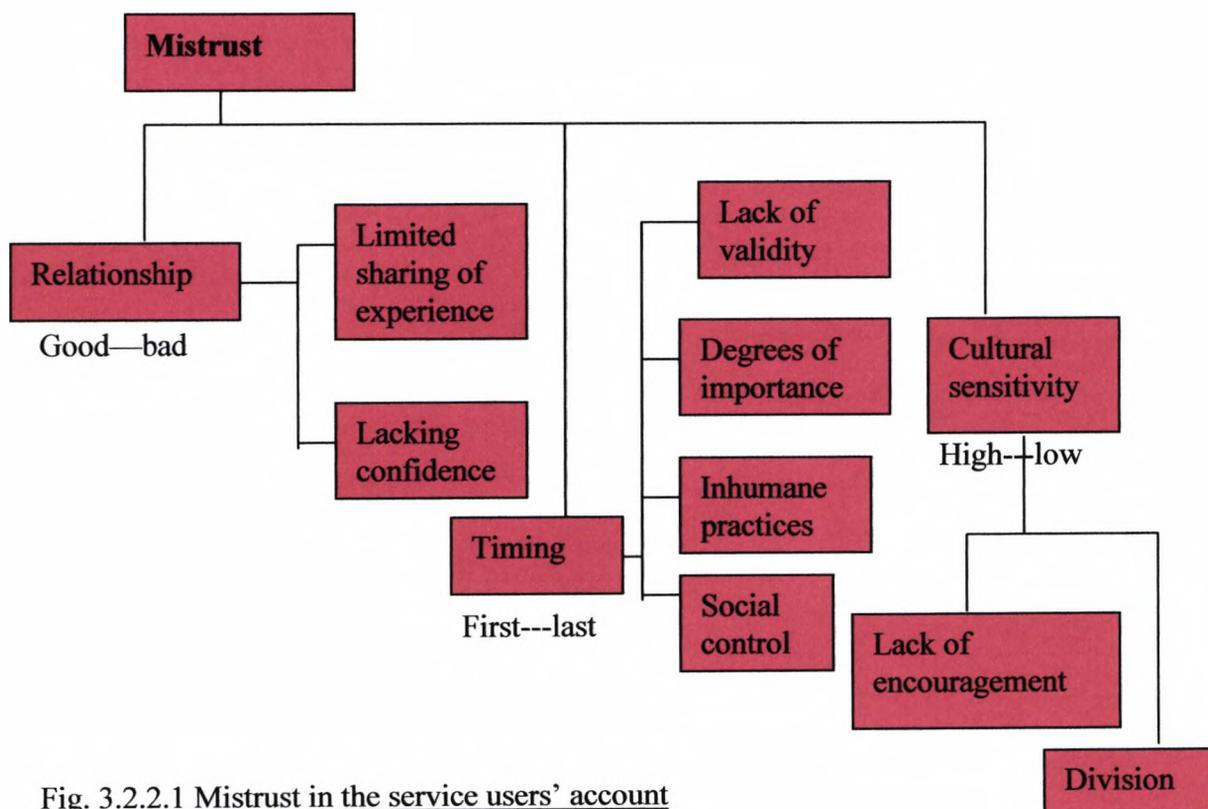


Fig. 3.2.2.1 Mistrust in the service users’ account

Carers also described a lack of cultural sensitivity as a barrier (see Fig. 3.2.2.2). They highlighted the important factors to consider as being the acceptability and representativeness of services in terms of how they might appear to people from minority ethnic groups.

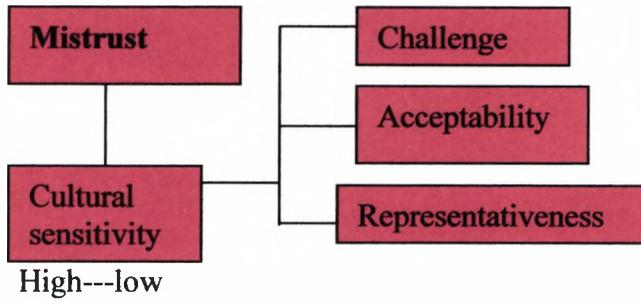


Fig. 3.2.2.2 Mistrust in the carers' account

Finally, mental health professionals spoke about a relationship between cultural sensitivity and mistrust between service users, carers and mental health professionals (see Fig. 3.2.2.3). The main factors they offered were: racial discrimination; low socio-economic status; first language differences and the representativeness of mental health professionals in terms of reflecting the cultural diversity of the local population.

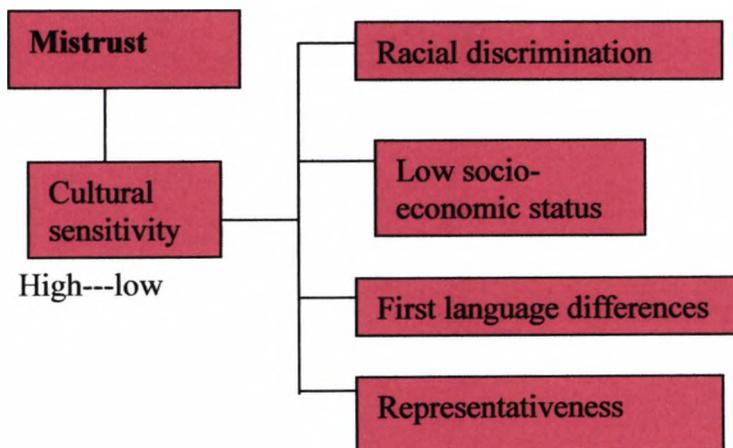


Fig. 3.2.2.3 Mistrust in the mental health professionals' account

### 3.2.3 Core Category Service hostility

A core category surrounded the notion of the hostile environment of the mental health service. This was viewed as a barrier to accessing CBT and FIs.

**Table 3.2.3.1 Core Category “Service Hostility”, Main Sub-categories and Dimensions**

| <b>Core Category</b> | <b>Main Sub-categories</b>                              | <b>Dimensions</b>                |
|----------------------|---|----------------------------------|
| 3. Service hostility | 3.1 Exclusive, discriminatory boundaries                | N/A                              |
|                      | 3.1 Anxieties about psychoses’ amenability to treatment | Refer-----Do something different |
|                      | 3.3 Frustrated efforts                                  | Agreed-----Not agreed            |
|                      | 3.4 Defining one’s role                                 | High-----Low                     |
|                      | 3.5 What is perceived as ‘good enough’?                 | Modern----Outdated               |
|                      | 3.2 Valuing psychosocial interventions                  | High-----Low                     |

This category was used to organise discussion around exclusive, discriminatory boundaries, anxieties about psychoses’ amenability to treatment, frustrated efforts, defining one’s role, what is perceived as a ‘good enough’ service? and valuing psychosocial interventions. Table 3.2.3.1 shows the core category “Service hostility”, its main sub-categories and their dimensions. Data from focus groups with each type of participant (mental health professional, service user and carer) are presented and analysed interspersed with data from the interviewees.

### *3.2.3.1 Exclusive, discriminatory boundaries*

Whilst defining the limits of the service, mental health professionals commented that there were particular constraints on how provision was made to people from minority ethnic groups. There was a sense that “mainstream” psychological therapy services (those offered by the NHS) were over-stretched; this afforded them little opportunity to develop so that they were culturally sensitive. The perception was that there were service users from particular ethnic groups suffering from persistent and distressing symptoms of schizophrenia/schizoaffective disorder and their carers that were faced with a greater number of barriers to accessing psychosocial interventions which made the service appear particularly hostile toward these groups:

*‘I think they’re quite limited...And I think it’s more so specially to ethnic minorities.’ (MHPI2)*

The theme of cultural sensitivity was also discussed under the core category “3.2.2 Mistrust”.

### 3.2.3.2 Anxieties about psychoses' amenability to treatment

It was evident that some participants were of the opinion that staff were anxious and bewildered about whether psychosis could be treated. Staff discussed waiting lists for the psychosocial interventions and debated about what should happen whilst people were waiting for services which were oversubscribed. They suggested that services offering CBT and FIs as part of research trials appeared distant from the routine provisions offered by teams on a daily basis and as such, were difficult for mental health professionals to identify with. There was a sense that some people were only given access to treatment for research purposes. It was argued that people allocated to waiting list control groups lost interest in therapy whilst waiting. They also suggested that there was discrimination against people with a diagnosis of schizophrenia in terms of whether a service user was able to access CBT and FIs in comparison with people who presented to mental health services and were given other diagnoses:

*'But I've been to ward conferences and ward rounds where they say, 'well the waiting lists for that particular service is so long' and it's like 'well then go on put that name on the list then'. And they say well there's no point because it's such a long list. You know there seems to be some sort of block on because there might be a waiting list...' (MHPG2)*

*'Even for the most needy one when we refer here it takes ages how about the psychotic one? They will never be seen at all.'* (MHPG3)

*'Lots of places won't do CBT if people have got active psychosis. Will they?'* (MHPG4)

They stated that waiting lists for CBT offered by specialist units were problematic. This resulted in teams relying on their limited knowledge of interventions and practising without specific guidance:

*'I think ...within this community mental health team if there are people who need CBT and obviously if there's long waiting lists and whatever, we do that in our own way even though we're not qualified to do it. We do various interventions.'* (MHPG5)

It was also indicated that it appeared highly unlikely that carers would be able to access psychosocial interventions due to constraints on resources which led to lengthy waiting times:

*'But if you are talking about CBT treatment for schizophrenia sufferers and their carers, so if its just CB treatment if the patients themselves can wait up to two years to access that, what about the carers? Do we have we ever referred a carer for CBT?' (MHPG6)*

However during the mental health professional interview it was stated that:

*'Even though there might be a waiting list of eighteen months I'd rather in eighteen months time be able to say well now we're ready to see this person. Rather than say oh we'll have to wait another eighteen months. (MHPI2)'*

Hence, it was deemed possible by some to circumnavigate the obstacles.

It was also stated during the mental health professional interview that people were not being referred for CBT and FIs as a result of long waiting lists. One view was that participants were anxious about the amenability of psychosis to treatment of this kind. There was a sense of the importance of staff 'doing something' even if one felt out of one's depth in terms of offering a service to someone suffering from distressing symptoms:

*'...there's such a long waiting list that we'll do it ourselves or we'll do something else but I do think we're under definitely under referring people.'*  
(MHPI2)

The implication was that mental health professionals were anxious about whether psychosis could be treated using psychosocial interventions and experienced the service as hostile as it did not seem to facilitate the implementation of these types of treatment.

### *3.2.3.3 Frustrated efforts*

Mental health professionals discussed having trained staff without protected time to carry out interventions as a barrier to accessing CBT and FI for service users and their carers:

*'We've got actually got two nurses trained in its called the (X) course its like CBT/Family Interventions combined. But its difficult for them to do that kind of work because of the time it takes when they've got large caseloads of ...thirty-nine to forty patients. And Family Interventions do take time because you've got to set it up, you've got to work with the family and its got to be regular and ongoing so in a way we've got the sort of embryo of resources but*

*it can't develop.* (MHPG7)

*'But really, ideally, we should be offering it here. I mean we should be using CBT here but we haven't got enough people trained and even the ones are trained haven't got the time to be able to offer it to everyone that needs it....'*

(MHPG8)

The service was perceived as hostile here as it frustrated the good intentions of mental health professionals to provide CBT and FIs rather than facilitating the use of psychosocial interventions.

#### 3.2.3.4 Defining one's role

The mental health professional interviewee mentioned that mental health professionals acted as though psychologists were the only discipline to offer psychosocial interventions rather than this role being one other members of the multidisciplinary team might see themselves adopting:

*'I think they think of it as something that is happening that is sort of provided by psychology and is something that people have to be referred to rather than using themselves as a resource'* (MHPI2)

During the carer's interview it was stated that there was an expectation that the most likely people to be in a position to offer CBT and FIs would be community mental health nurses and counsellors:

*'The most likely to well I would only imagine maybe a CPN, maybe probably a counsellor'* (CI1)

Mental health professional focus group discussion led to the suggestion that there were a number of factors it was necessary to take account of within a particular team prior to applying for continuing professional development (CPD). Those factors included a consideration of staffing levels and budgets:

*'...when you apply it depends on the staffing levels it depends lots of things doesn't it?'* (MHPG5)

*'So we haven't the resource.'* (MHPG9)

*'...there's so many internal constraints whether it's financial or whatever...'*  
(MHPG1)

*'It's also about being able to release staff to go off and do training.'*

(MHPG10)

During the mental health professional interview it was stated that the lack of CBT training was a particular concern. The member of staff described feeling as though one's understanding of CBT was limited. It was also suggested that attending a workshop on CBT did not equate with feeling one had been equipped to apply one's knowledge of the theory in a competent manner. The notion was that there would need to be ongoing revision of techniques and the addition of adequate quality assurance procedures (a category which is discussed further under the category 3.2.6 "Overcoming barriers"):

*'I have very little experience of understanding CBT though I've actually attended a workshop but it was so long ago. I think it was something that was sadly lacking in my own training really.'* (MHPI2)

In focus groups mental health professionals discussed the tension of having skills to carry out psychosocial interventions without this activity being perceived as part of one's role and valued by others. There was a sense that people who were trained in psychosocial interventions could not for example work effectively as "a nurse" (using their nursing training) whilst using their additional specialist skills. Mental health professionals argued that the decision about how people operated within teams was one made by the service, which meant that it was ultimately beyond the control of the individual with the specialist skills. There were also internal team pressures dictating how other team members ought to function. Mental health professionals described a sense that there was a lack of flexibility in career progression where continuing professional development (CPD) was not viewed as a valued activity since newly acquired skills were not then put into practice. There was a sense of lacking faith in line managers/team leaders/service managers in terms of their ability to create opportunities for people to engage in professional development and contribute to service development. The notion was that there were limited possibilities in terms of applying specialist knowledge and skills to the work environment. People with specialised CBT and FIs competencies would move on to find positions where these attributes were valued. This then limited the range of therapies that were offered by the service:

*'I think its whether ...they work in their role as the nurse or they work in their role as a counsellor I don't think they're allowed to be, you've got to be one or the other really. I don't know whether ...the opportunities come about that*

*they can sort of stay within this sort of work but you know bring forward their counselling stuff.'* (MHPG11)

*'I just think that there's lack of resources and lack of availability of people being trained and not just in CBT but lots of different therapies so we've got a range of I think we've got a range of skills but we haven't got a range of different therapies that we offer.'* (MHPG10)

Mental health professionals described a time when it was believed that people working for Social Services would not have access to such training in psychosocial interventions. However, following the integration of Health and Social Services, staff indicated that it would have been helpful if people had been better prepared for the requirements of working within a multidisciplinary team by having had access to relevant training:

*'...I know that from Social Services point of view we were asked about a year or two ago about training CBT and that was so much in the Health Service domain and that actually was considered that we wouldn't be having that access to that training. Here we are working in a community mental health team'* (MHPG2)

### 3.2.3.5 What is perceived as a 'good enough' service?

There was a sense that the preliminary design of services no longer met the expressed needs of the population. Staff indicated that the lack of therapists offering CBT and FIs was a breach in the construction of the multidisciplinary team where the required skill mix was not adequately reflected in the content of job descriptions. This was judged to be an oversight on behalf of those who were responsible for commissioning services. They suggested that a team was not a multidisciplinary team if it did not include people who were qualified to offer- and supported in providing psychosocial interventions (see also category 3.2.6 "Overcoming barriers"). There was a sense of the 'falsehood' of making a claim that the service was equipped to meet the needs of the population when in fact it was felt that it was completely unprepared to do so.

There was a strong feeling of the inadequacies of the team:

*'I mean, we're supposed to be a multidisciplinary team and I think the higher management at the top or wherever it comes from needs to realise that we're very short on a multidisciplinary team 'cause we don't have CBT, we don't have family worker family therapists right.'* (MHPG5)

*'...one psychologist between all these people and one psychiatrist. Someone's not planned it properly.'* (MHPG5)

It was suggested that referrers did not refer people with medication-non-responsive schizophrenia/schizoaffective disorder for psychosocial interventions based on the rationale that they would be too unwell to engage in therapy. Staff were of the opinion that the level of distress experienced by service users was inversely related to their suitability for CBT/FIs. There was a sense that therapists engaged in therapy with the aim of demonstrating their effectiveness rather than targeting interventions toward people with the greatest levels of distress and social disability this made the service appear hostile:

*'I mean I would imagine as well that they would be seen that the therapy would be seen as less effective when someone's got symptoms. So I would have thought they'd be lower down as a priority. I don't know but that is what I would assume. It wouldn't stop me referring but I would have thought that.'* (MHPG12)

*'Well if somebody's got the symptoms of schizophrenia and it was would they the therapy be not as effective... They'll be not a priority'* (MHPG12)

### 3.2.3.6 Valuing psychosocial interventions

Mental health professionals suggested that prior to the development of CBT for psychosis there was an argument that talking treatments were ineffective with schizophrenia spectrum disorders. They spoke about a resistance to considering a CBT approach toward working with people with psychosis. However, it was stated that this view had begun a radical shift since models of CBT were able to demonstrate their utility in terms of helping people cope with distressing psychotic symptoms (see also category 3.2.5 "Information and Communication"):

*'It's very good thing I think cognitive behavioural therapy to help psychotic patients. I mean the last few years it has proven it is effectively but previously*

*it was said that its not really helpful people with psychotic patient its not going to help at all. I think more recently they say it does help people coping with the symptoms.* ' (MHPG3)

Mental health professionals, suggesting they were aware of the finite resources of the NHS, discussed the cost-effectiveness of talking therapy and argued that medication was more cost-effective than individual psychological therapies. There was a sense of the period of time required to deliver psychosocial interventions being responsible for what was described as lack of cost-effectiveness:

*'I was just thinking its quite all labour intensive. If you think, therapy is a very intensive spell for one person I don't think that its groups but its quite labour intensive and that's where most of the finance in the NHS is getting put on labour. So you can see why treatment like medication is a very cheap alternative. Trouble is its only the it has I think it well they shouldn't underestimate it actually because without advances you wouldn't be able to think about CBT if people weren't treated with medication you know with schizophrenia that is.'* (MHPG1)

The service user interview also revealed a sense that psychosocial interventions were not cost effective:

*'I should think I should think it's quite expensive to run'* (SUI7)

Mental health professionals and service users conceded that it might be more cost effective to deliver CBT in a group format (see also category 3.2.6 "Overcoming barriers"). Mental health professionals stated that if one were aiming to provide CBT to everyone in the country with a diagnosis of schizophrenia the NHS would not realistically be able to support such a notion:

*'Well if you look at it realistically the amount of people with schizophrenia in this country people wouldn't be able to offer that much therapy.'* (MHPG1)

The mental health professional interviewee stated that changes in terms of the provision of talking therapies that had occurred in primary care were valuable steps in the direction towards providing CBT and FIs for service users and their carers:

*'...each surgery is supposed to have its own primary counselling service so I would have thought that's a very good start'* (MHPI2)

In summary, this category was used to organise discussion around the exclusive discriminatory boundaries, anxieties about psychoses amenability to treatment, frustrated efforts, defining one's role, what is perceived as a good enough service and valuing psychosocial interventions. Service users discussed this category in terms of how the volume of information on the efficacy of CBT and FIs was low and psychosocial interventions were considered expensive (see Fig. 3.2.3.1). Thus the perception was that the service was hostile to the implementation of psychosocial interventions.

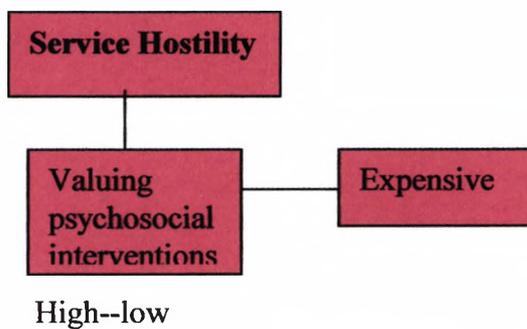


Fig. 3.2.3.1 Service hostility in the service users' account

Carers suggested that role clarity for mental health professionals was a barrier as nurses and counsellors were tentatively described as the people whom carers might expect to be in a position to offer psychosocial interventions (see Fig. 3.2.3.2). Difficulty in defining ones role was born out of a hostile service that did not prioritise psychosocial interventions. For mental health professionals the issues about the hostility of the service showed greater complexity (see Fig. 3.2.3.3).

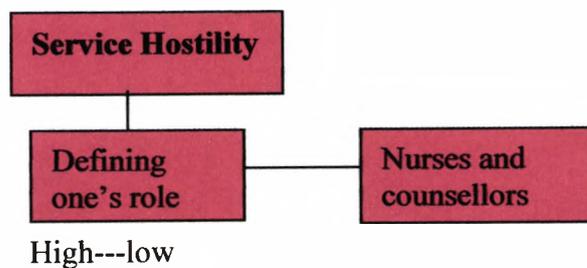


Fig. 3.2.3.2 Service hostility in the carers' account

Similar to service users, mental health professionals discussed the cost of the interventions as an important factor. Mental health professionals also concurred with carers that role clarity was an important issue to consider as a barrier to CBT and FIs. However, for mental health professionals the theme of defining one's role organised discussion about staffing levels, seeing oneself as a resource, managing budgets, feeling incompetent, team function and staff turnover. It was also asserted that when role clarity for mental health professionals was low, this was the most difficult condition under which to attempt to offer CBT and FIs.

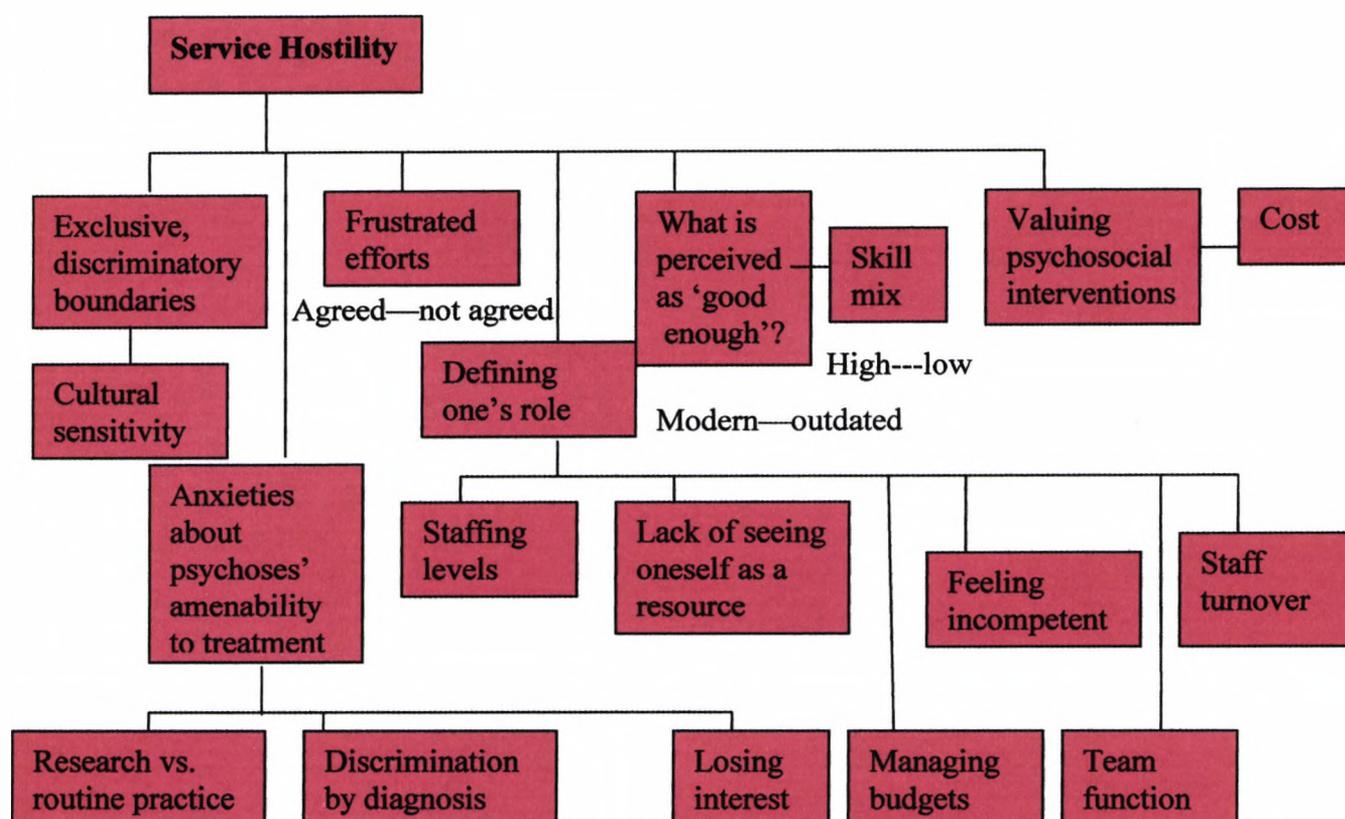


Fig. 3.2.3.3 Service hostility in the mental health professionals' account

In addition to those areas discussed by service users and carers, mental health professionals spoke about the cultural sensitivity of the service and anxieties about psychoses amenability to treatment. For example, they suggested that long waiting lists resulted in people who had been referred for psychosocial interventions losing interest in those types of treatment over time. Further, mental health professionals noted that there appeared to be a discrepancy between research and routine practice. They also suggested that there was discrimination by diagnosis in terms of who was

able to receive CBT and FIs. Lastly, mental health professionals indicated that outdated service designs were problematic, as they did not support the skill mix required for delivering CBT and FIs effectively. Once again, the suggestion was that services were designed to provide medication and social support rather than evidence-based psychosocial interventions.

### 3.2.4 Core Category Perception of Services as ‘Elitist’

A core category was constructed which centered on a perception of services offering psychosocial interventions CBT and FIs as “elitist”. This category was used to organise discussion around, the importance of meeting the needs apparent within each locality and the sense that there was a divide between research and clinical practice. Table 3.2.4.1 shows the core category “Perception of Services as Elitist”, its main sub-categories and their dimensions. This is followed by analysis of excerpts of the views provided by mental health professionals gathered from focus group data.

**Table 3.2.4.1 Core Category “Perception of Services as Elitist”, Main Sub-categories and Dimensions**

| <b>Core Category</b>                   | <b>Main Sub-categories</b>          | <b>Dimensions</b> |
|--|-------------------------------------|-------------------|
| 4. Perception of services as ‘elitist’ | 4.2 Needs of the local Community    | High-----Low      |
|  | 4.3 The researcher-clinician divide | High-----Low      |

#### 3.2.4.1 Needs of the local community

Mental health professionals spoke about the importance of meeting the needs of service users in each directorate within the Trust. They highlighted the excellent reputation of particular services. The suggestion was that demand for ‘elitist’ services would be high. However, some speakers commented that the centralised locality of specialist/national services was a barrier to service users and their carers residing in other directorates. Perhaps what was not said was that mental health professionals working in other areas might feel undervalued. Having areas where a number of people were seen as possessing ‘specialist skills’ had the potential to lead to staff in surrounding areas feeling de-skilled. Mental health professionals expressed a sense

that government objectives were to offer appropriate services to people within the communities wherein they had their base:

*'It makes it so elitist then 'cause that's where the 'Centre of Excellence' and all that kind of its got all of those kind of connotations hasn't it? And so it takes people away from the community which is not what we're being told is the Department of Health guidelines and local services and all that so actually flies in the face of that really so.'* (MHPG2)

Mental health professionals discussed the notion of a 'postcode lottery' of access to interventions to treat schizophrenia and schizoaffective disorder within the Trust.

They expressed concern about inequalities in terms of treatment availability.

*'I think depending on what part of the Trust as a user that you are in is the quality of care that you'll get.'* (MHPG5)

*'I think, yes, some parts of our Trust have a, I don't think we're all equal. I think some people are ahead with sort of their treatments, some of us behind.'* (MHPG11)

They discussed a potential challenge for service users in accessing services providing CBT and FIs being the distance that they would be required to travel. Further, there were comments to the effect that therapists who did not travel to people's homes might prevent service users and carers obtaining access to psychosocial interventions. There was an indication of the necessity to consider the physical health of potential service users in terms of how it affected their ability to travel to therapy sessions. In addition, the mental health professional interviewee suggested that people who experience symptoms of schizophrenia/schizoaffective disorder might find it difficult to travel great distances to novel settings for treatment:

*'I don't suppose too many therapists go out to people's homes but it might be that people are sort of home stuck at home and can't get out because of physical health problems.'* (MHPI2)

*'Well if someone has symptoms as well I mean they're paranoid as it is going locally they don't even want to come here sometimes and they're used to coming here so they're not going to...'* (MHPI2)

Funding of specialist services was also an issue. There was some suggestion that local services were poorly resourced whilst 'elitist' services were well funded. Others in the focus group justified discrepancies in funding offering the argument that specialist services were allocated resources to meet the demands of their remit as national providers:

*But I think the perception of the (X) it's skewed because of the national provision ... They've got this thing about being very well funded and they've got national funding from directly from the Department. ' (MHPG8)*

To some group members having close links with specialist services was considered an advantage the people using the Trust. Yet, mental health professionals described a necessity of ensuring there was continuity of services, which took account of local needs:

*'... you've got to adapt to our local needs local community. ' (MHPG7)*

In essence, having a local community with unmet needs led to the centralised services offering psychosocial interventions being perceived as elitist which was a barrier to accessing those types of intervention.

#### *3.2.4.2 The researcher-clinician divide*

Mental health professionals also spoke about the sense that the amount of research carried out in and around the Trust that was being devolved into mainstream (widespread) clinical practice was minute. With the reputation of the 'elitist' services came the expectation that there would be a discernible impact on the surrounding mental health provision. However, the actual experience of working in the Trust was unsatisfactory. Hence, the perception that services were 'elitist' was challenged by the lack of dissemination of specialist skills to more remote areas. It seemed research findings were not being translated into developments in services, this was clearly disappointing for group members:

*'...you look down here and you see all this research is with (X), (X) and everything in psychiatry but then my actual experience of working down here I feel its very shoddy comparative to working in (X) where they've got services... ' (MHPG13)*

Participants suggested that the division between researchers and clinicians led to a perception that researchers operated in an elitist service. This was a barrier to accessing psychosocial interventions CBT and FIs for service users and their carers.

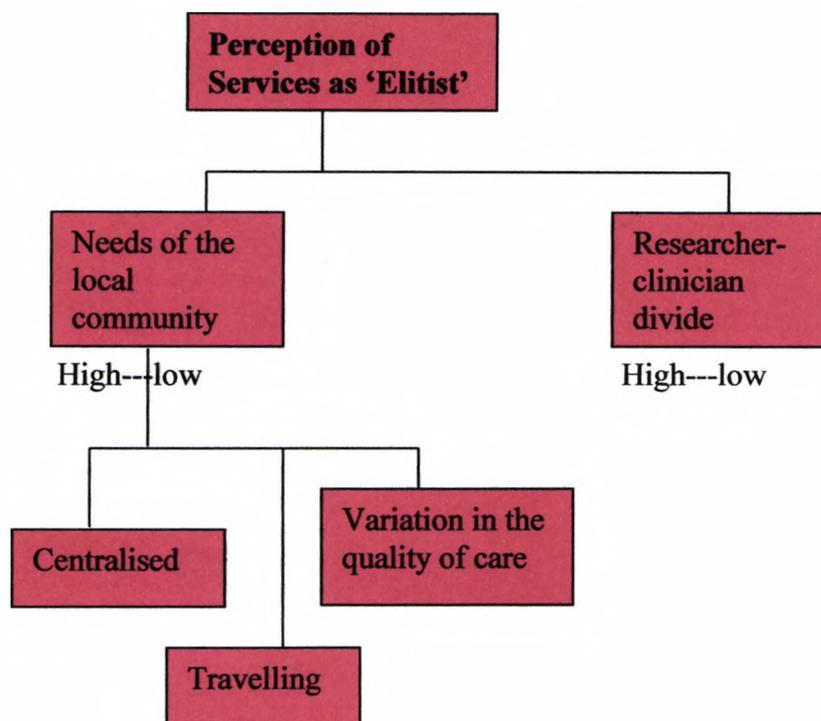


Fig. 3.2.4.1 Perception of the service as 'elitist' in the mental health professionals' account

In summary, mental health professionals discussed the issue of unmet needs faced by certain service areas. For some participants, the location of services providing psychosocial treatments and the disparity in the quality of care were problematic. This led to a perception of services offering psychosocial interventions as elitist. It was also suggested that a division between researchers and clinicians led to a perception of services offering CBT and FIs as elitist. When services offering CBT and FIs were described as “elitist” the potential for unmet needs within the local community was described as “high”. Similarly, when the researcher-clinician divide was “high” these “specialist” services were deemed to be essentially unattainable. The core category Perception of Services as ‘Elitist’ was an area spoken about solely by mental health professionals (see Fig. 3.2.4.1).

### 3.2.5 Core Category Information and Communication

Particular participants in the present investigation spoke about the lack of utilisation of the potentially pivotal role of carers as a barrier to accessing CBT and FIs. This category was used to organise discussion around, relaying information, identifying services, engagement with and the acceptability of services, carers' expectations and clash of interests. Table 3.2.5.1 shows the core category "Information and Communication", its main sub-categories their and dimensions. Data from focus groups with each type of participant (service user, carer and mental health professional) are presented and analysed interspersed with data from the interviewees.

**Table 3.2.5.1 Core Category "Information and Communication", Main Sub-categories and Dimensions**

| Core Category                    | Main Sub-categories              | Dimensions    |
|----------------------------------|----------------------------------|---------------|
| 5. Information and Communication | 5.1 Relaying information         | Good-----Bad  |
|                                  | 5.2 Identifying services         | Easy-----Hard |
|                                  | 5.5 Engagement and acceptability | High-----Low  |
|                                  | 5.6 Carers' expectations         | High-----Low  |
|                                  | 5.5 Clash of interests           | High-----Low  |

#### 3.2.5.1 Relaying Information

Carers emphasised the importance of relaying information, they spoke about a sense that information about CBT and FIs was being withheld from people like themselves. They suggested that ideally there would be a two-way process of giving and receiving information which carers were more involved in. They discussed utilising carers as a channel of information and the position carers have in terms of being able to provide information that may inform the service user's care programme. The indication was that carers' were not being appropriately engaged with the service and their needs were not being met:

*'I was wondering if it might probably be best to disseminate some of the information. '* (CG1)

During the service user interview it was stated that carers could be in a position to communicate information about services to service users:

*'I suppose if perhaps a carer carer might be able to sort of explain a bit more because they know the person well. '* (SUI7)

However, in the carer's interview it was stated that this would be a challenge for carers:

*'I can imagine it would be quite difficult and for those who have carers that might have some understanding for them to relate that understanding to their child who's suffering from mental health it would be extremely difficult.'* (CI1)

### 3.2.5.2 Identifying Services

Carers described a lack of awareness of services:

*'I think it's all an awareness of the services that are there initially because so far I haven't I don't see that any of the services are there, certainly none that we've mentioned with this focus group today.'* (CG1)

They explained that in their view services for people with schizophrenia/schizoaffective disorder were either non-existent or they did not appear "approachable". One carer stated that there was an expectation that carers should actively seek information about services and training on how to work with mental health professionals. However, it was suggested elsewhere that the responsibility and burden of caring for someone with a severe mental illness often made it difficult for carers to get access to information and services (see section 3.7). Carers gave an indication that mental health professionals lacked genuineness, "they may listen", also there was a sense that any carer-involvement was tokenistic. Carers stated that mental health services did not seem accessible and found identifying services a challenge:

*'I probably feel that the primary reason is probably that many of the services don't really seem approachable they're not perceived to be there or maybe they're not there.'* (CG1)

Carers described a sense of isolation which they alluded relatives might feel at times. They suggested that if this were not addressed by services it would be an immense oversight and barrier to developing a working alliance. There was a suggestion of the importance of identifying services at appropriate times to gain an accurate level of support:

*'It's often the case when you need the services its not there that's about the isolation that's about the isolation part of it.'* (CG1)

*'And maybe you know it might sound a bit ludicrous but its knowing that even at any time of the day maybe you ought to be able to pick up the phone and say you know you have a problem' (CG1)*

They spoke about the importance of the carer being supported as they stated that caring could be a difficult task:

*'I mean one of the things that's coming up in my mind is much more focus should be put on on their carer of the individual in supporting that person and perhaps then you now they can at least feel that they are being supported because its no easy task' (CG1)*

Carers stated that there were no guarantees that service users would adopt their viewpoint (see also sub-category 3.2.5.1 "Relaying Information"):

*'Probably request that the main work may need to be done with the carers to ensure that they're aware and hopefully then, hopefully then the patients and then (inaudible) with the carer, not that they would respond of course but it is a way forward' (CG1)*

During the carer interview it was mentioned that it appeared services had not been commissioned with provision to carers in mind, this made it difficult to identify appropriate services:

*'I think you know in many cases carers are are kind of left out really you know of the of the service provision system.' (C11)*

The mental health professional interview revealed a similar view that it was difficult to identify services addressing carers' needs:

*'I think I think all along I've been saying carers are sort of rather kind of neglected group of people really 'cause I do think often we often meet very depressed carers, very sad carers...' (MHPI2)*

The suggestion was not only that mental health professionals might disregard the needs of carers, in addition, that carers themselves at times would discount their own experience or might view accessing psychosocial interventions as a further burden:

*'I just think that perhaps carers would minimise it a little bit and that just wasn't something that they would go for but perhaps need encouragement to go for. But I see perhaps it's a barrier though unless they see actually see the need and sometimes being a carer is exhausting enough without having to*

*think about having a sort of therapy and support. Some people just won't go for it.'* (MHPI2)

### 3.2.5.3 Engagement and acceptability

During focus group discussion carers described how a service user's perspective on his/her experience could lead to help-seeking behaviour which did not include attempting to access mental health services. The suggestion by carers was that mental health services had attempted to make themselves available to potential service users who were making the choice not to engage with them. Carers spoke of people positioned as carers as being of use in the process of engaging potential service users within the mental health service. They described the unique role of the carer in attempting to facilitate engagement with services emphasising that they believed this would lead to a beneficial outcome. The sense was that mental health professionals were able to assist the carer with "supervising" service users once the engagement process had been negotiated:

*'regularly he's in partial if not complete denial of his mental health.'* (CG1)  
*'Personally I think he needs to be a bit more supervised but... being in denial he's not really going to approach anybody who might be in a position to help so thus far I've been the one to try and find avenues that might at least take on his case at least for his own benefit help him to engage'* (CG1)

During focus group discussion carers offered the hypothesis that service users refused to engage with services as a result of the stigma associated with having mental health needs:

*'He refuses to engage with people from mental health at all. He's had social workers, CPN's and various others. He just refuses, ... it's probably the stigma'* (CG1)

Carers spoke about how the stigma attached to mental illness could be a barrier to accessing psychosocial interventions. The suggestion was that some service users might cope with stigma by avoidance of anything associated with mental illness. There was a sense of the impact stigma could have on self-esteem – adding to a service user's perception of him/herself as a failure:

*'He just refuses, ... it's probably the stigma. So and then having been expelled that rose brought up other issues about him coming to terms with that you*

*know feeling I suppose a bit of a failure and you know again you know it's the stigma. (CG1) '*

There was a sense that stigma was an ongoing problem:

*'There's still a lot of stigma attached to it.'* (CG4)

### 3.2.5.4 Carers' Expectations

Mental health professionals discussed carers' knowledge of the mental health system – stating that initially a barrier to accessing CBT and FIs might be that one does not view oneself as a carer:

*'...you don't even think in the beginning you're a carer.'* (MHPG9)

The carer's interview highlighted how carers' needs could be overlooked by the mental health system unless they were particularly assertive:

*'I think you know in many cases carers are are kind of left out really you know of the of the service provision system. You know in many ways, not unless they really are prepared to tackle the issue.'* (CI1)

*'So it just depends on the individual how you know the carer if they're willing to push.'* (CI1)

Mental health professionals suggested that, for carers, a barrier might be the lack of expectation that one would receive a service:

*'Yes so the carers I think there's a lot of despondency amongst carers generally. They're not not always expecting to get a service.'* (MHPI2)

Other mental health professionals suggested that there was a “focus” on provision to carers:

*'I think that's as well it 'cause there is this focus which is really good but there's a focus on carers ...'* (MHPG12)

Carers discussed solutions to the problem of providing the best care package for service users:

*'What we really need is a better relationship between CPN's, consultants, nurses and the carers that is the only thing that will bring I mean a mutual understanding and help the patient.'* (CG2)

Carers suggested that other carers should be proactive about accessing information. Where working alliances between carers and mental health professionals were not formed it was suggested that carers would be partly responsible for this:

*'When it comes now to this doctors and thing now we some parents some carers it might be parents it might be uncle aunt and so on they have got to blame themselves.'* (CG3)

Some carers commented that they were interested in and proactive about gaining knowledge about treatments and services:

*'I'm very interested in gaining knowledge and you cannot gain knowledge by hearsay, you've got to move forward to gain knowledge.'* (CG3)

Participants in the carers' focus group stated that it was the responsibility of carers to approach mental health professionals to gather information about services:

*'You are the person who going to have to approach them to find out this and find out that and then for them'* (CG3)

They suggested that there was a particular method of doing this:

*'Now, there's a method of approach you've got to have the right approach to these people and if you believe that you of yourself don't have that ability then there are places where you can seek that ability to approach these people. You've got to have the right approach with these people.'* (CG3)

### 3.2.5.5 Clash of interests

There was a suggestion that the family members' appraisal of the service user's illness would differ significantly from that of the mental health professional. From service user focus group discussion it became clear that mental health professionals and carers were described as having differing views on how service users should be treated which was communicated as a fundamental "clash of interests". It was suggested that whilst family members might be in a position to consider a variety of remedies for the service user's presentation, mental health professionals would elect to medicate the individual in the initial stages of treatment. The barrier was ineffective attempts to facilitate carers' expression of their viewpoint and ensure that their perspective was valued in order to promote engagement with the service and actively involve carers in the care package of the nominated service user:

*'You know (X) when you have a, when you have a family, that is looking after you when you are ill as well as the medical team there is always a clash of interest. Your family member sees you and thinks he knows what is wrong with you. The medical team are coming they do not know you what they are,*

*all their analysis is based on their experience. Now I think that is why first of all they opt out for the medicine first. You know because they are thinking that while your family think they know you the best way to cure you is to start with the medication because I think your family has known you and been able to stay with you but things are getting worse so I think there is always a clash of interests.’ (SUG4)*

Service users stated that some people suffering from mental health problems might be isolated and that this would make things more difficult for them:

*‘Some people that get ill ain’t got a family it’s harder for them.’ (SUG5)*

Mental health professionals postulated that there were groups of service users without carers who were unable to access services for this reason (see also category 3.2.3

“Service Hostility”):

*‘...and some services that you can’t access unless that person has a carer so you’ve got somebody who’s more vulnerable because they haven’t got a carer and you can’t get services. And I think that, that’s a real worry for me is that if you’re on your own, then surely you’re more vulnerable than somebody who’s got a carer.... (MHPG12)’*

Mental health professionals described a problematic mental health system whereby people who have relatives who make complaints receive innovative treatments whereas those without do not (see also category 3.2.3 “Service hostility”):

*‘I mean its only those that are empowered a lot of our (inaudible) they’ve got parents then some of them I see them challenge often what’s being presented and say what about these things aren’t they available? They’ve read up and check with other organisations see what other treatments are possible therapies whatever. And those are the people that will more likely get some services because they will challenge their consultants on the team, they will question, criticise, they will maybe write and complain and so that’s the problem with the system isn’t it?’ (MHPG1)*

Mental health professionals discussed the notion that within the mental health Trust there was a lack of consistency regarding the dissemination of information:

*'It feels like a few people hold that information and the rest everybody else doesn't at all...'* (MHPG13)

There was some discussion about how CBT and FIs services were advertised so that carers and service users were aware of them:

*'Who publicises it? Who publicises it for the carers to actually know? I mean how would a carer actually know that that exists, how would anybody know it exists?'* (MHPG9)

*'...unless they have undergone a carer's assessment with someone who knows about these services then perhaps they may not have come across it at all'* (MHP12)

*'That's the problem you see, if we don't tell what services are available or aren't sure about imagine being a user they're even less (inaudible) I mean you accept what you're given don't you?'* (MHPG1)

Communication regarding services was viewed as inexpensive:

*'It doesn't take a lot of money though does it to communicate what services we have in the Trust it doesn't'* (MHPG13)

Others argued that access to information about services offering psychosocial interventions for schizophrenia/schizoaffective disorder was possible via the Trust's Intranet:

*'I think there's better access we've got CCS for information and like with the Intranet I've found useful...'* (MHPG12)

This category was used to organise discussion around, relaying information, identifying services, engagement with and the acceptability of services, carers' expectations and clash of interests. This was discussed by service users in terms of a focus on relaying information and the importance of carers being in a position to explain information about psychosocial interventions to service users (see Fig. 3.2.5.1). Service users also stated that a barrier in terms of Information and Communication was a perceived clash of interests between carers and mental health professionals, which meant that carers' expression was limited. Service users argued that when there was a perceived "high" clash of interests between carers and mental health professionals this was a barrier to accessing CBT and FIs.

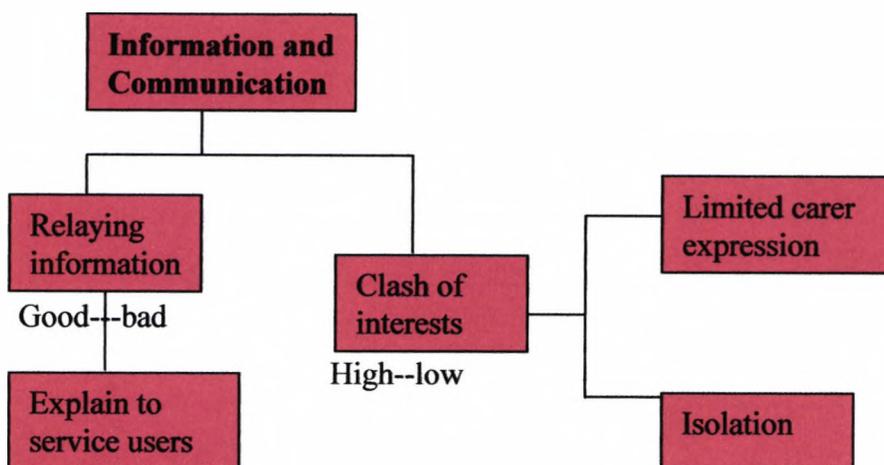


Fig. 3.2.5.1 Information and Communication in the service users' account

In contrast, carers identified barriers across the other four main sub-categories of the core category Information and Communication. Evidently, this category brought together a number of particularly complex issues for carers that highlighted many barriers to accessing CBT and FIs (see Fig. 3.2.5.2). It was asserted that when relaying information was viewed as, “ineffective” carers were unable to facilitate the process of service users engaging with CBT and FIs. Identifying services was described as a barrier by carers. They discussed a lack of awareness of services offering CBT and FIs. There was also some discussion about carers being personally affected by the process of caring which encompassed a sense of carrying responsibility, burden and guilt in association with one’s role as a carer and how this might prevent them from coming to access psychosocial interventions. It was suggested that services were “unapproachable” which had the effect of leaving carers feeling isolated and lacking support. When identifying services was difficult, carers’ sense of feeling isolated was described as being at its peak. Carers discussed the engagement with- and acceptability of services as a barrier to psychosocial interventions where denial and stigma were described as essential elements of such which were not adequately addressed.

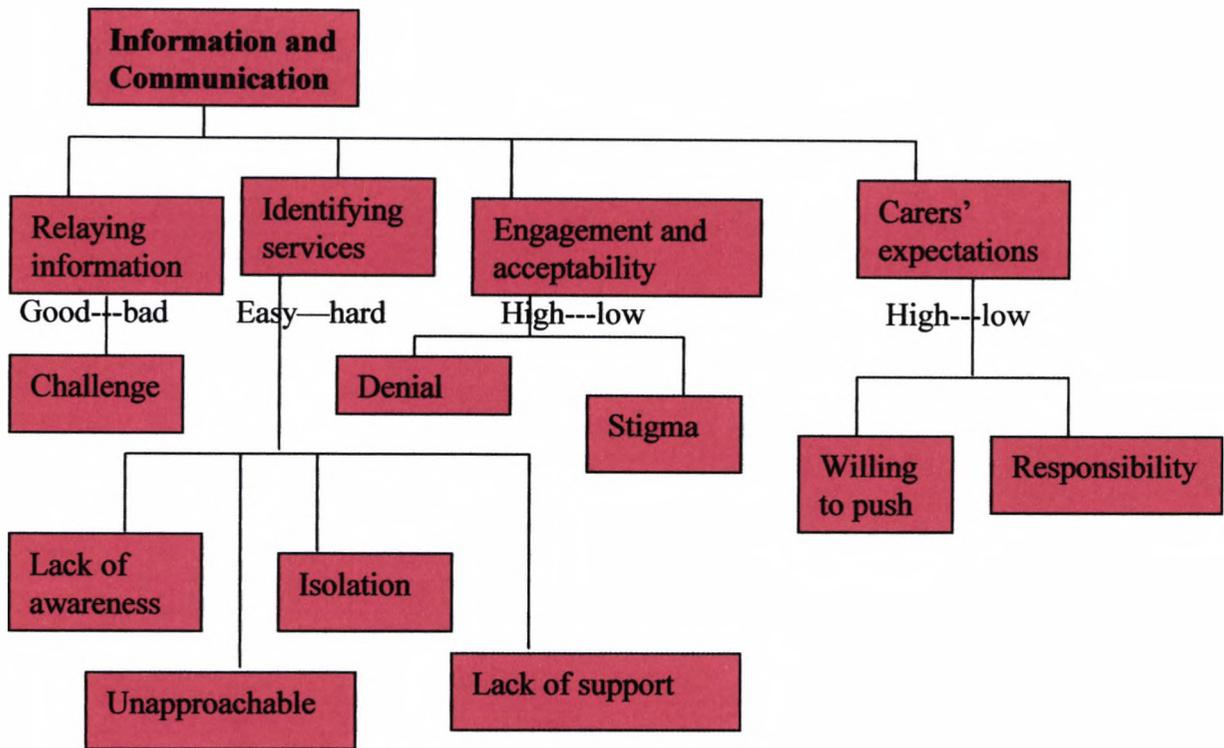


Fig. 3.2.5.2 Information and Communication in the carers' account

There was the notion that the engagement with- and acceptability of the service was perceived as “low” when social stigma was described as “high”. Finally, in terms of Information and Communication, carers suggested that it was a barrier to accessing psychosocial interventions that carers had to be “willing to push” to get those services and that carers expected to be responsible for the working alliance between themselves and mental health professionals.

Mental health professionals highlighted identifying services and carers' expectations as being barriers in terms of Information and Communication (see Fig. 3.2.5.3). When carers' expectations were at either extreme of being too “low” or too “high” this was described as an impediment to information sharing about psychosocial interventions. They particularly suggested that carers' expectations in terms of whether or not they perceived themselves to be carers, the lack of publicity and the knowledge that there were service users without carers were essential areas to consider.

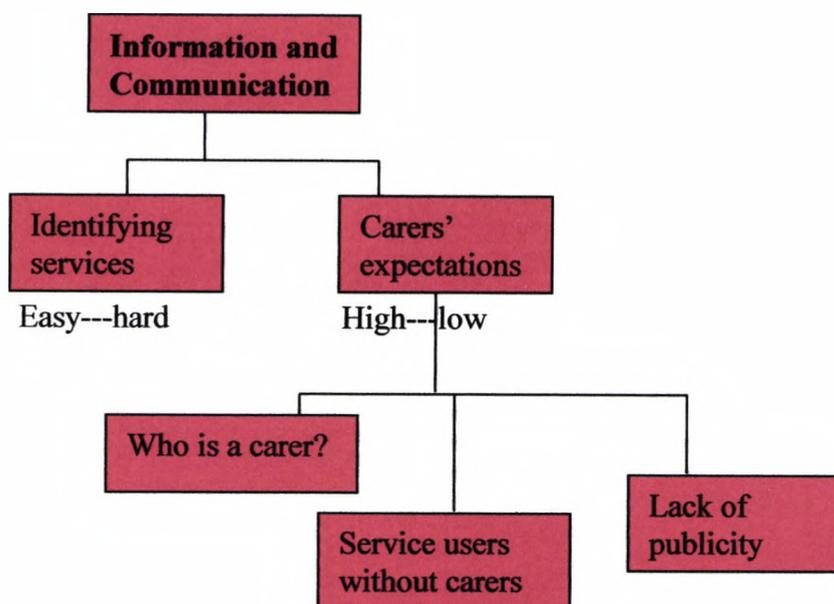


Fig. 3.2.5.3 Information and Communication in the mental health professionals' account

### 3.2.6 Core Category Overcoming barriers

Alongside a consideration of the barriers to accessing CBT and FIs participants discussed creative solutions to the obstacles to these types of psychosocial intervention. This category was used to organise discussion around, effective communication, research, training, supervision and recommendations for service development. Table 3.2.6.1 shows the core category “Overcoming barriers”, its main sub-categories their and dimensions. Data from focus groups with each type of participant (service user, carer and mental health professional) are presented and analysed alongside data from the interviewees.

**Table 3.2.6.1 Core Category “Overcoming barriers”, Main Sub-categories and Dimensions**

| Core Category          | Main Sub-categories                    | Dimensions                 |
|------------------------|--|----------------------------|
| 6. Overcoming barriers | 6.1 Communication                      | Good-----Bad               |
|                        | 6.2 Research, training and supervision | Available----Not available |
|                        | 6.3 Service development                | Good-----Bad               |
|                        | 6.4 Valuing cultural diversity         | High-----Low               |
|                        | 6.5 Modes of delivery                  | N/A                        |

### 3.2.6.1 Communication

Service users identified that essential to building a trusting relationship with mental health professionals was clear communication from initial contact. For example, they suggested that keeping people informed about what was to take place would make the admission process less distressing for them:

*'...if in the beginning if we're informed that because you are paranoid you are a danger to yourself and to other people we'd be able to understand and relax.'*  
' (SUG4)

To avoid mistrust that could arise between service users and mental health professionals and act as a barrier to accessing CBT and FIs, service users discussed the importance of being informed about their legal status and being encouraged to use information about medication and its side effects to inform decisions about their care. They suggested that the way information about, for example, the Mental Health Act (1983) and/or medication was presented could be modified so that it was accessible and helpful to service users:

*'I think first of all when we are brought in and sectioned, we should be told our rights.'* (SUG4)

*'So every time you are prescribed a new drug you should have the right to receive the information, the literature and so on and if you can't understand it it could be simplified.'* (SUG3)

Service users mentioned that in some settings the routine provision of information leaflets and the availability of details about a telephone enquiry line had facilitated engagement with mental health services. They suggested that information on CBT and FIs could be provided in a similar way. They also suggested that the visibility of those providing CBT and FIs could be enhanced:

*'you can simply be given usually way things happen information and leaflet and given a number to call or whatever and then there should be the people there who supply the service.'* (SUG3)

Mental health professionals stated that it could be useful to have people visiting different sites around the service providing information:

*'I think sometimes you know someone coming round from the Trust making sure that people are aware of what is available and how soon it can be accessed for a patient.'* (MHPG14)

Service users discussed the possibility of a member of staff giving a presentation to everyone about the options that are available and service users being empowered to state what their needs were (see also category 3.2.1 “Dominance of the medical model”):

*‘ Give people information about what’s on offer... in the service. ’ (SUG7)*

*‘...perhaps get one of the staff to talk to everyone, mention it different options that we’d prefer’ (SUG7)*

*‘I think the care staff need more feedback from the patients so they can see what they what patients need.’ (SUG8)*

Carers suggested campaigns to promote awareness of CBT and FIs among the general public:

*‘It should be more in the public domain what you know its awareness I guess really.’ (CG1)*

Mental health professionals argued that best practice required recognition of the carers’ needs and of the importance of involving carers in the work with service users:

*‘I just see them usually in most cases parts of the person’s treatment as well in terms of making sure that the carer is recognised yes and is also going to get all the services that they require. Because they’re going to keep, they’re probably going to be monitoring the person more than I am really but we do we recognise that we need to keep carers involved.’ (MHPI2)*

There was the suggestion that involving carers by assessing their needs might be a method of preventing them from suffering from becoming unwell:

*‘That’s something we sort of are recognising. It’s a little bit overwhelming for the workers because there’s so much to do but again we all know that that we don’t want to the carers to become too unwell as well.’ (MHPI2)*

### *3.2.6.2 Research, training and supervision*

Carers suggested that it was essential to carry out in-depth investigations into the needs of carers, followed by targeted interventions designed to support carers of people with schizophrenia and schizoaffective disorder. There was a sense of the potential that there were a number of positive changes that could be made, which would have a direct impact on carers:

*'I think probably a bit more research will have to be done and a bit more supportive work with the carers.'* (CG1)

Discussion between mental health professionals suggested an alternative immediate focus than the one on listening to and supporting carers identified by the carer's group. From focus group discussion arose the construction of a sense of anxiety about some mental health professionals being in a position of low competence regarding how one might listen to or support carers. Indeed, mental health professionals mentioned that it was necessary to place emphasis on training provided to mental health professionals in CBT and FIs for schizophrenia/schizoaffective disorder. They described an urgency to refute the belief that psychologists were the only health professionals in a position to offer these types of intervention:

*'more of an emphasis should be on someone being trained now because of the care co-ordinator role.'* (MHPG11)

*'most importantly like (X) was saying for the keyworker if the keyworker have that training then the keyworker can sort of like carry carry on with the treatment.'* (MHPG6)

*'it doesn't necessarily have to be psychologists and they don't have to hold that you know the whole CBT approach...'* (MHPG13)

They suggested that mental health professionals could view training in CBT and FIs as an important aspect of their personal development with the knowledge that the team would also gain from it:

*'...they're offering this training I mean its like for your own personal development ...it benefits me but it benefits the team I'm working in.'*  
(MHPG11)

Further it was suggested that it was the responsibility of the team to encourage its members to pursue training opportunities so that people providing CBT and FIs within the team were not isolated:

*'But I don't know I don't know if enough of that is done enough teambuilding people saying you've got to go for you've got to go for more. That you know we've only got a couple of people the (X) training.'* (MHPG11)

Mental health professionals described a sense that there needed to be a substantial financial commitment by the organisation to providing these types of treatment:

*'It's also about the Trust making some sort of commitment towards it. Doing so to commit the resources.'* (MHPG1)

It was stated that it was essential that, for example, a community mental health nurse interested in offering CBT has protected time to apply his/her knowledge and skills during training and once training is complete. Mental health professionals recommended that there be an increase in staffing levels to accommodate this:

*'If you've got like people like a CPN ...and they're doing CBT with some of their clients and then they're going to take clients from other people's caseload just to do CBT they've got to like have time set aside really haven't they?'* (MHPG4)

*'And not just whilst they're training but also once they're working so that its not something that we do from within the resources we've got it needs to be in addition.'* (MHPG8)

During the carer's interview there was a sense of the need for a greater number of mental health professionals to be trained to deliver these types of treatment:

*'...you do need some sort of training obviously and a great deal of understanding of course.'* (CI1)

During the mental health professional interview there was an expression of training needs:

*'I have very little experience of understanding CBT though I've I've actually attended a workshop but it was so long ago. I think it was something that was sadly lacking in my own training really.'* (MHPI2)

*'...it's a training need for me because its something that I'm not very good about counselling skills, listening skills ...I need to have topped up every now and again because I probably do forget'* (MHPI2)

### 3.2.6.3 Service development

It was suggested that services be localised to increase the consistency between areas. Others spoke of the difficulty that someone experiencing symptoms of schizophrenia/schizoaffective disorder might face with travelling and commented that

mental health professionals should be in a position to bring the service to the service user:

*'...most services need to be local and accessible...'* (MHPG1)

*'Somebody with symptoms I mean I think that if that services is realistically going to be offered I think people should come to the person.'* (MHPG12)

It was also suggested that people offering psychosocial interventions should be "onsite" for the service user to visit:

*'And also have somebody onsite to offer the therapy that would be ideal because that is going to be a barrier.'* (MHPG12)

Mental health professionals argued that specialists in the interventions described could provide supervision to teams and create a network of people offering psychosocial interventions:

*'I mean I feel that these big teams instead of operating from a base if they could have offer a supervision type of say they've got ten members if they could put one one of their staff with our team and one another team and then go back for the supervision and support ...'* (MHPG8)

Further it was suggested that people with specialist skills should work together in a 'core centre':

*'I think there should be a core centre for CBT.'* (MHPG8)

They went on to state that people who had an interest in offering CBT and FIs could have access to specialist supervision:

*'...and get the proper supervision so that they can go off to meet other clinicians who are doing the same specialist work both with CBT and family interventions.'* (MHPG8)

*'Support for people who have been trained not from their general supervisor'* (MHPG8)

Although staff were stating that they were aware of the hostility of the mental health service in terms of creating the kind of environment in which psychosocial interventions could thrive, they described the ability to remain optimistic and use creativity to circumnavigate obstacles, with a commitment to giving their best efforts despite difficult conditions:

*'I think the thing that keeps things together are the people the people that are working here. I think there are a lot of people that are optimistic, who are*

*very creative people that work hard despite anybody who's working for the NHS is under-resourced anyway we've done that and I think you know we've done it despite the system not because of it it hasn't helped us in anyway'*  
(MHPG1)

#### 3.2.6.4 Valuing cultural diversity

The service user interviewee commented on the importance of considering cultural diversity. Indeed, the degree of representativeness of those offering psychosocial interventions in terms of reflecting the cultural diversity of the local population was questioned. The service user suggested that cultural diversity in the workforce was an issue for service providers to consider:

*'I suppose it might help if you've got the same the psychologist is from the same cultural background as the service user.'* (SUI7)

The service user interviewee also considered it essential to inform clinicians, design services and interventions so that they were sensitive to cultural differences:

*'I suppose its getting someone to understand their point of view. And where they're coming from.'* (SUI7)

It was suggested by the mental health professional interviewee that those who offer psychosocial interventions should be adequately prepared and have the infrastructure to support working with people for whom English is not a first language:

*'...and certainly if there's any service that can be offered in different languages...'* (MHPI2)

In addition, the mental health professional interviewee stated that it was essential to be creative about how services might be restructured so that they overcame social stigma:

*'...I'm thinking that we do need to create spaces for people and whether it is actually in places that were traditionally mental health services I'm not sure. Though it could be just within say the doctors surgery something just quite a bit more "normal" I suppose and I use that sort of inverted commas "normal" meaning in you know de-psychiatrising it and making it sort of a little bit more something that we all do ...I think maybe mental health services need to be a bit more creative about where they place themselves.'* (MHPI2)

The mental health professional interviewee spoke about developing partnerships with local communities and using their facilities to provide a service that was acceptable to those communities:

*'And I suppose also with I was thinking of some of the communities where you've got multi-racial communities where there's a community centre or where there's other therapy treatment rooms or somewhere that's different from the general from the general sort of psychiatric mental health hostel hospital or whatever.'* (MHPI2)

During the mental health professional interview it was suggested one might educate the organisations interfacing with mental health in order to facilitate the access to CBT and FIs:

*'...we're encouraging our GPs we're linked to GP practices now actually to promote those things before even thinking of referring to us.'* (MHPI2)

As suggested in sub-category 3.2.5.5 "Carers' expectations" the mental health professional interviewee stated that many carers (particularly women) might not be aware of their role as carers. The interviewee commented that enhancing public awareness of what being a carer involves would improve carers' access to mental health services. However, there was also a sense that although carers may identify themselves as such, this role might not be perceived as one requiring support from public services:

*'a lot of women are considered to be carers and so perhaps don't ...even recognise their role as carers so that sort of raising awareness would improve that but that may still be a barrier to them actually even thinking about accessing services.'* (MHPI2)

*'I just think that perhaps carers would minimise it a little bit and that just wasn't something that they would go for but perhaps need encouragement to go for'* (MHPI2)

### 3.2.6.5 Modes of Delivery

There were suggestions regarding improving access to CBT by considering other modes of delivery. Service users stated that CBT could be offered more widely if it was commonly delivered in a group format:

*'...create a new grade of cognitive therapy worker or something. Something that could be in a group like this maybe'* (SUG3)

Service users described how other service users could offer support to people with persistent and distressing symptoms of schizophrenia/schizoaffective disorder:

*'I mean in fact the person who's been a very severely ill patient in the past could well be a good tutor or help someone who's going through the trouble now.'* (SUG3)

It was argued that carers might appropriately have their needs met within the voluntary sector:

*'I think there's probably more available for them but that's by voluntary groups if you look at it.'* (MHPG1)

In summary, alongside a consideration of the barriers to accessing CBT and FIs participants discussed creative alternatives to the obstacles to these types of psychosocial intervention. This category was used to organise discussion around, effective communication, carers approaching professionals, research, training, supervision and recommendations for service development. Service users suggested that communication in terms of modifying information and being informed about psychosocial interventions were important in terms of overcoming barriers (see Fig. 3.2.6.1). It was argued that when communication was described as "good" it facilitated the process of building a collaborative therapeutic relationship between mental health professionals and service users. Also considered important from a service user perspective was valuing cultural diversity in terms of the representativeness of people delivering the service and mental health professionals being able to understand diverse cultural backgrounds. Lastly, from the service user's standpoint, was the idea that psychosocial interventions could be delivered using a group format and/or using service user tutors.

In contrast, the carer focus groups and interview highlighted that essential to overcoming barriers were better communication, research, training and supervision (see Fig. 3.2.6.2). They suggested that raising awareness of the interventions in the public domain could effect better communication. Research, training and supervision

could be impacted by researching the experience of being a carer and training mental health professionals to “understand” carers and service users.

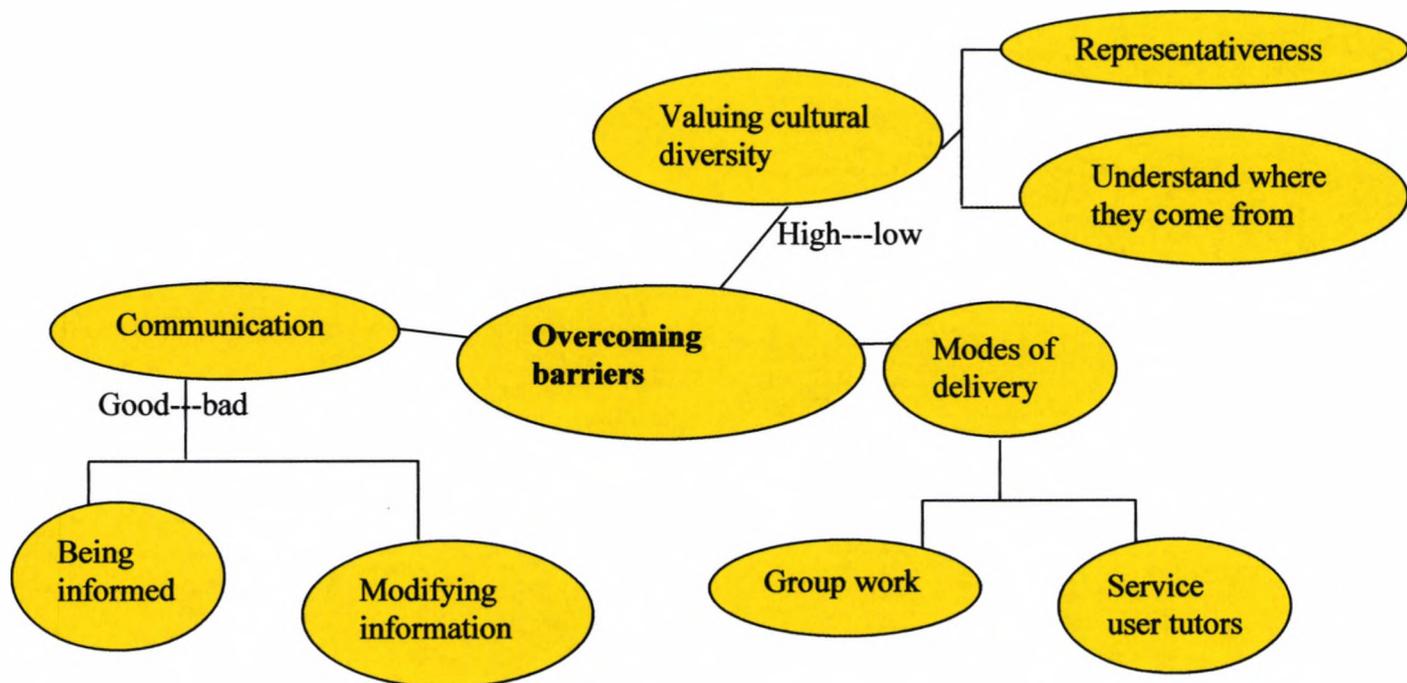


Fig. 3.2.6.1 Overcoming barriers in the service users' account

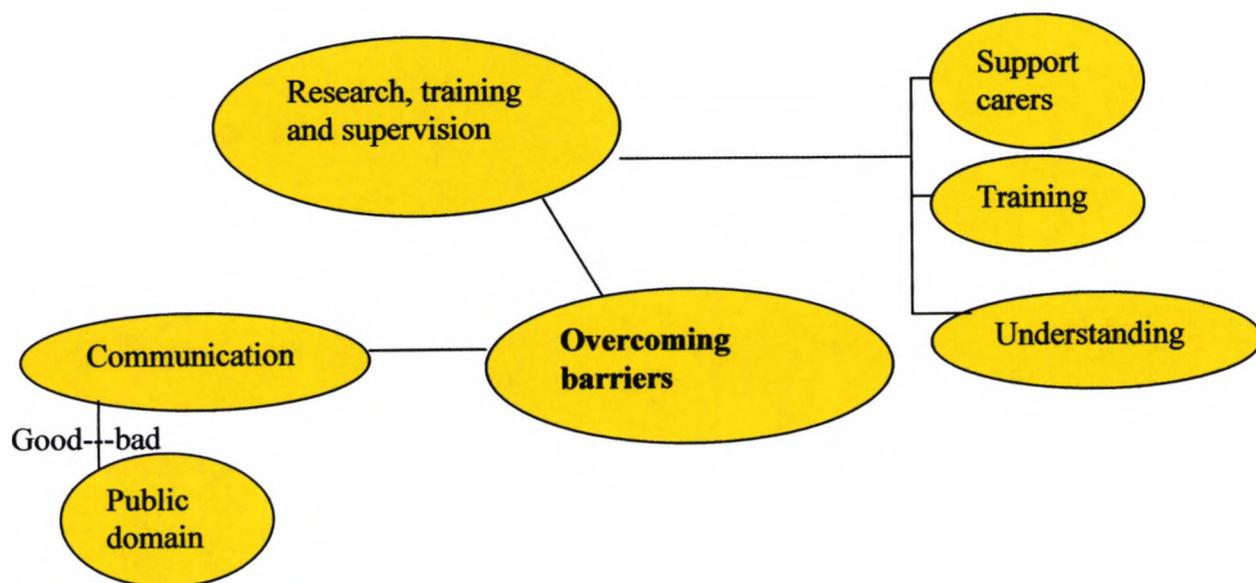


Fig. 3.2.6.2 Overcoming barriers in the carers' account

Concepts surrounding overcoming barriers emerging from mental health professionals' interview and focus groups covered all of the main sub-categories

identified for this core category (see Fig. 3.2.6.3). In terms of communication, mental health professionals suggested that there could be visits by people who were specialists in CBT and FIs. Also, that carers could be involved in a service users' care. It was argued that research, training and supervision were related to factors such as: Personal development; Teambuilding and supporting staff. When research, training and specialist supervision were described as being available, this was viewed as being beneficial to carers, mental health professionals and ultimately to service users. Service development was discussed as being a key alternative to barriers to accessing CBT and FIs for service users and carers.

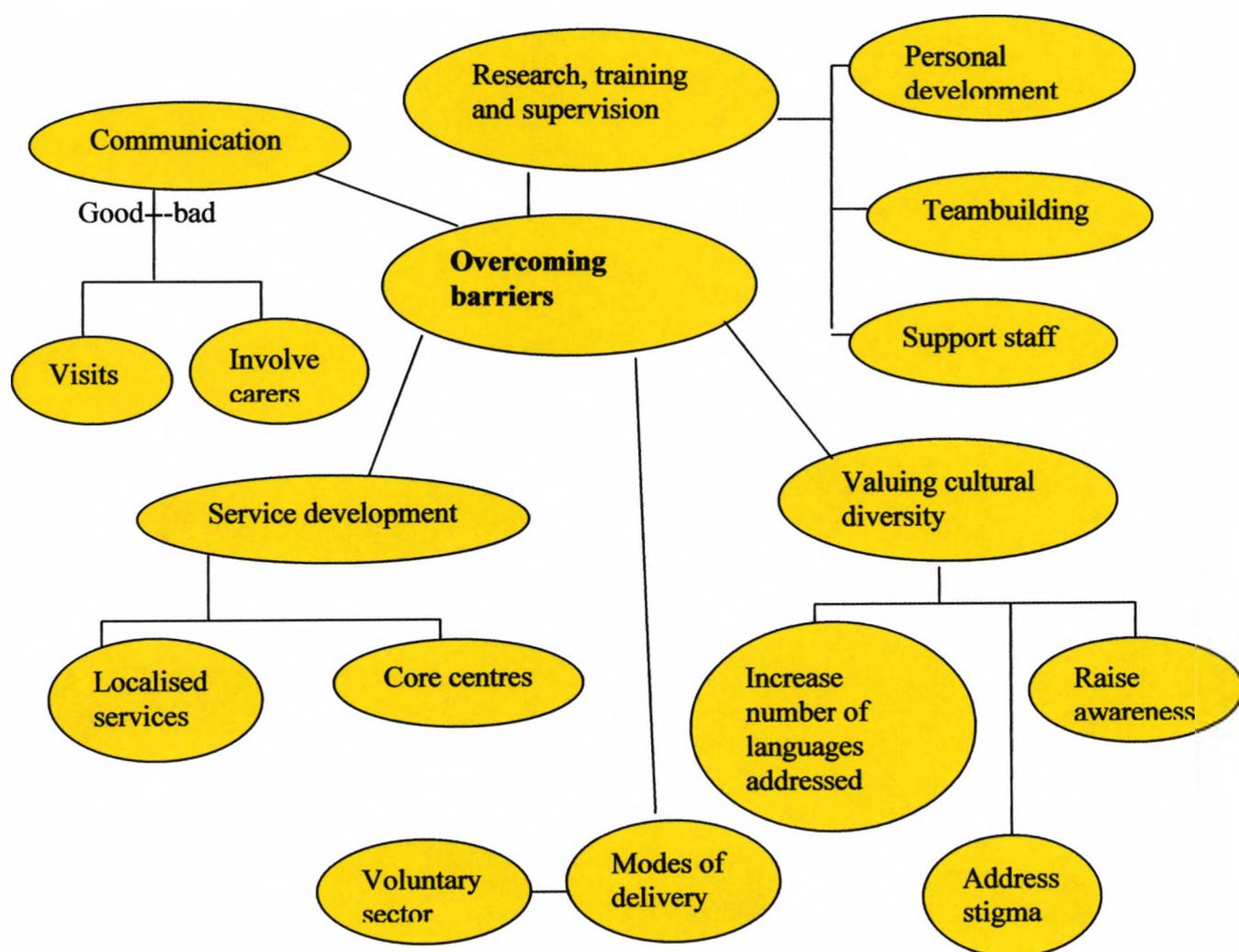


Fig. 3.2.6.3 Overcoming barriers in the mental health professionals' account

Ideas for service development suggested that it was possible to negotiate barriers to accessing psychosocial interventions related to the hostility of the service and take into account the needs of the local community. Mental health professionals disagreed

however, on whether services should be centralised or localised. As with service users, mental health professionals argued that modes of delivery of psychosocial interventions could be organised so that the voluntary sector was working closely with mental health services to promote access to CBT and FIs for service users and carers. In terms of valuing cultural diversity, mental health professionals concurred with service users that it was essential to address this to overcome barriers. It was suggested that when valuing cultural diversity was “high” access to diverse communities would be greatly enhanced. Mental health professionals also stated that this might be addressed by increasing communication in languages used within the local population, addressing stigma and encouraging allied organisations to value cultural diversity.

### *3.3 Main relationships between core categories and sub-categories*

Sections 3.2.1 to 3.2.6 have addressed the core categories namely: Dominance of the medical model; Mistrust; Service Hostility; Perception of Services as Elitist; Information and Communication and Overcoming barriers, which were constructed along with their sub-categories and dimensions. As described previously, Figure 3.1 depicts the core categories of barriers to accessing CBT and FIs for service users and carers, along with their main sub-categories and dimensions. It also shows overcoming barriers. This section is concerned with examining the main relationships between core categories, the main sub-categories and their dimensions. Figure 3.3 focuses on demonstrating those relationships across four topics that highlight the themes connecting the categories and main sub-categories namely: Information, Culture, Role expectation and Identifying needs. This section refers to transcript presented in the sections above without duplicating those excerpts.

#### *3.3.1 Information*

Here the relationship between core categories and their main sub-categories in terms of discussion about the dissemination of information regarding the cost-effectiveness and ease of identification of psychosocial interventions is examined. Firstly, the sub-category “Valuing psychosocial interventions” of the core category “3.2.3 Service Hostility” was related to the sub-category “Relaying information” of the core category “3.2.5 Information and Communication”. Mental health professionals in focus groups

and the service user interviewee gave a strong sense of a hostile environment where psychosocial interventions CBT and FIs were devalued and information about their effectiveness was not disseminated. Carers and service users suggested that it was difficult to be “good” at relaying information about the efficacy of CBT and FIs where the information was sparse.

The latent nature of the information about the efficacy of CBT and FIs alluded to above also meant that there was a lack of clarity regarding the cost-effectiveness of the interventions. Hence the sub-category “Valuing psychosocial interventions” of the core category “3.2.3 Service hostility” was also related to the sub-category “Modes of delivery” of the core category “3.2.6 Overcoming barriers”. This was because, despite perceived costs, service users and mental health professionals alike were keen to encourage pursuit of CBT and FIs including a willingness to consider alternative modes of delivering the interventions if necessary to ensure that they were provided. Mental health professionals went further to suggest that CBT and FIs could be prioritised for specific groups of people with schizophrenia/schizoaffective disorder, noting that some would be denied a service, in order to economise.

Secondly, the sub-category “Identifying services” of the core category “3.2.5 Information and Communication” was related to the sub-category “Relaying information” also in the core category “3.2.5 Information and Communication”. The statements of service users and carers concurred that carers first needed to be able to identify services offering psychosocial interventions before they could relay any information about those services to service users. Since identifying services could be difficult, the carers’ group in particular considered it essential that carers were supported in this task. Therefore, carers’ ability to inform service users about psychosocial interventions was dependent on those carers being adequately supported by mental health professionals in terms of assistance with identifying services and help with relaying that information. Information was a factor, which it was suggested affected different groups of people discussed at differing levels.

### *3.3.2 Culture*

As discussed above, participants described the careful consideration of cultural diversity as essential to the provision of an acceptable service. The sub-category “Clash of interests” of the core category “3.2.5 Information and Communication” was related to the sub-category “Exclusive, discriminatory boundaries ” of the core category “3.2.3 Service hostility”. According to service users, when there was a “high perceived clash of interests” between mental health professionals and carers in relation to differences in culturally diverse beliefs and values the service was at its most hostile. Both sub-categories mentioned above shared links with “Engagement and acceptability” a sub-category of “3.2.5 Information and Communication”. Mental health professionals and service users spoke about the importance of examining the process of engagement with carers. The service was considered “hostile” when cultural sensitivity was low and the service did not engage carers in a culturally congruent manner. This concept was related to the notion of “Cultural sensitivity” a sub-category of “3.2.2 Mistrust” which was constructed in relation to data from service users, carers and mental health professionals’ focus group discussions and interviews. This sub-category was associated with, “Valuing cultural diversity” a sub-category of “3.2.6 Overcoming barriers”. It was in relation to the sub-category “Valuing cultural diversity” where constructive solutions were offered by service users and mental health professionals on how one might enhance the acceptability of the service to a culturally diverse population. It was suggested that where there was a demonstration of adequate efforts to value cultural diversity minority ethnic groups would be more likely to engage with the service.

### *3.3.3 Role expectations*

Here an examination of the roles of mental health professionals and carers demonstrates that when expectations are not adequately responded to, the clarity of one’s role is compromised and/one’s perceived level of burden is affected. Firstly, the sub-category “Defining one’s role” of the core category “3.2.3 Service hostility” was related to “Research, training and supervision” a sub-category of “3.2.6 Overcoming barriers”. Mental health professionals’ focus group discussion suggested that when ongoing training and supervision for staff offering CBT and FIs was perceived as not being available this was associated with low role clarity. Conversely, there was the

suggestion that providing ongoing training and supervision would enhance the role clarity of staff offering psychosocial interventions within a multidisciplinary team.

Secondly, sub-category “Carers’ burden” of core category “3.2.1 Dominance of the medical model” was closely related to sub-category “Carers’ expectations” of core category 3.2.5 Information and Communication”. Mental health professionals and carers (in their focus groups and in individual interviews) suggested that carers’ burden was high when carers’ expectations of services were at either extreme of being high or low. When carers’ expectations were at moderate levels, “burden” was perceived as being low to moderate. Hence, it was suggested that clarity surrounding the roles of mental health professionals and carers’ expectations of services (and their own abilities) was a fundamental issue to address in connection with the provision of psychosocial interventions.

#### *3.3.4 Identifying needs*

There were clear relationships between categories and sub-categories regarding identifying needs. Sub-category “Diagnosis” of core category “3.2.1 Dominance of the medical model” was related to “Engagement and acceptability” a sub-category of core category “3.2.5 Information and Communication”. Mental health professionals highlighted that having a diagnosis of schizophrenia/schizoaffective disorder could put service users at a social disadvantage. They suggested that having a diagnosis was open to being perceived by service users as either “good” or “bad”. Carers commented that when having a diagnosis of schizophrenia/schizoaffective was perceived as “good” by service users, engagement with- and acceptability of services was described as “high”. However, they suggested that when it was perceived by service users that having a diagnosis of schizophrenia/schizoaffective disorder was “bad” engagement with and acceptability of services was described as “low”. Mental health professionals and carers suggested that service users would engage with services offering psychosocial interventions when service users identified that they had needs which could be met by those services.

In sum, the above is similar to the selective code transmission process described by Strauss and Corbin (1990). I looked for main categories or core concepts, which

expressed the main complex of issues that other categories could be related to. In this way, further relationships between core categories and their sub-categories were expounded with regard to four topics namely: Information, Culture, Role expectations and Identifying needs. Evidently, as stated elsewhere (see 3.2.1 p69), the dominance of the medical model and medication as the primary treatment led to issues such as the importance of CBT and FIs and cultural sensitivity being neglected. It was suggested that it was difficult to be “good” at relaying information about the efficacy of CBT and FIs when there was little information available. It was implied that minority ethnic groups would be more likely to engage with a service that valued cultural diversity. Training and supervision for staff offering CBT and FIs was associated with role clarity. In addition, when carers’ expectations of the service were at moderate levels, “carers’ burden” was perceived as being low to moderate. It was suggested that service users would engage with services offering CBT and FIs when service users identified needs which they believed could be met by those services. It emerged that services had been designed to deliver medication and social support rather than evidence-based psychosocial interventions.

Figure 3.3 shows the main relationships between core categories, main sub-categories and their dimensions. Core categories are in bold type in red boxes with the exception of the core category Overcoming Barriers, which is in a yellow box. Sub-categories are also in red boxes with the exception of the sub-categories for Overcoming Barriers, which are in yellow boxes. The arrows in the model relate to evidence from varying combinations of groups/interviewees – this is made explicit in the text above. The purple arrows indicate relationships between categories. The blue arrows depict relationships between sub-categories. The main relationships shown are those which represent the following four topics: Information, Culture, Role expectation and Identifying needs. Some categories did not emerge within all sets of data.

# Main Relationships Between Categories and Sub-categories

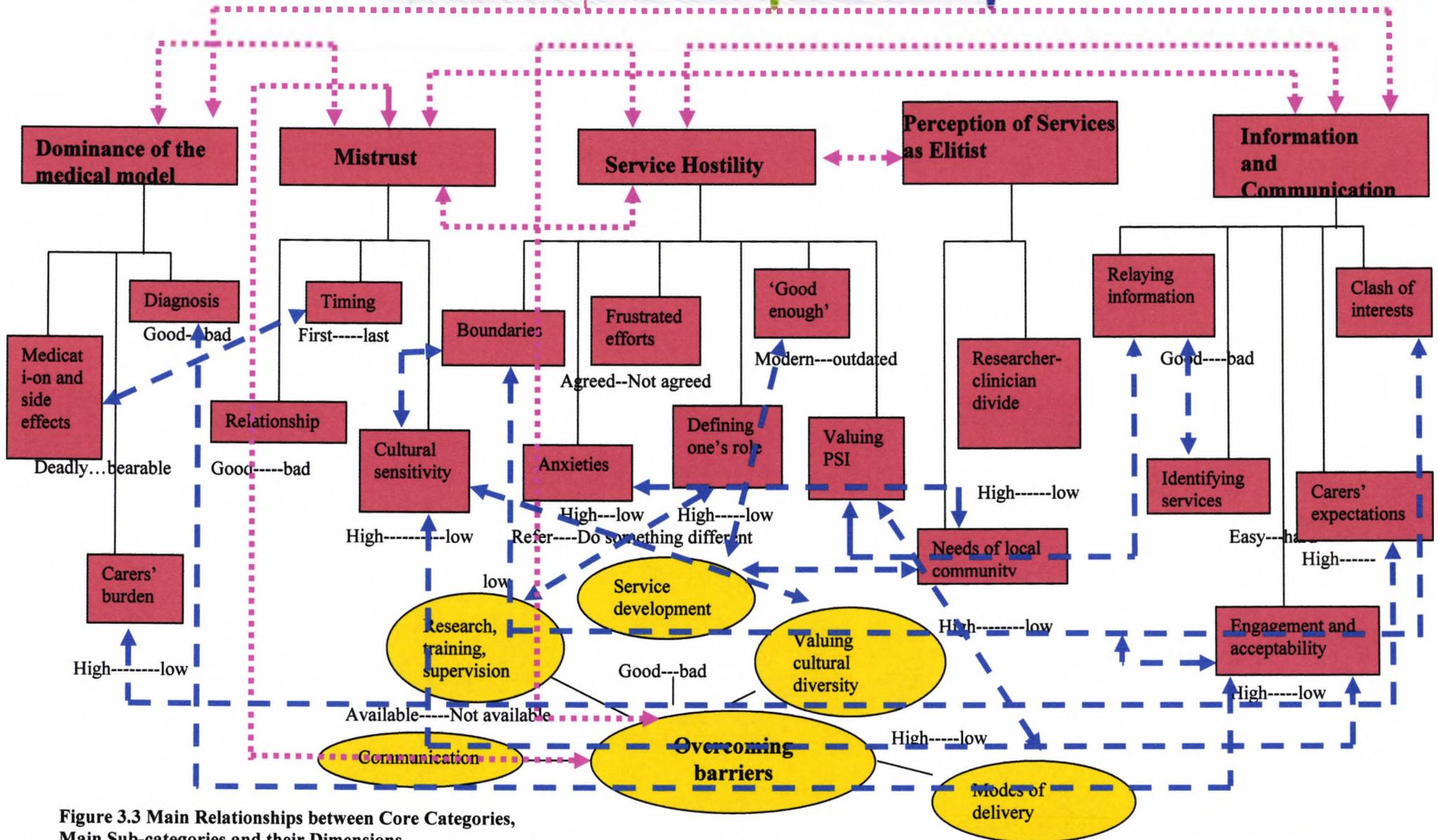


Figure 3.3 Main Relationships between Core Categories, Main Sub-categories and their Dimensions

### 3.4 Summary

In sum, as stated above, limitations on space prevented the inclusion of all identified categories. The categories not presented here were ones that did not directly address the research questions. The above focused on 6 core categories which were presented in sections 3.2.1 – 3.2.6 namely: Dominance of the medical model; Mistrust; Service hostility; Perception of services as ‘elitist’; Information and communication and Overcoming barriers along with their sub-categories and dimensions. As highlighted using illustrations, some categories did not emerge within all sets of data. Section 3.3 examined the main relationships between core categories, the main sub-categories and their dimensions across four topics namely: Information; Culture; Role expectation and Identifying needs.

## **Chapter 4: Discussion**

### *4.1 Introduction*

The aims of the present study were to explore and illuminate barriers to accessing CBT and FIs for service users and their carers. It was particularly concerned with developing theories about the barriers identified from the perspectives of service users, carers and mental health professionals. It sought to address the following research questions, aiming to elucidate meaning rather than truth:

- A. How might services users, carers and mental health professionals perceive and account for the barriers that service users and carers face in accessing CBT and family interventions?
- B. How do views of service users/carers and mental health professionals differ? If they converge, at what points does this happen?
- C. How might answers to these questions be used to inform psychology practice/research?

A summary of the main findings is presented according to the core categories that were constructed in relation to the source data. Following on from this is a consideration of how the present results relate to the existing literature, a discussion about the methodological limitations of the study and implications of the research for the psychology profession both in terms of clinical practice and suggestions for future research.

### *4.2 Summary of main findings*

The following is a summary of the main findings across the six core categories: Dominance of the medical model; Mistrust; Service hostility; Perception of services as elitist; Information and communication and Overcoming barriers. Some participants asserted that the dominance of the medical model was a barrier to service users with medication non-responsive schizophrenia/schizoaffective disorder and their carers accessing CBT and FIs. The dominance of the medical model led to the first-line treatment being medication. Service users in particular stated that this was problematic. For example, they highlighted that the side effects of the medicines were often seen as ‘deadly’. This meant that in their view it was disconcerting that the medical model was privileged over a more holistic approach. Evidently, aiming to engage a service user by introducing medication which he or she may believe has the

potential to cause serious harm, is a potential barrier to engaging with psychosocial treatments.

Participants suggested that an individual's first impression of the service where the medical model was dominant would be likely to intensify any suspicion one might have in engaging with such a service. It was suggested that adopting a holistic method would have enhanced the acceptability of the service. As it has been shown, service users had priorities such as the need for practical and emotional support. This was at odds with the implicit message they received from the service i.e. 'we know what you need – take these tablets'. Clearly, the dominance of the medical model has been shown to be a major block to empowering service users to engage in a process where they were negotiating with mental health professionals about aspects of their care. Also, when carers' burden was expressed as being "high" e.g. in relation to expectations that they would "manage medication", the suggestion was that attempting to engage carers on this level reinforced the power imbalance between them and mental health professionals. When diagnosis was discussed as representing something "bad" it was linked with disempowered socially excluded service users. The effects of being marginalised and stigmatised were to make accessing psychosocial treatments all the more difficult. In particular, it was suggested that service users who internalised such labels might suffer from low self-esteem which in turn would make the prospect of 'recovery' seem impossible, therefore psychosocial treatments would not appear worthwhile or valuable. A core category surrounding a sense of "Mistrust" between service users and people working in the mental health professions was discussed as a barrier to service users and their carers accessing psychosocial treatments. Evidently, service users placed great emphasis on establishing confidence in mental health professionals as a prerequisite for engaging in psychosocial interventions. They suggested that there was a preference among service users for beginning CBT and FIs prior to commencing on antipsychotics. This would involve redressing the balance in terms of the dominance of the medical model.

Participants highlighted the necessity of ensuring that services were acceptable to the culturally diverse communities they were to serve. It was found that working with cultural difference without legitimate attempts to demonstrate that one had an

understanding of the complex issues related to culture and showing that one valued diversity would increase the likelihood of service users and carers being misunderstood and facing racial discrimination. Clearly, preoccupation with the medical model made it difficult to offer an appropriate service to diverse groups of people for whom Western medicine may have had little significance. In addition, the core category “Service Hostility” captured a sense that services were “limited” in terms of their provision to culturally diverse communities instead they had been designed to accommodate the medical model. For example, services were not organised in a way that gave service users a range of treatment options incorporating those that might have more validity i.e. ‘alternative medicines’. A further limitation to the service, demonstrating its hostility, was the length of waiting lists. It was suggested that as a result of long waiting lists, mental health professionals were under-referring people for CBT and FIs. Instead they were “doing something different” with service users on their caseloads. Staff who were trained in CBT and FIs did not have protected time to carry out those interventions due to the hostility of the service environment which seemed to privilege medical interventions. In addition, when role clarity for mental health professionals was low, this was the most difficult condition under which to attempt to offer CBT and FIs to people with schizophrenia/schizoaffective disorder and their carers. When the service design did not support staffing that included people offering psychosocial interventions it was described as “outdated”. It was also suggested that the lack of dissemination of information about the efficacy of CBT precluded staff being in a position from which to adequately consider the cost-effectiveness of the intervention. Hence it emerged that the service was a hostile environment in which to try to cultivate psychosocial interventions, as it had been designed to deliver medical rather than psychosocial interventions. Mental health professionals’ described a perception of services offering psychosocial interventions CBT and FIs as ‘elitist’. Discussion around this concept warranted a core category of its own. It was found that when the potential for unmet needs within the local community was “high” services offering CBT and FIs were considered to be ‘elitist’. There was a sense that psychosocial interventions were ‘different’ and something that had been ‘tagged onto’ treatment as usual in some areas rather than having infiltrated the service as a whole. There was a strong notion of it being a ‘postcode lottery’ as to whom would actually be most likely to be seen for this

type of intervention. Being an 'elitist' service also suggested that high demand for treatment resulted in it being oversubscribed.

Inappropriate attempts to engage carers led to Information and communication being identified as core category. Participants suggested that carers might usefully act both as a channel between service users and professionals and a buffer between service users and the negative public perception of mental health problems. It was also found that the process of caring personally affected carers. This notion encompassed a sense of carrying responsibility, burden and guilt in association with one's role as a carer and how this might prevent one accessing psychosocial interventions. It was found that when relaying information was viewed as, "ineffective" carers were unable to facilitate the process of service users engaging with CBT and FIs. It was also suggested that when identifying services was described as "difficult", carers' feeling of isolation, the lack of communication was regarded as being at its peak. Evidently, the engagement with- and acceptability of the service was perceived as "low" when social stigma was described as "high". Further, when carers' expectations were at either extreme of being too "low" or too "high" this was an impediment to information sharing about psychosocial interventions. Finally, when there was a perceived "high" clash of interests between carers and mental health professionals this too was a barrier to accessing CBT and FIs. Carers concerns would need to be taken into account in order to successfully facilitate the process of engagement with psychosocial interventions.

Alongside discussion of the barriers to accessing CBT and FIs participants generated creative ideas of how they might be overcome. It was found that when communication was described as "good" this had the potential to facilitate the process of building a collaborative therapeutic relationship between mental health professionals and service users. When research, training and specialist supervision were described as being "available" this was viewed as beneficial to mental health professionals and ultimately to service users and carers. Ideas for service development proposed that it was possible to overcome barriers to accessing psychosocial interventions related to the hostility of the service and take into account

the needs of the local community. Finally, it was suggested that when valuing cultural diversity was “high” access to diverse communities would be greatly enhanced.

Following on from a discussion of the six core categories, similar to Strauss and Corbin’s (1990) ‘selective code’, additional relationships between core categories and their subcategories were expounded across four subheadings namely: Information; Culture; Role expectations and Identifying needs these are briefly stated below. It was found that it was difficult to be “good” at relaying information about the efficacy of CBT and FIs when there was little information available. Neither mental health professionals nor carers would be in a position to introduce psychosocial interventions to service users if they themselves had little or no information about them. In addition, it was found that when carers’ expectations of the service were at moderate levels, “carers’ burden” was perceived as being low to moderate. Further, minority ethnic groups were considered more likely to engage with a service that demonstrated that it valued cultural diversity. It was found that service users would engage with services offering CBT and FIs when service users identified needs which they believed could be met by those services. Finally, the provision of training and supervision for staff offering CBT and FIs was associated with defining one’s role. Staff could develop clearer professional identities as providers of CBT and FIs when specialist training and supervision were in place.

Clearly views of service users, carers and mental health professionals differed in a number of ways. For example, service users were chiefly concerned with promoting the earlier introduction of psychosocial interventions rather than the use of medication as a sole treatment. Carers were concerned primarily with the complexity of the carers’ role and the difficulties surrounding the lack of information on CBT and FIs. Whilst mental health professionals seemed to describe problems with the way service had been organised as a significant barrier to accessing psychosocial interventions. Participants views appeared to concur that dominance of the medical model was problematic. Further, that clear communication was essential to building trusting relationships and facilitating access to these approaches.

### 4.3 The Existing Literature

Having discussed the main findings of the study, focus now turns to a consideration of how those findings relate to the existing literature.

#### *4.3.1 Dominance of the medical model*

There were three subcategories identified under the core category Dominance of the medical model these were as follows: Medication and its side effects; Carers' burden and Diagnosis. Each of these subcategories is considered below in terms of how it relates to the existing literature. As a barrier to accessing psychosocial treatments the topic of most discussion for service users was medication. There was a parallel with the dominance of the biological discourse within the field where the medical profession in particular view medication as the preferred treatment for schizophrenia/schizoaffective disorder. The emerging theory was that the pervasive use of medication as a first-line treatment had as a consequence a power imbalance between service users and mental health professionals. Participants indicated that service users who felt as though they had had their "rights" taken away by the mental health system, were disempowered and clearly would not be in a position to assertively access psychosocial interventions CBT and FIs. There is evidence from literature to support the notion that there is a power imbalance between service users and professionals inherent in mental health services (Linnett, 1999). It also suggests that empowerment is a necessary precursor for the process of recovery (Deegan, 1993).

Shepherd, Murray and Muijen's (1995) study demonstrated service users and mental health professionals' differing views in relation to medication. They found that service users with severe mental illness emphasised the importance of practical help (e.g. housing, finance, occupation, physical health and counselling), whilst professionals highlighted medication and symptom monitoring as essential (Shepherd, Murray and Muijen, 1995). Perhaps one issue is that the concern of professionals is more on managing the risk to the service user in terms of disengagement with treatment and relapse in mental state and/or the risk to others if service users are not adherent to their medication regimes and symptoms persist. Findings from the

present investigation concur with those suggesting that service users who are administered neuroleptics face potentially crippling side effects such as sexual dysfunction (Tarrier, Barrowclough, Haddock, McGovern, 1999; Tarrier, Yusupoff, Kinney, McCarthy, Gledhill, Haddock and Morris, 1998; Pilling et al 2002a; National Collaborating Centre, 2002). The current finding that some service users described medication and its side effects as “bearable” lends tentative support for the notion that illness metaphors can be acceptable to service users (Fowler, Garety and Kuipers, 1995). Kinderman and Cooke (2000) maintain that for some service users prophylactic treatment is recognised as important in preventing relapse. Further, some participants described a sense that it was possible to appreciate advantages to taking medication and did not view it as a barrier to accessing psychosocial interventions.

The finding that the responsibility and burden of caring for someone with schizophrenia/schizoaffective disorder made it difficult for carers to get access to information and services related to CBT and FIs echoed that of previous authors (Barrowclough and Tarrier, 1997). Also supported by previous research was the finding that carers would describe issues other than medication as areas they wished to be addressed. For example, previous studies demonstrated that assistance with matters such as benefits was prioritised by carers (Weinberg and Huxley, 2000). This suggests that medication is sometimes less of a priority for carers than for mental health professionals. The present study demonstrated that carers described a situation where mental health professionals devalued issues which were depicted as salient to carers. In accordance with previous investigations, carers in the study maintained that support from mental health professionals would be beneficial to carers (Kuipers, 1998; National Collaborating Centre, 2002), particularly since they suggested that carers felt they did not have the authority to effect change in terms of the service user’s care planning.

The present findings that service users were positioned as “powerless” and described as being discriminated against on the basis of their diagnosis is well established in the literature (for example, Deegan, 1993; Linnett, 1999; Birchwood, Meaden, Trower, Gilbert and Plaistow, 2000). As stated in Chapter 1, the National Collaborating Centre, (2002) assert that within the NHS there is prejudice against people suffering

from symptoms of schizophrenia. This prejudice results in inadequate numbers of people being referred for appropriate psychosocial interventions. In the present study this was particularly apparent in terms of discussion about whether people with schizophrenia/schizoaffective disorder were referred for psychosocial interventions. This concurs with Birchwood, Meaden, Trower, Gilbert and Plaistow, (2000) who argued that people who had a diagnosis of schizophrenia/schizoaffective disorder faced “social disempowerment and marginalization”. It is also in accordance with others who have asserted that the concept of schizophrenia is potentially detrimental (Drayton, 1995; Burbach 1996; Bentall, 1990; Bentall, 1993). Bentall (2004), proposed that the notion of a unitary construct “schizophrenia” be abandoned in favour of a focus on the particular symptoms with which individuals present.

In addition, the finding that ethnicity and power were related to diagnosis also provided support for previous considerations about similar issues as stated previously (Birchwood, Meaden, Trower, Gilbert and Plaistow, 2000). The rich qualitative data of the present study afforded further evidence that service users from diverse ethnic groups had not been engaged in psychosocial interventions as a result of racial discrimination.

In sum, a number of the constructs that emerged from the present study in relation to the dominance of the medical model found support in the existing literature. For example, the finding that there can be a difference of opinion between mental health professionals, service users and carers found support in the literature. It was suggested that diagnosis could be used in a way that meant a consequence was to prevent people suffering from psychotic symptoms accessing psychosocial interventions. It was also found that although diagnosis could be problematic for some, with others it may be useful to discuss illness metaphors. Lastly, it was highlighted that caring for someone with schizophrenia/schizoaffective disorder can be an isolating experience. This notion found support in existing research.

#### *4.3.2 Mistrust*

There were three subcategories identified under the core category Mistrust – the perception that others will intentionally harm one, these were as follows:

Relationship; Timing and Cultural Sensitivity. Each of these subcategories is considered below in terms of how it relates to the existing literature. The relationship - service users described a lack of confidence in professionals with the responsibility for delivering care. This finding reflected established patterns in the literature which suggested that mistrust between health care providers and service users rendered working collaboratively to engage service users in CBT or FIs a near impossible task (Corrigan, 2002). Timing of interventions - findings of the present investigation lend support for the biopsychosocial model as discussed in Chapter 1 (Engel, 1977; Zubin and Spring, 1977; Sellwood, Haddock, Tarrier and Yusupoff, 1994). Service users described developing a holistic understanding of the problems faced by service users as being potentially more helpful than a linear medical model. This argument is also reflected in the literature which states that developing such an understanding of one's experience promotes a sense of opportunities to build hope for the future and gain control (Deegan, 1993; Fowler, Garety and Kuipers, 1995; Kuipers, Garety, Fowler, Dunn, Bebbington, Freeman and Hadley, 1997). Therefore, it was suggested that a discussion about treatments in addition to medication could be held either prior to commencing discussions about medication or in tandem with them.

The legacy of medical science, and psychiatry's positioning within it - offering a reductionist view of the experience of mental distress, contributed to the scarcity of psychosocial treatments being offered. The theory that emerged was that failure to take a holistic approach hindered access to CBT and FIs for service users and carers. In harmony with previous research it was suggested that adhering to a uni-dimensional medical model was a barrier to accessing CBT and FIs for service users with schizophrenia/schizoaffective disorder and their carers (Barrowclough and Tarrier, 1997) as it was related to a sense of hopelessness. The present results suggested that dependence among service users may have arisen as service users were stated to be given medication and told they were required to keep taking it in order to avoid relapse. However, as stated in Chapter 1, as many as 40% of service users have symptoms that persist despite the use of anti-psychotic medication (Tarrier, Barrowclough, Haddock, McGovern, 1999; Tarrier, Yusupoff, Kinney, McCarthy, Gledhill, Haddock and Morris, 1998; Pilling et al 2002a; National Collaborating Centre, 2002).

The finding that having discussions about medication and psychosocial interventions alongside one another might reduce a sense of mistrust between service users and mental health professionals is reflected in the literature. It is argued that CBT increases the likelihood that medication will be effective when they are co-occurring (Roth and Fonagy, 1996; Fowler, Garety and Kuipers, 1995). Further, the present findings provide support to the notion that administering medication in the absence of psychosocial interventions is often insufficient to promote the management of- and recovery from the symptoms of schizophrenia/schizoaffective disorder (Tarrier, Barrowclough, Haddock and McGovern, 1999; Sensky, et al, 2000). The narratives of service users reject the notion that psychotic symptoms are not amenable to psychological intervention and that psychosocial interventions were contraindicated with people with schizophrenia/schizoaffective disorder. This is mentioned by authors such as Yusupoff, Haddock, Sellwood, and Tarrier, (1996); Birchwood, Meaden, Trower, Gilbert and Plaistow, (2000).

Considering cultural sensitivity, service users mentioned the importance of applying an awareness of diverse cultures when addressing mental health needs. It was suggested that mental health professionals should be aiming to “understand” diverse cultural beliefs in order facilitate openness between them and the users they served. As stated above in Chapter 1, it is reported that African-Caribbeans born in the U.K. develop psychosis at a rate 4 times higher than white-British people (Tarrier, et al; Burnett, Mallett, Bhugra, Hutchinson, Der, Leff, 1999). This suggests that meeting the needs of people from diverse cultures who are suffering from psychosis ought to be prioritised. Service users in the present investigation described the harrowing effects of being sectioned and treated against their will. As African-Caribbeans were shown to be more likely to be admitted involuntarily under the Mental health Act, (1983) following their first admission than other ethnic groups (Burnett, et al., 1999) evidence from the present investigation supports the notion that mistrust arising from coercion appears to be a barrier to accessing psychosocial interventions, particularly for people belonging to minority ethnic groups (Corrigan, 2002; Reynolds, 2001).

In sum, constructs emerging from the current findings that were organised under the core category Mistrust found support in the existing literature, e.g., the finding that a lack of confidence in relationships with mental health workers was a barrier to accessing CBT and FIs for service users and carers. It was suggested that services that adopted a holistic understanding of the individual. Finally, it was noted that there was a need to understand culturally diverse beliefs in order to prevent barriers to accessing CBT and FIs for service users and their carers, this notion found support in existing research.

#### *4.3.3 Service hostility*

There were six subcategories identified under the core category Service Hostility these were as follows: Exclusive, discriminatory boundaries, Frustrated efforts, Defining one's role, What is perceived as 'good enough', Anxieties about psychoses' amenability to treatment, and Valuing psychosocial Interventions. The subcategories are considered below in terms of how they relate to the existing literature. Findings suggested that exclusive, discriminatory boundaries were seen as a service limitation and evidence of the hostility of services that made it particularly difficult for service users and carers from minority ethnic groups to gain access to psychosocial interventions. In terms of 'frustrated efforts' the present study found that staff who were trained to carry out CBT and FIs for people with schizophrenia/schizoaffective disorder often did not have protected time to do so. This finding offers support for that notion that time constraints can be a barrier to accessing psychosocial interventions for schizophrenia (Durham, Swan and Fisher, 2000). The findings accord with those mentioned in Chapter 1, the provision of CBT involves the investment of time of professionals with skills in this area of which there are relatively few such professionals (NHS Centre for Reviews and Dissemination, 2000; Durham, Swan and Fisher, 2000). Prerequisite for engaging families in family intervention was a degree of flexibility that a hostile service often did not permit. This concurred with literature suggesting that professionals offering interventions such as CBT are required to be flexible in their approach which includes being in a position to creatively negotiate appointments with service users and carers (Fowler, Garety and Kuipers, 1995; Corrigan, 2002 Durham, et al., 2000).

The theme of defining one's role asserted that mental health professionals seemed to believe offering psychosocial interventions was the responsibility of psychologists alone rather than valuing their own potential to take on this role. This was described as a barrier to the provision and thus access of psychosocial interventions for service users and carers. The notion of the lack of role clarity as a factor of a hostile service environment was concordant with previous research (Tarrier, Barrowclough, Haddock, McGovern, 1999). Interestingly, a carer expressed what appeared to be an expectation that mental health nurses and counsellors would be in a position to offer psychosocial treatments. The lack of convergence on this point between mental health professionals and carers perhaps raised carers' expectations. As discussed above, where carers' expectations were too high, carers' perceived burden was also described as "high", this in turn was described as a barrier to accessing psychosocial interventions. The suggestion that professionals with backgrounds in disciplines other than psychology might provide CBT and FIs is one that has found support in the literature (for example, Barrowclough and Tarrier, 1997). It was also suggested that where additional specialist CBT and FIs skills had been acquired by such mental health professionals and were devalued in the workplace, staff turnover would increase. This would clearly be a barrier to accessing CBT and FIs for service users and carers served by those areas. Again this notion was resonant with existing theory (Barrowclough and Tarrier, 1997).

Participants discussed what would constitute a 'good enough' service. This led to further barriers such as a lack of specification of the number of multidisciplinary team members required to carry out psychosocial interventions and a lack of job descriptions reflecting this purpose being identified. This finding concurs with Tarrier, Barrowclough, Haddock and McGovern's (1999) who also found that structural problems with services such as the lack of management support were a barrier to the provision of these types of interventions. The finding that mental health professionals most frequently targeted interventions toward service users who were without active symptoms has yet to find support in the literature. Indeed, guidance recommends that people with persistent and distressing symptoms of schizophrenia/schizoaffective disorder should be offered CBT and FIs as a matter of course (NICE Schizophrenia Guidelines, 2002). Perhaps this reflected a lack of

knowledge about referral criteria and efficacy information for CBT and FIs among participants. Anxieties about psychoses' amenability to treatment - the finding that waiting lists were viewed as a barrier to accessing CBT and FIs is reflected in the literature. For example, it is suggested that the demand for formal talking therapies exceeded the supply of such interventions (NHS Executive DoH, 1996). This was one issue that prevented professionals making referrals and led to them inventing their own treatments, which they actually viewed as insufficient.

Valuing psychosocial interventions - mental health professionals suggested that historically CBT had been viewed as ineffective as a treatment for schizophrenia spectrum disorders. To the extent that this view prevailed, it was considered to be a barrier for service users accessing this treatment. As previously stated, research evidence gathered over the past decade provides support for the notion that CBT is efficacious with schizophrenia/schizoaffective disorder (Garety, Kuipers, Fowler, Freeman and Bebbington, 2001; Pilling et al, 2002a) although the effects were only shown to be maintained for two years. The current findings were that CBT and FIs were considered to have poor cost-efficiency. Mental health professionals stated that releasing staff to engage in CBT and FI training courses was limited by budgets. This was viewed as a barrier to accessing CBT and FIs for service users and carers. The perception that cost was a potential barrier to psychosocial treatments has been discussed elsewhere in the literature (for example, Tarrier, Barrowclough, Haddock and McGovern, 1999). However, as stated in Chapter 1, Leff, et al., (2001) showed that the cost of training was relatively moderate compared with that of in-patient care. Further, the results of two studies suggested that CBT is likely to be more cost-effective than 'non-specific counselling' (Healey et al., 1998) or 'standard care' (Kuipers et al., 1998). This suggests that information concerning the cost-effectiveness of the interventions was either unconvincing or had not been made widely available to mental health professionals in the present study.

In sum, as has been shown, many of the themes emerging from the current findings that were organised under the core category Service Hostility found support in the existing literature.

#### *4.3.4 Perception of the Service as 'Elitist'*

There were two subcategories identified under the core category Perception of the Service as 'Elitist' these were as follows: Needs of the local community and Researcher-clinician divide. Each of these subcategories is considered below in terms of how it relates to the existing literature. In terms of the needs of the local community, mental health professionals commented that the centralised locality of specialist/national services was a barrier to service users and their carers residing in other directorates accessing psychosocial interventions. This is what they argued made services "elitist". Established guidelines on the treatment of schizophrenia promote the requirement of assessing need for psychosocial interventions nation-wide (National Collaborating Centre, 2002). The findings presented the argument that therapists who did not travel to people's homes might prevent service users and carers obtaining access to psychosocial interventions. In concordance with this outcome, the existing literature argues that the provision of psychosocial interventions requires services to demonstrate flexibility (National Collaborating Centre, 2002).

Within the present investigation the theme researcher/clinician divide maintained that for mental health professionals, the research carried out in and around the Trust was inadequately generalised to widespread clinical practice. This finding was reflected in the existing literature which suggested that transferring knowledge gained from research conducted surrounding the clinical effectiveness of psychosocial interventions into service provision presented a challenge (Yusupoff, et al., 1996; Tarrier, Barrowclough, Haddock and McGovern, 1999; Tarrier and Bobes, 2000).

In sum, both of the themes emerging from the current findings that were organised under the core category Perception of services as 'elitist' found support in the existing literature. The finding that centralised psychosocial intervention services were a barrier to service users and carers accessing those services found support in the literature. The present results also provided support for existing literature suggesting that disseminating knowledge gained from research was a challenge

#### *4.3.5 Information and Communication*

There were five subcategories identified under the core category Information and Communication these were as follows: Relaying information; Identifying services; Engagement and acceptability; Carers' expectations and Clash of interests. Each of these subcategories is considered below in terms of how it relates to the existing literature. The theme relaying information recorded a service user stating that carers could communicate information about services to service users. This notion provides support for previous research that demonstrated how carers might usefully act as a channel between service users and mental health professionals where tension exists and professionals and service users find it challenging to work collaboratively (Shepherd, Murray and Muijen, 1995). Carers in the Shepherd, Murray and Muijen, (1995) study were well-positioned as mediators as they were able to hear the views of service users and professionals and argued that all aspects of care regarding service users were worthwhile considerations. However, in the current study a carer revealed that this would present a challenge for carers. Perhaps some further explanation for this can be found in the existing literature which states that the importance of psychoeducation to carers can be underestimated by mental health professionals (TARRIER, Barrowclough, Haddock, McGovern, 1999) although it may be a powerful tool for engagement (Kuipers, 1998; Fadden, 1998). Further, there can be conflicting relationships between service users and carers rendering positioning carers as a channel of information between mental health professionals and service users difficult (TARRIER, Barrowclough, Haddock, McGovern, 1999).

Within the subcategory identifying services, the current findings suggest that carers viewed psychosocial interventions for schizophrenia/schizoaffective disorder as either non-existent or unavailable. This was coupled with a sense of isolation that carers described. Support for this notion is found in the literature where Fadden (1998), for example, asserts that it is essential that there are outreach provisions available and that there are close links between services in order to enable carers to engage with family interventions.

Within the theme engagement and acceptability, carers offered the hypothesis that service users refused to engage with services as a result of the stigma associated with

having mental health needs. Thus, social stigma was discussed as a factor that prevented service users and carers accessing psychosocial interventions. As argued in Chapter 1, the existing literature states that the social undesirability of the terms schizophrenia or schizoaffective disorder may make them difficult to tolerate for service users and their carers (Deegan, 1993; Drayton, 1995; Fowler, Garety and Kuipers, 1995; Tarrier, Barrowclough, Haddock, McGovern, 1999).

In terms of carers' expectations, participants (i.e., carers and mental health professionals) were divided in their views. It was found that carers highlighted a disregard for carers' needs among mental health professionals. This supported previous research stating that carers often felt as though the caring role was devalued by staff, which left them feeling rejected (Shepherd, et al., 1995). The current study found that this occurred when carers acquiesced - complying with what was required of them without challenging perceptions about their role or the comprehensiveness of what had been offered. It was found that mental health professionals, on the other hand, argued that carers' low expectations of services was a barrier to accessing CBT and FIs for service users and carers. Further, mental health professionals described a problematic mental health system whereby people who had relatives who made complaints received innovative treatments whereas those without did not. Previous research would suggest that mental health professionals ought to be aware that the caring role can be extremely emotionally demanding and act sensitively towards this (Kuipers, 1998; Barrowclough, Labbon, Hatton and Quinn, 2001).

Findings indicated that mental health professionals and service users had differing views on how service users should be treated which was described as a fundamental "clash of interests". Integral to this was a consideration of the role of carers that emerged from discussion between service users. Service users described the barrier as being ineffective attempts by mental health professionals to facilitate carers' expression of their viewpoint and ensure that their perspective was valued in order to promote engagement with the service. This concurs with previous research suggesting that there is often friction in relationships between mental health professionals and carers which is a barrier to the access of psychosocial interventions (Fadden, 1997). In sum, in general the themes emerging from the current findings that were organised

under the core category Information and Communication found support in the existing literature.

#### 4.3.6 *Overcoming barriers*

There were five subcategories identified under the core category Overcoming barriers these were as follows: Communication; Research, training and supervision; Service development; Valuing cultural diversity and Modes of delivery. Each of these subcategories is considered below in terms of how it relates to the existing literature.

Service users identified it as essential to have clear communication with mental health professionals from initial contact in order to build a trusting relationship. This notion found support in the existing literature that states that there are occasions where relationships between mental health professionals and service users are problematic (Deegan, 1993; Linnett, 1999). Service users in the current study argued that the provision of information leaflets and the availability of details facilitated engagement with mental health services, which promoted engagement with psychosocial interventions. In order to disseminate information, mental health professionals suggested that it could be useful to have people visiting different sites around the Trust. Carers suggested campaigns to promote public awareness of CBT and FIs. Mental health professionals argued that best practice required recognising carers' needs and involving carers in work with service users, it was suggested that this might be a method of promoting the carers' wellbeing.

Under the theme research, training and supervision, carers suggested it would be helpful to carry out in-depth investigations into the needs of carers, followed by targeted interventions designed to support them. As stated in Chapter 1, there is increasing demand to canvass and incorporate the views of consumers of mental health services in order to inform service development (Barrowclough and Tarrier, 1997; Linnett, 1999; Barker, Lavender and Morant, 2001). The complexity involved in accessing service user and carer views presents an exciting challenge for mental health services (Tarrier, Barrowclough, Haddock, McGovern, 1999; Linnett, 1999).

There were a number of issues regarding training in psychosocial interventions with schizophrenia. Mental health professionals mentioned that it was necessary to place

emphasis on training in CBT and FIs for schizophrenia/schizoaffective disorder. The findings from the present investigation support previous research suggesting that for some mental health professionals the prospect of working with families might be daunting (Tarrier, Barrowclough, Haddock, McGovern, 1999). Elsewhere, training for mental health professionals from various disciplines has been described as essential for implementation into routine clinical practice (Fadden, 1998; Leff, Sharpley, Chisholm, Bell and Gamble, 2001).

Mental health professionals argued that it was the responsibility of the team to encourage its members to pursue training opportunities in CBT and FIs.

It was considered essential that, for example, a community mental health nurse interested in offering CBT have *protected time* to apply his/her knowledge and skills during training and once training was complete. Fadden (1997) emphasised the importance of a context that was supportive to mental health professionals in order to afford them the possibility of offering psychosocial interventions. Tarrier, Barrowclough, Haddock, McGovern, (1999) argued that the clinical techniques involved in offering psychosocial interventions presented a challenge to mental health professionals as they were difficult to learn and apply in routine practice.

Within the present study the theme of service development highlighted that people offering psychosocial interventions ought to be evenly dispersed in order to increase the consistency in the service between areas. In the literature, for example, Fadden (1998), asserts the importance of having the option of therapists seeing carers at their homes. It was argued that having this option enhances the likelihood of carers engaging with family interventions. In addition, mental health professionals commented that specialists in the interventions described could provide supervision to teams and create a network of people offering psychosocial interventions - a notion again supported by the literature (Fadden, 1998).

The service user interviewee viewed it essential to argue for a position that valued cultural diversity. This included a consideration of the degree of representativeness of those offering psychosocial interventions in terms of reflecting the cultural diversity of the local population in order to promote engagement with psychosocial interventions.

According to a Department of Health publication, a number of user groups and voluntary bodies reported that black and minority ethnic groups, lesbian and gay people, older adults, people with chronic illness, people with physical or learning disabilities, people from socially disadvantaged backgrounds and children were underserved by psychological therapies (NHS Executive DoH, 1996).

It was asserted that those who offered psychosocial interventions should have the infrastructure to support working with people for whom English was not a first language and to overcome social stigma. NHS Executive DoH, (1996) suggested that equality of access, comprehensive provision, service user choice, and services which were client-centred were essential. Findings of the present study suggested that partnerships might be developed with local communities, which would enable the NHS to use their facilities to provide a service that was acceptable to those communities. Innovations like the Sainsbury Centre for Mental Health's, "Breaking the Circles of Fear" have been considered good examples of how services to black and minority ethnic groups might be evaluated and developed to ensure they reflected an ethos of valuing cultural diversity (IoP Research Report, KCL, 2002). Once the providers of mental health organisations demonstrate consistently that diversity is valued, there may be an opportunity to gain more understanding about the social and environmental factors leading to the overrepresentation of people from some ethnic minority groups in the mental health service and how their needs might best be addressed. Further, it was found that it was essential to be creative about how services might be structured so that they overcame the barrier that social stigma might present for some service users and carers. The existing literature maintains that social stigma is a particular concern in some cultures that might relate to a tendency to delay accessing services (Shimodera, Inoue, Tanaka and Mino, 1998).

In terms of the theme modes of delivery, there were suggestions about improving access to CBT by, for example, delivering it in a group format. Further, service users described how other service users could offer support to people with persistent and distressing symptoms of schizophrenia/schizoaffective disorder. The notion of service users facilitating discussions about recovery found support in the existing literature (Deegan, 1993). It has been noted that service users sharing their experiences with

other service users can be beneficial, particularly where there is a focus on “surviving mental illness” (Deegan, 1993). It was also suggested in the findings that carers might appropriately have their needs met within the voluntary sector. In sum, the constructs emerging from the current findings that were organised under the core category Overcoming barriers found support in the existing literature. For example, the finding that there was a need to research the views of carers was supported by the literature. Also supported by the existing literature was the view that lack of training and a lack of client-centred services were barriers to service users and carers.

#### *4.3.7 Main relationships between core categories and their subcategories*

Of the main relationships between core categories and their subcategories identified across four topics namely: Information; Culture; Role expectation and Identifying needs, the latter topic will be presented here alone as the preceding topics have been addressed above. Identifying needs - carers in the present study suggested that when it was perceived by service users that having a diagnosis of schizophrenia/schizoaffective disorder was viewed as “bad” engagement with and acceptability of services was described as “low”. Further, mental health professionals and carers asserted that service users would engage with services offering psychosocial interventions when service users identified that they had needs which could be met by those services. This found support in the existing literature which states that service users are experts on their own needs (Linnett, 1999). Also, it suggests the importance of moving away from seeing someone as an “illness” towards seeing him/her as an individual (Deegan, 1993).

### 4.4 Critique of the study

#### 4.4.1 Introduction

In the previous section, the main findings were reviewed in terms of the existing literature. The qualitative approach used enabled the researcher to interact with the data to co-construct, refine and develop theory relating to barriers to accessing CBT and FIs for service users with medication non-responsive schizophrenia/schizoaffective disorder and their carers. This investigation adds to the existing literature, which is lacking in exploratory studies using qualitative research methods specifically with service users with schizophrenia/schizoaffective disorder

and their carers alongside mental health professional participants. This section turns to a brief critique of the study examining its methodological limitations.

#### 4.4.2 Grounded theory, focus groups and semi-structured interviews

Grounded theory was well suited to facilitate the process of discovery. The findings were therefore exploratory rather than definitive. The researcher was able to move from data to theory so that new theories evolved (Willig, 2001). As stated in Chapter 2, according to Shepherd, Murray and Muijen, (1995), in comparison with quantitative methods, a qualitative design was viewed as more suitable where the questions to be investigated were difficult to specify clearly in advance. It is acknowledged that it can be difficult to select which aspects of a qualitative study to present. However, this study focused on the key themes which emerged from focus group discussion and semi-structured interviews which were relevant to the research questions. The focus group questions and semi-structured interview schedule were designed to explore socio-cultural/political/contextual factors that may have been related to barriers to accessing CBT and FIs for service users and carers. On reflection it is perhaps striking that there were no more constructions of categories which highlighted internal psychological processes for participants.

Strauss and Corbin's (1990) development of grounded theory offers a coding process that consists of three types: open, axial, and selective. The initial phase in the coding process is 'Open coding' it involves examining and comparing data so that incidents or events are grouped together (Wilson Scott, 2004). The next stage is 'Axial coding'; at this point data are grouped in new ways that suggest relationships between categories and subcategories. Finally, selective coding may be described as the process by which subcategories are related to the core category (Babchuk, 1997). This is the phase in which the 'storyline' is developed alongside interpretation of the evolving theory (Wilson Scott, 2004). However, it is important to note here that during analysis of the present data, whilst asking questions of the data the researcher was aware of Charmaz' (2000) admonition that, 'Every qualitative researcher should take heed of his {Glaser's} warnings about forcing data into preconceived categories

through the imposition of artificial questions' (p.514). Hence, Strauss and Corbin's (1990) coding process was not rigidly adhered to.

#### 4.4.3 Participants

The sample was not a randomly selected statistical sample but specially designed to elicit views on barriers to accessing cognitive behaviour therapy and family interventions. Focus groups usually employ "purposive" sampling techniques selecting the membership of the group because of the nature of the research questions (Shepherd, Murray and Muijen, 1995). This enables readers and researchers to determine the extent to which the findings might be considered similar to other groups or individuals. The research included only participants who were willing volunteers – these were perhaps not those service users and carers who would typically have the most difficulty accessing psychosocial interventions. However the findings demonstrated that the participants were able to discuss barriers to accessing CBT and FIs. It is not possible to generalise the findings of the present study to a wider population due to the small number of participants. However, being a qualitative study, the present investigation did not aim to use a representative sample. As with other grounded theory studies the theories were not mutually exclusive and were considered to be specific to the context in which they were developed (Willig, 2001).

Participants were required to speak English fluently – this meant other groups were excluded. However, the study was rich with cultural diversity largely as a reflection of the region from which participants were selected. It is accepted that the location of the groups and interviews may have impacted on the data collection and theory development. In particular, service users' and mental health professionals' groups and interviews took place in NHS settings, this may have influenced the responses they gave. Only Rehabilitation service users were included although there were in-patients from two units and community service users.

The researcher did not attempt to achieve "authenticity" or respondent validation (Mays and Pope, 2000) although attempts were made to "ground" interpretations in the data. Evidently, the findings of the study represent the researcher's interpretation

of the data, which includes analysis of processes that respondents may not have been consciously aware of. Any attempts to “validate” the findings by returning to respondents may have caused them unease (see further discussion under ‘Quality’ 4.4.4 below). The data were discussed as “reconstructions” of experience, not the original experience itself (Charmaz, 2000). It has been stated that the researcher’s interpretation of the data shapes the emergent codes in grounded theory (Charmaz, 2000).

The verbatim transcripts that formed the data were limited by the absence of contextual information such as voice tone and volume. Time and space would not have permitted a thorough consideration of the influence of those factors on theory development. Further, due to financial constraints the researcher was also the focus group moderator and interviewer. However, the reflexive preface to this study and the Reflexivity section in Chapter 2 allow for alternative conclusions about the data to be drawn.

The focus group design involved group processes that may have inhibited full and open participation hence individual semi-structured interviews were also used in the present study as a means of triangulation. Focus groups took place before individual interviews to raise issues for more in-depth discussion in dyads. The moderator was able to make use of clinical skills to facilitate discussion particularly where groups appeared to have an impasse in order to open up discussion by, for example, summarising what had been said. Indeed, the focus groups demonstrated participants’ use of an opportunity to creatively discuss a topic within a dynamic of like type of participant, which largely contributed to theory development.

#### 4.4.4 Quality

As mentioned in Chapter 2, Mays and Pope (2000) argue that concepts such as Triangulation, Respondent validation, Reflexivity, Attention to negative cases and Fair dealing are considered crucial to the evaluation of qualitative research.

Elliot, Fischer and Rennie (1999) suggested that it was particularly important to consider the following whilst judging the quality of qualitative research: Owning one’s own perspective; Situating the sample; Grounding in examples; Providing

credibility checks; Coherence; Accomplishing general versus specific research tasks and Resonating with the reader. Here, the notion of Quality in qualitative research is examined as it relates to the present investigation under the following subheadings: Triangulation; Respondent validation; Accounts of methods of data collection and analysis; Attention to negative cases; Fair dealing; Owning one's own perspective; Situating the sample; Grounding in examples; Coherence; Accomplishing general versus specific research tasks; and Resonating with the reader.

1. *Triangulation* – It is acknowledged that potential problems with triangulation were that it assumed any weakness in one method of collection was compensated for by the other method (Mays and Pope, 2000). The researcher included both focus groups and semi-structured individual interviews with different “types” of participant (service users, carers and mental health professionals) in the design of the study in order to address this issue. The researcher was aware that triangulation in the present study merely ensured comprehensiveness and could not be taken as a pure test of validity (Mays and Pope, 2000).
2. *Respondent validation* – Careful consideration was given to the subject of respondent validation. This issue was also discussed in supervision. The researcher had the opportunity during the data collection and analysis phase of the study to discuss findings with the participants. However, in this instance, in common with many other qualitative investigators the researcher chose not to engage in the process of respondent validation as the informants may not have been aware of the processes which had been identified during the analysis (Elliott, Fischer and Rennie, 1999). The researcher's view was that, although the processes involved and the issues being addressed were already potentially distressing for some participants, it may have caused them further distress to hear an additional representation of the data from someone who had identified herself as a mental health professional at that stage. In the future, a similar study could make use of a team of trained analysts including mental health professionals, carers and service users to assist with collating and analysing the data in order to establish a form of concordance or ‘inter-rater reliability’ in

terms of analysis of the processes involved. The passing of time allows the researcher to be assured in her intention to make the present study accessible to participants on their request and she would welcome their comments.

3. *Accounts of methods of data collection and analysis* – As stated in Chapter 2, the “*abbreviated version*” of Grounded Theory was used to work with the original data (Willig, 2001). This resulted in the researcher exercising *theoretical sensitivity* (moving from a descriptive to an analytic level of interaction with the data) being amenable to implementation solely within the texts that were being analysed (Willig, 2001). Perhaps a further issue related to the abbreviated version of grounded theory was that in this case it did not allow for analytically deep selective code.
4. *Attention to negative cases* – The researcher’s intention to achieve *theoretical saturation* – where the researcher continued to sample and code the data until no new categories could be identified was limited by resources. As mentioned in Chapter 2, using the “abbreviated version” of Grounded Theory resulted in the processes of theoretical saturation and negative case analysis being amenable only to implementation within the texts that were being analysed (Willig, 2001). However, the analyst was able to carefully review the data for discrepancies, and/or errors and make use of supervision with a clinical psychologist experienced in the field of mental health in order to consider any corrections or elaboration to the original analysis (Elliott, Fischer and Rennie, 1999).
5. *Fair dealing* - The “types” of participant included in the current research were: service users; carers and mental health professionals. This ensured that the design of the study incorporated a range of perspectives enabling the views of a number of “types” of participant to be gathered (Mays and Pope, 2000).
6. *Owning one’s own perspective* – The disclosure of the researcher’s own perspective on the research was designed to facilitate the reader’s consideration of possible alternatives (Elliott, Fischer and Rennie, 1999). The

researcher was aware of her theoretical orientations, personal anticipations relating to relevant experiences and beliefs about the topic of research.

7. *Situating the sample* – The demographic characteristics of the research participants and their relevant life circumstances were detailed in order to assist the reader with considering the transferability of the findings (Elliott, Fischer and Rennie, 1999).
8. *Grounding in examples* – The researcher accepted the relevance of the notion of “*The importance of fit*” (Henwood and Pidgeon, 1992) which is concerned with ensuring that analytic categories generated by the researcher fit the data well. Therefore, examples of the data taken from transcripts of both focus groups and individual interviews were provided in Chapter 3, and in the Appendix 5 in order to illustrate the analytical procedures used and the process of theory development (Elliott, Fischer and Rennie, 1999; Willig, 2001).
9. *Coherence* – Through supervision with an experienced clinical psychologist in the field of mental health, steps were taken to enable the research to be represented in a way that achieved coherence and integration whilst maintaining nuances in the data (Elliott, Fischer and Rennie, 1999).
10. *Accomplishing general versus specific research tasks* – Due to small numbers of participants, the findings of the present study were limited in terms of their generalisability across persons and contexts. However, the aim of this investigation was to explore in-depth accounts of a small number of participants, rather than make more general and less detailed claims. Also, theoretical sampling was used to ensure that an initial sample was drawn “to include as many of the possible factors that might affect variability” (Mays and Pope, 2000 p.52). In addition, as mentioned in Chapter 2, the provision of detailed demographic data about participants’ lives enables readers and researchers to determine the extent to which the findings might be considered similar to other groups or individuals.

11. *Resonating with the reader* – One of the researcher's aims was to clarify and expand the reader's understanding and appreciation of the research area. The researcher was aware of the importance of presenting information in such a way that the reader could judge it to accurately represent an account of the subject matter. This was facilitated by discussion with both the research and field supervisors who had extensive knowledge of the methods used and experience in the field of mental health (Elliott, Fischer and Rennie, 1999).

In sum, the above has listed eleven goals of qualitative research and stated how the present study was constrained in its purpose of meeting those goals.

#### 4.5 Clinical Implications

Despite the limitations of the present study as stated above, many clinical implications can be drawn, these are presented here. A number of barriers to accessing CBT and FIs for service users with schizophrenia/schizoaffective disorder emerged that were concerned with the dominance of the medical model. A priority area for clinicians to address would be how and when medication is administered. For example, it is considered good practice that mental health professionals consider service users' religious beliefs when prescribing/administering medication. Further, it is important that the provisions of the Mental Health Act (1983) be used in the knowledge that service users with schizophrenia/schizoaffective disorder might feel discriminated against, particularly when they are from minority ethnic backgrounds, which would have the potential to exacerbate their distress. Clinicians are required to be thorough when informing service users and carers about the side effects of medication in order to assist service users with making decisions about their treatment.

When service users and carers are able to access CBT and FIs it might be appropriate to explore some of the topics mentioned above during clinical interviews. For example, discussion could include an assessment of the effects of stigma on the service users' self-esteem. One may have had to subscribe to practices that were contrary to one's individual/cultural beliefs and values in order to access psychosocial interventions, where this is acknowledged it may facilitate engagement, particularly for minority ethnic groups. Barrowclough and Tarrier, (1997) argue that if

psychosocial factors are associated with the experience of symptoms of schizophrenia, this suggests attention to these factors could be instrumental in the management of the condition. This may include a consideration of how cultural factors impact on the individual and his/her carers. In tandem with this approach one could consider a programme of mental health promotion within the community to assist with reducing stigma.

It is argued in the literature that people who are labelled with a mental illness are devalued by Western culture (Deegan, 1993). Fowler, Garety and Kuipers (1995) suggest that internally, labels can be self-defeating and exacerbate the experience of distressing psychotic symptoms. In terms of “illness models”, negative beliefs about oneself may, for a time, be reinforced so that one can obtain psychosocial interventions. The possibility that individuals have overcome such obstacles in order to access CBT and FIs could be acknowledged in therapy sessions. Where it is unhelpful to relate to a service user in terms of a diagnosis, psychologists and the teams they work with could adopt alternatives to this. For example, one might choose to encourage the service user to develop a language about his/her experience that is acceptable to him/her. This could include a functional description of the impact of the distress on the service user. Engaging service users with the service by developing a shared language may facilitate access to psychosocial interventions for service users and carers (Barker, Lavender and Morant, 2001).

The findings suggest that it is crucial to engage carers in terms of collaboratively negotiated interests, this requires mental health professionals to actively listen to carers. When working with carers it would appear particularly essential to examine how they feel about how they are expected to be involved in the service user’s care and that mental health professionals arrange support for carers where it is needed. Otherwise, isolation and a lack of effective support pose potential barriers to accessing CBT and FIs for service users and their carers. Subsequent to successful engagement of carers, as suggested by the findings, one could work with carers to inform service users of psychosocial interventions where appropriate.

The findings would seem to argue that psychosocial therapists have a responsibility to disseminate information about treatment availability and promote the notion of recovery from schizophrenia/schizoaffective disorder among the service users and carers they come into contact with. Indeed, this responsibility might also extend to facilitating discussion about recovery with other members of the multidisciplinary team in order to instil hope in service users, carers and other professionals (Deegan, 1993). Mental health trusts have a role in facilitating the dissemination of research. For example, it is important that Trusts are able to inform stakeholders about the cost-effectiveness of CBT and FIs as these studies emerge (Leff, et al., 2001). The present findings also indicate that service users would relish the opportunity to talk about their distress. Therefore, the fact that one is in distress could be viewed as a reason for mental health professionals to make a referral for CBT and FIs rather than the converse. The findings also suggest that mental health trusts have a responsibility to increase the number of staff available to offer psychosocial interventions in order to decrease waiting lists. Care Programme Approach (Department of Health, NHS Executive, 1999) care co-ordinators might consider using feedback from service users to measure the level of confidence service users in their care have in their relationship in order to facilitate the service user's exploration of services available to them. For care co-ordinators, this could include checking with service users and carers how they feel about accessing psychosocial interventions. If it emerges that they perceive barriers to accessing those types of intervention, given the opportunity to suggest alternatives, they may construct viable innovative solutions to those barriers. One such action might be to specifically promote psychosocial interventions to people from minority ethnic backgrounds.

It is important to note that although psychosocial models in the treatment of schizophrenia/schizoaffective disorder have gained more credence in recent years, CBT and FIs are not perceived as a panacea. However, perhaps greater emphasis could be placed on psychosocial approaches as a treatment option on a service user's/carer's initial contact with the service.

In summary, there were a number of clinical implications that followed from the findings of the present study. Clinical implications included the need to acknowledge

particular barriers service users and carers may have had to face in order to access CBT and FIs in clinical interviews when they are able to access those services. Also considered essential was the task of developing a language with service users and carers that was meaningful for them and did not contribute to the negative impact that stigma can have on the service user's self esteem. It was also stated that there was a necessity to engage carers in terms of a discussion about how they feel about perceived expectations regarding how they will be involved in the service user's care. Lastly, it was stated that psychologists have a responsibility for promoting the notion of recovery in their day-to-day work. The following section examines implications for future research.

#### 4.6 Implications for future research

Given the methodological limitations of the present study and the clinical implications arising from it, this section provides suggestions for future research. As a research approach, grounded theory demonstrated particular utility regarding collating and analysing data from service users, carers and mental health professionals. The analytical process produced theory that was "grounded in the data" and suggestive of the rich qualitative detail that emerged from discussion. Therefore, it is recommended that this method be used more widely in research with similar types of participant. Likewise, the focus group methodology showed itself to be a useful format for eliciting views of participants, which became essential to the process of developing theory. It is recommended that psychologists use a focus group design with service users, carers and or mental health professionals where researchers are aiming to explore and contrast views on a particular topic within and between groups. A researcher might begin with replicating the present investigation as a longitudinal study.

Future research in the area of barriers to accessing CBT and FIs for service users with medication non-responsive schizophrenia/schizoaffective disorder and their carers could further explore carers' expectations of services and the impact of their expectations on perceived burden. As stated in Chapter 1, research is needed to develop and refine screening procedures with the power to predict who would gain most from a course of CBT for schizophrenia/schizoaffective disorder (Garety,

Fowler, Kuipers, Freeman, Dunn, Bebbington, Hadley and Jones, 1997) and enhance its clinical efficacy (Durham, Swan, Fisher, 2000). This research could focus on the timing of the introduction of psychosocial interventions and whether CBT can consistently demonstrate efficacy where service users refuse medication. A further area for research surrounds the necessity of developing models of psychosis that examine in detail the role of social adversity in the development and maintenance of distress relating to psychotic experiences particularly highlighting the experiences of people from minority ethnic groups. It is also recommended that similar research is carried out with other types of participant such as survivors of mental health services or people who access primary care and as yet have not engaged with mental health services. Further, the subjective experience of the clarity of one's role as a clinician and one's perceived level of competence and confidence in providing psychosocial interventions could be examined. In terms of training in CBT and FIs, as Tarrier et al (1999) argue, high quality evaluation of training is necessary particularly if training can be demonstrated as being cost-effective as this would reduce perceived barriers to offering CBT and FIs.

## **Chapter 5: Conclusions**

This study aimed to explore and illuminate barriers to accessing CBT and FIs for service users with medication non-responsive schizophrenia/schizoaffective disorder and their carers. It emerged that participants were able to provide rich accounts of a number of barriers namely: Dominance of the medical model; Mistrust; Service hostility; Perception of services as ‘elitist’; and Information and communication. Participants also discussed creative overcoming barriers. Barriers were described differently by service users, carers and mental health professionals.

In terms of the Dominance of the medical model, service users were particularly concerned with medication and its side effects. Carers’ primary concerns seemed to be the burden carers experienced. In contrast, mental health professionals spoke mostly about the effects of diagnosis. Mistrust was a complex issue for service users. They argued that psychosocial interventions should be offered in the initial phase of a service user’s engagement with a mental health service. Further, service users highlighted the importance of utilising a culturally sensitive approach within the mental health service. Carers also described a lack of cultural sensitivity as a barrier to accessing psychosocial interventions. Mental health professionals too described a relationship between cultural sensitivity and mistrust between service users, carers and mental health professionals. Service users discussed Service Hostility in terms of the lack of information provided on the efficacy of CBT and FIs. Carers argued that a lack of role clarity among mental health professionals was a barrier for service users and carers. For mental health professionals, the issues about the hostility of the service included the cost of the interventions, a lack of role clarity, the cultural sensitivity of the service, long waiting lists and outdated services. The Perception of Services as ‘Elitist’ was an area spoken about solely by mental health professionals. Information and Communication was discussed by service users in terms of carers being in a position to explain information about psychosocial interventions to service users and a clash of interests between carers and mental health professionals. Carers indicated relaying information, identifying services, feeling isolated and lacking support as barriers. Lastly, mental health professionals argued that identifying services and carers’ expectations were barriers.

In terms of overcoming barriers, service users suggested that good communication facilitated the process of building relationships between mental health professionals and service users. Service users indicated that psychosocial interventions could be delivered using service user tutors. Carers argued that raising awareness of the interventions in the public domain could improve communication about the interventions. Also, that research and training were essential overcoming barriers. Mental health professionals considered effective communication, carer involvement, research, training and supervision, service development and alternative modes of delivering psychosocial interventions to be overcoming barriers. They also concurred with service users that it was essential to address valuing cultural diversity.

These findings are encouraging as they suggest that it is clinically relevant to address barriers to accessing CBT and FIs. For example, where clinicians are sensitive to the potential impact of stigma on one's self-esteem this affords them the opportunity to consider alternatives to diagnostic labels. Further, there is utility in demonstrating that the mental health service values cultural diversity as insensitivity in this area is a barrier to engagement with psychosocial interventions. It is recommended that clinicians are mindful of the need to promote the notion of recovery in their areas of work and beyond. Finally, it is suggested that there is value in offering psychosocial interventions as a treatment option in the initial phase of a service user's engagement with the mental health service. Future research could make good use of qualitative methods with similar types of participants to those in the present investigation. Research is needed to explore carers' expectations of themselves and of services. Also, it would be useful to research the impact of social adversity in the aetiology and maintenance of psychosis, particularly with people from minority ethnic groups.

In conclusion, this research has highlighted the complexity of barriers to accessing CBT and FIs for service users with medication non-responsive schizophrenia/schizoaffective disorder and their carers from the perspectives of service users, carers and mental health professionals and suggested how the barriers might be addressed.

**SECTION C PROFESSIONAL PRACTICE:**  
**A CASE STUDY USING A COGNITIVE**  
**BEHAVIOURAL THERAPY APPROACH TO**  
**WORKING WITH AN INDIVIDUAL WITH**  
**SCHIZOPHRENIA**

## **Case Study: I Heard it on the Grapevine**

### **1 Introduction**

This section presents a case study that demonstrates how Cognitive Behavioural Therapy (CBT) can be used to treat positive symptoms of psychosis. This case study has the goal of demonstrating how as a therapist I linked practice with theory. Key aspects of the interaction are presented here. The focus of the study is on the reasoning behind my assessment, formulation and interventions. I aim to give an account of my clinical skills and ability to select and apply theoretical concepts in practice. My aim is also to demonstrate how my style and interventions were guided by theory and how theory helped me make sense of what was happening.

I will briefly provide information about the context in which the work I describe occurred. I was employed as a counselling psychologist and for four sessions each week I worked on a Rehabilitation Unit. This is where the referral for RH originated. Following an initial meeting we contracted for 12 sessions of CBT. Throughout this work I had clinical supervision.

### **2 The reason for the referral**

RH had a diagnosis of schizophrenia and was referred for psychological therapy following a period of being on the unit where it had become clear that he was not engaging with the therapeutic programme. Staff within the multidisciplinary team were concerned about his prominent negative symptoms. In particular he seemed to lack motivation to engage in dialogue and ward-based activities. At referral stage they were unclear about whether he suffered from any persistent, distressing positive psychotic symptoms.

### **3 Client's background (from RH)**

RH was a 53-year-old man. He said he chose his own date of birth when travelling from Nigeria to Britain in order to meet the legal requirements. Although his medical notes stated that he was of Nigerian ethnic origin he said he was not. He viewed himself as the child of white parents to whom someone had given a tablet to cause his skin to appear dark brown. He did not know where he was born. It seemed important to him to say that he had no relations in Nigeria. In his view this compounded his

problems as it meant that people in authority could abuse him since he had no parents. As he spoke these words his tone of voice dropped and he was choked with distress, his eyes welling with tears. However, in a very helpless manner he said he did not worry about this as there was nothing he could do to change it. He stated that he believed Nigerians killed his parents (he got this information from the *grapevine* discussed further later). He believed that his primary caregiver whilst in Nigeria may have been killed although he questioned the reliability of his source (also the *grapevine*).

He reported having had good schooling where he enjoyed mathematics and economics had friends and was not bullied. He obtained school-leaving certificates and worked as a teaching assistant. He came to the UK in 1978 at the age of 27 years old for an “adventure”. He wanted to go on to become an Accounts Clerk. However, this was difficult because of the differences in accounting in Nigeria and the UK. In 1978 he had “associates” that were part of a political party that he later lost contact with since then he had been socially isolated. He described having had relationships with five women in total since being in the UK. An important relationship he had in 1983 was with someone he met through a magazine. In 2002 he changed his name from a Nigerian one to an English name. He stated that his reason for doing this was that people he did not know had given him his former name.

### **3.1 Additional relevant personal history (from medical notes)**

According to RH’s medical notes his maternal grandmother raised him until the age of 5 years old. He had no contact with his mother and never met his father. He attended a mainstream school and achieved the equivalent of 6 GCSEs. He worked as an assistant primary school teacher until age 26 years. When he came to the UK in 1978 he studied accountancy. He had temporary posts such as cleaning work whilst studying. In 1983 he had a relationship with a woman. He has not been employed since 1984. He has no history of drug or alcohol abuse. There is no known family mental health history.

### **3.2 Client's mental health history (from RH's medical notes)**

At the age of 22 years old, whilst in Nigeria RH is reported to have first complained of a headache which he believed was "caused by a wire in his brain". He was prescribed Chlorpromazine and Diazepam. Since that time he has had numerous mental health admissions – often on a section of the Mental Health Act (1983). He has typically presented with a marked deterioration in self-care.

### **3.3 Medical history**

In terms of his medical history RH had surgery as a child following a head injury sustained due to alleged physical abuse. Subsequent MRI scans could detect no abnormality.

### **3.4 Forensic History**

His forensic history records two incidents. In 1990 he was charged with criminal damage to his property. In 2002 he was charged with harassment and indecency in a public place. Both incidents predated mental health admissions.

## **4 Initial assessment of the problem**

RH and I had individual sessions and used formal assessment measures Psychotic Symptom Rating Scales (PSYRATS: Haddock, McCarron, Tarrier and Faragher, 1999) and the revised Beliefs about Voices Questionnaire (BAVQ-R: Chadwick, Lees and Birchwood, 2000) in order to assess the problems he presented with. This section of the study goes on to report on the content of individual assessment sessions followed by an analysis of the formal assessment measures. The initial assessment was conducted over three sessions. One of the aims I had for our first meeting was to establish his main concerns. It emerged that he was distressed by voices that provided a running commentary on his thoughts and actions. According to Slade and Bentall (1988), voice hearing is considered the most common symptom in schizophrenia and occurs in over 50% of people with this diagnosis. People can experience voices as any of the following: hearing voices speak one's thoughts out loud; hearing two or more voices talking about one in the third person or; hearing voices as a running commentary. This can be a highly distressing experience. RH described thinking

something that was then followed by what he referred to as “the grapevine” confirming his thoughts.

Garety and Freeman (1999), comment that far from CBT treatment goals being exclusively limited to the reduction in the frequency or duration of symptoms, improvement can be appreciated along many other dimensions such as the reducing the level of distress. Following the Fowler, Garety and Kuipers (1995) treatment manual I used an ABC approach derived from functional analysis to assess the voices he described. As part of the assessment of his experience my aim was to ascertain the information about the following, A: Activating event (voice); B: Beliefs about the event; C: Distress caused by beliefs about the event. Within cognitive therapy the clinician’s goal is to alleviate the distress by working with the associated beliefs (Garety and Freeman, 1999). I was mindful that for RH the distress he experienced may have been influenced by the content of the voice and his appraisal of his experience. For example, Chadwick and Birchwood (1994) suggest that the belief that voices are malevolent is associated with negative emotions and resistance of voices. Conversely, they found that the belief that voices were benevolent was associated with positive emotions and engagement with the voices. In line with what has previously been demonstrated through research, at times, RH viewed the voices as positive and at other times as negative (Miller, O’Connor and DiPasquale, 1993). One example of the positive content of the voice was that it said he was owed £105bn for a particular technique of teaching Mathematics that he developed in Nigeria.

RH described the grapevine as qualitatively different from normal communication. For him social isolation, the feeling of loneliness and a lack of activity triggered activation of the voice. He was more likely to hear it when alone and he described it as following him everywhere. It mostly happened at night whilst he was awake, just prior to falling asleep. However, it also occurred at other times. On the morning of one of the assessment sessions, when RH heard the voice it made him feel “emotionally naked”. At the time he was taking a shower. He could reflect that the voice was not as clear or strong as it had been whilst he was on an acute ward although at this stage we did not explore possible reasons for this. In terms of the content of the voice he said he heard things like “you need money to survive”.

He attributed the voice to some kind of communication system supported by state of the art technology. He could not describe the technology the voice used to communicate with him. At this stage he was certain it was not under his control. He wanted to find out who was controlling it and appeared puzzled about this. We considered what might have been going on and he was quite sure there were no video cameras or computers where he was living. I held in mind the notion that hallucinations may result from an impairment in monitoring one's own inner speech or thoughts (Frith, 1987). Also, the theory that the mechanisms underlying voices could relate to a misattribution of internal thoughts to an external source as a bias in self-monitoring (Bentall, 1990).

The voice sometimes spoke simultaneous to conversations he was having with professionals. At these times it would be particularly distracting and disruptive, saying negative things about him. However, it was no longer as loud, strong or frequent as it had been. According to RH the "voice had changed tack" as it used to send broadcasts in the morning whilst he was on the acute ward. More recently it seemed to comment on his behaviour to a greater extent. The voice told him he was a "sitting duck". He identified the dominant voice as the former governor of the Bank of England Eddie George. It was sometimes accompanied by the voice of the acting junior governor. He did not argue with it and believed that replying when it was negative would encourage it.

RH reported that it was as if the grapevine delved into his childhood and this surprised him. It said things about his early life in Nigeria and seemed to know all the facts. He also attributed events to the voice for example, he said the grapevine had used two young girls to tease him. One was a carol singer that knocked on the door of his flat. His view was that as if she teased him for sex. Another example was that a girl on a bus hit him with her bum whilst passing. He thought the grapevine was using these girls to embarrass him. He began to think these events were deliberate when the grapevine said they were. RH described having negative thoughts about himself or others and then hearing "other opinions" in the form of the grapevine that either reinforced his thoughts or made him feel better by disaffirming his worse fears. He

had an 80% conviction that the grapevine controlled the isolation he felt. Therefore, he viewed the voice as very powerful.

As suggested above I completed a PSYRATS Auditory Hallucinations scale with him on assessment. The highest scores for RH were for location, beliefs about origin and disruption to daily life these all scored 4. Frequency, duration and intensity of distress rated the lowest at 2. I completed a BAVQ-R with him. Clinically significant findings were that on assessment he believed the voice was helpful, that it was evil, very powerful, made him feel anxious and made him feel confident. His relationship with the voice seemed paradoxical. When he heard the dominant voice he tried to take his mind off of it, tried to stop it and he was reluctant to obey it. I also completed a CORE-OM (Evans, Mellor-Clark, Margison, Barkham, Audin, Connell and McGrath, 2000) assessment with him where the only area of morbidity identified was problems/symptoms. Although RH did not sustain eye contact, following the assessment sessions my impression was that we had established a reasonable rapport.

#### **4.1 The client's presentation of his problems and reason for attending sessions**

RH came to the first session stating that it was a problem for him that there was a difference of opinion between him the doctors on the ward. He agreed to engage in sessions in order to “come up with an explanation” for his experiences so that he could get “rest”. According to RH he was in hospital as a result of people with “wicked attitudes” having inserted a ringworm parasite into his groin as a child. His view was that scars from the ringworm had only disappeared since the late 1990s, it continued to cause him to itch. When he itched he noticed that the back of his head became warm. He believed that this was what had caused schizophrenia.

#### **4.2 History of the presenting problem**

It was essential to gather information on the history of the presenting problem in order to begin to explore its onset and form the basis for the formulation. It was particularly difficult to pinpoint the onset of RH's difficulties. He reported that he had always known that he had ringworm and he could not identify a time when there had been a change from his normal self. Although the unusual beliefs RH had about headaches whilst in Nigeria that brought him to the attention of services occurred as early as 22

years of age, he reported that the voices started in 1989. At 22 years old he was working in a Nigerian school. This was when the pounding in his neck and the tension headaches started. He described the pounding as racing thoughts about day-to-day things such as looking after his money. He self-presented to a psychiatrist and was given Diazepam and Chlorpromazine (he says with little effect). In 1983 he had a significant relationship that had broken down. He had failed his accountancy exams and been unemployed since 1984. As suggested above the onset of the voices was much later and happened prior to him being charged with criminal damage his to property in 1990. He was arrested and remanded in prison for 6 weeks. Prior to his arrest he had become suspicious of the people in the house that he lived in - believing that they were changing things in his flat. He reported being worried about his health, as he did not know what was wrong with him. It is possible that the onset of psychosis was at 22 years old with subsequent relapses and his first mental health admission in 1990 on Section 3 of the Mental Health Act (1983).

## **5 Summary of main issues**

As described above, the main issues for RH were persistent, distressing auditory hallucinations and a difference of opinion between him and the medical staff which meant that he was detained in hospital on a Section 3 of the Mental Health Act (1983). At times he presented as guarded and suspicious. For example, his narrative and personal history were mysterious in nature. Information that was missing largely related to his family relationships. He seemed to deny having live family or caregivers. One hypothesis regarding this that I did not have the opportunity to share with him in detail was that he perhaps had seen himself as being abandoned by them and discounted them for this reason.

## **6 Formulation**

According to Fowler, Garety and Kuipers (1995), in cognitive therapy an individualised, collaboratively developed and shared formulation is the essence of the therapeutic intervention. Formulation has also been referred to as the “first principle” in CBT (Chadwick, Williams and Mackenzie, 2003). It is accepted that there are different levels of formulation work. For example, there is often a distinction made between a person’s developmental history, the maintenance of their current difficulties

and their relapse profile. This section presents the initial formulation developed with RH using the Garety, Kuipers, Fowler, Freeman and Bebbington (2001) model of the positive symptoms of psychosis. It focuses on the maintenance of his current difficulties. However, it also includes some reference to his developmental history.

According to Garety, et al (2001) in general there is consensus that psychosis occurs in people with a biopsychosocial vulnerability. RH noted traumatic events in childhood. For example, the social impact of physical abuse from his primary caregiver as a child, cultural identity development issues and having no family. Cognitively, in terms of early core beliefs RH formed he seemed to see himself as “unprotected”, “unlovable” and “vulnerable”, “a victim” and other people as “untrustworthy”, “wicked”, “bullies” and “intrusive”.

Living away from home, financial pressures and difficulty at work precipitated the onset of RH’s psychosis. I hypothesised that these events activated his beliefs about being unprotected, vulnerable and other people being wicked bullies. I postulated that emotionally things began to change for him and he became anxious about his ability to meet the demands that were being made of him, felt threatened and as though he could not cope. Garety, et al (2001) propose that for people who go on to develop the positive symptoms of psychosis there is a basic cognitive disturbance that leads to what they term “anomalous conscious experiences” (e.g. heightened perception). For RH it appears that his biopsychosocial vulnerability and certain triggering events led to him experiencing auditory hallucinations, a cold sensation in his neck and the sense that things looked and tasted different. He went on to develop an external appraisal of these experiences i.e. that people were trying to communicate with him, that he had been infected with ringworm and that people had poisoned his food and drink. He also believed that he had a wire in his brain and that his brain had melted. Over time, these beliefs developed into positive symptoms so that he was having auditory, tactile, visual and olfactory hallucinations. He also had developed grandiose and persecutory delusional beliefs. For example believing that he had invented a method of teaching mathematics that made him a genius and the belief that his isolation was a deliberate attempt by the grapevine to cause him harm.

The factors maintaining his positive symptoms appeared to be as follows:

- ◆ His external appraisal of his illness
- ◆ A history of poor adherence to medication
- ◆ A strong confirmatory bias
- ◆ Lack of structured activity
- ◆ Low self-esteem
- ◆ Isolation
- ◆ Poor communication skills

Whilst collaboratively developing this formulation we discussed whether traumatic events in early childhood could have made him vulnerable to becoming unwell. He said that the abuse “almost ruined” his life and that as a consequence he no longer took things at “face value”. I also attempted to make links between accountancy exams that he was not able to pass as a trigger for the onset of the voice.

## **7 Aims of treatment**

An important part of the treatment was sharing the formulation with RH and allowing him to make amendments to it. Therefore, the formulation was subject to review and revision throughout the treatment. The aims of the treatment were derived from a thorough assessment of RH’s presenting problems and a detailed initial formulation of the factors maintaining some of his difficulties. RH wanted to develop an understanding of his condition. He also wished to engage in meaningful activities that gave him satisfaction and a sense of personal achievement. His life goals/expectations were to work and have relationships. He stated that if he did not hear the voice this would be preferable to him as along with the anxiety, the interruption would stop and he would not miss the voice in any way.

### **7.1 Treatment phase**

Mindful of the client and therapist goals established during assessment, the aim was for RH to surmise that we were there to address what was important to him rather than any other agenda he may have thought I brought to sessions. This was an essential part of engaging him in the therapeutic relationship (Tarrier and Bobes, 2000). His history

had revealed that he had often been in conflict with mental health professionals having been admitted to hospital under the provisions of the Mental Health Act several times. Indeed, I reflected that he was subject to Section 3 of the MHA (1983) during his current in-patient stay. I hypothesised that he may have had a fear that I thought he was 'mad' or 'bad' and that my judgement of this would influence his overall treatment on the ward. It was essential to allow him to develop a sense that he had some control over the process of the treatment and that we would make decisions together about how to proceed. Engagement was a particularly important aspect of the work with RH it involved using accurate empathy in response to his distress. It was evident that therapy would not be able to progress without this degree of empathy in the relationship. From the assessment it became clear that he found it difficult to form trusting alliances and that he had suspicions about people that attempted to engage with him. His discomfort in the armchair during the first session suggested he was anxious. His responses were also usually hesitant and he seemed to be carefully guarding against disclosing detailed information about his concerns. On occasion I attempted to demonstrate my understanding of how difficult it must be for him to attend sessions by stating the following, 'some of the people I see for this type of therapy find it really difficult to come along and talk through their concerns. I don't know if that is the case for you but if it is it must put you in a really difficult position'. The fact that he continued to share details about his concerns following this seemed to suggest that it was a helpful comment to make. During the treatment phase I found that there were a number of additional methods of creating situations where I was able to be empathic at my disposal. For example, I would begin sessions by asking him how he was. He generally replied hesitantly, in a low tone of voice with, 'not too bad'. I would respond with a variation of, 'it sounds like you've had a really hard week and lots of things to struggle with is that right?'. I did this with him in order to encourage reflection on some of the difficulties he had faced so that we could collaboratively focus on his key behaviours and cognitions providing a link between sessions. As part of the treatment it was important to allow RH the opportunity to provide feedback about whether my understanding of the issues he had faced was accurate (Beck, 1970). The question, 'is that right?' afforded him such an opportunity. My responsibility as a therapist was to check the appropriateness of my statements and revise them where necessary (Fowler, Garety and Kuipers, 1995).

Once we had established what his main difficulties had been over the past week we proceeded to negotiate a realistic agenda/focus for the session. Agreeing a focus for the session allowed us to ensure that it was paced to match RH in terms of the extent of what he felt able to share. I took account of his hesitation and anxiety and was able to move with him relatively slowly in comparison with if I had been working with someone who suffered solely from a depressive illness for example (Hawton, Salkovskis, Kirk and Clark, 1989). In this way we were able to spend an appropriate amount of time on each issue and limit unproductive discussion.

During the course of treatment I was able to use guided discovery with RH in order to encourage him to reflect on his experience and develop his understanding as well as to foster change (Pilling, et al, 2002a). For example, RH spoke about his first mental health admission and the days leading up to it. He stated that he had suspicions that someone had entered his flat and contaminated his food and drink to “put pressure” on him. In order to examine the evidence for his delusional beliefs I asked, “How have you come to that conclusion?” His response was that his food and drink tasted different. Gently challenging his delusional beliefs I asked whether there was anything about what had taken place that did not seem to fit with the idea that intruders had entered his flat. His response was that it perplexed him that he could not go to the police since there was no “firm ground” in his evidence and he was not completely sure that this was what had happened. I went on to gently suggest possible alternative explanations for his experiences to further verbally challenge his beliefs (Fowler, Garety and Kuipers, 1995). For example, I questioned whether his perception of the taste of food and drink might have changed during this time. I suggested that for some people an anomalous heightened perceptual awareness could be related to an overwhelming emotional response, which due to an externalising bias and schema about himself, others and the world might be attributed to a cause outside of himself (Garety et al, 2001). For him, the context or triggering event was being harassed by his neighbour’s noise pollution. He had reported being extremely anxious, feeling vulnerable in his home and may have been hypervigilant to threat related stimuli. I hypothesised that during his search for the meaning of the event he may have arrived at his delusional belief as it fit with his core beliefs about himself, others and the world i.e. that he was vulnerable, others were bullies and boundaries in

the world were permeable. Due to biases in reasoning he may have found it difficult to attend to and incorporate disconfirmatory evidence and instead jumped-to-conclusions about what had taken place. He was able to consider this as a possible alternative although his conviction in the delusional belief remained strong.

As suggested above throughout the course of therapy we examined some of RH's information processing and reasoning biases (Garety and Freeman, 1999). Garety and Freeman's (1999) review of research in this area suggests that people with psychotic features to their illness often display a 'jump-to-conclusions' style of reasoning. Later, in our work, through logical reasoning we established that some of the voice's claims were not true. RH reported that this helped him to cope. His experience was that in recent times the grapevine had said things that were not reasonable. Working within his belief system we considered alternative viewpoints to what the grapevine had produced. I aimed to continue to normalise some of his experiences in the context of his formulation (Johns and van Os, 2001). I was attempting to make links between the mistrust he had of his primary caregiver in childhood and his current suspicions about people. For example, he was unsure of the credentials of the nurses offering the groups on the unit much as he had been mine in the first few sessions. For this reason he would not attend groups. Throughout the assessment and intervention stages I was careful to demonstrate accurate empathy in order to maintain his engagement in the process of therapy (Fowler, Garety and Kuipers, 1995).

In terms of the behavioural aspects of the treatment we agreed to develop a strategy for change based on our formulation of the problem and work towards his goals in a graded manner. We had established that a lack of structured activity, isolation, poor communication skills and low self-esteem were factors maintaining his distress. He was prepared to begin to address these maintaining factors by going to the local newsagent to buy magazines about fast cars (an interest of his). Prior to this he had occupied himself by watching sport on T.V. in pubs for 2 hours per day using his Section 17 leave. The rationale for this was so that he could begin to use it as a topic of conversation around which to build his communication skills and reduce his social isolation. Following on from this was the idea that he would be in a better position to engage in activities on the unit. Initially, RH said he believed he was doomed to live a

life of isolation as in 1989 a man on the street said he would never have friends. Whilst conducting the behavioural experiments we were able to reality-test this delusional belief. He came to a point where he stated that he wanted to make friends freely so that he could get emotional support from them. He reported the lack of friendship meant he did not have a counter point of view and was susceptible to suggestions from the grapevine without knowing whether they were correct or not. He did not want to engage in homework tasks that involved speaking to particular people for a specified amount of time on certain topics. He suggested that this would be formalising things too much. I was careful to be flexible in my approach and asked him to monitor his interaction with people informally (Fowler, Garety and Kuipers, 1995). We discussed the issue of control over his experience and looked at some of the important things RH could do to enhance his recovery. He said he found it helpful to believe that he had some control over his fate. For example, he acknowledged that a good nights sleep was important to help him control the voice and that thinking about what triggered the voice meant that it was becoming more predictable. We discussed using distraction techniques as a coping strategy to reduce the distress related to the voice (Tarrier, 1992). He listened to music and found this helpful. He said this worked as it caused interruption to the voice.

Working with RH involved liaising closely with the team on the unit. This included the medical and nursing staff. I was able to attend his care reviews and share a version of the initial formulation with the multidisciplinary team. The rationale for this was to promote a psychological understanding of some of his difficulties. The team found it helpful to consider that RH's early experience of receiving care was that it either led to being abandoned (in the case of the loss of his grandmother) or was abusive. This went some way to help describe some of the reasons for the problems he had with establishing trusting relationships, particularly with authority figures. RH's schema of himself as vulnerable and others as bullies predisposed him to believe that others' intentions towards him would be to harm him. With this in mind, as I had been careful to be clear about my reasons for engaging with him, I encouraged others to do the same. This involved stating their intentions and avoiding making ambiguous statements. I suggested how they might use a collaborative approach with him adopting a cognitive therapy communication style that gave a sense that he was able to

negotiate with them and be involved in decisions about his care (TARRIER and BOBES, 2000). It was important that they encouraged him to provide them with feedback to check they had understood him correctly. The idea was to empower him by, for example, giving him choices about what he wanted to do on the ward and being as flexible as possible with him regarding this. For the team, the initial formulation also provided an insight into how his positive psychotic symptoms were maintained by his isolation and poor communication skills. They were able to encourage him to use coping strategies we had developed and provided him the opportunity to reality test some of his delusional beliefs by engaging in informal discussions. I encouraged the team to make every effort to reward RH's attempts at social interaction with verbal praise in order to reinforce this adaptive behaviour.

## **7.2 Outcome**

RH suggested that what the voice said was no longer important as it was mostly faint or not present at all. He had a certain indifference to it. He scored the PSYRATS Auditory Hallucinations scale highest on the component Beliefs about the origin of the voice at 4. He continued to believe that people with wicked intentions caused the voice. Otherwise, he scored 0 on location, disruption to daily life, frequency, duration and intensity of distress. This contrasts with scores on assessment which showed the highest scores for RH were for location, beliefs about origin and disruption to daily life, these all scored 4. Frequency, duration and intensity of distress rated the lowest at 2. His score on the CORE-OM indicated that there were no areas of morbidity. This contrasted with his initial CORE-OM score where the area of morbidity identified was problems/symptoms. The BAVQ-R was carried out with him at follow-up a year after discharge. Clinically significant findings were that although the voice remained 'evil' in his view, as it had on assessment, it was no longer deemed 'very powerful' nor did it make him feel anxious. He no longer tried to take his mind off of the voice nor did he try to stop it. The voice was no longer perceived as helpful, nor did it make him feel confident. RH reported that he remained reluctant to obey the voice.

RH said meeting with me had influenced his thinking in a positive way. He described feeling more confident stating that it showed itself in the way he talked and that he was more able to speak with everyone. He suggested he was more able to negotiate with staff around issues that concerned him. He could assert himself and take control over his experience (which was the alternative to being a “sitting duck”). Staff also reported that he was approaching them and initiating conversation and spending much less time alone in his bedroom. RH and I had gradually built a trusting relationship where we were able to begin to share an understanding of his condition. Overtime, he became less suspicious of my interventions and no longer required me to repeat my reasons for trying to engage him or provide him with information about my professional status.

He has recently been discharged from hospital and lives in supported housing. I had arranged a further six follow-up sessions with him to reinforce some of the gains he made and to develop and share a relapse formulation with him (Birchwood, Smith, Macmillan, Hogg, Prasad, Harvey and Bering, 1989).

## **8 Summary**

In sum, this study focused on work with RH a client with positive and negative symptoms of schizophrenia. RH was referred for psychological therapy following a period of being on the unit where it had become clear that he lacked motivation to engage in relationships and ward-based activities. This case study has shown how CBT an individualised, formulation based approach was used to treat his persistent, distressing psychotic symptoms.



**SECTION D EXTENDED ESSAY:**  
**ISSUES & PRACTICE OF**  
**TRANSCULTURAL COUNSELLING :**  
**A BRIEF GUIDE FOR TRAINEES**

## **Introduction**

Being a black counselling psychologist living and working in Britain means that a great deal of my clinical work has been with culturally distant clients. Mainly through reflective practice, I have come to appreciate that how I perceive and value cultural diversity affects the validity and efficacy of my approach. This experience suggests that as a therapist, it is essential to be aware of how both the client's and one's own cultural identity impacts on the process of therapy. An in-depth consideration of issues in transcultural counselling should therefore be an integral part of training in counselling psychology.

This guide seeks to provide an introduction to some of the issues in transcultural counselling. It will consider how the emerging body of literature surrounding transcultural counselling may be applied to clinical practice. It aims to include suggestions of how the trainee therapist might manage practice dilemmas. Part one locates transcultural counselling within a contextual frame of reference. In particular, it considers the historical context of transcultural counselling. In this section, the definitions of race, culture and ethnicity are expounded. It also aims to ask and provide answers to the question, 'Why think about issues and practice of transcultural counselling?'

In part two, the person of the therapist is considered. It conceptualises the notion of universality and goes on to outline how a model of racial identity can be used to examine an individual's developmental processes. Having considered the therapist in part two, section three focuses on managing difference in therapy. It affords an opportunity for the trainee to consider how a difference in culture between clients and him/herself might influence the therapeutic relationship. This part of the guide examines the issues of Power and Racism.

Finally, part four aims to provide trainees with insight into developing culturally sensitive practice skills. Based on case material from the author's own practice it highlights the process of transcultural counselling; and considers the impact of religion on the therapeutic process. It offers an example of how trainees could include

a consideration of cultural difference in therapy when assessing, formulating, hypothesising and selecting interventions. It also suggests how trainees might manage practice dilemmas.

## Part One

### The Context of Transcultural Counselling

In this section, the context of transcultural counselling is established historically. The definitions of race, culture and ethnicity are expounded. It aims to ask and provide answers to the question, 'Why think about issues and practice of transcultural counselling?'

#### 1 What is Transcultural Counselling?

##### **A Historical Context**

In order to consider what transcultural counselling is, it is necessary to place it within a historical perspective. The tale begins with migration to Britain in the 16<sup>th</sup> century. According to Lago and Thompson (1996), it is likely that West Africans first entered London in 1554. This is thought to have come about as a result of growing trade between Britain and West Africa. At this time, some West Africans were sold to white households as servants. During the mid eighteenth century, Britain became one of the leading slave-trading nations in the world. More recently, in the nineteenth century, the predominant migrant population to England has emanated from Ireland, Europe and the British Commonwealth (for example, the Caribbean: Lago and Thompson, 1996).

The slave trade ended centuries ago. Unfortunately, however, some of the prejudice which was characteristic of those times remains. Kareem and Littlewood (1992) argue that British-born children whose parents migrated to Britain suffer the effects of 'culture shock' – a psychological reaction to living in a country where they are regarded as 'immigrants'. Lago and Thompson (1996) cite recent evidence that 4 out of 5 Afro-Caribbeans and 56% of Asians described Britain as 'very' or 'fairly' racist.

The use of psychological approaches to counselling across cultures has been established for many years (Eleftheriadou, 1994). Within the concept of transcultural counselling, the term 'trans' refers to the, 'active and reciprocal process involved' in

working, 'across, through and beyond' cultural differences (D'Ardenne and Mahtani, 1989). Recently, as a perspective on counselling, it has undergone rapid expansion. This is perhaps as a result of the transcultural counsellor recognising the struggles clients from ethnic minorities may have had to face as a result of their ethnicity and beginning to acknowledge this in therapy. Here, transcultural counselling is defined as a perspective on therapy where the therapist is aware of how both his/her own and the client's racial identity impact on the process of therapy and is sensitive in responding to the client's experience of ethnicity.

### 1.1 Defining Race, Culture & Ethnicity

The general tenet within academia is that each of the terms 'race', 'culture' and 'ethnicity' have distinct yet related meanings (Carter, 1995). What follows is a consideration of these terms from different perspectives.

#### **'Race'**

The concept of 'race' has a long history of use within psychology. Traditionally it has been used to relate to appearance and other physical characteristics (Eleftheriadou, 1994). However, more recently its usage has begun to include some notion of social and political factors. It can no longer be seen solely as a biological construct (Carter, 1995). Carter (1995) suggests that the concept of 'race' is more inclusive than that of ethnicity as it embraces a number of ethnic groups within a given racial category.

Unfortunately, historically and also the to present date, the term 'race' is often used in a derogatory manner (D'Ardenne and Mahtani, 1989). This term continues to be applied to discriminate against groups of people who differ in skin colour. However, despite traditional ideas that races differ inherently in genetic terms, scientific research has shown that there are more differences within racial groups than between them (Eleftheriadou, 1994). 'Race', then, is defined here as a concept that relates to the common aspects of a cultural group in terms of appearance, physical characteristics and observable behaviours that occur within a socio-political context.

## **Culture**

The term culture has shown itself to be immensely difficult to define (Lago and Thompson, 1996). In one attempt to expand on the notion of culture, Carter (1995) argues that it,

‘...represents learned systems of meaning that are shared by people in a particular context where meanings are transmitted from generation to generation. Within a country, it is possible, as a result of group separation and isolation, for several (i.e., racial) groups to have some distinct cultural patterns while at the same time sharing some cultural patterns...(p. 12-13)’

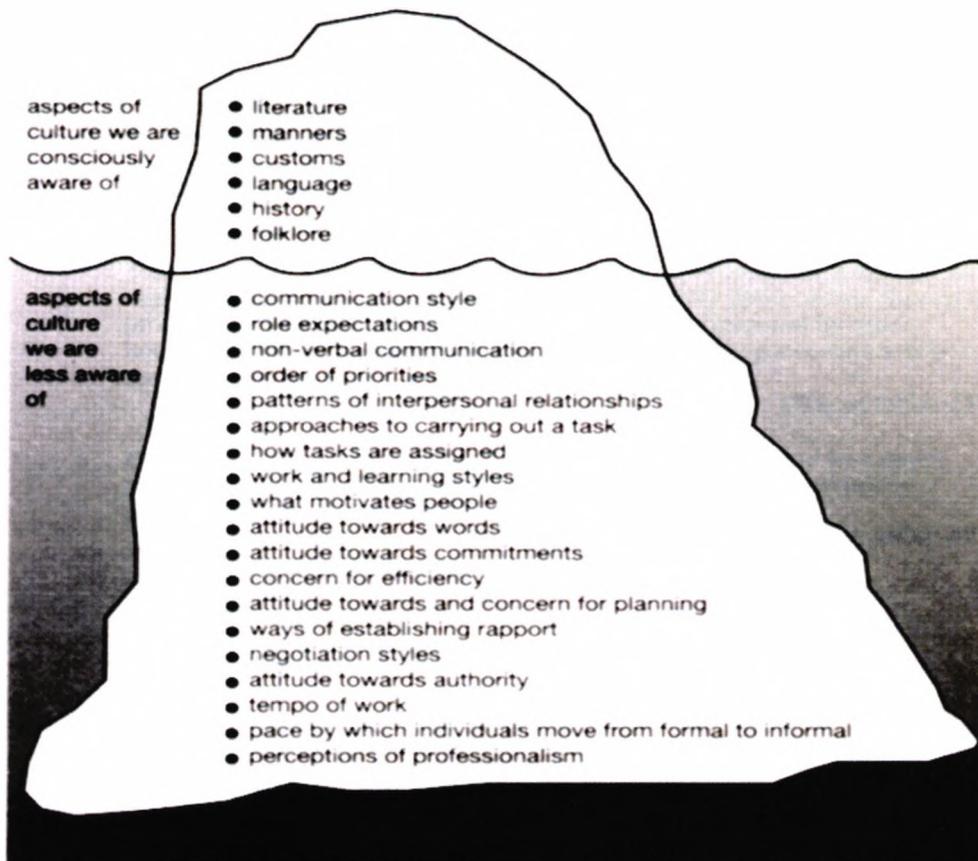
Others have argued that culture influences all behaviour, interpersonal relations, cognition and emotion (Eleftheriadou, 1994; Lago and Thompson, 1996). Culture allows for communication of a set of roles, values, myths, rules and beliefs to be shared within a large group of people (Eleftheriadou, 1994). A person’s culture will affect how he/she interprets and responds to mental illness within the family. For example, Chinese cultural considerations indicate that an incident of mental illness is likely to be kept within the family to protect from social stigma, shame and disgrace (Lau, 1994).

Lago and Thompson (1996) use the notion of the iceberg conception of the nature of culture to elucidate levels of culture that we may be consciously aware of and aspects of culture we may be less aware of (see Figure 1.1 below). For example, they suggest that whilst we may be aware of differences in culture which relate to language and customs, other differences relating to role-expectation and non-verbal communication may be more latent. Rather than simply referring to festivals, art or music then, the term ‘culture’ incorporates all areas of experience.

## **Ethnicity**

There remains confusion around the definition of the concept of ethnicity. However, Fernando (1995) asserts that, ‘The term ‘ethnic’ generally refers to ,‘a sense of belonging based on both culture and race’. In this sense, ‘ethnicity’ is primarily a

'psychological state' (Eleftheriadou, 1994). An ethnic group, then, refers to a group who has a shared history and common culture.



**Source:** C. Lago & J. Thompson, 'Race, Culture and Counselling', Open University Press: Buckingham. (1996), p. 51.

**Fig. 4** The Iceberg Conception of the Nature of Culture

## 1.2 Why Think About Issues and Practice of Transcultural Counselling?

This section aims to provide some reasons for thinking about issues and the practice of transcultural counselling. Ethnocentric monoculturalism is a term used to refer to where – for example, white people in Britain (the group with socio-political power within a community), hold a Western view and perceive non-Western culture as pathological, problematic and or deviant (D'Ardenne and Mahtani, 1989; Wing Sue and Sue, 1999). Where such views are held, cultural diversity is likely to be met inappropriately.

Dein (1997) cites data which estimates that ethnic minorities in Britain comprise 5.5% of the population. Transcultural counselling suggests that the differing conflicts and needs of the approximately 1:18 people in Britain who could be categorised as ethnic minorities, should be addressed sensitively both at service level and within the therapeutic relationship.

In general, findings of British psychiatric research into the diagnosis and treatment of people from ethnic minorities (Goodwin and Power, 1986; Fernando, 1988; Mental Health Task Force, 1994; Dein, 1997) has highlighted the following:

- ◆ Over diagnosis of schizophrenia in West Indian, West African and Asian patients.
- ◆ Under identification of non-psychotic disorders among minority ethnic groups at primary care level.
- ◆ Excessive admission of 'offender patients' of people of West Indian background.
- ◆ In South London the ethnic population had an admission rate to medium secure units 7 times higher than their white counterparts, 28 per 100000 as opposed to 4 per 100000.
- ◆ Irish people are the group most likely to be admitted to psychiatric hospitals and are over-represented in most of the diagnostic categories, especially depression and alcohol-related disorders.
- ◆ People from ethnic minorities are more likely to be given 'physical' treatments (medication and ECT) than their white counterparts. With African people being given higher doses of medication in comparison to other groups.
- ◆ Ethnic minority clients have been found to be under-represented within psychology departments. They are less likely to be offered counselling, other forms of talking treatments and non-medical interventions than majority culture people. This contrasts with over-representation of Afro-Caribbean and Irish patients in psychiatric departments (Table 4 shows the demography of people using psychiatric services in Britain).
- ◆ Over-use of detention under the Mental Health Act (1983) for people from ethnic minorities. Whilst approximately 8% of white patients in psychiatric hospitals are

detained under the provisions of the Mental Health Act (1983), the figure for ethnic patients is about 25%.

- ◆ High rates of suicide among young Asian women.

| Hospital admission for schizophrenia by country of birth* |     |       |
|---|-----|-------|
|   | Men | Women |
| England   | 9   | 9     |
| Ireland   | 18  | 22    |
| Caribbean   | 39  | 35    |
| India   | 11  | 18    |
| Pakistan  | 19  | 12    |

\*Rates of hospital admission per 100 000 of each population over a period of 15 years (includes paranoid psychoses). Data from Cochrane R, Bal SS. Migration and schizophrenia: an examination of five hypotheses. *Social Psychiatry* 1987;22:181-91

**Table 4 Demography of People Using Psychiatric Services in Britain**

Source: S. Dein, 'ABC of mental health: Mental health in a multiethnic society', *British Medical Journal*, (1997) **315**, p. 6.

The above statistics illuminate the fact that in Britain, race, culture and ethnicity influence decisions made about service users within primary care, counselling settings, psychology departments and psychiatry. For service users, access to services, diagnosis, admission, use of the provisions of the Mental Health Act (1983), type and dose of treatment, are often *erroneously* associated with ethnicity. These figures do not adequately reflect the occurrence of mental health problems in ethnic communities. Instead, they are confounded by the stigmatisation and racism within Western culture (Dein, 1997).

Actively thinking about issues and practice of transcultural counselling might prevent therapists recreating discriminatory processes within the context of therapy. It could equip the therapist to be sensitive to what clients may have faced at societal and service levels. It may assist the therapist in working across, through and beyond cultural differences.

In summary, part one considered migration, slavery and present-day racism as the historical context within which transcultural counselling in Britain is located.

Perspectives on the definitions of race, culture and ethnicity were examined. It also argued that the issues and practice of transcultural counselling should be considered

by counselling psychologists in training in order to ensure the provision of a culturally sensitive practice. What follows in part two is an examination of the concept of universality and a consideration of models of racial identity.

## Part Two

### Considering the Therapist

Part one located transcultural counselling within a historical context. It provided definitions of the concepts of race, culture and ethnicity and suggested why it is essential to think about issues and practice of transcultural counselling. Here, in part two, a conceptualisation of the notion of universality is offered. It then goes on to outline how a model of racial identity can be used to examine an individual's developmental processes.

#### 2.1 Universality

Considering the therapist includes an examination of some of the challenges a counselling psychologist might face whilst working transculturally. These challenges are related to the therapist's skill and knowledge base as well as to personal issues. They are linked to his/her awareness of how the same may be utilised across cultures. Here, the notion of 'universality' is taken to entail two related points. Firstly, it refers to the assumption that professionals should be able to work through, across and beyond all cultures (Kareem and Littlewood, 1992). Secondly, 'universality' includes the wider consideration that there is some identifiable presentation of mental illness across cultures. Further, that there exists a clear world-wide concept of mental health. It is postulated here, that rather than being agreed cross-culturally, perceptions of what is normal and what is abnormal are largely informed by an individual's culture or subculture. Hence, notions of normality and abnormality are, to some extent, culture-specific and not universal to all groups (Eleftheriadou, 1994).

Kareem and Littlewood (1992) argue that for the professional, there are obvious challenges in attempting to work therapeutically with the culturally different. For example, a client from an Arab culture may respond to bereavement very differently from the way in which a therapist with experience solely of Western culture would expect. A therapist could find him/herself working on the assumption that the client's

presentation is somehow pathological. However, Arab culture may consider the client's presentation to be within the accepted/normal range of responses.

Lago and Thompson (1996) use anecdotal encounters to argue that in Britain, many white therapists are unable to respond appropriately to the standpoint, pain and anger of some ethnic minorities in relation to their experience of racism. They contend that in order to be in a position to respond therapeutically to the experience and views of people from ethnic minorities, white therapists must acknowledge their cultural identity and the impact this may have on the therapeutic relationship (Lago and Thompson, 1996). Reassuringly, perhaps, Kareem and Littlewood (1992) assert that it is possible for a client and therapist of differing ethnicity to engage in a therapeutic relationship. They maintain that this, 'involves the therapist being able to gather information about the client's culture'. It is considered here, that the challenge for the white therapist is to begin to *hear* the client and locate his/her experience within a socio-cultural/political context.

## 2.2 Models of Racial Identity

Continuing to consider the therapist, the present guide now turns to the processes thought to be involved in the development of racial identity. Here, 'racial identity' is defined as a psychological construct about the self associated with a personal perception of ones race, culture and ethnicity, which develops in relation to changing internal and external factors. In the interests of being a brief guide, two models of racial identity are presented here. One model outlines the stages of white racial identity; the other is a description of the processes involved in black racial identity development.

According to Wing Sue and Sue (1999), Helms' (1984) white racial consciousness model delineates five stages of development: namely, Contact, Disintegration, Reintegration, Pseudo-Independence and Autonomy. This model is represented in Table 5 below. Cross, Parkham and Helms (1991) propose a six-stage model of the process of 'becoming black'. The stages are as follows: Pre-encounter, Encounter,

Immersion, Emersion, Internalisation and Internalisation-Commitment. This model is represented in Table 6 below.

Within transcultural counselling, the therapist first needs to perceive him/herself as a racial being, then to assess where he/she is in terms of his/her own personal journey of racial identity. From here, the therapist can begin to consider where his/her client is terms of racial identity development. In the therapeutic relationship, each party's level of racial identity development is important (Carter, 1995).

“Every worker in the mental health field should be trained to recognise the ways in which their own cultural upbringing is likely to have affected their perceptions of the problems which their clients bring...(Murphy, 1986: in Lago and Thompson, 1996: p. 14).”

The above quote from Murphy (1986) cited in Lago and Thompson (1996) emphasises the impact the racial identity of a therapist can have on how clients' presenting problems are heard and valued. Thinking about issues related to racial identity within the process of forming a collaborative therapeutic relationship is paramount. It is suggested here that it is crucial for a therapist to have a sensitivity to the ramifications of the phase of both his/her own and the client's racial identity development in order to negotiate goals of therapy with the client. Therapists must be aware of their culturally informed beliefs, values, stereotypes and preconceived notions. Goals one would set with a client from a Western culture may not be culturally congruent for a client from another culture. The proposal here is that, for example, it may be inappropriate to work towards the goal of enhancing the level of assertiveness with a female client who strongly identifies with an Indian culture. There continues to be debate regarding the applicability of Western therapeutic approaches to ethnic groups. Wing Sue and Sue (1999) argue that attrition rates among ethnic minorities in counselling settings are often related to the therapist's inability to correctly identify the stage of racial identity which their clients have achieved. However, Lago and Thompson (1996) caution that some models of racial identity are oversimplified. Further, they call for British researchers to submit models of racial identity for publication since the above rely solely on research carried out in the U.S.A.

| <i>Five Stages of White Racial Development</i>   |  |   |  |   |
|--|--|---|--|---|
| Contact  | Disintegration   | Reintegration   | Pseudo-independence  | Autonomy  |
| <ul style="list-style-type: none"> <li>◆ Unawareness of self as a racial being</li> <li>◆ Aware that minorities exist</li> <li>◆ Searches for resolution through withdrawal</li> </ul> | <ul style="list-style-type: none"> <li>◆ Aware of racism</li> <li>◆ Feelings of guilt/depression</li> <li>◆ Dissonance in terms of cultural expectations</li> <li>◆ Over-identification with black people or a retreat into white culture</li> </ul> | <ul style="list-style-type: none"> <li>◆ Hostility towards minorities</li> <li>◆ Positive bias in favour of own racial group</li> </ul> | <ul style="list-style-type: none"> <li>◆ Increasing interest in racial group similarities and differences</li> <li>◆ Intellectual acceptance of other groups</li> <li>◆ Limited cross-racial interactions</li> </ul> | <ul style="list-style-type: none"> <li>◆ Acceptance of racial differences and similarities</li> <li>◆ Valuing difference</li> <li>◆ Actively seeking cross-racial interactions</li> </ul> |

**Table 5 Helms' (1984) Five-Stage Model of White Racial Identity**  
**Source: C. Lago & J. Thompson, 'Race, Culture and Counselling', Open University Press: Buckingham. (1996), p. 151-152.**

| <i>Six Stages Of Black Racial Identity Development</i>   |   |   |  |  |   |
|--|---|---|--|--|---|
| Pre-encounter stage  | Encounter stage   | Immersion   | Emersion   | Internalisation  | Internalisation-Commitment  |
| <ul style="list-style-type: none"> <li>◆ World view is white-oriented</li> <li>◆ Being black either has no meaning or is seen as a stigma</li> </ul> | <ul style="list-style-type: none"> <li>◆ Reinterpreting the world as a result of awareness of racism</li> </ul> | <ul style="list-style-type: none"> <li>◆ Struggle to remove all semblance of old identity</li> <li>◆ Blackness is glorified</li> <li>◆ White culture is rejected</li> <li>◆ An intensely emotional phase</li> </ul> | <ul style="list-style-type: none"> <li>◆ View of black glorification recedes</li> <li>◆ A more critical analysis of blackness is made</li> </ul> | <ul style="list-style-type: none"> <li>◆ Separation from the old identified self</li> <li>◆ Moves towards a positive black identity</li> </ul> | <ul style="list-style-type: none"> <li>◆ Advances on the previous stage</li> <li>◆ Involves self with black or minority group and community services</li> </ul> |

**Table 6 Cross et al (1991) Six-Stage Model of Black Racial Identity Development**  
**Source: R. Carter 'The Influence of Race and Racial Identity in Psychotherapy: Toward a Racially Inclusive Model.' (1995) p. 90. John Wiley & Sons Inc: New York.**

In conclusion, part two considered the particular challenges the therapist might face in applying his/her skills and knowledge base to a culturally diverse population. It also examined the concept of universality in terms of the cultural specificity of the constructs of normality and abnormality. In this section, models of white- and black racial identity were presented. It was suggested that it is essential for the therapist to be aware of his/her own phase of racial identity development. Also, to have an awareness of where a client is in terms of the development of his/her racial identity. In part three, the trainee is invited to consider how a difference in culture between a client and him/herself might affect the therapeutic relationship. This section will discuss the issues of Power and Racism.

## **Part Three**

### **Managing Difference in Therapy**

Having considered the therapist and examined models of racial identity in part two, the focus in section three is on managing difference in therapy. Part three affords an opportunity for the trainee to consider how a difference in culture between a client and him/herself might influence the therapeutic relationship. This section aims to illuminate the issues of Power and Racism.

#### **3.1 Power in the Therapeutic Relationship**

In terms of managing difference in therapy, the trainee should be aware of how power is perceived within the therapeutic relationship. Jones (1993) argues that the therapist is in a more powerful position than the client from the start of the relationship. She states that the therapist is on 'home territory' whether seeing the client within an organisational setting or the client's own home. This is so, as the therapist is in a familiar professional situation whereas the client may be unaccustomed to the roles taken in therapy (Jones, 1993).

Pinderhughes (1990) asserts that for the therapist, possessing an understanding of power dynamics in the relationship is a critical factor in the therapeutic process. Neglecting to analyse power relations may result in a therapist being more likely to engage in an oppressive relationship with a client (Jones, 1993). Further, D'Ardenne and Mahtani (1989) argue that the therapeutic alliance will not progress if the issue of power is not addressed. For example, a therapist might begin to empower a client by asking him/her how he/she would like to be addressed i.e. by their first or last name and if by their last name using which title. It is important, whilst engaging in this initial introductory process, to ensure that one pronounces the client's name correctly and apologises if this is a struggle rather than allowing it to appear as though the client's name is a problem. A therapist might ask a client to repeat the pronunciation of his/her name to aid this process. In some cultures naming is an important ritual,

acknowledging that the client's name might have a particular significance could facilitate engagement.

### 3.2 Racism and its Effects

In a relationship which involves working across cultures, power dynamics can be more pronounced than they typically might be in counselling a culturally close (Furnham and Bochner, 1986) client (Lago and Thompson, 1996). We all have our own prejudices and expectations. When a culturally distant (Furnham and Bochner, 1986) client and therapist are brought together within the context of a therapeutic relationship, one or the other may experience racism.

Although racism has been mentioned earlier in other sections of this guide, here is the juncture at which a definition of the concept will be posed. This is the case as, in this discussion about transcultural counselling, racism within the therapeutic relationship is taken to be the height of cultural difference between therapist and client. Racism has been defined as, 'a prejudice against race...an activity within history and culture...where races are oppressed' (Kovel, 1984 cited in Carter, 1995: p.17).

Another consideration which this guide finds useful to include in a definition of racism is that it is 'prejudice plus power' (Lago and Thompson, 1996). This latter statement alludes to a critical factor in the concept of racism whereby the dominant culture possesses political and economic power within which prejudice is manifested. In addition, Wing Sue and Sue (1999) draw attention to the concept of 'unintentional racism'. They maintain that a well-intentioned therapist may exude a covert form of bias of which he/she is unaware. They caution that this covert bias may have a phenomenal impact on the process of therapy. Here, the suggestion is that within the therapeutic relationship racism may at times be subtle nonetheless, it is an example of how the effects of a power imbalance in the relationship might be born out.

Lago and Thompson (1996) maintain that in a therapeutic relationship with a client from an ethnic minority, the white therapist has the power. Therefore, it is argued that in order to arrest the perpetuation of the construct of 'white superiority', the white therapist must be culturally sensitive (Lago and Thompson, 1996; Wing Sue and Sue,

1999). The suggestion is that therapists must be in a position to critically evaluate their own attitudes and expectations (D'Ardenne and Mahtani, 1989). This is particularly so as people who present to therapy typically consider that they need some form of help. Clients may be acutely aware of the power imbalance in the relationship. In many cases, immediately, the client offers him/herself as less 'psychologically competent/aware' and less powerful than the therapist. According to D'Ardenne and Mahtani (1989), the prevailing notion is that through being culturally sensitive, the transcultural therapist may begin to assist in redressing the power imbalance in the relationship. Acknowledging and tackling the notion of white superiority within therapy may facilitate this process. One suggestion is then, that in order to manage the difference that a power imbalance and racism in the therapeutic relationship afford, therapists should find an appropriate time during the assessment to discuss the issue of prejudice (D'Ardenne and Mahtani, 1989).

This guide suggests that therapists should be wary of viewing the client's ethnicity as 'the problem' (D'Ardenne and Mahtani, 1989). Although it is important to consider culture, the therapist also must remember to consider individual differences. Further, the transcultural counsellor *should not* aim to be 'colour-blind' which involves seeing black people as, 'white with black skin' (D'Ardenne and Mahtani, 1989; Wing Sue and Sue, 1999). D'Ardenne and Mahtani (1989) argue that being colour-blind is potentially harmful as it minimises the experience of the client from an ethnic minority.

Here, suggestions are made regarding how the trainee might manage difference when the trainee is from an ethnic minority and the client from the majority culture. The position of the person from a minority ethnic group as, 'expert' goes against convention (Lago and Thompson, 1996). Although within the therapeutic relationship the therapist has power, a therapist from an ethnic minority might find that some of his/her majority-culture clients communicate racist attitudes towards him/her (D'Ardenne and Mahtani, 1989). As therapists, it is important to note that by virtue of the nature of the relationship, the client is likely to be in a more vulnerable position than oneself. Where a therapist feels unsafe or unable to contain the process

of therapy, addressing racism where appropriate, such issues should be taken to supervision so that the processes involved can be carefully examined.

In summary, part three aimed to provide an opportunity for the trainee to consider how a difference in culture between a client and him/herself might influence the therapeutic relationship. In order to do this it discussed the issues of Power and Racism. The suggestion was made that there are power imbalance within all therapeutic relationships linked with perceptions related to social construction. In order to form a useful therapeutic alliance, one of the necessary conditions is that a therapist who works with culturally distant clients should have an awareness of how to manage both his/her own and the client's racism. Part four uses some ideas which are based on case material from the author's own practice specifically to illuminate the process of transcultural counselling.

## **Part Four**

### **Developing Culturally Sensitive Practice Skills**

In section three factors affecting the therapeutic relationship were expounded in terms of managing difference in therapy. Part four aims to provide trainees with insight into developing culturally sensitive practice skills. Based on case material from the author's own practice (Rhule, 2000) it: highlights the process of transcultural counselling; and considers the impact of religion on the therapeutic process. It provides an example of how trainees could include a consideration of cultural difference in therapy when assessing, formulating, hypothesising and selecting interventions. It also indicates how trainees might manage practice dilemmas.

I hope that what becomes clear through the presentation of the following case material is some of the challenges I faced as a therapist working transculturally and how I dealt with them.

#### **4.1 The Process of Transcultural Counselling: The Mohammed Family**

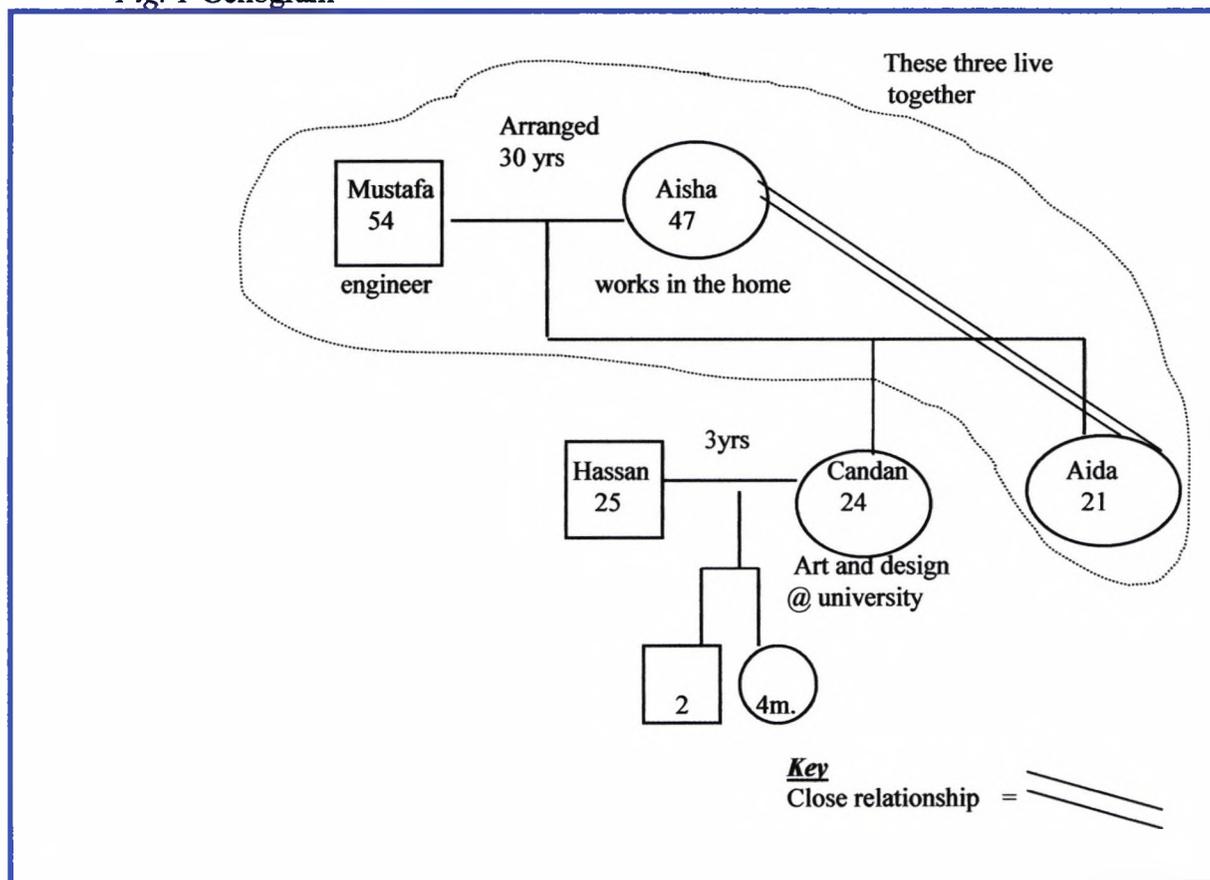
##### **Background Information**

This consideration of the process of transcultural counselling is based on my work with a Turkish family who embrace Islam. The identified client was a 21 year old female, the youngest of two sisters. I have referred to her as "Aida", to preserve her anonymity (the following are also pseudonyms). I saw Aida and her family within the context of a NHS mental health community team. Aida lives with her father Mustafa and her mother Aisha. Mustafa is an engineer and Aisha works in the home. Aida's sister Candan is 24 years old. She is married with two children (see Fig. 1 Genogram).

Leading up to the referral, Aida's involvement with the mental health team had been characterised by poor engagement in activities over a 15-month period. Following these difficulties within the team, I received a referral from Aida's nurse. It requested a psychological assessment of Aida's 'independence', in view of her mental health

needs. Aida had been involved in a road traffic accident (RTA) when she was four years old. She had a five-year history of bipolar affective disorder. Her paternal grandmother had a diagnosis of schizophrenia and her mother was diagnosed as clinically depressed.

Fig. 1 Genogram



### Assessing

During the initial assessment phase, taking a transcultural perspective to therapy with the Mohammed family enabled me to begin to get a sense of how important and influential their Muslim faith was in their daily lives. Engaging in this process was designed to begin to establish my credentials as a culturally sensitive practitioner (D'Ardenne and Mahtani, 1989). It was essential to assess their view on the problems they were facing within a sociocultural/political context (Lago and Thompson, 1996). This included discussion about what they felt had triggered the problem and a consideration of the methods that had already been used to address it. Also, this was

the place for me to begin to be curious about how the problems they had identified fit or did not fit with their perception of health and illness within both Turkish and Western societies. It was necessary to facilitate the process of gathering information about what they knew of psychiatric services in the U. K (Dein, 1997). Further, to ascertain what their experience of working with health professionals in the community had been.

The assessment revealed that connected with the onset of her illness, Aida was taken to see a Muslim leader every night for three months as her family viewed her behaviour as 'uncontrollable'. The 'uncontrollable behaviour', was identified by the family as the presenting problem. It involved Aida staying out late at night and socialising with members of the opposite sex. From discussion with the family, I concluded that their view was that aid from the Muslim leader to address this problem had more validity than help from health professionals.

The process of joining with this family from an ethnic minority was particularly important. Utilising the technique of joining, I was able to accommodate to the family's style and create an environment in which family members could feel supported (Rhule, 2000).

### **Formulating**

As noted above, transcultural counselling is not an approach in itself. Rather, it is a perspective on counselling or a counselling style (D'Ardenne and Mahtani, 1989). I found that I was able to use a systemic theoretical framework and a transcultural perspective to my clinical work (Boyd-Franklin, 1989). In this way, I began to formulate that it was possible that the RTA Aida suffered had been a dynamic horizontal stressor in the family's life cycle (Carter and McGoldrick, 1988: see Figure 4.1). This seemed to have catapulted the family into a pattern of relating to Aida, which made her symptomatic behaviour likely to continue to occur. Perhaps, along with genetic and organic factors, this way of responding to Aida had contributed to the presenting problem of her 'uncontrollable behaviour'.

## **Hypothesising**

As suggested elsewhere in this guide, therapists should seek to acquire information about a family's culture from the family itself (Wing Sue and Sue, 1999). Also, therapists should aim to expose themselves to cultural diversity both inside and outside of the counselling room (D'Ardenne and Mahtani, 1989). From information I had previously gained from the family during the assessment phase and from an earlier inquiry into Muslim culture, I was able to form a hypothesis on the basis of my knowledge that Muslim family members often sacrifice themselves for the sake of their religion (Lau, 1994). As part of the process of working transculturally, I began to hypothesise that Aisha was offering herself as a 'martyr' within the family by forming an enmeshed subsystem with Aida. I tested this hypothesis out with the family [directed at the sister]-

*"What does your Mum stand to gain from offering herself as the 'martyr' when it comes to the family?"*

Through Candan's response, new information was introduced into the system. Her view was,

*"Mum thinks she would be saying she was a failure if she asked for support."*

I began to consider that the way Aisha was positioned within the family may have been heavily steeped in cultural specifications of how a mother *should* cope with illness in the family (Rhule, 2000). This enabled me to be culturally sensitive in my next utterance.

## **Selecting Interventions**

The transcultural therapist is sensitive to the need to thoughtfully select interventions which are culturally congruent for his/her client (Eleftheriadou, 1994; Wing Sue and Sue, 1999). The following intervention was designed to value the family's experience of their ethnicity, whilst still aiming to provide alternatives to the way things had been in the family up until this point. It did this by coupling a statement about how vital Muslim culture appeared to be to the family with a future-oriented question which was

as follows:

“[Directed at Candan] Given the Muslim culture you have said is important to your family, what kind of support would your Mum accept?”

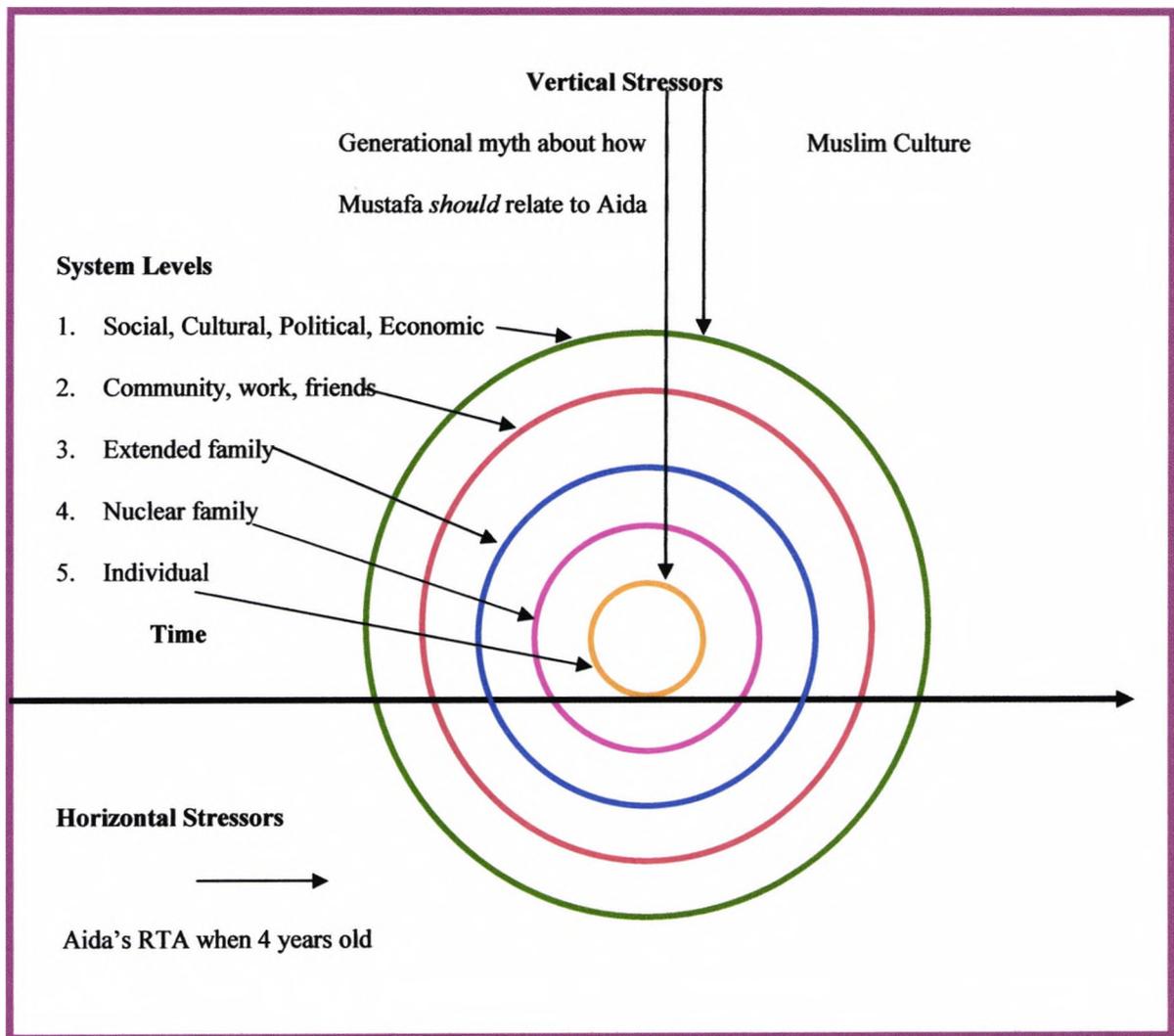
Later, I discovered that even though Mustafa was absent from the home much of the time (and did not attend sessions), other members of the family would feedback to him the occurrences of our sessions (Rhule, 2000). In a Muslim family, the father is often viewed as the most influential (Lau, 1995). In line with my previous investigation into Muslim culture, it emerged that Mustafa seemed to make the final decision regarding how much the family changed in the way they related to one another. In an intervention which followed my discovery, I summarised what members of the family had said and reflected that Mustafa seemed to make the decisions whilst being largely absent from the scene. This intervention was intended to promote enough conflict in the relationships of the family members present with Mustafa, without completely undermining his authority, and so produce change (Rhule, 2000). Further, I postulated that Mustafa’s individual experiences with his family may have confirmed a belief that this is how a symptomatic woman should be responded to. It appeared that he related to Aida in much the same way as he had done his schizophrenic mother and his depressed wife ~ from a distance. I tentatively hypothesised that he was perpetuating a generational myth (Jones, 1993), as this was also how his father related to his mother (leaving her with 5 children when she became ill at 39 years old). This was identified as a vertical stressor on the system (Carter and McGoldrick, 1988: see Figure 4.1).

### **Managing Practice Dilemmas**

Working transculturally, therapists are likely to face dilemmas in their practice which they might otherwise never meet. Here, I was confronted with a situation which initially appeared as though it was a positive change in the way Aisha was relating to Aida. However, being culturally sensitive alerted me to consider the impact the proposed change might have had on the family and on the wider community.

Through liaison with my colleague, I discovered that Aisha had approached the nurse to suggest that she look for somewhere where Aida could move to be supported in the community (Rhule, 2000). According to Aisha's specifications, this would need to be a home just for females, which was outside of the Muslim community. Aisha expressed that she did not want the rest of the community to know that the family had resorted to such measures to look after one of its members. She further stated that for the time being, this would need to be kept secret from Aida and her father. Aisha reported that her fear was that if Aida knew about the change, she would inform Mustafa who would ensure that it was blocked. As alluded to above, at first this sounded like an attractive proposition. It would have meant that there was change in the system, Aida's 'uncontrollable behaviour' might become extinct and she would certainly have been physically more independent of her family (Rhule, 2000). However, when I later reflected on the consequences this might hold for the family, change in this direction looked less attractive. This change suggested that Aisha and the nurse had entered into a coalition which could be potentially damaging to the system (Selvini-Palazzoli, Boscolo, Cecchin and Prata, 1980). Being culturally sensitive enabled me to question whether by doing this Aisha was distancing herself from her family and wider culture. The questions I planned to ask Aisha in our next session were as follows:

- ◆ How would Mustafa respond to the changes in Aisha?
- ◆ How would Aida respond to the changes in her mother (and in the relationship between her mother and father)?
- ◆ How would Candan respond to the changes in the relationship between her mother and Aida?
- ◆ How would Candan respond to the changes in the relationship between her mother and father?
- ◆ How would the Muslim community respond to the changes in the family?
- ◆ Who would gain the most/least from these changes?



**Fig. 5 Mohammed Family: Horizontal & Vertical Stressors**

**Source:** Adapted from E. A. Carter and M. McGoldrick, (1988) *Overview: The changing family life cycle: A framework for family therapy*. In B. Carter & McGoldrick (Eds.), *The changing family life cycle: A framework for family therapy* (2<sup>nd</sup> ed.) Boston: Allyn & Bacon.

In response to the above questions (Rhule, 2000), Aisha and I considered that gradually introducing change was perhaps preferable to the drastic measure of alienating herself within her family and wider community.

In summary, part four used case material based on family work from the author's own practice to: illuminate the process of transcultural counselling; and consider the impact of religion on the therapeutic process. It provided an example of how trainees could include a consideration of cultural difference in therapy when assessing, formulating, hypothesising and selecting interventions. It also suggested how trainees might manage practice dilemmas. In presenting this case, I emphasised the importance of carefully considering the family's sociocultural context within the

practice of therapy with families. In conclusion, there are some additional points I would like to make about culturally sensitive practice. The four points listed below were adapted from Dein (1997). Culturally sensitive practice involves:

1. The therapist being aware of the need to work with ethnic minority clients where possible to develop his/her own confidence in working with people across different races and cultures.
2. The therapist aiming to get information about racial and cultural differences directly from clients and using terms which value people from ethnic minorities.
3. The therapist attempting to get the client's view on the problem and beliefs about treatment.
4. The therapist knowing the limitations of his/her skills and or agency and using knowledge of the availability of specialist services for ethnic clients to direct clients to these services as appropriate.

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**Appendix 1.**

January 1996

THIS FORM SHOULD BE COMPLETED IN TYPESCRIPT AND RETURNED TO THE RESEARCH ETHICS CO-ORDINATOR, ROOM W109, INSTITUTE OF PSYCHIATRY. PLEASE REFER TO THE NOTES FOR GUIDANCE AS YOU COMPLETE THE FORM. PLEASE NOTE THAT IT IS THE APPLICANT'S RESPONSIBILITY TO ENSURE THAT SUBMITTED FORMS ARE OF SUFFICIENT QUALITY TO BE LEGIBLY REPRODUCED AND THAT SIGNATURES OF APPLICANT, PRINCIPAL INVESTIGATOR AND INVESTIGATOR (S) ARE APPENDED AT THE END

**Applicants are reminded that ethical justification must be given for the inclusion of special groups of subjects e.g. mentally incapacitated in research projects**

REF NO. 260/01

NHS TRUST

**APPLICATION TO THE ETHICAL COMMITTEE RESEARCH FOR APPROVAL OF A RESEARCH PROJECT**

**Section 1 Details of Applicants\***

(NOTE 3A)

- |     |                               |   |
|-----|-------------------------------|---|
| (a) | <b>Applicant</b>              | Status  |
|     | Lorraine Rhule                | Chartered Counselling Psychologist (A grade)                |
|     | Department                    |   |
|     | Community Rehabilitation Team |   |
|     | Address for Correspondence    |   |
|     | Telephone Number              |   |
| (b) | <b>Principal Investigator</b> | Status  |
|     | Dr. Ingrid Doherty            | Consultant Clinical Psychologist Borough Head of Psychology |
|     | Department                    |   |
|     | Rehabilitation Services       |   |

Address

Telephone No.

*(the principal investigator should be of Consultant or Senior Lecturer Status and hold a contract with the South London and Maudsley Trust or Institute of Psychiatry. The Principal Investigator is responsible for the study to the Trust/IOP. Please refer to the Notes for Guidance)*

(c) **Investigator(s)** Status

Lorraine Rhule Chartered Counselling Psychologist (A grade)

\*Please note that a 1 page curriculum vitae is required for each applicant or investigator not under contract to, or a student of, the Trust or Institute of Psychiatry. Principal Investigators must hold a contract with either the Trust or Institute

(d) **Research Strategy Group**

Psychosis research strategy group

(e) **Sponsoring Organisation**

N/A

Please give details of any organisation sponsoring the research proposal e.g. pharmaceutical or device manufacturer or charitable organisation

**Section 2 TITLE OF PROJECT**

Barriers to Access of Cognitive-Behavioural Therapy and Family Interventions for Service Users of the NHS Trust with Medication-Non-Responsive Schizophrenia/Schizo affective Disorder and Their Carers

PROPOSED START DATE January 2002

**Section 3 Purpose of Project**

(NOTE 3B)

(This section should state, **as far as possible in lay language**, the hypothesis to be addressed and the clinical relevance and benefit of the study)

## **Background**

Specific psychosocial treatments have been shown to be effective with people suffering from severe mental illness. Access to psychosocial treatments: cognitive-behavioural therapy (CBT) and family interventions is paramount for every mental health service user with a diagnosis of schizophrenia/schizoaffective disorder and their carers (NHS Executive, 2000). However, it is questionable whether people with persistent and distressing mental health needs and their carers do indeed have access to these types of treatment. The present study explores barriers to accessing CBT and family interventions which service users of the NHS Trust with medication-non-responsive schizophrenia/schizoaffective disorder and their carers face.

## **Aim**

The aim of this research is to explore barriers to accessing CBT and family interventions for people with medication-non-responsive schizophrenia/schizoaffective disorder and their carers.

## **Hypothesis**

The main hypothesis of this study is that there are barriers to accessing CBT and family interventions for people with persistent, distressing symptoms of schizophrenia/schizoaffective disorder and their carers.

## **Literature Review**

The Mental Health National Service Framework (NSF) is clear in detailing the commitment the NHS should have to treating people with serious mental illness such as schizophrenia/schizoaffective disorder (NHS Executive, 1999). Indeed, the focus of Clinical Governance is on improving the quality of care from a service user/carer perspective (NHS Executive, 1999). The National Institute for Clinical Effectiveness (NICE 2003) is currently developing a standard regarding access to psychological treatment for people with persistent, distressing symptoms of psychosis (Garety, 2001). The present study will both be impacted by and influence the revision of such standards in Psychological Treatment nation-wide.

Prevalence rates of schizophrenia range from 0.2 – 2% of the general population (APA, 1995). Schizoaffective disorder appears to be less common (APA, 1995). A significant number of these people (20%) are severely distressed by persistent symptoms despite attempts to treat them with antipsychotic medication and periods of in-patient treatment (Clozapine Study Group, 1993). In some cases, adherence to medication programmes is a particular area of contention for service users (Fowler, Garety and Kuipers, 1995). Unfortunately, non-adherence with medication regimes often precipitates readmission to noisy/over-stretched in-patient wards (Kuipers, Garety, Fowler, Dunn, Bebbington, Freeman and Hadley, 1997). As an intervention, medication alone is often inadequate to promote management of and recovery from the symptoms of schizophrenia/schizoaffective disorder (Tarrier, Barrowclough, Haddock and McGovern, 1999).

CBT and family interventions are two psychosocial treatments that have shown to be effective with people suffering from severe mental illness (Garety, Kuipers, Fowler, Freeman and Bebbington, 2001). The present study aims to illuminate barriers to accessing these two types of treatment which service users of the NHS Trust with medication-non-responsive schizophrenia/schizoaffective disorder and their carers face.

### **Cognitive Behavioural Therapy**

Used in conjunction with neuroleptics (antipsychotic medication), CBT aims to:

- ❖ Reduce the distress, emotional disturbance and disability caused by psychotic symptoms
- ❖ Help the person arrive at an understanding of the psychotic cycle in order to promote his/her active participation in the regulation of relapse and social disability (Fowler, Garety and Kuipers, 1995)

The approach is also concerned with working in collaboration with the individual to assist him/her with making sense of symptoms. The techniques involved in treatment are:

- ❖ Building and maintaining a therapeutic relationship
- ❖ Enhancing and developing strategies in order to cope with distressing symptoms and experiences (for example hallucinations)
- ❖ Normalising and destigmatising the psychotic experience
- ❖ Modification of psychotic symptoms (for example delusions and hallucinations)
- ❖ Promoting self-esteem
- ❖ Modification of anxiety and depression
- ❖ Relapse management

Evidence which has accumulated over the past decade (Garety, Kuipers, Fowler, Freeman and Bebbington, 2001), shows that CBT is effective at reducing distress for people suffering from schizophrenia/schizoaffective disorder (Garety, Kuipers, Fowler, Freeman and Bebbington, 2001). Moreover, gains made during a course of treatment are sustained at 18-month follow-up (Kuipers, Fowler, Garety, Chisholm, Freeman, Dunn, Bebbington and Hadley, 1997). Clearly, CBT enhances the efficacy of medication when it is used as an adjunct to medical treatment (Roth and Fonagy, 1996). Indeed, cognitive therapy significantly increases the likelihood that service users will adhere to medical recommendations (Fowler, Garety and Kuipers, 1995).

### **Family Interventions**

The family interventions programme is based on work begun in the mid 1970's looking at expressed emotion in families (Leff, 2001). It involves the following:

1. Educating the family about schizophrenia/schizoaffective disorder
2. Developing problem-solving techniques with the family
3. Improving communication within the family
4. Dealing with expressed emotion within the family
5. Reducing over-involvement of family members with the service user
6. Expanding social networks of the service user
7. Lowering the expectations of the service user and his/her family members relating to what the service user is likely to achieve depending on the phase of his/her illness

Family work sessions are conducted in the family home in order to aid the process of engagement of the family with the mental health professional (Leff, 2001). Research over the last 25 years has indicated that family interventions are effective in reducing relapse rates (Burbach, 1996). Family interventions are one way of meeting the needs of carers as stipulated in the Carer's Act (1996).

#### **Criteria for Medication-Non-Responsive Schizophrenia/Schizoaffective Disorder**

The criteria for medication-non-responsive schizophrenia/schizoaffective disorder are at least one current positive psychotic symptom (within DSM IV criteria such as a hallucination or delusion). It is necessary that this symptom is distressing, unremitting (at least for the past six months) and has not responded to a previous trial of at least six months of appropriate neuroleptic medication (Kuipers, Garety, Fowler, Dunn, Bebbington, Freeman and Hadley, 1997).

#### **Barriers to Access of Psychosocial Interventions**

Previous studies have examined areas such as barriers to the treatment of social anxiety (Olfson, Guardino, Struening, Schneier, Franklin, Hellman, and Klein, 2000), correlates of unmet need for mental health services by children and adolescents (Flisher, Kramer, Grosser, Alegria, Bird, Bourdon, Goodman, Greenwald, Horwitz, Moore, Narrow and Hoven, 1997), service awareness and use among older North Carolinians (Mitchell, 1995), cultural competence and quality of care: Issues for mental health service delivery in managed care (Abe, Jennifer and Takeuchi, 1996), and opportunities for improving community mental health services for elderly persons (Colenda and Van-Dooren, 1993). However, the present research is the first of its kind to explore barriers to accessing CBT and family interventions for people with medication-non-responsive schizophrenia/schizoaffective disorder from the perspective of the service user, carer and health professionals most likely to be offering these types of treatment.

#### **Section 4 Conduct of Project**

(NOTE 3C)

- (a) Location  
NHS Trust (CMHC's)

(b) Nature of Subjects

The service users will have a current diagnosis of schizophrenia/schizoaffective disorder, which is medication non-responsive (according to DSM IV criteria, with symptoms of at least 6 months duration which have been unremitting despite 6 months trial of appropriate neuroleptics). Service users and carers will be 18 plus years old. Nurses and Psychologists in the NHS Trust are the professionals most likely to be offering CBT/family interventions to this client group and are therefore included. Also included are those professionals who are likely to be in a position to refer service users for psychosocial interventions. Participants will be recruited from all boroughs of the Trust (CMHC's).

Number

Each focus group will be limited to one 'type' of participant. There will be maximum of 2 focus groups for each type of participant, totalling 12 groups in all. The groups will consist of:

- ◆ 8 current service users (x2)
- ◆ 8 carers (x2)
- ◆ 8 nurses (x2)
- ◆ 8 psychologists (x2)
- ◆ 8 psychiatrists (x2)
- ◆ 8 G. P. s (x2)

Inclusion criteria

Carers are to be currently caring for someone with schizophrenia/schizoaffective disorder. Carers will also be required to have at least 10 hours of direct contact time with a service user suffering from medication non-responsive schizophrenia/schizoaffective disorder per week.

Will any of the subjects involved in this study be detained service users under the Mental Health Act? If so, please justify in Section 6.

Yes

(c) Will service users/volunteers be recruited from within the Trust?

Yes

Please give details of any service users/volunteers who will be recruited from outside the Trust

N/A

(d) Is it proposed to use staff members of the Institute or the Joint Hospital as subjects in this study?

Yes it is proposed to use staff members of the Joint Hospital as participants in this study.

- (e) Does the researcher foresee any interference with their duties?

No. This investigation will encourage clinicians to be mindful of the importance of exploring service user and carer views on services offered by the NHS.

- (f) Expected duration of Project

One year

- (g) Proposed frequency and duration of procedures:

- i) for research subjects

The procedure will involve 45-minute group discussion and following sampling, 1 participant from each group will go on to take part in a 15-minute exploratory semi-structured interview. This study will be conducted with participants using mental health services, carers and mental health professionals who volunteer to take part.

- ii) for controls

N/A

- (h) Proposed payment (if any) to subjects

Service users and carers will be paid for their involvement in the groups.

The exact amount remains to be determined. It is likely to be a modest sum to cover expenses, not exceeding £10.00 per person.

- (i) Funding (if any) sought for project

(NOTE 3C cont.)

Funding is currently being sought.

Please state i) Source

ii) Amount

ii) to whom payable (please complete whichever is applicable):

(as a personal emolument)

(Institute/Hospital funds)

(j) Grant Reference Number (if known) N/A

(k) Will data relating to subjects/controls resulting from the research be stored on computer

YES/ NO

If so, please state that the requirements of the Data Protection Act will be complied with  
The requirements of the Data Protection Act will be complied with.

(l) Please state that you will observe the Code of Practice on the Use of Audio-Visual Material (if applicable)

I will observe the Code of Practice on the Use of Audio-Visual Material

(m) **Description of design, methodology and techniques**

(as far as possible in lay language)

**Design**

The design will be piloted in one directorate. Data will be analysed using a qualitative content analysis (grounded theory) of focus group discussion alongside individual semi-structured interviews.

Conducted over one year, costs of the study are likely to be payment to service users and carers, room hire and hire of equipment.

**Measures**

There will be a maximum of 12 focus groups. A counselling psychologist will facilitate discussion within the groups and conduct 1 exploratory semi-structured interviews following sampling from each of the 12 focus groups. These measures have been chosen in order to elicit views of people with medication-non-responsive schizophrenia/schizoaffective disorder using mental health services, carers of current service users with schizophrenia/schizoaffective disorder and mental health professionals.

**Procedure**

The procedure will involve 45-minute group discussion and 1 participant from each group will go on to be involved in a 15-minute exploratory semi-structured interview. This study will be conducted with participants using mental health services, carers and mental health professionals who volunteer to take part.

**Section 5 Scientific Background**

(NOTE 3D)

(a) Has this investigation been carried out previously with human subjects? If so, why is it being repeated?

No this investigation has not been carried out before.

- (b) Which research instruments will be used? (avoid using acronyms)  
Focus group discussion and individual semi-structured interviews.
- (c) How has the number of recruits been decided upon? (please justify the statistical viability - see Notes for Guidance Note 3D)  
It is an exploratory, qualitative study, using a focus group and individual semi-structured interview design. Hence, 96 participants are adequate.

### **Section 6 Ethical Considerations**

(NOTE 3E)

- (a) Please provide a brief account **IN LAY LANGUAGE** of the ethical considerations raised by this project
- The confidences of research participants will be respected. Information, which does not reveal the identity of a research participant, may be disclosed. Personal information will remain confidential unless prior written informed consent is given by the individual stating that this information may be disclosed. However, if circumstances arose which alerted clinical concern (e.g. child abuse/conflict with public interest), the relevant statutory services will be informed (in line with related statutory provisions).

#### **The involvement of subjects detained under the Mental Health Act:**

The design of this study is such that it is not anticipated that participants will be distressed by their participation.

- (b) What are the benefits of the study to the NHS?
- As mentioned above, The Mental Health National Service Framework (NSF) is clear in detailing the commitment the NHS should have to treating people with serious mental illness such as schizophrenia/schizoaffective disorder (NHS Executive, 1999). Indeed, the focus of Clinical Governance is on improving the quality of care from a service user/carer perspective (NHS Executive, 1999).

Part of the NHS Trust's Clinical Governance aim is to review access to psychosocial treatments: cognitive-behavioural therapy (CBT) and family interventions for service users with persistent and distressing medication non-responsive schizophrenia/schizoaffective disorder and their carers (NHS Executive, 2000). The present study explores barriers to accessing CBT and family interventions which service users of the NHS Trust with medication-non-responsive schizophrenia/schizoaffective disorder and their carers face.

The benefits of the present study will be medium and long term as the findings will inform service users/providers, clinicians, referrers and carers as to what some of the barriers to accessing psychosocial interventions are and discuss how they might be addressed.

**Section 7 Safety and Other Controls**

(NOTE 3F)

- (a) Does this study involve ionising radiation e.g. x-rays, Nuclear Medicine?

YES/NO

If so, please complete and submit the Application Form for Procedures which involve the use of ionising radiation (available from Committee Administrator)

- (b) Have you obtained a certificate from the Administration of Radioactive Substances Act Committee (ARSAC?)

YES/PENDING/NOT APPLICABLE

**Section 8 Drug Studies**

(NOTE 3G)

- (a) If drugs are to be used, then does the drug that is the subject of the investigation have: N/A

i) a full Clinical Trial Certificate YES/NO

ii) a Clinical Trial Exemption Certificate YES/NO

iii) If neither (i) or (ii), apply, is the substance being used without a Product Licence for the stated indication YES/NO

- b) Please state all other drugs involved in the study N/A

Are these being supplied by a Drug Company? YES/NO

If yes, by whom

- (c) Pharmacy Support

(NOTE 3G  
contd.)

Has the Principal Pharmacist been informed of this research proposal?

YES/NO

**Section 9 Insurance and Indemnity**

(NOTE 3H)

- (a) Is this study being sponsored by an Industrial or drug company? YES/NO

If yes, have you obtained indemnity from the sponsoring industrial or drug company?

YES/PENDING/NOT APPLICABLE

(Please attach a copy where applicable to your application)

- (b) If the study is not sponsored and involves healthy volunteers, please indicate what insurance arrangements have been made for these participants (See Note 3Hb) of the Notes for Guidance) N/A

**Section 10 Consents**

(NOTE 3I)

- (a) Please state how you propose to obtain informed consent, how such consent will be recorded, and why you consider the proposed method to be appropriate to this particular project. A copy of the information and the consent form (both duly headed) should be supplied.

One-month prior to the date when the focus group will be conducted, I will send consent forms and information documents to participants. Consent forms will require participant's to sign a statement agreeing to participate in the study. They will also highlight confidentiality issues. See attached 'Consent Form' and 'Information about the Study' document.

**Statement given to participants:**

"Thank you for volunteering to be part of this research project. The aim of this study is to gather views on accessing cognitive behavioural therapy and family interventions, in the NHS Trust. This will help the Trust develop services in line with the views of the people who might use them and those who might provide them.

Firstly, we will have a group discussion for 45 minutes. One person in each group will be selected for a 15-minute individual interview. Any personal information you share will be treated as confidential as far as the law allows.

Anyone who takes part in this study is free to withdraw from it at anytime without giving a reason for this. [If you are a service user/carer, withdrawing from the study will not in anyway affect your treatment/the service you receive. Service users and carers will be paid for taking part in the study.]

In an emergency, please contact Lorraine Rhule on the telephone number above or write to me at the above address.

- (b) Please indicate how you are gaining permission from consultants in charge of service users (if applicable)

I will send copies of the consent form, statement given to participants and study information document to consultants in charge of service users.

**DECLARATION**

The above information is correct to the best of our knowledge. We have read and approved all the relevant supporting documents.

We have read and understood the responsibilities of researchers and principal investigators undertaking research in the NHS as set out in the Department of Health's Research Governance Framework for Health and Social Care.

(<http://www.doh.gov.uk/research/rd3/nhsrandd/researchgovernance.htm>)

Signed \_\_\_\_\_ (Principal Investigator)

Signed \_\_\_\_\_ (Applicant)

(if different from above)

Signed \_\_\_\_\_ (Investigator(s))

(if different from above)

Date of Submission \_\_\_\_\_ 19/10/2001 \_\_\_\_\_

Form to be returned to: Research Ethics Co-ordinator, W109, Institute of Psychiatry, De Crespigny Park, LONDON SE5 8AF

**Barriers to Access of Cognitive Behavioural Therapy and Family Interventions  
for Service Users and Their Carers**

***Consent Form: Service-user***

I \_\_\_\_\_, do give consent to take part in the research project 'Barriers to Access of Cognitive Behavioural Therapy and Family Interventions'. Also, I consent for my views on this topic to be shared with service users, providers and researchers in order to bring to light barriers to accessing these interventions for people in the NHS. I understand that my personal details will be kept confidential as far as the law allows.

I understand that I am free to withdraw from the project at anytime without giving a reason and that this will not in anyway affect my treatment or the services I receive.

Signed: \_\_\_\_\_

Dated: \_\_\_\_\_

**Barriers to Access of Cognitive Behavioural Therapy and Family Interventions  
for Service Users and Their Carers**

***Consent Form: Carer***

I \_\_\_\_\_, do give consent to take part in the research project 'Barriers to Access of Cognitive Behavioural Therapy and Family Interventions'. Also, I consent for my views on this topic to be shared with service users, providers and researchers in order to bring to light barriers to accessing these interventions for people in the NHS. I understand that my personal details will be kept confidential as far as the law allows.

I understand that I am free to withdraw from the project at anytime without giving a reason and that this will not in anyway affect the services I receive.

Signed: \_\_\_\_\_

Dated: \_\_\_\_\_

**Barriers to Access of Cognitive Behavioural Therapy and Family Interventions  
for Service Users and Their Carers**

***Consent Form: Mental Health Professional***

I \_\_\_\_\_, do give consent to take part in the research project 'Barriers to Access of Cognitive Behavioural Therapy and Family Interventions'. Also, I consent for my views on this topic to be shared with service users, providers and researchers in order to bring to light barriers to accessing these interventions for people in the NHS. I understand that my personal details will be kept confidential as far as the law allows.

I understand that I am free to withdraw from the project at anytime without giving a reason.

Signed: \_\_\_\_\_

Dated: \_\_\_\_\_

**Barriers to Access of Cognitive Behavioural Therapy and Family Interventions  
for Service Users and Their Carers**

***Information about the Study: Service-User***

I am inviting you to participate in a study designed to look at Barriers to Accessing Cognitive Behavioural Therapy and Family Interventions for Service Users and Their Carers.

The aim of this study is to gather views on accessing cognitive behavioural therapy and family interventions, in the NHS Trust. This will help the Trust develop services in line with the views of the people who might use them and those who might provide them.

Firstly, we will have a group discussion for 45 minutes this will be video taped. One person will be chosen from each type of participant to take part in a 30-minute individual interview on another day this will be audio taped. The video and audio tapes will be erased once the information has been analysed.

There will be 6 groups in all. Each focus group will be limited to one 'type' of participant. There will be minimum of 2 focus groups for each type of participant. The groups will consist of:

- ◆ 8 current service users (x2)
- ◆ 8 carers (x2)
- ◆ 8 mental health professionals (x2)

Any personal information you share will be treated as confidential as far as the law allows.

Anyone who takes part in this study is free to withdraw from it at anytime without giving a reason for this. If you are a service user, withdrawing from the study will not in anyway affect your treatment/the service you receive. Service users will be paid for taking part in the study.

In an emergency, please contact Lorraine Rhule on the telephone number above or write to me at the above address.

Lorraine Rhule  
**Chartered Counselling Psychologist**  
Community Rehabilitation Team

Dr Ingrid Doherty  
Consultant Chartered Clinical Psychologist Professional Head of Psychology

August 2002,

Dear Carer,

**Re: Research on Barriers to Access of Cognitive Behavioural Therapy and Family Interventions for Service Users and Their Carers**

I am inviting you to participate in a study designed to look at Barriers to Accessing Cognitive Behavioural Therapy and Family Interventions for Service Users and Their Carers.

The aim of this study is to gather views on accessing cognitive behavioural therapy and family interventions, in the NHS Trust. This will help the Trust develop services in line with the views of the people who might use them and those who might provide them.

We will have a group discussion for 45 minutes this will be video taped. One person will be chosen from each type of participant to take part in a 30-minute individual interview on another day this will be audio taped. The video and audio tapes will be erased once the information has been analysed.

There will be 6 groups in all. Each focus group will be limited to one 'type' of participant. There will be minimum of 2 focus groups for each type of participant. The groups will consist of:

- ◆ 8 current service users (x2)
- ◆ 8 carers (x2)
- ◆ 8 mental health professionals (x2)

Any personal information you share will be treated as confidential as far as the law allows.

Anyone who takes part in this study is free to withdraw from it at anytime without giving a reason for this. Carers will be paid expenses for taking part in the study.

***Details of the group you are invited to attend:***

*Carers Research, Garden Room, Cambridge House, 131 Camberwell Road, London SE5, Thursday 22<sup>nd</sup> August 2002 at 3pm.*

In an emergency, please contact Lorraine Rhule on the telephone number above. or write to me at the above address.

Lorraine Rhule

**Chartered Counselling Psychologist**

Community Rehabilitation Team

Dr Ingrid Doherty

Consultant Chartered Clinical Psychologist Professional Head of Psychology

**Barriers to Access of Cognitive Behavioural Therapy and Family Interventions for Service Users and Their Carers**

***Information about the Study: Mental Health Professionals***

I am inviting you to participate in a study designed to look at Barriers to Accessing Cognitive Behavioural Therapy and Family Interventions for Service Users and Their Carers.

The aim of this study is to gather views on accessing cognitive behavioural therapy and family interventions, in the NHS Trust. This will help the Trust develop services in line with the views of the people who might use them and those who might provide them.

Firstly, we will have a group discussion for 45 minutes this will be video taped. One person will be chosen from each type of participant to take part in a 30-minute individual interview on another day this will be audio taped. The video and audio tapes will be erased once the information has been analysed.

There will be 6 groups in all. Each focus group will be limited to one 'type' of participant. There will be minimum of 2 focus groups for each type of participant. The groups will consist of:

- ◆ 8 current service users (x2)
- ◆ 8 carers (x2)
- ◆ 8 mental health professionals

Any personal information you share will be treated as confidential as far as the law allows.

Anyone who takes part in this study is free to withdraw from it at anytime without giving a reason for this.

In an emergency, please contact Lorraine Rhule on the telephone number above. or write to me at the above address.

Lorraine Rhule

**Chartered Counselling Psychologist**

Community Rehabilitation Team

Dr Ingrid Doherty

**Consultant Chartered Clinical Psychologist Professional Head of Psychology**

## **Appendix 2: Semi-structured interview schedule**

### **Awareness**

1. How much do you think service-users with symptoms of schizophrenia/schizoaffective disorder know about CBT and family interventions?
2. How much do you think carers of service users with symptoms of schizophrenia/schizoaffective disorder know about CBT and family interventions?
3. How much do you think mental health professionals in general know about CBT and family interventions?
4. What do you think about talking treatments?

### **Skill Mix**

1. Can you think of the people who would be most likely to offer CBT and family interventions to service users with symptoms of schizophrenia/schizoaffective disorder and carers?
2. What support do you think the people who offer CBT and family interventions to service users with symptoms of schizophrenia/schizoaffective disorder and their carers might be lacking which stops them providing these types of treatment?

### **Culture and Ethnicity**

1. In what ways do you think the cultural background of a service user with symptoms of schizophrenia/schizoaffective disorder plays a part in whether he/she has access to CBT and/or family interventions?

2. In what ways do you think the cultural background of a carer of a service user with symptoms of schizophrenia/schizoaffective disorder plays a part in whether he/she has access to CBT and/or family interventions?
3. What would you say are the particular barriers to accessing CBT and/or family interventions for white service users with symptoms of schizophrenia/schizoaffective disorder?
4. What would you say are the particular barriers to accessing CBT and/or family interventions for service users with symptoms of schizophrenia/schizoaffective disorder from ethnic minorities?
5. What language barriers do you think there might be for service-users with symptoms of schizophrenia/schizoaffective disorder which prevent them accessing CBT and/family interventions?
6. What language barriers do you think there might be for carers of service users with symptoms of schizophrenia/schizoaffective disorder which prevent them accessing CBT and/or family interventions?

### **Religion**

1. What difficulties might religious service-users with symptoms of schizophrenia/schizoaffective disorder face in accessing CBT and/or family interventions?
2. What difficulties might religious carers of service users with symptoms of schizophrenia/schizoaffective disorder face in accessing CBT and/or family interventions?

### **Age**

1. What difference do you think the age of a service-user with symptoms of schizophrenia/schizoaffective disorder makes to his/her chances of getting access to CBT and/or family interventions?
2. What difference do you think the age of a carer of a service user with symptoms of schizophrenia/schizoaffective disorder makes to his/her chances of getting access to CBT and/or family interventions?
3. Can you think of reasons why an older service-user with symptoms of schizophrenia/schizoaffective disorder might not get access to CBT and/or family interventions?
4. Can you think of reasons why an older carer of a service user with symptoms of schizophrenia/schizoaffective disorder might not get access to CBT and/or family interventions?
5. Can you think of reasons why a younger service-user with symptoms of schizophrenia/schizoaffective disorder might not get access to CBT and/or family interventions?
6. Can you think of reasons why a younger carer of a service user with symptoms of schizophrenia/schizoaffective disorder might not get access to CBT and/or family interventions?

### **Gender**

1. What would you say are the barriers to access of CBT and/or family interventions for female service users with symptoms of schizophrenia/schizoaffective disorder?
2. What would you say are the barriers to access of CBT and/or family interventions for male with symptoms of schizophrenia/schizoaffective disorder?

3. Can you think of reasons why male and female service users with symptoms of schizophrenia/schizoaffective disorder might not have the same chances of getting access to CBT and/or family interventions?
4. What would you say are the barriers to access of CBT and/or family interventions for female carers of service users with symptoms of schizophrenia/schizoaffective disorder?
5. What would you say are the barriers to access of CBT and/or family interventions for male carers of service users with symptoms of schizophrenia/schizoaffective disorder?
6. Can you think of reasons why male and female carers of service users with symptoms of schizophrenia/schizoaffective disorder might not have the same chances of getting access to CBT and/or family interventions?

### **Sexuality**

1. What are the barriers heterosexual service-users with symptoms of schizophrenia/schizoaffective disorder face in accessing CBT and/or family interventions?
2. What are the barriers heterosexual carers of service users with symptoms of schizophrenia/schizoaffective disorder face in accessing CBT and/or family interventions?
3. What are the barriers gay/lesbian service-users with symptoms of schizophrenia/schizoaffective disorder face in accessing CBT and/or family interventions?
4. What are the barriers gay/lesbian carers of service users with symptoms of schizophrenia/schizoaffective disorder face in accessing CBT and/or family interventions?

5. What are the barriers bisexual service-users with symptoms of schizophrenia/schizoaffective disorder face in accessing CBT and/or family interventions?
6. What are the barriers bisexual carers of service users with symptoms of schizophrenia/schizoaffective disorder face in accessing CBT and/or family interventions?

### **Resources**

1. What part do you think money has to play in being a barrier to service users with symptoms of schizophrenia/schizoaffective disorder accessing CBT and/or family interventions?
2. What part do you think money has to play in being a barrier to carers of service users with symptoms of schizophrenia/schizoaffective disorder accessing CBT and/or family interventions?
3. What part do you think having enough space has to play in being a barrier to service-users with symptoms of schizophrenia/schizoaffective disorder accessing CBT and/or family interventions?
4. What part do you think having enough space has to play in being a barrier to carers of service users with symptoms of schizophrenia/schizoaffective disorder accessing CBT and/or family interventions?
5. What part do you think having enough time has to play in being a barrier to service-users with symptoms of schizophrenia/schizoaffective disorder accessing CBT and/or family interventions?
6. What part do you think having enough time has to play in being a barrier to carers of service users with symptoms of schizophrenia/schizoaffective disorder accessing CBT and/or family interventions?

### **Mental Health Diagnosis**

1. Do you think service-users with depression are more likely to have access to CBT and/or family interventions than service-users with symptoms of schizophrenia/schizoaffective disorder?
  
2. Do you think service-users with anxiety are more likely to have access to CBT and/or family interventions than service-users with symptoms of schizophrenia/schizoaffective disorder?
  
1. Do you think carers of service-users with depression are more likely to have access to CBT and/or family interventions than carers of service-users with symptoms of schizophrenia/schizoaffective disorder?
  
2. Do you think carers of service-users with anxiety are more likely to have access to CBT and/or family interventions than carers of service-users with symptoms of schizophrenia/schizoaffective disorder?

### **Physical Disability**

1. What barriers to accessing CBT and/or family interventions might service-users with symptoms of schizophrenia/schizoaffective disorder with a physical disability face?
  
2. What barriers to accessing CBT and/or family interventions might carers of service users with symptoms of schizophrenia/schizoaffective disorder with a physical disability face?

- 
1. Are there any other barriers to accessing CBT and/or family interventions for service users with symptoms of schizophrenia/schizoaffective disorder that we have not mentioned that you would like to comment on?

2. Are there any other barriers to accessing CBT and/or family interventions for carers of service users with symptoms of schizophrenia/schizoaffective disorder that we have not mentioned that you would like to comment on?

**Appendix 3: Demographic Questionnaire**

Please complete the following without stating your name at any point. Where appropriate, please circle the answer that applies to you.

1. Gender: Male Female
  
2. Age (in years): .....
  
3. How would you describe your ethnicity using the NHS Trust Ethnicity Classification Categories and Codes?.....
  
4. What is your occupation? .....

## **Appendix 4: Focus Group Questions**

### **Preamble**

Thank you for volunteering to be a part of this research into Barriers to Accessing Cognitive Behavioural Therapy and Family Interventions for Service Users suffering from symptoms of schizophrenia/schizoaffective disorder of the NHS Trust and their carers. For those of you who do not know me my name is Lorraine Rhule. As you can see we are recording this session. We are here today to explore views on accessing two psychosocial treatments: cognitive behavioural therapy and family interventions in the NHS Trust. We will have a group discussion for 45 minutes. You are free to withdraw at anytime during the discussion. There are five questions in all. After the first question, feel free to discuss your answers among yourselves. Do you have any questions?

### **Opening: Question 1.**

Introduce yourselves using your first name (clockwise/anticlockwise). Then tell us which part of the NHS Trust you are connected to.

### **Introduction: Question 2.**

What do you think about the NHS Trust?

### **Question 3.**

What do you think of treatments available for people using NHS Trust who suffer from symptoms of Schizophrenia/Schizoaffective disorder and their carers?

### **Question 4.**

What prevents people suffering from symptoms of Schizophrenia/Schizoaffective disorder and their carers having cognitive behavioural therapy/family interventions in the NHS Trust?

### **Question 5.**

If you could, how would you change things so that it was easier for service users with symptoms of schizophrenia/schizoaffective disorder and their carers to get access to cognitive behavioural therapy/family interventions?

## **Appendix 5**

### **Data Analysis Process**

Here is an examination of the analytical processes involved in theory development. In the interests of time and space, codes and categories were developed as they related to the research questions. Emergent themes that did not directly relate to the research questions were not included in the analysis.

The specific analytic steps were as follows:

- 1) Each transcript for each type of participant was read and re-read closely
- 2) A memo pertaining to those transcripts was developed to record “active” codes emerging from the researcher’s interaction with the source data line-by-line
- 3) The codes were numbered
- 4) The date the code emerged was recorded
- 5) Definitions of codes were “grounded in the data” – excerpts of transcript were used to communicate the intended meaning of the code
- 6) The memos were used to record the definitions of codes as they arose
- 7) Relationships between codes were identified by examining themes that emerged: between participants during interaction; as consequences of interaction; between groups with a similar type of participant; and across particular participants over time
- 8) The transcript was checked to ensure that emergent themes were closely related to the source data
- 9) Stages 1 – 7 were repeated for each type of participant for the focus groups and for the interviews. The list of categories was then added to or amended accordingly as they emerged
- 10) The analytic process was reviewed in supervision and any further amendments were made
- 11) High order core categories subsuming active codes were developed to encapsulate the essence of the theme being considered
- 12) Sub-categories of the core categories were delineated in terms of their dimensions
- 13) The relationships between the core categories, sub-categories and their dimensions were examined

- 14) The core categories, sub-categories and their dimensions were reviewed in supervision to ensure that they were consistent with the source data
- 15) The theory was presented using transcript, commentary and figures to illustrate participants' views on the barriers to accessing CBT and FIs for service users and carers

### **Questions asked of the data**

During the process of data analysis the following questions were asked of the data:

what would the speakers have to believe about:

- a) Themselves?
- b) The world?
- c) The future?

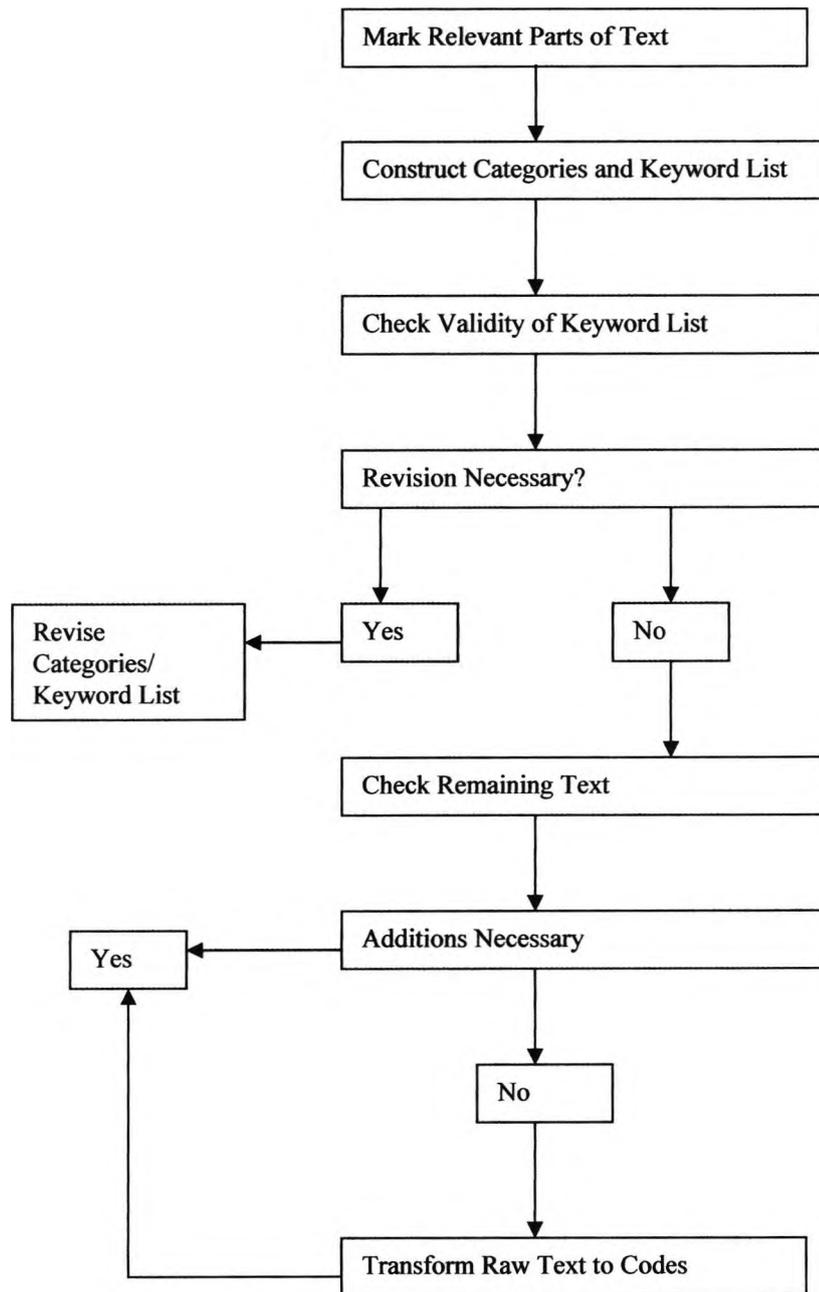
in order to say the things they do.

- d) How does this relate to the questions I have asked or in what context does it emerge?
- e) How are they co-constructing meaning through interaction?

The following method was used to analyse the data:

- ◆ Listen to tapes concentrating on one question at a time
- ◆ Consider the words and their meanings
- ◆ Frequency count of commonly used words, cluster of similar concepts
- ◆ Arrange responses according to categories
- ◆ Consider the context (e.g. preceding questions, tone and intensity of speech, non-verbal communication)
- ◆ Consider the internal consistency/shifts in topic or opinion
- ◆ Consider the specificity of responses

Focus Groups - Stewart and Shamdasani (1990).



**Record of theory development: Mental Health Professionals Group (C)**

| Action Code               | Date       | Definitions of codes   | Justification for code label                  | Relationship with code(s) #                        | Integration with/analytical category  | Date |
|---------------------------|------------|--|---|--|---|------|
| 1. Feeling insignificant  | 19/09/2002 | I don't feel my views personally were heard or anyone's view really, you don't feel very respected, not recognised.  | Concept used frequently by group participants | A 29, 32, 33, 38, 44<br>B -<br>C 2, 10, 19, 20, 23 | 1. Perception of elitist services<br>A1, 29, 32, 33, 38, 44<br>B-<br>C2, 10, 19, 20, 23 |      |
| 2. Discrimination by area | 19/09/2002 | I think depending on what part of the Trust as a user that you are in is the quality of care that you'll get. So there is perception that they've got this, this, a special this and a special that. | Concept used frequently by group participants | A 24<br>B -<br>C 1, 4, 7, 10, 15, 16, 19, 20       |   |      |

**Record of theory development: Mental Health Professionals Group (C)**

|  |            |  |   |                                      |  |  |
|--|------------|--|---|--------------------------------------|--|--|
| 3. Evidence based practice/providing innovative services | 19/09/2002 | I think some people are ahead with sort of their treatments, some of us behind, We've had lots of new initiatives but we're too busy doing to go around the world and say what we've done. | Concept used frequently by group participants | A 27<br>B 23<br>C 10, 15, 16, 19, 21 |  |  |
| 4. Adapting to local needs                               | 19/09/2002 | So you've got to adapt to our local needs local community, each area has its own different needs.  | Concept used frequently by group participants | A -<br>B -<br>C 2, 5, 15, 16, 18, 19 |  |  |
| 5. Adapting to change                                    | 19/09/2002 | Its too much to keep taking, they're changing I think too often as well, obviously a lot of people have been confused and obviously because of the effects of                              | Concept used frequently by group participants | A -<br>B -<br>C 4, 6, 19, 21         |  |  |

**Record of theory development: Mental Health Professionals Group (C)**

|                          |            |   |   |  |  |  |
|--------------------------|------------|---|---|--|--|--|
|                          |            | change, effects its having on the clients/patients  |   |  |  |  |
| 6. Lacking knowledge     | 19/09/2002 | I don't know much about it in a way, We don't even know where it is so how would we know where to or who to contact? Who publicises it for the carers to actually know? | Concept used frequently by group participants | A 13, 14, 41, 42<br>B 1, 2, 3, 15, 21<br>C 5, 18, 22, 23 |  |  |
| 7. Aiming for uniformity | 19/09/2002 | And you know we're saying about trying to get some sort of uniformity, I think it would be more accessible and available if the services were within individual teams   | Concept used frequently by group participants | A 1<br>B 22<br>C 2, 8, 10, 15, 16, 19, 22                |  |  |

**Record of theory development: Mental Health Professionals Group (C)**

|                               |            |   |   |   |  |  |
|-------------------------------|------------|---|---|---|--|--|
| 8. Moving towards integration | 19/09/2002 | I think that's well I certainly agree with the idea of integration to avoid duplication   | Concept used frequently by group participants | A -<br>B -<br>C 7, 10, 18                     |  |  |
| 9. Measuring performance      | 19/09/2002 | if figures were to say what we did I don't think it proves the quality of our work, we are up against quite a lot of competition and I think it actually does sound a competitive when we're saying the figures aren't the same as this borough | Concept used frequently by group participants | A -<br>B -<br>C 1, 11, 15, 19                 |  |  |
| 10. Establishing priorities   | 19/09/2002 | We still feel the most important thing is service delivery and good quality service delivery  | Concept used frequently by group participants | A -<br>B -<br>C 1, 2, 3, 7, 8, 15, 18, 19, 21 |  |  |
| 11. Defining the limits       | 17/10/2002 | specially to ethnic   | Concept used frequently by group              | A 2, 41, 42<br>B 1, 8, 10, 12, 15,            |  |  |

**Record of theory development: Mental Health Professionals Group (C)**

|  |  |  |              |   |  |  |
|--|--|--|--------------|---|--|--|
|  |  | minorities, you try and refer somebody and you have to go through many hoops and it could take six months, once you've done the assessment with the carer its hard enough finding workers for the patients, You also haven't got the time because you've got twenty other seriously mentally ill patients, having all those things available would make this work more attractive to people so you'd get more people | participants | 16, 18, 20, 22, 23<br>C 9, 15, 16, 19, 21, 22, 23 |  |  |
|--|--|--|--------------|---|--|--|

**Record of theory development: Mental Health Professionals Group (C)**

|                                      |            |  |   |   |  |  |
|--------------------------------------|------------|--|---|---|--|--|
| 12. Placing emphasis on training     | 17/10/2002 | more of an emphasis should be on someone being trained   | Concept used frequently by group participants | A -<br>B 21<br>C 13, 16                               |  |  |
| 13. Making recommendations           | 17/10/2002 | I'd make them local services to start with, I think some of our staff could be trained, providing we get a replacement   | Concept used frequently by group participants | A 13, 14<br>B 22, 23<br>C 12, 16, 21                  |  |  |
| 14. Considering carers               | 17/10/2002 | I think there is a carers there's a carers' care plan, there's a carers' needs assessment plus there's a carers' agency set up now, But you don't even think in the beginning you're a carer | Concept used frequently by group participants | A 31, 32, 41<br>B 1, 4, 8, 14, 22<br>C 16, 17, 18, 23 |  |  |
| 15. Justifying the lack of provision | 17/10/2002 | its difficult for them to do that kind of work because of the time it takes when they've got large caseloads   | Concept used frequently by group participants | A 27<br>B -<br>C 2, 3, 4, 7, 9, 11, 16, 19, 22, 23    |  |  |

**Record of theory development: Mental Health Professionals Group (C)**

|  |            |   |   |   |  |  |
|--|------------|---|---|---|--|--|
| 16. Using information                                    | 17/10/2002 | we need to be educated a bit more in order to educate both clients.   | Concept used frequently by group participants | A 13, 14, 29, 41, 42<br>B 1<br>C 2, 3, 4, 7, 10, 11, 12, 13, 14 |  |  |
| 17. Formal vs. informal versions of family interventions | 17/10/2002 | I think as a care co-ordinator or CPN nurse, OT whatever you need to be jack of all trades and use all of the skills you've got, I think it's a very specialised thing and that you need a specialised worker | Concept used frequently by group participants | A 27<br>B -<br>C 2, 3, 4, 6, 7, 11, 14, 18                      |  |  |
| 18. Managing risk  | 17/10/2002 | there may be a child who has extra needs but that's all but not in an abusive sense but just maybe needing to make sense of what's happening for the parent   | Concept used frequently by group participants | A 3<br>B -<br>C 4, 6, 8, 10, 14, 17                             |  |  |
| 19. Taking pride in the service                          | 17/10/2002 | we are doing quite well, What we seem to lack   | Concept used frequently by group participants | A 23<br>B -<br>C 1, 2, 3, 4, 5, 7, 9,                           |  |  |

**Record of theory development: Mental Health Professionals Group (C)**

|                                    |            |  |   |   |  |  |
|------------------------------------|------------|--|---|---|--|--|
|                                    |            | is the ability or the to blow our own trumpet  |   | 10, 11, 15                                  |  |  |
| 20. Feeling isolated               | 31/10/2002 | I find it its very isolated and it isn't much facilities round haven't got not much hope that things will get better. There is so many facilities not available here so.   | Concept used frequently by group participants | A -<br>B 14<br>C 1, 2                       |  |  |
| 21. Going beyond the medical model | 31/10/2002 | you know its really a full capacity for doing things people aren't going to they're going to need more than I think the medical model I keep harping back to that but I think if we stick to that I mean t doesn't take into account | Concept used frequently by group participants | A 1, 5, 33<br>B -<br>C 3, 5, 10, 11, 13, 22 |  |  |

**Record of theory development: Mental Health Professionals Group (C)**

|                                 |            |   |   |   |  |  |
|---------------------------------|------------|---|---|---|--|--|
|                                 |            | anything about the mind spiritual or anything   |   |   |  |  |
| 22. Discrimination by diagnosis | 31/10/2002 | Even for the most needy one when we refer here it takes ages how about the psychotic one? They will never be seen at all. | Concept used frequently by group participants | <b>A</b> 27, 34, 42<br><b>B</b> -<br><b>C</b> 6, 7, 11, 15, 21, 23        |  |  |
| 23. Considering power dynamics  | 31/10/2002 | people with schizophrenia they're quite disempowered  | Concept used frequently by group participants | <b>A</b> 7, 11, 44<br><b>B</b> 1, 14, 22<br><b>C</b> 1, 6, 11, 14, 15, 22 |  |  |

1 **Transcript:** Focus Group 4 (Mental Health Professionals)

2  
3 LR: Thank you all for volunteering to be part of this research. As you can see for  
4 those of you who have just come in, this is being recorded but its going to be, its  
5 confidential to myself and the person who's going to help me analyse it at City  
6 University. Ok, right, I've got five questions here and I'd really like it if you would  
7 talk among yourselves as well. So as I ask a question, you may sort of talk to one  
8 another about it, how you feel about it, what you think about it ok. So I mean, you  
9 probably all know each other but I don't know everyone here. So I just wonder if you  
10 could go around in a circle or in a line, firstly introduce yourselves stating just your  
11 first name for my benefit in case I need to ask you a question and then say which part  
12 of the Trust you're affiliated with, ok. So, who'd like to start?

13 RM: I'm R, what else you wanted us to say? I'm part of X. I think we're all part of  
14 X.

15 LR: That's fantastic, ok well we can leave that bit out then can't we.

16 MD: I'm M, I'm a CPN.

17 JR: J

18 MB: I'm M.

19 EE: I'm E

20 EEv: I'm E

21 SL: S.

22 LR: Thank you that was the first question. It wasn't difficult at all was it? Ok, so the  
23 next question is, anyone can answer this, in any order, I'd like you to talk amongst  
24 yourselves as well. What do you think of the X?

25 MD: Too big.

26 LR: Don't be shy, just talk among yourselves.

27 MD: I think depending on what part of the Trust as a user that you are in is the  
28 quality of care that you'll get.

29 JR: I think, yes, some parts of our Trust have a, I don't think we're all equal. I think  
30 some people are ahead with sort of their treatments, some of us behind. I'm not quite  
31 sure I know that we sometimes if we get audits we might be told where we place stand  
32 but I'm not quite sure that's what happens.

33 LR: Talk among yourselves don't be shy.

34 EE: Because of its largeness you get ideas and policies and they want to roll them  
35 out right across the Trust but you've got so many different areas within this part of  
36 London I mean you've got X which everybody thinks of as a nice leafy suburb and  
37 then you've got inner city areas X, X that you know, what applies in one part it  
38 doesn't necessarily apply in another part. So you've got to adapt to our local needs  
39 local community.

40 JR: I think cause they, I think their working on for example yesterday I attended  
41 training and they talk about standardising a lot of I think it was our referral forms just  
42 standardising our paperwork. Its too much to keep taking, they're changing I think  
43 too often as well.

44 LR: What do other people think?

45 SL: I don't feel I that I'm working for the Trust 'cause I'm Social Services  
46 perspective I don't feel that that I am. I don't know much about it in a way. Not adult  
47 old age psychiatry. I think its brilliant as far as X's concerned 'cause that's where  
48 I've worked and I think they're exceedingly good. But I've yet to form my opinion.

49 EEv: I think there are so many changes their sort of going through. I work for social  
50 services as well so I'm kind of attached to I'm a part of the integrated new integrated

51 team but I think a lot of the development that's going on there's far too much and its  
52 confusing I think people are very confused about what's been doied out to us. And  
53 you know we're saying about trying to get some sort of uniformity and that sounds  
54 quite comfortable to think that way we'll be much more equal but we are as people  
55 have said quite such a different sort of, each area has its own different needs as well  
56 so I don't know how you can do that really.

57 RM: There's not just integrated with the other boroughs within the Trust. Each  
58 borough then has to integrate with local authority. And as far as the work on the  
59 ground its more important for us to integrate and have the same paperwork as the  
60 London Borough of X because we're working with the same group of patients. So  
61 that becomes a priority over standardising forms within the Trust 'cause we are  
62 working with the same group of patients. So, but on the same token we feel that  
63 we're part of the Trust we should have a standardised assessment and the rest of it.  
64 But then you've got four local authorities to negotiate that with so its enormously  
65 complicated.

66 MD: Coming back to what E said. I mean obviously a lot of people have been  
67 confused and obviously because of the effects of change. I think its one change after  
68 the other. But I think also the effects its having on the clients/patients. If we're  
69 feeling confused and demoralised our patients feel its and its sort of the input that  
70 we're trying to give to the patients and not only because I come from (inaudible) but I  
71 think our patients are really well adapted we've put a lot of input in and we're quite a  
72 good team here.

73 LR: Other people, what do you think of the X?

74 JR: They want us they want us to integrate this is something that's ongoing they want  
75 us to integrate say for example just this as an example like nurses with like social  
76 workers but there's still so much social workers for like figures and you have to do  
77 separate things its sometimes you just think that's all, I mean I know they need their  
78 figures and that's all I don't know if that means very much because again in doubt  
79 where I work downstairs in day care if figures were to say what we did I don't think it  
80 proves the quality of our work and things and I think that's we keep going on figures  
81 and I think that's very fair. I don't think anything measures the sort of work I do or  
82 that we all do.

83 MD: And the hours that you actually will put in on one patient. And they talk about  
84 integration I mean we're supposed to be integrated but there's different systems  
85 there's duplication different paperwork this one's got to sign this and this one's got to  
86 so there's no they haven't really go their act together yet.

87 EEv: I think that's well I certainly agree with the idea of integration to avoid  
88 duplication but like we're saying, there are so many different systems that still are still  
89 existing and I suppose if you comparc it with a company that was so sort of in  
90 merging and these are services that are merging if you like they usually have put in  
91 some financial injection into the into the new enterprise and I think that we've  
92 probably tried to do this in a sort of piecemeal kind of way on a bit by bit basis. And I  
93 think this is why we cover up quite a lot. We still feel the most important thing is  
94 service delivery and good quality service delivery and that is what's sort of the root of  
95 it all in our hearts really but we are up against quite a lot of competition and I think it  
96 actually does sound a competitive when we're saying the figures aren't the same as  
97 this borough or we're trying to get as good as X or X are trying to get as good as X, or  
98 whatever and I just think it actually there's something else to sort of beat ourselves up  
99 with so we're actually really trying very hard to deliver a good service.

100 JR: They're also, they're talking I think in our new day-care system's coming around  
101 this is happening within X about having generic workers and I think that's quite  
102 exciting to be able to, you cover so many different areas. But also there is from our  
103 different backgrounds and disciplines we've got a certain sort of code of practice we  
104 should we have to follow, we can't forget that either and yet that's I think that's quite  
105 separate as well I mean. So you just don't feel certainly what's happened us in X you  
106 don't feel very respected, I don't feel my views personally were heard or anyone's  
107 view really. But you had these sort of meetings with like hardly any staff involved all  
108 the information we've had is all in bits. And certainly its going to be a challenge for  
109 whoever else has to take on this new day-care system and it certainly not going to be  
110 they'll be people leading it it'll be all their good ideas but its going to be people like  
111 ourselves who have got to the one's who'll be doing all the hard work.

112 LR: This is a lot of very valuable information I just want to move on now to the next  
113 question which is, What do you think of treatments available for people using the X  
114 who suffer from symptoms of schizophrenia/schizoaffective disorder and their carers,  
115 what do you think of treatments available for people using this Trust who suffer from  
116 suffer with those symptoms?

117 MD: I think they're quite limited. Especially the psychology input and CPD things  
118 like that. And I think its more so specially to ethnic minorities and.

119 JR: I think it they've got this great I think there's a good team I think X and they're  
120 very good 'cause they take people as young as fourteen that now we're sort of I think  
121 they deal with up to sort of thirty-five years. I think we've got great opportunities for  
122 young people if you can get in quick and treat people a lot a lot younger now there's a  
123 better life ahead for them. But I think, I don't know unless other people know, I'm  
124 not quite aware of all other treatment really what's really immediate to where I'm  
125 working.

126 RM: I think they might be available but its accessing them is very difficult you try  
127 and refer somebody and you have to go through many hoops and it could take six  
128 months before you even get anywhere near that person being assessed. What do you  
129 do with that person in the meantime? You have to start more conventional treatments  
130 or with what you've got available. So although they seem to be available and it looks  
131 all very good on what services are available within X, most of them are very elitist  
132 and you can't access them. So when you make a referral, you might as well have  
133 referred them to the moon sometimes not part of our own Trust it doesn't feel like it  
134 belongs to us.

135 LR: Talk amongst yourselves.

136 MD: I think I think also what happens within this I don't know what happens in other  
137 mental health teams, but I think within this community mental health team if there are  
138 people who need CBT and obviously if there's long waiting lists and whatever, we do  
139 do that in our own way even though we're not qualified to do it. We do do various  
140 interventions.

141 MB: Lots of places won't do CBT if people have got active psychosis. Will they?

142 MD: Yes sometimes that's a part of it as well.

143 MB: Because there was a trial at the X that was doing it but when we tried to refer  
144 people there and its really it was for people that and they were so (inaudible) and they  
145 only took one person in nine months from our team. And so with the others they're  
146 waiting to hear and then they feel really rejected that they don't get on and then they  
147 don't get anything and you just think well.

148 MD: I think even like with the X outreach and that CPN's do a lot more outreach  
149 than they really do a lot more outreach than the outreach teams are doing. Because  
150 we have this ethos if you want that we keep our patients in the community.

151 MR: I think it would be more accessible and available if the services were within  
152 individual teams

153 ALL: Yes, yes

154 MR: Rather than having these specialist services miles away I mean you tell a patient  
155 you've got to go to X and their thinking go to the end of the world. They don't want  
156 to go to X. X is central London to people who live round here. Its not South London.

157 EEV: No and I know that from Social Services point of view we were asked about a  
158 year or two ago about training CBT and that was so much in the Health Service  
159 domain and that actually was considered that we wouldn't be having that access to  
160 that training. Here we are working in a community mental health team. So in a sense  
161 I think some of us actually would like to do that training and perhaps know a bit more  
162 about it and like you say we could actually operate that in the community mental  
163 health teams. I suppose some of us have had bits and pieces of training in CBT but I  
164 know I've only attended a couple of workshops. Know just about what it is but you  
165 know the how you can use it with various different people with different illnesses I  
166 really wouldn't know so its lack of knowledge.

167 JR: I think its what you're saying E as well you see with more of an emphasis should  
168 be on someone being trained now because of the care co-ordinator role because co-  
169 ordinating for various sort of clientele. When you said, again I think something you  
170 said R about where the services if the services I agree whereas it should be in the  
171 teams because a lot of people they're not motivated they're motivations coming in  
172 coming in here and they need, they a lot of the time they might you know guard  
173 symptoms until they really get to know you and if you have to send them off for  
174 another treatment somewhere else you know yes.

175 MD: There's no continuity

176 RM: I mean I feel that these big teams instead of operating from a base if they could  
177 have offer a supervision type of say they've got ten members if they could put one  
178 one of their staff with our team and one another team and then go back for the  
179 supervision and support so that there is a link that would be much much better use of  
180 resources than having them all congregated up at the X or at X.

181 EEV: It makes it so elitist then 'cause that's where the Centre of Excellence and all  
182 that kind of its got all of those kind of connotations hasn't it? And so it takes people  
183 away from the community which is not what we're being told is the Department of  
184 Health guidelines and local services and all that so actually flies in the face of that  
185 really so.

186 JR: You've asked one thing about carers didn't you what there is available for carers.  
187 I mean I know that obviously the family work, that's based around the sort of carer  
188 but I think other than that. I know there's like a recently we downloaded something  
189 off the Intranet I think about carers assessments. But that's all quite new. But its not  
190 I'm not sure where that would be leading because once you've done the assessment  
191 with the carer its hard enough finding workers for the patients.

192 MD: I think there is a carers there's a carers' care plan, there's a carers' needs  
193 assessment plus there's a carers' agency set up now.

194 RM: Yes but if you do a carers' assessment, that's another assessment, so you're  
195 doubling up the number of patients really. We're hardly resourced to deal with the  
196 patients it would be good if we could offer a carers' assessment but then as minimum  
197 but then what do you do once you have done an assessment, you raise expectations,

198 we actually haven't got the resources. We have got huge number of patients,  
199 everyone's got a huge caseload so then you've if you're just assessing that's going to  
200 take another whatever length of hours. You're doubling the number of assessments.  
201 But then what do you do once you've identified a need? Who is going to provide that  
202 service? We haven't got the resources so it's a very good idea but it needs to come  
203 resourced. The idea is going to come resourced. Carers' assessments.  
204 SL: From the carers' Act, that initial Act, I mean yes you have to do it but it didn't  
205 actually say in the Act that you had to provide anything and that's the problem.  
206 RM: Well what is the point?  
207 MD: Yes  
208 RM: Of assessing somebody's needs and saying well you need this, this, this and that  
209 fine bye bye. It's not going to the person actually. It raises expectations. If you don't  
210 do it, it's not good. But if you do it and then say right you need this, this and this  
211 tough we're not going to give it to you anyway, its even worse, its cruel. So, that is  
212 where we are with it. We haven't we haven't actually taken it on board fully because  
213 we know that we haven't got the resources to do from the first start even just the basic  
214 assessments and then if we do them we haven't got, we definitely haven't got the  
215 resources to provide a service for those carers. A carers' group is the most we'd  
216 probably be able to go to.  
217 ALL: Yes  
218 RM: You do two hundred assessments, not all of them are going to come up in the  
219 end attend carers' group.  
220 EEI: We've got actually got two nurses trained in its called the Thorn course its like  
221 CBT Family Interventions combined. But its difficult for them to do that kind of  
222 work because of the time it takes when they've got large caseloads of or 's got large  
223 caseload of thirty-nine to forty patients. And Family Interventions do take time  
224 because you've got to set it up, you've got to work with the family and its got to be  
225 regular and ongoing so in a way we've got the sort of embryo of resources but it can't  
226 develop.  
227 MB: Do we have access to any family therapy? Who do we refer to for family  
228 therapy? Actually from a family therapist.  
229 EEI: Well for this client group with schizophrenic and schizoaffective group I  
230 honestly don't know. Because when I worked at CAMHS when I was doing a course  
231 I never got, I never came across any families there with schizo..  
232 RM: That was usually revolve around a child, or the adolescents not with a parent  
233 they haven't got the capacity to take family of an adult schizophrenic or an adult  
234 manic depressive. There were some people who were trying to do some family  
235 intervention work but they've got so many other commitments, they can't  
236 EEV: So we tend to do an informal version of our own. We don't know family  
237 therapy do we in terms of certainly with carers and support, we know how valuable it  
238 is to keep carers well and to keep them in tune with what's going on with the cared for  
239 person. But you know, its not through any training, its just out of necessity. You just  
240 know that that's something that's going to alleviate the home situation if you can offer  
241 some even if sometimes it is just trying to talk about what carers is going through. I  
242 mean identifying young carers we're still trying to sort of unfold what's available for  
243 young carers in X as well and whether we raise that as a child protection issue or just  
244 a child in need. You know there are lots of issues about that we actually protect our  
245 people the people with see with as well. Because I think a lot of people are worried  
246 because you know because a parent is mentally unwell, that we're actually saying this  
247 is a child protection issue. We're not necessarily saying that we're saying that there

248 may be a child who has extra needs but that's all but not in an abusive sense but just  
249 maybe needing to make sense of what's happening for the parent.

250 RM: Sometimes you have to be over-creative really getting a service for what you  
251 consider to be the priority (inaudible) for instance, going through that route rather  
252 than just offering support to the whole family saying oh there's a child, I know, I can  
253 go through child protection. So people have to be creative to get a service because  
254 otherwise we don't. But then you prioritise I suppose.

255 EEv: I suppose I'm saying is not a child protection issue so if children services don't  
256 want to take her on unless it's serious. So in a sense I'm quite happy to continue  
257 supporting that family so long as I've had the blessing from children and family  
258 services that I'm not acting out of my remit. Because you know for instance I'm an  
259 adult worker although I'm a social worker and I know how to recognise children and  
260 childcare needs you know if I'm starting to take work with a young child of nine or  
261 ten, talking to them about their mother's experience or father's experience of mental  
262 illness, am I is it within my

263 RM: Treading on someone else's toes.

264 EEv: Yes I mean there's kinds of issues around boundaries around which service  
265 should be supporting that person

266 RM: You also haven't got the time because you've got twenty other seriously  
267 mentally ill patients.

268 EEv: Yes the reason why I mentioned this is because I'm actually at the moment  
269 have a live case. But I have spoken to the children services and we are gradually  
270 trying to see if we can actually get this child to have some support in its own right.  
271 But it is you know in terms of sort of we're talking helping people and families.

272 MD: I think X don't get all the services that they should have all the other areas like  
273 X, X places like that when we've been joined together let's say X do not get  
274 their fair share of resources. And certain things we should have.

275 LR: What do other people think?

276 EEv: I'm wondering if it's a perception thing.

277 RM: I think it is.

278 EEv: Well, I'm just wondering.

279 MB: We've got more, much more voluntary 'cause I worked in X before and you've  
280 got a lot more voluntary and charity provision lots more opportunities for your clients  
281 than there are in X lots more there's lots more options in terms of that. And I don't  
282 notice occupational therapy wise; I don't notice a vast difference really between  
283 services that you've got here for the clients than that you've got there. But X I think  
284 is very well overall very well provided for.

285 RM: Especially in the community, community services. But I think the perception of  
286 the X it's skewed because of the national provision I know that they have been I don't  
287 know whether they still are. They've got this thing about being very well funded and  
288 they've got national funding from directly from the department. Its not so much now  
289 it used to be when it was a special health authority. So there is perception that they've  
290 got this, this, a special this and a special that.

291 MB: They don't have you know your day care obviously changing its being  
292 reorganised there is no day care in X, there is no day care provision. There's none  
293 there's one day care place in X but that's only for long term continuing there's no  
294 acute day care.

295 JR: But then again, that's exciting as well then 'cause they're saying that our  
296 women's service are looking at day care. So that we are doing quite well.

297 MB: Even though you've been moved that day care thing is really good.

298 MD: That was developed by X and I think initially X.  
299 MB: But its still something you've got that they haven't.  
300 MD: We were the community because I think those other areas didn't have no  
301 community services with being such a big recognised hospital, elitist hospital,  
302 specialised hospital as they want to call it they didn't have no community facilities  
303 and what we have come from X Health originally isn't it.  
304 RM: Hmm  
305 MD: Because there was no day care facilities for those areas that you know.  
306 EEv: So you're saying it's historic historically  
307 MD: Well historically (inaudible) the first hospital to open the door.  
308 EEv: To community services.  
309 RM: And to the (inaudible) community services are comparatively well developed.  
310 What we seem to lack is the ability or the to blow our own trumpet. I mean look we  
311 never actually, X services, it's the first X service in the country but how often do you  
312 see it heralded and trumpeted? Oh its only old X, them in the sticks. We're not very  
313 good at blowing our own trumpet.  
314 MB: Yes they've chosen X to, they chose X to pilot the X team though whatever you  
315 think about the X team but its still a new development (inaudible).  
316 RM: We've had lots of new initiatives but we're too busy doing to go around the  
317 world and say what we've done.  
318 MD: But I think also we do a lot of work within this area but because they think its  
319 Purley it's very easy-going the patients are so, you know they're not difficult patients  
320 they're not complex mental health needs things like that. But they need to come here  
321 and look what really goes on in Purley and the amount of work and interventions that  
322 goes on because we keep our patients out of hospitals a lot more goes on. Because  
323 patients aren't easy.  
324 RM: Because its seen as an affluent area suburbia X being the Southeast part the  
325 concept is that there is no major problems there's no inner-city deprivation but there  
326 are an awful lot of hostels an awful lot of large hospitals with people that are taking in  
327 supportive lodgings so there's an awful lot of people with chronic mental illness. Ok,  
328 they might be migrated to the area but they are here and we've got a huge number  
329 hostels a huge number of residential homes plus many many homes with three or four  
330 supportive lodgings people with them. So that actually skews the figures although the  
331 miniscore say that's provided our mental illness needs should be down there but  
332 actually they're not.  
333 MD: And when they look you know like the revolving door patient, we don't have  
334 many because the interventions is going on in the community where we keep the  
335 patient in the community you know. We're always breaking our back doing that  
336 because it's more detrimental for them to go into hospital than it is to try being  
337 contained in the community. And that's not recognised. They just think our patients  
338 are so well maintained that they don't need admission. They don't live with things  
339 like that.  
340 LR: Ok thank you. I want to move on to question four now. I guess this has been  
341 answered in part but maybe you can explore it further. What stops people suffering  
342 from symptoms of schizophrenia and schizoaffective disorder and their carers having  
343 talking treatments cognitive behavioural therapy and family interventions in the X?  
344 Do you want me to say the question again?  
345 RM: No we understand the question.  
346 MB: They're not really readily available which we've already said. We were talking  
347 about.

348 MD: They're not readily available and they tend to choose who they want to take.  
349 RM: Well we can't really talk about X as a whole. I mean we talk about our bit  
350 because I'm not actually sure whether the other CMHTs in X have time to provide it.  
351 We its one organisation but it doesn't feel that we know what's going on not in the  
352 teams. We haven't got time to go and we don't even know the people if we met them  
353 in the street we wouldn't know. It doesn't feel as like one unit it feels.  
354 EEv: So a barrier one barrier would be that there's no evidence of it. We don't even  
355 know where it is so how would we know where to or who to contact? And the variety  
356 of systems in place to make a referral. I mean we can make a referral to psychology  
357 and hopefully the psychologist will make an assessment for that particular type of  
358 therapy. But I've been to ward conferences and ward rounds where they say well the  
359 waiting lists for that particular service is so long and its like well then go on put that  
360 name on the list then. And they say well there's no point because its such a long list.  
361 You know there seems to be some sort of block on because there might be a waiting  
362 list that  
363 MB: I've seen I've actually seen as well that people have been referred for things  
364 because there's such long waiting list they then people come up other options and  
365 actually then don't refer them for other options 'cause they so oh they're on the  
366 waiting list for so and so. So people actually end up with nothing because they're on  
367 one waiting list people think well we'll wait for that to come. And if that never comes  
368 then they don't end up with anything.  
369 SL: Who publicises it? Who publicises it for the carers to actually know? I mean  
370 how would a carer actually know that that exists, how would anybody know it exists?  
371 JR: Unless you've got unless you've got like we said we've got a couple of people  
372 done done the Thorn training. Well I'm wondering like I mean it must have come up  
373 on like our intranet that their offering this training I mean its like for your own  
374 personal development. If I saw things more available and and maybe was told a bit  
375 more about training you know I'd probably go for it also it benefits me but it benefits  
376 the team I'm working in. But I don't know I don't know if enough of that is done  
377 enough teambuilding people saying you've got to go for you've got to go for more.  
378 That you know we've only got a couple of people the X training.  
379 SL: But you as a worker may know but if somebody has someone ill and they are a  
380 carer, how will they know what services are if things are not publicised.  
381 MD: There is a published a carers week carers monthly or something coming out.  
382 SL: But you don't even think in the beginning you're a carer. So how do you actually  
383 all you know is somebody is ill.  
384 MD: It's all about education.  
385 SL: Yes so that's what needs to be dealt with, what is there.  
386 JR: That was my point, we need to be educated a bit more in order to educate both  
387 clients.  
388 SL: Yes that's what I'm asking, what actually is.  
389 RM: In ordinary circumstances, each one of us, when you see the patient with their  
390 carer we should be informed of what's available.  
391 JR: That's what I thought.  
392 SL: Yes that's right that's right. But then if you ask and you say well there's this and  
393 what E is now saying is that there's such a waiting list.  
394 MD: Not necessarily there's other they're ordinary organisations and there's things  
395 about it depends on you as an individual what your knowledge is and who you can tap  
396 into actually.  
397 RM: Remember we're talking what X what X has provided.

398 MD: But then, I mean  
399 SL: Yes that's right if its CBT that you want and you hear of it, then how do you  
400 actually get it?  
401 MD: What must (inaudible) but then again when you apply it depends on the staffing  
402 levels it depends lots of things doesn't it?  
403 RM: But really, ideally, we should be offering it here. I mean we should be using  
404 CBT here but we haven't got enough people trained and even the ones are trained  
405 haven't got the time to be able to offer it to everyone that needs it that's.  
406 SL: So we haven't the resource.  
407 RM: We've got one psychologist, for a team of seventy-two thousand population for  
408 our and we've got one psychologist who's here four days a week.  
409 MD: (Inaudible)  
410 RM: Yes. And we've got five CPN's. I mean, how we manage I don't know. And  
411 this particular the last psychologist we've had a gap well the other one left now that  
412 one's going to go on maternity leave they can't replace this person while they're on  
413 maternity leave because there's no money. So we're going to be psychologist-less.  
414 And the community workers have got caseloads of forty plus so.  
415 JR: You saying that in day care there's quite a good skill mix because someone's left  
416 he was training in CBT we've got another person training in counselling but then  
417 again I think its whether or not you know whether they will be they work in their role  
418 as the nurse or they work in their role as a counsellor I don't think they're allowed to  
419 be, you've got to be one or the other really. I don't know whether I don't the  
420 opportunities come about that they can sort of stay within this sort of work but you  
421 know bring forward their counselling stuff.  
422 LR: What do other people think?  
423 MD: I think as a care co-ordinator or CPN nurse, OT whatever you need to be jack of  
424 all trades and use all of the skills you've got. I think counselling can't go hand-in-  
425 hand as with a nurse 'cause maybe a counsellor (inaudible) you need to deal with your  
426 client.  
427 SL: I think it's a very specialised thing and that you need a specialised worker and if  
428 this if you've got somebody who will fit into the mode really needing CBT then that  
429 should come from a specialised person who actually is trained to do the work.  
430 RM: If somebody is actually trained why couldn't it be I don't think it conflicts if  
431 you're the care co-ordinator. If you've only got a caseload of fifteen, and you've got  
432 four patients who you're doing intensive CBT that's fine. But not if you've got a  
433 caseload of forty and people are relapsing all over the place and you're doing crisis  
434 interventions to stop them from.  
435 SL: It depends on what you're actually doing I think.  
436 JR: I think, I think it depends on the supervision they've given as well I mean say for  
437 example people someone I was speaking about does counselling but then she brings  
438 that into her role as a nurse whatever, what sort of supervision will she get? I mean  
439 sort of can she expect that sort of normal supervisor to supervise that sort side of it.  
440 EEV: That's what you were saying R isn't it?  
441 RM: Yes, I think there should be a core centre for CBT.  
442 MB: If you've got like people like a CPN who's an ex got into CBT and they're  
443 doing CBT with some of their clients and then they're going to take clients from other  
444 people's caseload just to do CBT they've got to like have time set aside really haven't  
445 they?  
446 MD: That's it and time for supervision.  
447 RM: Support for people who have been trained not for their general supervisor.

448 MD: They don't need to take time out from their caseload. They'd have a reduced  
449 caseload and their caseload would have to be of patients of CBT needs and that would  
450 be also

451 LR: What you're saying at the moment fits very well with my next question which is  
452 if you could, how would you change things so that it was easier for services users with  
453 symptoms of schizophrenia and schizoaffective disorder and their carers to get access  
454 to cognitive behavioural therapy and family interventions, if you could how would  
455 you change things? I mean the discussion you were having was I think fit quite well  
456 with that but in answer to that question.

457 MB: I'd make them local services to start with.

458 MD: They'd have to be local.

459 RM: I think some of our staff could be trained, providing we get a replacement. And  
460 not just whilst they're training but also once they're working so that its not something  
461 that we do from within the resources we've got it needs to be in addition.

462 MD: It has to be external

463 RM: It needs to be an additional resource so that people feel that they can have time  
464 to go and train and then practice and get the proper supervision so that they can go off  
465 to meet other clinicians who are doing the same specialist work both with CBT and  
466 family interventions. If we had one or two of each within this team as extras that's  
467 important because I mean we've sent people to do training and then they come back  
468 and their frustrated because there isn't the time to allow them to do the work they've  
469 been trained to do properly. And most of the people that do that they just then leave  
470 and go work where they're.

471 JR: That's it they've done it and they leave so they've done the training and so you  
472 don't get the benefit of it.

473 RM: Yes, not everybody. Some people have stayed because of other reasons and  
474 loyalty to the team but they are still very frustrated that they're not able to use that  
475 fully.

476 MD: I mean, we're supposed to be a multidisciplinary team and I think the higher  
477 management at the top or wherever it comes from needs to realise that we're very  
478 short on a multidisciplinary team 'cause we don't have CBT, we don't have family  
479 worker family therapists right.

480 RM: And one psychologist to share.

481 MD: And one psychologist between all these people and one psychiatrist. Someone's  
482 not planned it properly. Or someone's taking...

483 EEv: I suppose, sorry M, I was going to say one other way in which we could  
484 perhaps try and meet the needs for this client group that we're talking is possibly for  
485 the X to buy into the voluntary services. I understand that Mind, again they have  
486 waiting lists but Mind in X do have a counselling service. I don't know if they do  
487 specialist CBT, no.

488 JR: No.

489 MD: But its ongoing in the Trust. Why should we have to go elsewhere for it or why  
490 should it come from elsewhere when its ongoing in the Trust and why shouldn't the  
491 local teams have it

492 EEv: Because they can't. That's what I'm saying.

493 MD: Well I don't think there's such word as can't.

494 EEv: Well yes

495 MB: Although saying that you have access to these services but you have to refer

496 JR: Some people have to pay for the service.

497 MD: I have to go.

498 LR: Actually we're towards the end of our discussion now. Thank you all very much  
499 for your comments and as I say I'll be analysing this along with other focus groups  
500 that I've facilitated and you'll see some results published somewhere but there won't  
501 be any names or identifiers as I said and I am interviewing other teams as well. So  
502 thank you.

## Ethnic Codes

|                               |    |                                 |    |                            |    |
|-------------------------------|----|---------------------------------|----|----------------------------|----|
| <b>WHITE</b>                  |    | <b>ASIAN</b>                    |    | <b>OTHER BLACK ORIGIN</b>  |    |
| British                       | AA | Indian/British Indian           | HA | Black British              | PA |
| English                       | AB | Pakistani/British Pakistani     | JA | Black Irish                | PB |
| Scottish                      | AC | Bangladeshi/British Bangladeshi | KA | Other black origin         | PC |
| Welsh                         | AD | Mixed Asian                     | LA | <b>CHINESE</b>             |    |
| Irish                         | BA | Punjabi                         | LB | Chinese                    | RA |
| <b>OTHER WHITE BACKGROUND</b> |    | Kashmiri                        | LC | <b>OTHER ETHNIC GROUPS</b> |    |
| Spanish                       | CB | Sinhalese                       | LD | Afghani                    | SA |
| Italian                       | CC | Sri Lankan                      | LE | Arab                       | SB |
| Portuguese                    | CD | Tamil                           | LF | Filipino                   | SC |
| Cypriot (part not stated)     | CE | East African Asian              | LG | Iranian                    | SD |
| Greek (inc Greek Cypriot)     | CF | Other Asian, British Asian      | LH | Iraqi                      | SE |
| Turkish (inc Turkish Cypriot) | CG | <b>BLACK CARIBBEAN</b>          |    | Japanese                   | SH |
| Bosnian                       | CH | Jamaican                        | MA | Latin American             | SF |
| Kosovan                       | CJ | Other Caribbean                 | MB | Moroccan                   | SG |
| Romany                        | CK | <b>BLACK AFRICAN</b>            |    | Vietnamese                 | SH |
| Armenian                      | CL | Angolan                         | NA | Any other group            | SJ |
| Kurdish                       | CM | Congolese                       | NB |                            |    |
| Traveller                     | CN | Eritrean                        | NC |                            |    |
| Other Mediterranean           | CP | Ethiopian                       | ND |                            |    |
| Other former Yugoslian        | CR | Ghanaian                        | NE |                            |    |
| Other former USSR             | CS | Kenyan                          | NF |                            |    |
| Other white background        | CT | Madagascan                      | NG |                            |    |
| <b>MIXED BACKGROUND</b>       |    | Nigerian                        | NH |                            |    |
| White and black Caribbean     | DA | Somali                          | NJ |                            |    |
| White and black African       | EA | South African                   | NK |                            |    |
| White and Asian               | FA | Sudanese                        | NL |                            |    |
| Black and Asian               | GA | Tanzanian                       | NM |                            |    |
| Black and Chinese             | GB | Ugandan                         | NN |                            |    |
| Black and White               | GC | Other African                   | NP |                            |    |
| Chinese and White             | GD |                                 |    |                            |    |
| Asian and Chinese             | GE |                                 |    |                            |    |
| Other Mixed                   | GF |                                 |    |                            |    |

24/10/00

## RELATIVE ASSESSMENT INTERVIEW

### AIMS

This interview is designed for use in obtaining information from relatives about their experiences of coping with schizophrenic illness in a family member.

The aims of the interview are:

- To obtain information about the patients psychiatric history, symptoms, behaviours, social and role functioning.
- To elicit the relatives response in terms of their behaviours, beliefs or thoughts, and subjective feelings towards the patient and the illness; and the consequences of the illness related events to themselves and other members of the family.
- Elicit positive and successful coping responses of the family members, as well as areas of difficulty.

Unlike the *Camberwell Family Interview*, which is used to rate expressed emotion, this interview allows the interviewer to ask direct questions concerning the relatives' emotional reactions towards the patient. Topics which appear problematic should be probed extensively since this information may be used to identify areas of need. Specific examples of both the relative's and the patient's behaviour should be noted.

### STYLE OF INTERVIEW

The interviewer should attempt to become familiar with the interview schedule before carrying out the interview, since topics will come up out of order. An experienced interviewer can move around the schedule quite freely. The interviewer should use his/her judgement of the type and nature of the questions but all areas should be covered.

Questioning should begin with general questions, followed by specific questions to obtain more detailed information. The style of the interview should be *relaxed* and *conversational* and not time limited, with the interviewer giving empathic feedback that they are listening and understanding what the relative has to say.

Usually the relatives welcome the opportunity to speak at length about their experiences. The interviewer should adopt an approach that fosters a *collaborative* endeavour, whereby the interviewer and respondent work together to obtain the information necessary to identify problems and begin to work on resolving difficulties.

Remember: the interview schedule is a guide to the interview and not a checklist.

# Relatives Assessment Interview

## BACKGROUND INFORMATION

### Composition of Household

Who lives in the household? If the patient does not live with the respondent, then where and with whom does he/she live?

Elicit details about those who live with or who have contact with the patient, such as their age, sex, relationship to the patient, current education or employment status, including such details for the respondent and the patient if they are not already available.

| Name | Relationship to Patient | Age | Sex | Employment or Education |
|------|-------------------------|-----|-----|-------------------------|
| 1.   |                         |     |     |                         |
| 2.   |                         |     |     |                         |
| 3.   |                         |     |     |                         |
| 4.   |                         |     |     |                         |
| 5.   |                         |     |     |                         |
| 6.   |                         |     |     |                         |

### Contact Time

How does the patient usually spend his/her day? How much contact does the relative have with the patient on a typical day?

Try to elicit how many hours each day the patient and the relative are in direct contact with each other (i.e. in the same room) and the nature of this contact - what do they do together - do they talk or interact in some way, or are they performing separate activities? Enquire whether the patterns differ throughout the week, such as between weekdays and weekends. Where possible, follow up any leads about how the respondent feels about the frequency and nature of their interactions with the patient, e.g. how they get along when together.

Similarly, ask about who else the patient sees, how frequently and for how long. It can be helpful to ask direct questions about specific periods during the days, such as meal times, evenings, etc., and how various household members spend their time or come together.

## PSYCHIATRIC HISTORY (A)

### Complete Psychiatric History

Obtain a brief chronological account of the whole history of psychiatric illness. Include approximate dates and duration of episodes. Useful questions include:

- When did the patient's trouble first begin?
- When did the respondent first notice something different about/him/her?
- When did the respondent first realise there was something wrong?
- When was the patient last his/her normal self?
- Was there a sudden or gradual deterioration?
- How long has the patient's problem been going on?
- How did the respondent and others react? When the problems began?
- What was the patient's reaction to his/her problem and its development?

*(For each symptom or problem spontaneously mentioned by the relative, ask about onset, severity, context, reactions, how the relatives felt etc.,)*

### Current Episode (for relapse or acutely ill patients) or Recent Illness History

When the patient has had a recent relapse, obtain similar information as identified above about the current episode - its beginning and development. If no current episode, ask about patient's condition over the last three months.

For relapse patients, useful questions include:

- Did the patient go into hospital this last time or see the doctor/ other professional?
- When did the patient begin to get worse?
- What did he/she do? What happened?
- How did the patient feel about coming to the hospital or seeing the doctor?
- How did he/she behave?

Ask the respondent to describe the events around the admission and how the patient and others, including the respondent, reacted to this. Ask directly about the relative's thoughts, feelings and behaviours in response to symptoms and problems. What were the effects and consequences of any coping strategies? Look for examples of attempts to "control" the patient's behaviour and elicit details.

### For the patient who has not recently relapsed

Could you tell me how the patient has been getting along in the past three months?

Generally speaking, do you think they have shown improvement, or got worse or stayed about the same?

Pinpoint areas of improvement or deterioration, that is, identify specific behavioural examples and elicit the relative's thoughts, feelings and behaviours in response to the patient's improved or deteriorated behaviour.

### Psychiatric Symptoms (A) *Have the symptoms occurred in the last 3 months?*

**Patient Irritability:** enquire about any examples of the patient being irritable, snappy, losing their temper and so on.

What would happen - would they shout? Swear? Get impatient? Argue? Ask how frequently this would occur and elicit details by asking the respondent to describe one or two specific examples. What precipitated this sort of reaction in the patient / when did it happen? Who was there? How did they react? How similar/dissimilar are the situations described by the relative to other situations when the patient is irritable? Has the patient got more/less irritable in the past three months?

When the patient behaves like this how do family members behave/feel? How does the respondent behave/feel?

If the respondent reports no irritability in the patient in the last three months, ask whether the patient ever gets cross or impatient, or, if so, why? Can the respondent remember the last time the patient lost their temper or became irritable?

### Tension in the household and irritability of other family members

If the relative has suggested that arguments and quarrels do occur, elicit whether they result in an atmosphere of tension in the household. If so, how is this apparent? Does it affect people visiting the house? Or cause anyone to avoid the house or stay away? Who is involved and what do they do in the situation?

Probe all family members to find out if there are any arguments or disputes because of the patient, or concerning other matters. In most families there are disagreements from time to time. How do the rest of the family get along together? Are there times when family members argue or get on at one another? Which family members? What are the arguments about? What about the respondent? Are they involved in the disagreements? How do they feel/behave?

### Nagging, grumbling and irritability of other family members

Do you ever get irritable or snappy with the patient? Or nag, moan or grumble at them? For what reasons? What sort of things are complained about? What about other members of the family (specific by name)? *If there is some irritability towards the*

patient, ask about context, frequency, outcomes etc., Ask also about any irritability, nagging or moaning between other family members about the patient.

Query whether there has been any change in irritability or nagging over the past three months and if so, for what reason.

## PSYCHIATRIC HISTORY (B)

### Instructions

This section of questioning is important for establishing the patient's *symptom profile*; for understanding which areas of the patient's functioning are problematic for the relative or family members; for learning about the relative's understanding of the illness and the symptoms as well as how they cope with difficulties; and what consequences the problems have had on the individual relative and the family as a whole.

1. Ask all specified questions unless full information on the relevant behaviour collected in Section A.
2. Use this section to obtain a picture of pattern of severity of illness during primary period - if not done so in Section A.

In order to get a detailed behavioural description for each symptom, some useful probes are;

|                       |  |
|-----------------------|--|
| <i>Onset</i>          | When did this first begin? Has it occurred in the last 3 months?   |
| <i>Severity</i>       | How did this show itself? (obtain examples) At worst what was this behaviour/ideas like?   |
| <i>Frequency</i>      | How often did ..... happen? All the time? Every day, once a week?  |
| <i>Social Context</i> | Where does it happen? Who was there? What time of day?   |
| <i>Reactions</i>      | How did you react? What effect did this have on you/how did you feel about it? (similarly for the reactions of others).  |
| <i>Tension</i>        | Does/did it make you feel on edge? Is/was there an atmosphere in the home?   |
| <i>Legitimacy</i>     | Do you have any ideas why he/she behaves like that/does that? Is this behaviour different from his/her normal self, how he/she used to be before the illness? Do you think he/she could do/have done any more to control it? |
| <i>Coping</i>         | How did you deal with this? How effective was this? Did you find any way of preventing it? Or making the situation better?   |

## Introduce Topic

"I'd like to ask some questions about the way (patients name) may have been affected by this trouble. I'll go through some of the symptoms or difficulties we sometimes see in people who have (patients name) kind of problem. Of course some what apply but I would like to run through all of these and perhaps you'll tell me whether or not he/she has been like this, particularly in the last 3 months."

## Bodily Functions

*Sleep* Has the patient had any difficulties with his/her sleep recently? Such as, any difficulty in getting off? Nightmares? Waking up very early?

*Appetite* Ask whether the patient has had any difficulties/changes with his/her appetite.

Has he/she complained of any physical problems, such as headaches, dizziness, any other aches or pains?

## Activity

*Underactivity* Has the patient been inactive or lacking in energy eg: Doing less, sitting around, not helping out around the house? How different is this from past levels of activity?

*Slowness* Has he/she seemed particularly slow in doing everyday things, for example; dressing, (shaving), making beds, washing up etc.

*Overactivity* Have been times when the patient has been unusually active, excited or agitated for example, has there been excessive shouting, talking, swearing, excessive pacing.

*Violence* Have there been episodes of violence? What happened and to whom? Was anyone hit or hurt? Did you feel frightened? How did you cope with the situation? Do you feel threatened at present or worry that he/she could be violent again in the future?

*Destructive Behaviour* Have there ever been incidents when property or objects have been broken?

*Fears/Anxiety* Has the patient had periods of being afraid or anxious? Ask how the respondent knew that this was so. Did the patient stop doing things or change in anyway because of their fears? How did others react to the patient when they were like this?

*Worry* Has the patient been worrying about anything recently? If so, what? How does the respondent know? Has the patient talked about his/her concerns?

*Overt misery* Ask whether the patient has been depressed? Miserable? Tearful? Said that life is not worth living? Blamed him/herself? Tried to harm him/herself? How did the patient complain about feeling this way? How did the relative respond and how did they feel when the patient told them? Have you been worried that the patient may harm him/herself or attempt to end their life?

*Obsessions* Ask whether the patient has been unusually fussy or finicky about anything, like being very concerned about germs or cleanliness? Or has had routines of doing things only in a certain way, even though it may seem silly? Or doing things over

and over again? - like washing his/her hands or keep checking that the door is locked?

*Personal Care* Does the patient look after him/herself? Keep him/herself clean and tidy? Wash and dress appropriately, etc? Has this changed? Compared to others, ie; siblings?

*Delusions/  
Hallucinations* Ask whether the patient has expressed any strange ideas and if so, what about? Has he/she thought that people were against him/her? Has he/she had strange ideas about anyone in the family? Said that anything strange or odd was going on? Accused people of anything? Or said that there was anything unusual affecting him/her? Or that there was anything strange about the TV, food and drinks, neighbours?

*Bizarre  
Behaviour* Ask whether the patient has done anything else that seemed strange or bizarre or unusual for him/her? Has his/her behaviour seemed different in anyway? Such as wandering off from home? Has he/she been drinking a lot? Or gambling a lot?

*Street Drugs* Has she/he taken any drugs other than those prescribed for him/her by a doctor?

### Household Tasks

Ask about the various household tasks such as shopping, cleaning, cooking, gardening, repairs etc. Who does them? Has the situation changed recently or in association with any other change in the patient's behaviour? Is the respondent satisfied with the situation? If not, has he/she tried to do anything about it and with what result?

|   | Patient | Others |
|---|---------|--------|
| Shopping for food                             |         |        |
| Cleaning the house                            |         |        |
| Cleaning windows                              |         |        |
| Preparing meals family                        |         |        |
| Doing the dishes                              |         |        |
| Care of the garden/yard                       |         |        |
| Household repairs (eg. fuses, decorating etc. |         |        |

Who does the various jobs around the house? (Specify who does what) Does the patient help out with .....? What sort of things does the patient do? Has the way he/she has done the task changed since his/her troubles began? If so, how? Does he/she do it as well as before? When did the change occur? What seemed to be the reason for this? Do you do them together? Are you satisfied with the way things are done at home? Why not? Does this ever lead to disagreements?

## Money Matters

Find out how well the patient handles money and whether there have been any changes. What are the problems? Who handles the household finances? Does the patient pay towards his/her keep? Is the respondent satisfied with this arrangement? If not probe further. What would the respondent like to happen?

Ask about any changes in the households finances since the patient became ill. Has his/her illness caused any financial burden or hardship? Has the relative had to make any sacrifices because of the patient? For example, if the relative has given up work to be with the patient have there been any financial difficulties because of this? How have the difficulties been manifest, e.g. not paying rent/bills, getting into debt, use of credit card, cutting down on spending etc?

Since most people are quite sensitive about talking about their finances these questions should be asked with care and sensitivity.

## Interests and Activities of the Relative

Introduction of questioning: *"I'd like to ask you a few questions about how you spend your time, what your interests are and so on, and any ways in which these things have changed since (patient) has been ill"*

**Employment** If employed, nature of work and number of hours employed.

**Leisure** How does the relative spend their leisure time/what are their interests/hobbies?

**Social supports** Are there any friend/relatives/people who the respondent sees regularly? Is the respondent able to talk to them freely about any problems that come up at home? Do they find this helpful?

**Parental household** How much time do you and your husband/wife/partner spend together? What sort of things do you do/enjoy doing together? Do you find it helpful to talk problems over with your husband/wife/partner? If yes, how does it help? If no, why not and is there anyone else you find helpful to talk to?

---

## Changes in Interests, Occupations and Social Activities

Have you found that there have been changes in the way You spend your time since (patient's) problems first began?  
For example with work? with activities? with seeing friends? with the time you spend with your husband/wife/partner?  
Why have the changes taken place?  
What does the relative feel about them?

## Relationship with the Patient

Obtain information about the relative's relationship with the patient and any changes due to the illness.

Ask how the relative and patient get on.

Do you find him/her a friendly person?

Is he/she easy to get on with?

Can you get close to him/her?

In what ways would you like him/her to be different?

In what ways does he/she get on your nerves?

Ask whether the relative ever talks to the patient about these complaints.

Ask whether the relative has avoided or kept out of the patients way. Why?

Has the respondent felt any differently towards the patient?

Has the amount of affection for the patient changed in any way?

Elicit any change in the relationship on the part of the patient

Has he/she behaved any differently towards you since this trouble started?

Has the amount of affection he/she has shown to you changed?

Or the amount of interest he/she has shown you?

In general, how would you say <sup>1</sup> you got on together?

Can you tell when he/she is upset? or happy?

Elicit any large changes in the relative's behaviour or feelings since the illness began

What difference has his/her illness made to you and the family?

From your point of view, what is the most disturbing aspect of his/her troubles?

## Final Question

*"Is there anything else I have not covered or you would like to tell me?"*

Thank the relative for their co-operation.

---

South London and Maudsley   
NHS Trust

**AN EVALUATION OF**  
**ACCESS AND PROVISION**  
**OF COGNITIVE**  
**BEHAVIOURAL THERAPY**  
**TO CLIENTS WITH**  
**PSYCHOSIS**

**March 2002**

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## **EXECUTIVE SUMMARY**

### **Background**

Specific psychological treatments have been shown to be effective with people suffering from severe psychoses. These interventions include family interventions and individual cognitive behavioural therapy (CBT) (Pilling et al. in press). However, the dissemination of these interventions into routine practice has been slow to progress. The present study explores barriers to accessing CBT for psychosis in South London & Maudsley NHS Trust (SLAM).

### **Objectives**

1. To assess current SLAM-wide levels of provision of CBT for psychosis
2. To estimate the numbers of clients with medication resistant schizophrenia in SLAM.
3. To explore the barriers to accessing CBT among clients, carers & staff

### **Methods**

In April 2001 a steering group was established with nursing and psychology representation. A questionnaire was designed by the steering group which included questions relating to training, delivery and perceived barriers to accessing CBT for psychosis within SLAM. In November 2001 the questionnaire was sent to all clinical staff in Lambeth, Southwark, Lewisham, Croydon and the National Division via e-mail and hard copy in the post. The questionnaires were returned to the audit department by 14<sup>th</sup> December and the data were entered and analysed on SPSS by the audit staff.

### **Results**

**Objective 1:** Responses from 166 staff, 95% of whom are working with people with psychosis. Therapy is being provided by 49 respondents – who, in total, reported seeing, at the time of the audit, a total of 138 clients. Clearly, we do not know to what extent this underestimates provision – since some staff providing CBT for psychosis may not have responded to the questionnaire. It therefore provides a minimum estimate. Even if there is considerable under-reporting, the estimated number of suitable clients is very much higher (see below).

**Objective 2:** The total number of clients with schizophrenia within Lambeth, Southwark, Lewisham & Croydon is estimated to be approximately 8,000 clients (with a range of 5,000-1,1000). The literature (e.g. Fowler et al, 1995) suggests that approximately 50% of clients with a diagnosis of schizophrenia have persistent and enduring symptoms and thus an estimate of the total number of clients who would benefit from CBT for medication unresponsive psychosis in SLAM is between 2, 500 – 5,500 clients.

**Objective 3:** Out of the total number of questionnaire respondents (n=166), 67 (42%) reported that they had received some training in delivering CBT across a range of mental health disorders and 43 (26%) had received training in delivering CBT for psychosis. 116 people (81%) who had not had training in CBT for psychosis said they would like to be trained in this area in the future and 108 (74%) indicated they would like training within the next two years. Perceived barriers to accessing CBT included availability of trained therapists (reported by 47% of respondents); illness severity and client motivation factors (12%); referrers' beliefs and knowledge of the effectiveness of CBT (11%); training issues (14%); post-training environment and support (11%) and lack of information about services (5%).

### **Conclusions**

The study has shown that compared with the prevalence estimates of the numbers of clients with treatment resistant schizophrenia in SLAM (approximately 2,500-5,500), the numbers of clients currently receiving CBT for psychosis is much lower (n=138) and is offered by a small number of staff (n=49) - even if there is considerable under-reporting. The training courses in CBT for psychosis accessible for SLAM staff are limited and would benefit from a more structured and cohesive approach. Furthermore a lack of adequate supervision is a frequently reported barrier to implementation of CBT skills following training course completion. The main recommendations from this report are thus focused on expanding and reviewing the training courses in CBT for psychosis and increasing post-training supervision to improve access to CBT for psychosis for all clients who would benefit.

## Recommendations

1. Training on CBT for psychosis is expanded to meet the demand. Since existing courses provide limited training specifically for CBT for Psychosis – and some staff report that their training has not equipped them to deliver therapy – a review of training provision is recommended. Results of the audit to be taken to the SLAM Training and CBT Training committees for further discussion on the commissioning and provision of training courses in CBT for psychosis.
2. Identify sessions to provide supervision by trained and experienced staff and other incentives to increase supervision of newly qualified staff.
3. Improve managerial support to staff who wish to seek this training (time off ward, study leave, etc.)
4. Managers to ensure more considered planning of courses that staff attend (through appraisal and personal development planning) and early action planning following completion of training to allow time and resources to practice skills, receive supervision and carry out CBT therapy.
5. Consider alternative models of supervision and dissemination where groups of staff in clinical teams are supervised together. Provide education to potential referrers on treatment efficacy
6. Publicise widely referral criteria and pathways to treatment once more trained staff are in place.
7. To carry out focus groups with carers and clients to explore further the barriers to accessing CBT from clients and carers perspective in summer 2002 (Lorraine Rhule).

## **Service Response-** Proposal for CBT for Psychosis Course to be established by SLAM For the Education and Training Committee – 16.09.02 Philippa Garety, on behalf of Steering Group of Trust Audit of CBT for Psychosis

**Background:** The Trust audit has demonstrated that the Trust has a considerable shortage of staff competent to provide CBT for psychosis. Even fewer staff report that they are provide supervision. A large proportion of respondents (over 100) reported that they would like training in CBT for psychosis. There is no training course specifically in CBT for psychosis currently available, which aims to develop competent CBT for psychosis therapy practitioners, although there are a number of valuable KCL CBT courses and psychosocial skills courses (eg Thorn) which provide some CBT for Psychosis as part of the course. All of these courses provide a very useful introduction and a good basis for undertaking a specific CBT for psychosis course. The CBT Training Advisory Committee, whom we have consulted, suggests that we consider establishing a CBT for Psychosis course.

The National Institute of Clinical Excellence is about to issue (in Dec 2002) an evidence based guideline on core treatments for Schizophrenia. This is now out for consultation. It recommends that Trusts offer CBT to people with medication –unresponsive symptoms and to people at risk of relapse. The CBT should be of 6-9 months duration. Supervision should be provided to therapists. Trusts are asked to review provision and make plans for implementation including training and supervision. (We should note that the guideline also makes recommendations for the provision of family interventions.)

**Aim :** to develop a pool of competent therapists in CBT for Psychosis throughout the Trust, who will also become competent to lead peer group supervision.

**Students:** staff from all directorates working in community and rehab services – which serve people with medication-unresponsive psychotic symptoms and/or people with high risk of relapse and where staff work for at least 6 months with service users. Team leaders to nominate 1-2 staff per team. Managers to be asked to confirm that they will support staff to attend course, to take on clients for therapy and to attend subsequent supervision.

### **The Training:**

- To be skills and competence focussed, incorporating theory and reflective practice and supervision. Suggest certificate of competence not degree/diploma.
- To last 1 (academic) year enabling supervision of cases for 9 months
- One half day per week, incorporating – theory and skills teaching; case presentations; group supervision of training cases
- A second (optional?) year to provide ongoing group supervision, to consolidate skills and prepare students to become supervisors locally
- The training to be provided in-house or jointly with an education provider

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## **INTRODUCTION**

Although medication is the most common form of treatment for schizophrenia, there has been considerable research in recent years which has suggested that non-drug psychological interventions have benefits to patients suffering from psychoses. These interventions include family interventions and individual cognitive-behaviour therapy (Pilling et. al. in press).

In cognitive behavioural therapy (CBT), links are made between the person's feelings and patterns of thinking which underpin their distress. The aims of CBT are to i) reduce the distress, emotional disturbance and disability caused by psychotic symptoms ii) help the person arrive at an understanding of the psychosis in order to promote his/her active participation in the regulation of relapse and social disability iii) Reduce depression and anxiety and improve self esteem (Fowler, Garety and Kuipers, 1995). The approach is also concerned with working in collaboration with the individual to assist him/her with making sense of symptoms. The techniques involved in treatment are:

- Building & maintaining a therapeutic relationship
- Enhancing and developing strategies in order to cope with distressing symptoms and experiences (for example hallucinations)
- Normalising and destigmatising the psychotic experience
- Modification of psychotic symptoms (for example delusions and hallucinations)
- Promoting self-esteem
- Modification of anxiety and depression
- Relapse management

Evidence from several RCTs with patients with schizophrenia suggests that CBT is associated with a reduced risk of relapse and also improves the patient's mental state and global functioning particularly with clients who have persistent distressing symptoms (Cochrane Review, 2000). Moreover, gains made during a course of treatment are sustained at 18-month follow-up (Kuipers, Fowler, Garety, Chisholm, Freeman et al. 1997). CBT has also been shown to enhance the efficacy of medication when it is used as an adjunct to medical treatment (Roth and Fonagy, 1996).

The systematic review carried out by the Cochrane Schizophrenia Group (Jones et al., 2000) has been acknowledged in the recent Mental Health National Service Framework (NSF), which highlighted the growing evidence of effectiveness of CBT. In addition, a National Institute for Clinical Effectiveness (NICE) commissioned guideline is under development which includes a review of CBT. It is likely to lead to recommendations concerning provision.

Despite the emerging evidence of the effectiveness, the dissemination of such evidence-based practice has not progressed (Tarrier et al 1999) and CBT is not as widely available as an intervention for people with schizophrenia as it is for persons with other disorders (for example, depression and panic disorder). The Cochrane review acknowledged two barriers to implementation: First, that CBT requires active participation from both the therapist and the person receiving therapy and motivational factors may prevent initiation of this treatment in certain clients. Second, CBT is a fairly scarce commodity and its

application in day-to-day practice may be restricted by the availability of suitable practitioners. The present study aims to explore the both the above and other perceived barriers to accessing CBT from the clinician's perspective.

## **PROJECT AIMS**

1. To assess current SLAM-wide levels of provision of CBT for psychosis
2. To assess the numbers of clients with medication resistant schizophrenia in SLAM.
3. To explore the barriers to accessing CBT among clients, carers & staff

## **CORE STEERING GROUP MEMBERSHIP**

- Professor Philippa Garety, Head of Psychology
- Lorraine Rhule, Counselling Psychologist, Lambeth Community Rehab Team
- Patricia Smith, Clinical Psychologist, Lewisham Rehab Services
- Ian Brown, Project Officer, Specialist Directorate
- Rosie Peregrine-Jones, Clinical Audit Advisor, Specialist Directorate
- Sarah Gunning, Charge Nurse, Luther King ward, Lambeth

## **METHODOLOGY**

- In April 2001 a steering group was established with nursing and psychology representation
- A questionnaire was designed by the steering group (see Appendix 1) which included questions relating to training, delivery and perceived barriers to accessing CBT for psychosis within SLAM.
- The questionnaire was sent to all clinical staff in Lambeth, Southwark, Lewisham, Croydon and the National Division via e-mail & hard copy in the internal post on 21 November 2001. The questionnaires were returned to the audit department by 14<sup>th</sup> December (3 week data collection period)
- The data was entered and analysed on SPSS by the audit staff.

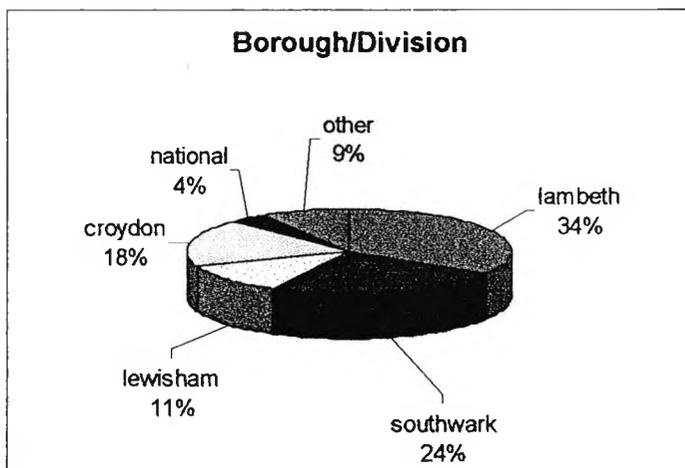
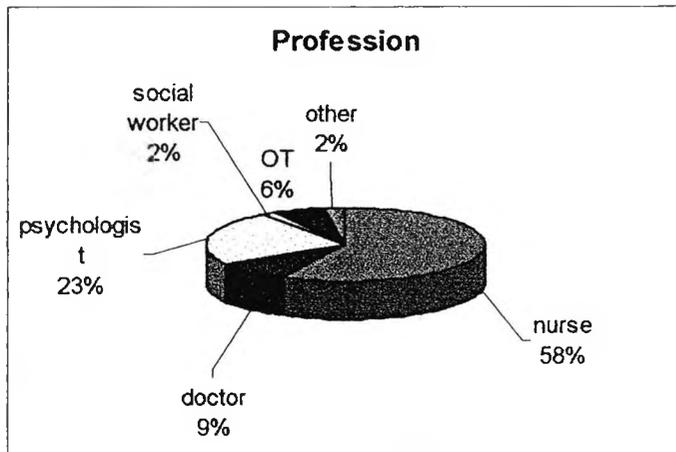
## RESULTS

**Table 1: Frequency of Questionnaire Responses by Profession**

| Profession    | Frequency | Percentage |
|---------------|-----------|------------|
| Nurse         | 95        | 58         |
| Doctor        | 15        | 9          |
| Psychologist  | 39        | 23         |
| social worker | 3         | 2          |
| OT            | 10        | 6          |
| Other         | 4         | 2          |
|               |           |            |
| Total         | 166       | 100        |

**Table 2: Frequency of Questionnaire Responses by Borough and Directorate**

| Profession | Frequency | Valid Percentage |
|------------|-----------|------------------|
| Lambeth    | 54        | 34               |
| Southwark  | 38        | 24               |
| Lewisham   | 18        | 11               |
| Croydon    | 29        | 18               |
| National   | 6         | 4                |
| Other      | 14        | 9                |
| Missing    | 7         |                  |
|            | 166       | 100              |



One hundred and sixty six responses were received of which 58% were from nursing staff and 23% from psychologists. 95% of respondents work with the client group of people with psychosis. Respondents worked in all Trust directorates with the highest proportions from the boroughs of Lambeth (34%) and Southwark (24%).

### **PART 1 – Training in CBT for clients with psychosis**

#### **1. Have you received training in delivering CBT across a range of mental health disorders?**

Yes = 67/161 (42%)

No = 94/161 (58%)

#### **2. a) Have you received specific training in delivering CBT for clients with psychosis?**

Yes = 43/163 (26%)

No = 118/163 (72%)

N/A = 2/163 (1%)

#### **2. b) Name of course**

| <b>Name of Course</b>   | <b>Frequency</b> | <b>Percentage</b> |
|---|------------------|-------------------|
| Clinical Psychology Training or Counselling Psychology Training | 13               | 28                |
| Short courses/lectures in CBT for psychosis                     | 8                | 17                |
| MSc/DIP in CBT/ENB650 – extensive CBT but little psychosis      | 6                | 13                |
| Short Course in CBT – not specifically psychosis                | 6                | 13                |
| Thorn Course  | 5                | 11                |
| Other including self taught                                     | 4                | 8                 |
| On job supervision from expert                                  | 3                | 6                 |
| Originators of CBT for Psychosis                                | 2                | 4                 |
| <b>TOTAL</b>  | <b>47</b>        | <b>100</b>        |

\*Please note numbers do not add up to 43 since some persons had undertaken more than one course

The course most frequently cited as providing training was the basic training in clinical or counselling psychology (28%). A further 11% had attended the Thorn course and 13% short courses in CBT for psychosis. There are currently no longer-term courses available to SLaM staff focussing exclusively on CBT for psychosis.

#### **3. If you have not had training would you like to be trained in the future in delivering CBT for clients with psychosis?**

Yes = 116/143 (81%)

No = 19/143 (13%)

N/A = 8/143 (6%)

**4. If you would like to receive this type of training in the future will you be seeking training within the next two years?**

Yes = 108/146 (74%)

No = 30/146 (21%)

N/A = 8/146 (6%)

Out of the questionnaire respondents, 67 (42%) had received training in delivering CBT across a range of mental health disorders and 43 (26%) had received training in delivering CBT for psychosis. 116 people (81%) who had not had training in CBT said they would like to be trained in this area in the future and 108 (74%) indicated they would like training within the next two years.

**PART 2: Delivery of CBT to clients with psychosis**

**5. Do you currently work with clients with psychosis?**

Yes = 154/162 (95%)

No = 8/162 (5%)

**6. Are you currently offering CBT to clients with psychosis?**

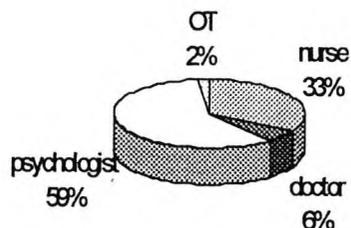
Yes = 49/157 (31%)

No = 108/157 (68%)

**By Profession**

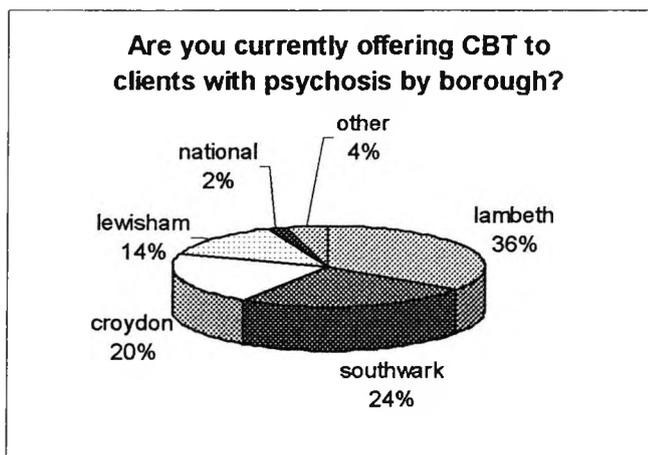
|              |    |
|--------------|----|
| nurse        | 16 |
| doctor       | 3  |
| psychologist | 29 |
| OT           | 1  |
|              | 49 |

**Are you currently offering CBT to clients with psychosis by profession?**



**By Borough**

|           |    |
|-----------|----|
| Lambeth   | 17 |
| Southwark | 12 |
| Croydon   | 10 |
| Lewisham  | 7  |
| national  | 1  |
| other     | 2  |
|           | 49 |



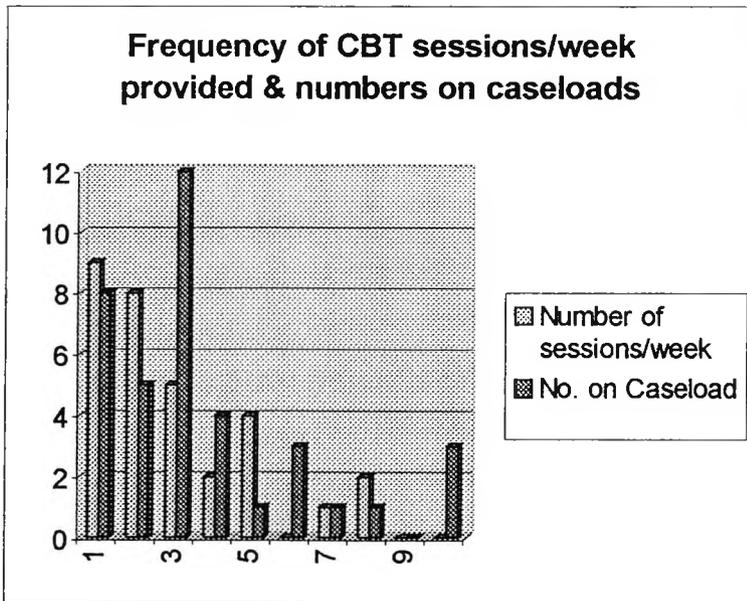
154 (95%) of respondents currently work with clients with psychosis and one third (n=49) currently offer CBT to clients with psychosis. The professional groups providing this therapy are predominantly psychologists (59%) and nursing staff (33%).

**7. If you are offering CBT for psychosis, please state:**

**a) The average number of treatment sessions you offer each client**

| No. Of Sessions | Frequency | Valid Percent |
|-----------------|-----------|---------------|
| 0-5             | 4         | 8             |
| 6-10            | 8         | 17            |
| 11-15           | 9         | 19            |
| 16+             | 27        | 56            |
| Missing         | 118       |               |
| TOTAL           | 166       | 100           |

On average, most clinicians (75%) offer more than 11 sessions of therapy. However, 25% offer short-term therapy (10 sessions or fewer) and this may be sub-optimal, since the evidence is accumulating for longer-term i.e. more than 10 sessions, and may reflect limitations of resources.



The total number of clients being seen for CBT for psychosis can be derived from the caseload numbers. The graph above shows that at the time of completing the questionnaire, at least 49 staff were seeing 138 clients across SLaM. The majority of clinicians offering CBT for psychosis see three or fewer clients and most for one session per week.

**8. If you are not offering CBT when you are trained to do so, please state why not**

| Barrier to offering CBT     | Frequency |
|-----------------------------|-----------|
| lack of supervisor          | 6         |
| wrong client group          | 6         |
| lack of time                | 5         |
| don't feel skilled          | 2         |
| lack of funding for service | 1         |
|                             | 20        |



The majority - 154 (95%) of respondents worked with clients with psychosis and 49 clinicians (31%) were currently offering CBT to this client group. The earlier finding that 43 therapists had received training in CBT indicates that at least 6 clinicians are practising CBT who are self-taught. The reasons given as to why 20 clinicians who had been trained to deliver CBT were not practising with this client group included working with a different client group (30%), lack of a supervisor (30%) and time (25%) and perceived lack of skills to carry out the treatment (10%). These reasons are similar to the barriers to accessing CBT reported later in the results section.

**9. If you are not offering CBT for psychosis, would you routinely refer a client with this diagnosis to another clinician for CBT?**

Yes = 69/124 (57%)

No = 51/124 (41%)

N/A = 4/124 (3%)

**10. Do you know who to refer your clients with psychosis to in order for them to receive CBT?**

Yes = 81/128 (63%)

No = 45/128 (35%)

N/A = 2/128 (2%)

**11. Do you advertise your CBT service and referral criteria?**

Yes = 13/49 (26%)

No = 36/49 (73%)

**12. Do you offer training and supervision?**

Yes = 25/59 (42%)

No = 32/59 (54%)

N/A = 2/59 (3%)

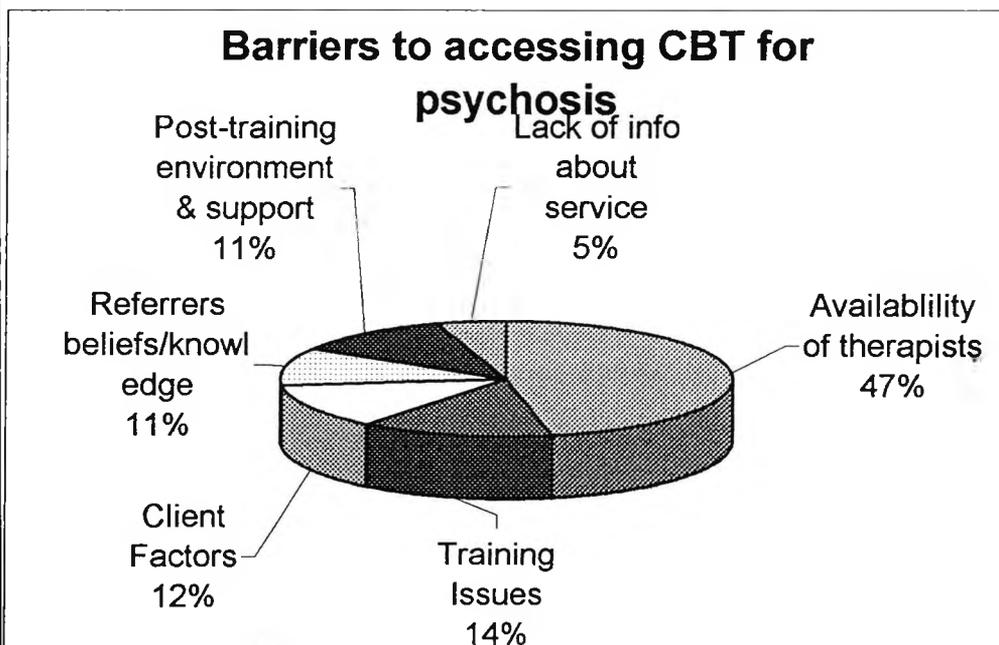
**13. Are you currently practising training and/or supervision?**

Yes = 8/49 (16%)

No = 41/49 (84%)

51 respondents (41%) indicated they would not routinely refer their clients with psychosis to another clinician for CBT and the reasons why are given below. Only 13 clinicians (26%) out of the 49 currently offering CBT for psychosis said they advertised their CBT service and referral criteria and one reason for this might be due to lack of capacity to increase caseloads. Only 8 clinicians (16%) were currently offering supervision a finding which is consistent with the perceived barrier of lack of supervision (later in the results).

### PART 3: Content analysis of barriers to accessing CBT for psychosis



#### 1. Client Factors (e.g. motivation & severity of illness) (15/122 = 12%)

"Being able to offer the service whilst clients are 1) motivated 2) well enough to use it and engage"

"Client un co-operative-operation, refusal"

#### 2. Referrers belief/knowledge of the effectiveness of CBT for psychosis (13/122=11%)

"Poor understanding among potential referrers of research that exists, that shows CBT is beneficial for the client group"

"Lack of consultant commitment to CBT, many have a medication focused approach"

"My client group - people over 65 - Therapeutic nihilism from the part of services for psychological interventions - especially in clients with psychosis"

#### 3. Lack of Information about Service (unclear of referral pathway & criteria for referral) (6/122=5%)

"Lack of awareness of referral criteria, lack of pre CBT prep for clients e.g. information on CBT"

#### **4. Availability of trained professionals (57/122=47%)**

"Lack of staff with relevant skills & training, particularly lack of psychological input to acute psychiatric wards"

- **Ethnic background of therapists (1)**

"Not enough black CBT specialists in this field"

#### **Current waiting list for access to psychology (16)**

- "Waiting lists are too long"

"Few experienced CBT therapists, whilst PICUP is a welcome service, because it is an RCT, 50% of those we refer are returned to us and seen by our service"

- "Lack of availability of specialist therapists in forensic"
- "Having enough practitioner hours"

- **Travel to therapy (3)**

"Our clients don't do so well having to be referred on to yet another distant clinic"

#### **5. Training issues (17/122=14%)**

- **Time to train (6)**

"Difficult to gain access to full CBT course, due to the lack of team members to work instead of me when on the course"

"Lack of support for training of staff from management i.e. funding, time off, management attitudes to CBT- more interested in covering the ward"

- **Access to training for nursing staff/black staff & non-academic staff (4)**

"Financial barriers, focus on training higher grades, who have much less client contact than d and e grades"

"CBT training should be accessible to ALL staff working with people who suffer psychosis. At present, it is the realm of the academics which is ridiculous and condescending to other staff"

- **Lack of support from management for staff wishing to train in CBT (4)**

"The trust should allow enough time off to complete studying in this area"

- **Type of training programme requests (3)**

"I would like to train in a way that did not take me away from the work place for too long"

"The training expects the participants to give up too much of their own time, time off from work inadequate. There are no courses that accommodate part-time study."

## **6. Post-training environment and support (14/122=11%)**

- **Access to supervision (5)**

"Access and availability of supervision"

- **Lack of post training support (2)**

"Lack of staff confident in using it in this area as it is traditionally used in anxiety/depression"

"Staff confidence/awareness needs to be developed principles of how to apply in a day to day practice. A need to identify CBT Specialists"

- **Heavy Caseloads (5)**

"Too many patients on case load 50+ unable to devote time required to do it properly"

"Other service priorities make it difficult to provide this intervention consistently in addition to other aspects of the team's functions"

- **Environmental factors (2)**

"Pure therapy is difficult to deliver when doing your nursing duties, even when extra appointments are made, specifically for CBT other aspects of care can intrude. Also need rooms and time structured and protected to offer regular appointments and supervision"

### **Estimate of numbers of clients with medication resistant schizophrenia in SLaM**

A recent draft report arising from the SLaM Psychological Therapies Working Party provides some estimates of the prevalence of schizophrenia nationally and within the four boroughs covered by SLaM. The national picture of the prevalence of schizophrenia in the known population of adults of working age is 4 per 1000. However, morbidity is higher in SLAM. Estimates for the local prevalence of schizophrenia in adults of working age in the year 2000 are as follows:

Lambeth – 2625 +/- 1125

Southwark – 2181 +/- 935

Lewisham – 2279 +/-977

Croydon – 896

Thus an estimate of the total number of clients with schizophrenia within Lambeth, Southwark, Lewisham & Croydon is approximately 8,000 clients with a range of 5,000-11,000. The literature (e.g. Fowler et al, 1995) suggests that approximately 50% of clients with a diagnosis of schizophrenia have persistent and enduring symptoms and thus an estimate of the total number of clients who would benefit from CBT for psychosis in SLaM is between 2, 500 – 5,500 clients. These figures are broadly consistent with another source for making this estimate: the data on numbers of clients on Enhanced CPA in SLAM. It Approximately 5,000 clients of all diagnoses are registered on Enhanced CPA in Adult Mental Health and Rehabilitation

services. Most of these clients will have a diagnosis of schizophrenia or a related disorder.

## **CONCLUSIONS**

In sum, questionnaire respondents reported that the main barrier to accessing CBT for psychosis is availability of trained therapists (57/122; 47%). Many clinicians are keen to seek this type of training (n=116; 81%) and the majority within the next 2 years (n=108; 74%). The principal recommendation from this audit is that the training on CBT for psychosis is expanded to meet the demand from both staff and clients.

This finding is supported by the Cochrane Review (Jones et. al, 2000) which reported that the application of CBT for psychosis in day to day practice may be restricted by the availability of suitable practitioners.

In our study, client factors accounted for only 12% of the perceived barriers. This was also reported in the Cochrane review as a limiting factor. The authors state that ' CBT requires active participation from both the therapist and the person receiving therapy. Accordingly, treatment requires that the person receiving therapy willing to participate actively in therapy.

In this study, other barriers to accessing CBT for psychosis included referrers' beliefs and knowledge of the effectiveness of CBT (11%); lack of information about the service (5%); training issues (14%) and post-training environment and support (11%). Planned arrangements for post training supervision and management support to undertake therapy are the key factors cited for this last point. Other authors (Corrigan & Mc Cracken, 1995a, 1995b; Corrigan et al., 1997), have addressed the issue of post-training environment and support from a U.S. perspective. They found that follow-up studies of staff in psychiatric rehabilitation settings who had been given skills training indicated that organisational barriers were impeding their introduction and maintenance. The main recommendation from these studies is that given the apparent relationship between collegial/supervisory support and beliefs about institutional constraints, team-focused training and team-building may be essential to successful change. We therefore recommend that plans are made for post training supervision and support and that team based supervision may be particularly helpful, where applicable,

## **Recommendations**

- 1) Training on CBT for psychosis is expanded to meet the demand. Since existing courses provide limited training specifically for CBT for Psychosis – and some staff report that their training has not equipped them to deliver therapy – a review of training provision is recommended. Results of the audit to be taken to the SLAM Training and CBT Training committees for further discussion on the commissioning and provision of training courses in CBT for psychosis.
- 2) Identify sessions to provide supervision by trained and experienced staff and other incentives to increase supervision of newly qualified staff.
- 3) Improve managerial support to staff who wish to seek this training (time off ward, study leave, etc.)
- 4) Managers to ensure more considered planning of courses that staff attend (through appraisal and personal development planning) and early action planning following completion of training to allow time and resources to practice skills, receive supervision and carry out CBT therapy.
- 5) Consider alternative models of supervision and dissemination where groups of staff in clinical teams are supervised together. Provide education to potential referrers on treatment efficacy
- 6) Publicise widely referral criteria and pathways to treatment once more trained staff are in place.
- 7) To carry out focus groups with carers and clients to explore further the barriers to accessing CBT from clients and carers perspective in summer 2002 (Lorraine Rhule).

## **SERVICE RESPONSE AND ACTION PLAN**

**For the Education and Training Committee – 16.09.02**  
**Proposal for CBT for Psychosis Course to be established by the Trust**

**Background:** The Trust audit has demonstrated that the Trust has a considerable shortage of staff competent to provide CBT for psychosis. Even fewer staff report that they are provide supervision. A large proportion of respondents (over 100) reported that they would like training in CBT for psychosis. There is no training course specifically in CBT for psychosis currently available, which aims to develop competent CBT for psychosis therapy practitioners, although there are a number of valuable KCL CBT courses and psychosocial skills courses (eg Thorn) which provide some CBT for Psychosis as part of the course. All of these courses provide a very useful introduction and a good basis for undertaking a specific CBT for psychosis course. The CBT Training Advisory Committee, whom we have consulted, suggests that we consider establishing a CBT for Psychosis course.

The National Institute of Clinical Excellence is about to issue (in Dec 2002) an evidence based guideline on core treatments for Schizophrenia. This is now out for consultation. It recommends that Trusts offer CBT to people with medication –unresponsive symptoms and to people at risk of relapse. The CBT should be of 6-9 months duration. Supervision should be provided to therapists. Trusts are asked to review provision and make plans for implementation including training and supervision. (We should note that the

guideline also makes recommendations for the provision of family interventions.)

**Aim :** to develop a pool of competent therapists in CBT for Psychosis throughout the Trust, who will also become competent to lead peer group supervision.

**Students:** staff from all directorates working in community and rehab services – which serve people with medication-unresponsive psychotic symptoms and/or people with high risk of relapse and where staff work for at least 6 months with service users. Team leaders to nominate 1-2 staff per team. Managers to be asked to confirm that they will support staff to attend course, to take on clients for therapy and to attend subsequent supervision.

**The Training:**

- To be skills and competence focussed, incorporating theory and reflective practice and supervision. Suggest certificate of competence not degree/diploma.
- To last 1 (academic) year enabling supervision of cases for 9 months
- One half day per week, incorporating – theory and skills teaching; case presentations; group supervision of training cases
- A second (optional?) year to provide ongoing group supervision, to consolidate skills and prepare students to become supervisors locally
- The training to be provided in-house or jointly with an education provider

Philippa Garety, on behalf of Steering Group of Trust Audit of CBT for Psychosis

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## Appendix 1: The Questionnaire

### Audit of Access and Provision of CBT to clients with psychosis

Specific psychosocial treatments have been shown to be helpful for people suffering from severe mental illness. Access to cognitive-behavioural therapy (CBT) is desirable for every mental health service user with a diagnosis of schizophrenia or schizoaffective disorder which is resistant to medication (i.e. has not responded to an adequate trial of at least six months of appropriate neuroleptic medication (Kuipers et al, 1997). The present study explores barriers to accessing CBT for SLAM service users with a diagnosis of schizophrenia or schizoaffective disorder which is medication resistant [hereafter shortened to 'psychosis']. This audit topic was one of the 12 audits voted as an organisational priority for implementation by April 2002 at the Trust-wide Clinical Governance Strategy Day on March 23rd 2001. We would be very grateful if you could assist us by completing this questionnaire and returning it in the envelope provided by 31<sup>st</sup> October 2001. This questionnaire should take approximately 5 minutes to complete.

PLEASE COMPLETE ONLY IF YOU CURRENTLY WORK OR INTEND TO WORK WITH CLIENTS WITH PSYCHOSIS OR YOU HAVE RECEIVED/WOULD LIKE TRAINING IN CBT FOR PSYCHOSIS

1) Name: \_\_\_\_\_

2) Profession/Location: Nurse  Doctor  Psychologist  Counsellor   
 Social Worker  OT  Other: Please Specify: \_\_\_\_\_

Grade: \_\_\_\_\_

Team/Service: \_\_\_\_\_

Borough: \_\_\_\_\_

#### PART 1: Training in CBT for clients with psychosis

1) Have you received training in delivering CBT across a range of mental health disorders? Yes  No

2.a) Have you received specific training in delivering CBT for clients with psychosis? Yes  No

2.b) If yes, please state:

Name of course: \_\_\_\_\_

Qualifications gained: \_\_\_\_\_

Length of course: \_\_\_\_\_

Date of course completion: \_\_\_\_\_

3) If you have not had training would you like to be trained in the future in delivering CBT for clients with psychosis? Yes  No

- 4) If you would like to receive this type of training in the future, will you be seeking training within the next two years? Yes  No
- 5) If you would like to receive training in CBT for psychosis but do NOT intend to seek it in the next 2 years, please let us know why not & what are the barriers to you accessing this type of training?
- 
- 

Part 2: Delivery of CBT to clients with psychosis

- 1) Do you currently work with clients with psychosis? Yes  No
- 2) Are you currently offering CBT to clients with psychosis? Yes  No
- 3) If you are not offering CBT and you are trained to do so, please state why not? (please tick all that apply)
- Wrong client group  Lack of funding for service  Lack of time   
 Travelling time   
 Lack of supervisor  Other : Please Specify:
- 

- 4) a) If you are not offering CBT for clients with psychosis would you routinely refer a client with this diagnosis to another clinician for CBT? Yes  No

b) If not, why not?

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- 5) a) Do you know who to refer your clients with psychosis, to in order to receive CBT? Yes  No

b) If yes, please state name of professional & location to whom you make referrals.  
 Name of Professional: \_\_\_\_\_ Location: \_\_\_\_\_

- 6) If you are offering CBT to clients with psychosis, please state:  
 a) How many sessions per week you provide this service
- 

b) The number of clients receiving CBT for psychosis on your caseload?

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- c) The average number of treatment sessions you offer each client?  
 0 - 5  6 - 10  11 - 15  16 +

d) Who refers clients to your service? (please tick all that apply)

GP  Psychiatrist  Nursing staff  Self-referral   
 Other  Please specify: \_\_\_\_\_

- e) Do you have referral criteria? Yes  No

f) If "Yes" what are they?

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g) Do you advertise your CBT service and referral criteria?      Yes       No

h) If "yes" where do you advertise

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i) Do you assess the patient's preference and motivation for CBT pre-treatment?      Yes       No

j) Do you document consent to treatment in the case notes?      Yes       No

k) Do you assess mood and symptoms at the start of treatment?      Yes       No

l) Do you assess patients at the end of treatment to monitor the outcome of the intervention?      Yes       No

m) Do you have supervision in delivering CBT for psychosis?      Yes       No

n) Do you offer training and/or supervision to other clinicians?  
    Yes       No       Currently Supervising/training  
   

7) What do you see as the principal barriers to accessing CBT for clients with psychosis?

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8) Do you have any further comments?

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Thank you for your co-operation

Please return this questionnaire to Ian Brown, Specialist Project Officer, Reay House,  
 108 Landor Road, Stockwell, SW9 9NT.