Understanding psychological treatment for psychosis from the perspective of those with lived experience:

'What's important to us?'

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Rory Byrne

School of Psychological Sciences

CONTENTS

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List of Tables

List of Appendices

List of Abbreviations

ACTION: Assessment of Cognitive Therapy Instead Of Neuroleptics

ARMS: At Risk Mental State

BABCP: British Association of Behavioural and Cognitive Psychotherapies

BLIPS: Brief Limited Intermittent Psychotic Symptoms

CAARMS: Comprehensive Assessment of At Risk Mental States

CAMHS: Child and Adolescent Mental Health Service

CBT: Cognitive Behavioural Therapy

CBTp: Cognitive Behavioural Therapy for Psychosis

CFT: Compassion Focused Therapy

CMHN: Community Mental Health Nurse

CMHT: Community Mental Health Team

CONSORT: Consolidated Standards of Reporting Trials

CR: Cognitive Remediation

CT: Cognitive Therapy

DSM: Diagnostic and Statistical Manual of Mental Disorders

DUP: Duration of Untreated Psychosis

ED: Early Detection

EDIE: Early Detection and Intervention Evaluation

EDIT: Early Detection and Intervention Team

EE: Expressed Emotion

EI: Early Intervention

EIS: Early Intervention Service

FE: First Episode

FI: Family Intervention

GP: General Practitioner

GT: Grounded Theory

HPA: Hypothalamic-Pituitary-Adrenal (axis)

HVG: Hearing Voices Groups

HVN: Hearing Voices Network

ICD: International Statistical Classification of Diseases and Related Health Problems

IEPA: International Early Psychosis Association

IPA: Interpretative Phenomenological Analysis

IPS: Individual Placement and Support

JTC: Jumping To Conclusions

LSD: Lysergic acid diethylamide

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

OCD: Obsessive Compulsive Disorder

PACE: Personal Assessment and Crisis Evaluation

PSW: Peer Support Workers

PTSD: Post-Traumatic Stress Disorder

S-REF: Self-Regulatory Executive Function

SAE: Serious Adverse Event

SURG: Service User Reference Group

TA: Thematic Analysis

Abstract

This thesis aimed to explore service users' priorities and preferences for treatment of psychosis-spectrum difficulties, and experiences of Cognitive Behavioural Therapy (CBT). A literature review (Chapter 1) summarised current understanding and treatment of psychosis. A narrative review of qualitative studies examined treatment priorities and preferences of people with experience of psychosis (Chapter 2), and found that common priorities and preferences included improving social and functional ability, reducing symptoms of psychosis, and individualised, collaborative approaches to care, including alternatives to routine psychiatric treatment. A Delphi study of priorities and preferences for treatment of psychosis was conducted (Chapter 3), and identified priorities that included improving difficult emotional and cognitive states, understanding, coping, and self-esteem, along with treatment preferences such as individualised, collaborative care, greater provision of information, and choice of treatment. Three qualitative studies were conducted. The first (Chapter 4) explored the subjective experiences of young people seen in an Early Detection (ED) for psychosis service. Findings indicated that reluctance to communicate mental health concerns delayed help-seeking for the majority of participants. Disclosure of such concerns to staff in the ED service was considered helpful, especially in the context of CBT. The second qualitative study (Chapter 5) explored subjective experiences of CBT for psychosis. CBT-specific processes were summarised as 'structured learning', and the most commonly perceived benefits included improved understanding of psychosis and self, and normalisation. The 'hard work' of CBT was also highlighted, especially the disclosure and discussion of difficult life experiences and psychological problems. The third qualitative study (Chapter 6) evaluated experiences of involvement in a randomised trial of CBT for young people at risk of developing psychosis. Having a 'chance to talk' about mental health concerns was consistently valued by participants in both the control and the treatment arm of the trial. Valued experiences of CBT included 'rethinking things', especially through psychological formulation and re-appraisal of distressing beliefs. Participants also described difficult aspects of CBT, such as personal disclosure, though these were often considered necessary for recovery.

Across studies, the importance of individualised, collaborative treatment was highlighted consistently. It is also evident that along with reductions in distressing psychological problems, participants across studies also highly valued social and functional aspects of recovery. The methodological limitations and strengths of these studies, along with implications for clinical practice and future research, are discussed.

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The Author

The author began to study for his first degree at Manchester Metropolitan University in 1999 while experiencing a kind of breakdown. Several attempts at help-seeking and months later, he was fortunate to be included as a participant in the first 'EDIE' trial in Manchester, UK (Early Detection and Intervention Evaluation). Receiving CBT during this trial was a turning point, and undoubtedly played a large part in helping the author recover, and to complete his degree. Through a continued series of fortunate events over the next couple of years, the author then became involved with the EDIE research team and associates as a user-researcher, and has been employed full-time in this role since 2006 at Greater Manchester West Mental Health NHS Foundation Trust. The author hopes to continue to work in this research area for the foreseeable future, and aims to pursue a number of research ideas in development. Ultimately, if possible, the author would also like to undertake professional training with the aim of acting as a therapist himself, and helping others with similar personal experiences.

Chapter 1: Literature review: Understanding psychological treatment for psychosis from the perspective of those with lived experience

1.1 Overview

The experiences and conditions we refer to as psychosis and schizophrenia have been understood for the last hundred years or so in biomedical terms, with treatment usually focused on medication and/or hospitalisation. Treatment for psychosis has usually been provided during or following an acute episode, or on the basis of chronic disorder. Individuals could experience untreated psychosis for many years before being offered help. Longer durations of untreated psychosis (DUP) may lead to worse long-term outcomes, and calls for treatment approaches to focus on earlier stages in the development of psychosis have been voiced for many years (eg., Sullivan, 1927; Cameron, 1938). Early Intervention (EI) for psychosis has now been developed in research and clinical settings, with therapeutic interventions being offered to identified individuals as soon as possible during or following a first episode (eg., Birchwood, 1992). Most recently, this approach has been expanded to explore Early Detection (ED) strategies for the prevention of psychosis (eg., Yung and McGorry, 1996).

The last twenty years or so have also seen the development of evidence-based psychological and psychosocial interventions for psychosis, especially cognitive behavioural therapy (CBT) and family interventions (FI) (eg., Kingdon and Turkington, 1991; Tarrier and Barrowclough, 1990). Growing evidence for the

effectiveness of CBT in the treatment and prevention of psychosis has led to CBT being a recommended treatment in the UK (Wykes et al., 2008; Hutton and Taylor, 2013; National Institute for Health and Care Excellence (NICE), 2009; 2013; 2014). Family interventions (FI) have also been recommended for psychosis and schizophrenia, with recent reviews showing FI, in combination with antipsychotic medication, to be effective in reducing the risk of relapse and hospitalisation (NICE, 2014; Pharoah et al., 2010; Onwumere, Bebbington, and Kuipers, 2011). FI may be particularly useful for families of people with psychosis or schizophrenia who have recently relapsed or who are at risk of relapse, or for those with persisting symptoms (NICE, 2009; 2014). However it has been argued that the implementation of FI in routine service settings has been poor and is inapplicable for the many service users without close carers (Garety et al., 2008). Although NICE guidelines recommend both individualised CBT and FI for psychosis with equal emphasis, and though it is certainly important to evaluate FI treatments by eliciting first-person experience (see eg., Allen, Burbach, and Reibstein, 2013; Wainwright et al., 2014), FI will not be explored in detail through this thesis, since the focus is on the experiences and perceptions of the individual in relation to their treatment.

It is increasingly argued that service users with lived experience of psychosis and of treatment for psychosis should be consulted to determine the treatment outcomes they themselves prioritise and the elements of treatment they find most helpful for achieving meaningful recovery (eg., Agar-Jacomb and Read, 2009; Morrison et al., 2012; Greenwood et al., 2010). This may be particularly important because there

are often significant differences in the priorities of service users and the professionals treating them (eg., Crane-Ross et al., 2000; Hansen et al., 2004).

Involving service users in the research process has also been widely advocated (eg., Deegan, 2005; Pitt et al., 2007), as has increased use of qualitative research methods (eg., Geekie, 2004). Direct involvement of service users and the use of qualitative research may offer a richer understanding of psychotic phenomena and experiences of involvement with mental health services than traditional quantitative evaluations and professional-led enquiries, and can offer service users valuable opportunities for meaningful discussion of their experiences and concerns (eg., May, 2007). It is hoped, therefore, that the following research studies, being conducted by someone with experience of psychosis-type difficulties and of accessing mental health services, will address the following topic areas with sensitivity to the kinds of questions that may be most important to others with lived experience of psychosis.

The following literature review and discussion will primarily use the term 'psychosis' to describe the condition, conditions, or range of experiences discussed, except when reporting literature or data that itself explicitly refers to 'schizophrenia'. The term 'schizophrenia' is often disliked or rejected by those with such lived experience or diagnoses, and may be both inaccurate and harmful (eg., McGorry, 1995; Bentall, 2003; Pitt et al., 2009; Schizophrenia Commission, 2012).

1.2 Understanding psychosis

The way we understand or try to understand psychosis has been shaped in great part by research and clinical practice led by professional psychiatrists or psychologists. This literature review and this thesis must, by necessity, draw from these areas of understanding to offer a representative view of the relevant research literature. However, a significant additional dimension is offered here through evaluation of qualitative research into psychosis, which seeks to draw understanding directly from the subjective expertise of people with lived experience of such phenomena. As Geekie and Read (2009) argue, "any understanding of madness which overlooks subjective experience will inevitably provide an incomplete and, ultimately, inadequate conceptualization of the experience. This is, we believe, true of much of human experience, but particularly true of madness given that it is the individual's subjective experience (such as hearing a voice, or having a 'delusional' belief) that is at the heart of how we define madness when we use terms such as psychosis and schizophrenia. To try to understand madness without recognizing, acknowledging and incorporating the subjective aspects of the experience into our understandings is an impossible task, doomed to failure" (p. 21, 2009). It is still important to evaluate subjective understanding of psychosis and treatment within the larger theoretical and clinical context, and therefore this literature review will offer a broad overview of current understanding.

1.2.1 The biomedical model of psychosis

The disease entity construct or 'medical model' of psychosis and schizophrenia has been the dominant conceptual paradigm for the direction of research and clinical practice for over one hundred years. Psychotic conditions and especially schizophrenia are commonly considered by psychiatric clinicians to be neurodevelopmental disorders associated with significant morbidity (Lieberman et al., 2001). Psychiatric models of the 'imbalanced brain' view of psychosis and schizophrenia tend to focus on, for example, interactions between emotional centres of the brain (eg., amygdala) and sensory and prefrontal cortices that generate affective states, attend to motivationally salient sensory events, and elicit related behaviours (Grossberg, 2000).

Medical psychiatry has employed surgical and, more recently, pharmaceutical interventions to treat psychotic conditions, treating them as primarily physiological disorders, inherited through genetic transmission, or borne of neurodevelopmental disorder. The bases for this biomedical approach are a group of theories looking at possible physiological causes of psychotic phenomena and the long-term morbidity associated with schizophrenia. This review will describe only the most prominent of these theories.

1.2.1.1 Genetic inheritance

There is a belief that a physiological vulnerability to psychosis is inherited genetically. Research has consistently identified an increased level of risk of developing psychosis for close family members of those who have been given a

psychiatric diagnosis (eg., Sham et al., 1994). However, although researchers have presented experimental evidence supporting the theory of genetic predisposition to psychosis (eg., Ben-Shachar and Laifenfeld 2004), the evidence to date remains unclear and equivocal (Read, 2004). The increased risk of experiencing psychosis among family members may indicate a genetic transmission of vulnerability, but nine out of every ten children of parents who have been given a diagnosis of psychosis or schizophrenia do not experience psychosis; similarly, nine out of every ten people who experience psychosis do not have a first-degree family member with a similar history (Gottesman and Erlenmeyer-Kimling, 2001; French and Morrison, 2004).

Read et al. (2014) argue that claims of genetic predisposition to schizophrenia have simply not been substantiated (Sanders et al., 2008; Joseph, 2013). Indeed, despite many years of genetic-based research, single genes of major effect have not been found (Craddock et al., 2007), high phenotypic heterogeneity has been acknowledged (Derks et al., 2012), and evidence to date suggests that any potential genetic susceptibility is not adequately defined within current operational diagnostic boundaries (Craddock and Owen 2007). As van Winkel et al. (2013) argue in relation to possible interactions between genetic and social factors in psychosis (especially childhood trauma), the current, limited evidence points to genes that are not specifically involved in psychosis but in more general processes such as mood regulation (serotonin transporter gene), neuroplasticity (brain-derived neurotrophic factor), and the stress-response system (FKBP5), and their effects on a range of psychological disorders (van Winkel et al., 2013). Therefore, it is likely that

factors other than fixed genetic inheritance exert instrumental influences on the emergence of psychosis or schizophrenia, and that such conditions may be best understood by integrating evidence of neurodevelopmental, psychological, and social influences, and the dynamic interactions between these that may lead to the development of psychotic phenomena (eg., Read et al., 2001; 2014).

1.2.1.2 Neurophysiology

Various causation theories focus on early abnormalities in brain development that may arise during pregnancy or infancy (eg., McNeil, 1995), or on neurobiological trait markers that could indicate vulnerability to psychosis, including increased ventricular brain ratio and ventricular enlargement (Lieberman et al., 1993), and neuropsychological markers related to information processing deficits (Cornblatt and Keilp, 1994). More recent research suggests psychotic conditions may arise in relation to neurodevelopmental lesions in frontal and/or cingulate regions of the brain, and neuropsychological deficits in executive function that may both be evident before the onset of frank psychosis (Pantelis et al., 2003). Abnormalities of cingulate gyrus activation while determining the self-relevance of ambiguous data, for example, may impair self-reflection in the persecutory deluded state (Blackwood et al., 2004).

It is important to note that examinations of the neurophysiology of those with experience of psychosis have in the past been conducted post-mortem, or more recently through neuroimaging with research participants who have usually taken very powerful antipsychotic medication. Lewis (2002) suggests that the kinds

of structural imaging now employed in such research has enabled a shift from a focus on early or inherited abnormalities, towards a more dynamic conceptualisation of psychosis, where the kinds of physiological changes suggested above could be related either to the onset of the condition, or to treatment. Indeed, a number of recent reviews suggest that structural changes observed in those with experience of psychosis may be attributable to the use of antipsychotic medication (eg., Navari and Dazzan, 2009; Moncrieff and Leo, 2010; Fusar-Poli et al., 2013), though it has been also been suggested that while antipsychotic medication is observed to affect specific changes in brain structure, more general changes may be caused by duration of relapse in psychosis (Andreasen et al., 2013).

1.2.1.3 The dopamine hypothesis

The so-called 'dopamine hypothesis' has suggested for some time that the symptoms of psychosis or schizophrenia are caused by an over-preponderance of dopamine receptors in the brain (Van Rossum, 1967), with similarities noted between the positive symptoms of psychosis and the psychosis-like symptoms induced by dopamine agonists, or by the dopamine releasing compound amphetamine (Conell, 1958; Randrup and Munkvad, 1967). The effects of antipsychotic medication also suggest a central role for dopaminergic transmission in the development of psychosis, particularly antisychotics' blockade of central D2-dopamine receptors (Carlsson and Lindqvist, 1963; Carlsson, 1978).

Recent research in this area suggests more specifically that psychosis is caused by a dysregulated hyperdopaminergic state and subsequent aberrant

assignment of novelty and salience to objects and associations in individuals

experiencing psychosis, where delusions arise to make sense of these aberrantly

salient experiences, and hallucinations reflect a direct experience of the aberrant

salience of internal representations (Kapur, 2003; Kapur et al., 2005). Although a

number of studies have suggested that presynaptic dopaminergic dysfunction (ie.,

increased dopamine synthesis capacity, dopamine release and baseline dopamine

levels) precedes the onset of psychosis (Howes et al., 2011) and appears to increase

with its development (Howes et al., 2012), it is most likely that external influences

(eg., social adversity such as migration and social isolation) and cognitive processes

(eg., biased appraisals leading to delusional beliefs) are necessary factors in the

development of such dysfunction (Broome et al., 2005).

1.2.1.4 The biomedical approach: helpful, or harmful?

The biomedical approach to understanding psychosis and schizophrenia

summarised above remains the dominant paradigm for research and clinical

treatment. This approach is also accepted by many who experience psychosis;

psychiatric diagnosis, based on a biomedical approach to classification, may offer

answers when no other explanations are available, and may facilitate access to

treatment. However, considerable evidence has amassed showing that the medical

approach to understanding psychosis is unhelpful for many others. Pitt et al. (2007)

argue that the medical approach to mental health problems, relying primarily on

pharmacological interventions, may be limiting and disempowering because it does

not address the wider personal, psychological and social dimensions central to a

broader conceptualisation of recovery from psychosis, or the development of coping skills to manage and live with symptoms. Biomedically-oriented beliefs among service users may also affect their engagement with treatment. For example a recent study of service users' beliefs about their psychotic experiences and subsequent engagement with psychological therapy (CBT) found that individuals with more biological beliefs about their experiences were less likely to engage with and benefit from therapy (Freeman et al., 2013).

While psychiatric diagnosis of psychosis and schizophrenia-spectrum disorders can be helpful as it 'names the problem' and serves as a means of access to treatment, diagnoses may not be as helpful in guiding treatment as they are intended to be (Division of Clinical Psychology, British Psychological Society, 2013). Importantly, psychiatric diagnosis also has the potential to be materially harmful for at least a significant proportion of service users due to the negative effects of diagnostic labelling which may cause disempowerment and social exclusion (Pitt et al., 2009; Schizophrenia Commission, 2012). Psychiatric diagnoses of psychosis or schizophrenia have been considered to be potentially traumatic (eg., Drury et al., 1996), and have been found to contribute significantly to depression (eg., Birchwood et al., 2000), social anxiety, and hopelessness (Birchwood et al., 2006). An individual told that they have an incurable disorder of such an unsettling and potentially disabling type may decide that the life ahead of them is not one worth continuing.

The UK's Schizophrenia Commission (2012) reported from a wide-ranging consultation that included many service users, that schizophrenia diagnoses were

particularly problematic for many individuals (eg., causing stigma and pessimism), but that not all service users felt negatively about diagnosis. For example, the Commission reported the following individual perspective which echoes the complexity of the findings reported by Pitt et al. (2009) above: "I have been ill for 15 years. I only found out my diagnosis by chance - when on one admission to hospital the doctor announced from a pile of notes "well it says he has schizophrenia". I was a bit concerned about this diagnosis but it was good in a way because I finally realised that there was a name for how I felt and it could be treated" ('My experience by Dan', Schizophrenia Commission, 2012, p13). Nonetheless, the Commission recommended that psychiatrists should be very cautious about making a diagnosis of schizophrenia, particularly following a first episode of psychosis, when such a diagnosis may cause more harm than good (Schizophrenia Commission, 2012). Interestingly a recent study examined mental health clinicians' experiences of communicating schizophrenia diagnosis to service users and their families and found that though most clinicians considered diagnosis necessary, most gave reasons for not doing so in practice (for example, from fear of incorrect diagnosis or causing distress) (Outram et al., 2014).

The role of biomedical explanations for psychosis and schizophrenia in influencing understanding among the general public has also been examined. For example Read and colleagues have conducted research which has shown that both in the general public and in mental health professionals, a biomedical illness model of psychosis is associated with greater desire for social distance, perceptions of dangerousness, and more negative attitudes about outcome and recovery than

those with psychosocial explanations (Read and Law, 1999; Read et al., 2006; Magliano et al., 2013). However further recent research in this area has suggested that these associations are complex and not yet fully understood. For example Reavley and Jorm (2014) conducted a large-scale survey of the Australian public to assess stigmatising attitudes and found that biogenetic causal explanations for psychological disorders were not statistically linked to increased or decreased belief in dangerousness, unpredictability, or desire for social distance, and concluded that perceived personality characteristics (eg., 'weakness') were more important factors in stigmatising attitudes than either biogenetic or psychosocial explanations. Schlier, Schmick, and Lincoln (2014) used an online survey method to examine attitudes towards people with schizophrenia among the general public, and found that neither biogenetic, psychosocial, nor stress-vulnerability explanations yielded significant stigma-reducing effects, though both psychosocial and stress-vulnerability explanations increased blame (ie., of people with schizophrenia-spectrum diagnoses). At present then, it is not entirely clear that biomedical explanations for psychosis and schizophrenia consistently increase negative beliefs among the general public, though it is clear that such explanations have the potential to do so.

1.2.2 The stress-vulnerability model of psychosis

"Nearly all geneticists gesture graciously toward the developmental model by acknowledging that genes do not work in a vacuum but rather require circumstances to elicit genetically encoded material" (Zubin and Spring, 1977). The

'stress-vulnerability' model of psychosis suggests that the kinds of neurodevelopmental disorders described above may predispose an individual to psychosis, but that psychosis will only become manifest with the occurrence of significant psychosocial or environmental stress, or following abuse of drugs or alcohol. In particular, use of cannabis and other dopamine-enhancing drugs may contribute significantly to an increased risk of developing psychosis or schizophrenia (Arseneault et al., 2004). Although geneticists have not yet identified reliable genetic markers to predict the development of psychosis (Falloon et al., 1996), the stress-vulnerability model of psychosis and schizophrenia remains a valid theoretical concept (Myin-Germeys et al., 2001). van der Gaag (2006), for example, has recently proposed a neuropsychiatric model of psychosis that accepts a role for genetic inheritance in neurodevelopmental vulnerability to psychosis, though the model also stresses the necessary role of social adversity and cognitive bias in the development of psychotic conditions (van der Gaag, 2006).

1.2.2.1 Environmental influences on psychosis

Jablensky (1997) argues that socio-demographic descriptors such as cultural ancestry, single marital status, and low socioeconomic status are more reliable predictors of heightened risk for psychosis than physiological factors such as winter birth, maternal influenza, or obstetric complications. Read et al. (2014) highlight a diverse range of potential influences on the development of psychosis including a mother's health, nutrition and stress during pregnancy, but which also includes the experience of being the product of an unwanted pregnancy, early abandonment or

parental bereavement, separation of parents, dysfunctional parenting and interparental violence, war trauma, rape or physical assaults in adulthood, and racial or other discrimination. It is well-established that there is a greater risk of receiving a schizophrenia diagnosis among individuals from ethnic minority groups in the UK, the US, or elsewhere (eg., Fearon et al., 2006; Bresnahan et al., 2007). This may be explained in part by experiences of discrimination (Bhugra et al., 1997; Veling et al., 2007) or social defeat and powerlessness, where individuals perceive themselves to be in a subordinate position in society or of 'outsider status' (Selten et al., 2005). Urban living has also been consistently implicated in increased risk for psychosis (Pedersen and Mortensen, 2001; van Os et al., 2001), as has poverty, which may be more closely associated with schizophrenia than other mental health problems, and which may even predict diagnosis and treatment selection (Read, 2010).

1.2.2.2 Social influences on psychosis

Adverse social experiences have also been associated with increased risk for psychosis and are considered a robust predictor of poor outcome, especially living within 'high expressed-emotion' families (that is, with family members who are frequently critical, hostile, or emotionally over-involved) (eg., Vaughn and Leff, 1976; Bebbington and Kuipers, 1994; Butzlaff and Hooley, 1998). Early separation from parents has also been found to predict an increased risk of developing psychosis (Agid et al., 1999; Parnas et al., 1985), while insecure attachment styles may influence the onset of psychosis and paranoid ideation in particular (MacBeth

et al., 2008; Pickering et al., 2008). Indeed, it is suggested that different types of adverse experience influence different types of symptoms associated with psychosis (Bentall and Fernyhough, 2008); while insecure attachments may contribute to paranoia (eg., being brought up in institutional care; Bentall et al., 2012), childhood trauma, especially sexual abuse, increases the risk of experiencing hallucinations (Read et al., 2004; Hammersley et al., 2003; Bentall et al., 2012). The role of social factors such as these in the development of psychosis will be considered in greater detail in the context of psychological models of psychosis, which will be discussed below.

1.2.2.3 Trauma and psychosis

Research has associated experience of traumatic events with the development of psychosis for many years (Moskowitz, 2011). For example, Romme and Escher (1989) found that 70% of voice hearers developed their hallucinations following a traumatic event. Mueser et al. (1998) found a lifetime prevalence of traumatic events among a sample of people with schizophrenia and bipolar disorder of 98%. The kinds of trauma histories commonly associated with increased risk of psychosis include sexual abuse, combat experience, or refugee-status (e.g., Ensink 1992; Butler et al., 1996; Kinzie and Boehlein, 1989). Childhood sexual abuse has been causally related to the development of psychiatric and substance abuse disorders (Kendler et al., 2000; Moskowitz, 2011). Fowler (1999) reported evidence that those with the most 'treatment-resistant' psychotic symptoms may also have the most severe trauma histories. Traumatic experiences and adverse circumstances in

childhood may also be related to relapse and rehospitalisation in schizophrenia

(Doering et al., 1998). Read and colleagues have conducted numerous systematic

reviews of this literature (eg., Read et al., 2005; Read et al., 2008), along with

studies demonstrating links between traumatic experiences and psychosis,

including links between content of symptoms and previous trauma (eg., Read et al.,

2003; Read et al., 2004).

The most recent research in this area confirms the strength of the

association between psychosis and childhood adversity in particular, with a 'dose-

response' relationship observed between the severity of experienced adversity or

trauma and the degree of risk of experiencing psychosis (Varese et al., 2012;

Kelleher et al., 2013). Indeed Varese and colleagues' large-scale meta-analysis

found that those with experience of serious adversity in childhood (sexual abuse,

physical abuse, emotional/psychological abuse, neglect, parental death, bullying)

were around 3 times more likely to experience psychosis in later life, with the risk

rising to up to 50 times the likelihood for those with the most severe trauma

histories. This meta-analysis did not identify one type of trauma to be a stronger

predictor of psychosis than any other, and the authors suggest that variables such

as age at the time of the adverse experiences, or experience of multiple types of

adversity may be more reliable predictors than trauma type (Varese et al., 2012).

However, as mentioned above, particular adverse experiences have been found in

individual studies to increase the risk of experiencing particular symptoms; being

brought up in institutional care may predict paranoia, while experience of

childhood rape may predict auditory hallucinations (Bentall et al., 2012).

Research has suggested possible neurobiological effects of childhood trauma that may contribute to the development of psychosis (eg., Grassi-Oliveira et al., 2008). Read and colleagues have developed a traumagenic neurodevelopmental model that aims to explain the links between such findings and the symptoms of psychosis (Read et al., 2001; 2014). This model integrates biological and psychological research by showing that the structural and functional differences observed between the brains of individuals diagnosed with schizophrenia and the brains of others are the same differences found between children who have, and have not, been traumatized. Such differences include over-reactivity of the hypothalamic-pituitary-adrenal (HPA) axis, dopamine, serotonin and norepinephrine abnormalities, and structural changes to the brain such as hippocampal damage, cerebral atrophy, ventricular enlargements and reversed cerebral asymmetry (Read et al., 2001; 2014). The traumagenic model of psychosis is considered to be consistent with the stress-vulnerability approach, with emerging evolutionary-based explanations for psychotic symptoms (Grace, 2010; Moskowitz, 2004), and with recent neuropsychiatric models (van der Gaag, 2006). However the traumagenic model can be seen as distinct in this context as it suggests that neurodevelopmental disturbance in psychosis or schizophrenia, along with the heightened sensitivity to stress consistently found in people diagnosed with psychotic disorders, is not necessarily genetically inherited, but can be caused by neurodevelopmental changes to the brain related to trauma, neglect, or chronic stress in childhood (Read et al., 2001; Teicher et al., 2003; Moskowitz and Corstens, 2007).

Support for the traumagenic model of psychosis can also be seen in research suggesting that experiences of social defeat and reduced self-value in particular, could lead to sensitisation of the mesolimbic dopamine system, changes in the stress and immune system, and concomitant changes in stress-related brain structures, such as the hippocampus and the amygdala (van Winkel et al., 2013). Hoy et al. (2012) have also found that experience of childhood trauma among a group with first episode psychosis was a significant predictor of effects in hippocampal and amygdalar volumes, and the hippocampal/amygdalar complex volume as a whole. Nonetheless, the specific processes and mechanisms by which childhood and later adversities can lead to psychosis are still not very well understood (Bentall et al., 2012), though further research into psychological processes such as dysfunctional cognitive processes, attachment and dissociation, psychodynamic defences, and coping responses may be productive (Read et al., 2014), and these will be discussed in the following section.

1.2.3 Psychological models of psychosis

Prominent psychological explanations for the emergence of psychotic phenomena have been posited by researchers such as Romme and Escher (1989) and Bentall (2003), who argue that phenomena such as hearing voices may occur as coping responses to stressful life experiences, while paranoia may be a functional or defensive phenomena, helping individuals to cope with genuinely threatening circumstances, or protecting self-esteem by externalising causal attributions for external events and reducing self-blame. Specific psychological influences thought

to contribute to paranoia include the role of an external locus of control, and specifically the belief that life is controlled by powerful others (Kaney and Bentall, 1989; Lasar, 1997), along with exaggerated anticipation of future negative events (Bentall et al., 2008; Corcoran et al., 2006). Hallucinations are thought to involve problems with source monitoring and meta-cognition (Bentall, 2000). The following section will describe in more detail a number of central psychological approaches to the understanding of the development of these phenomena.

1.2.3.1 Attachment theory

Attachment relationships and attachment styles have been identified as particularly important in the development of interpersonal and psychological functioning (Ainsworth 1978; Bowlby 1982; Gilbert, 2009), and in the development of psychological problems such as psychosis (eg., Bucci et al., 2014; Gumley et al. 2014). Attachment theory stems from a focus on affectionate interpersonal bonds, especially those first formed with primary caregivers such as parents (Bowlby, 1980; Bowlby, 1982). Experiences of being cared for in infancy are thought to establish mental representations about the self in relation to others, with internal working models creating expectations about future relationships (Danquah and Berry, 2013). Secure attachments in infancy enable early exploration and provide a source of safety from perceived threats. In adulthood, the benefits of secure attachments may be associated with positive self-image, resilience and ability to manage distress, comfort in forming relationships, and with the freedom and autonomy with which an individual is able to reflect on and explore painful experiences and

feelings. In contrast, insecure attachments in infancy may lead to preoccupation with attachment experiences and heightened emotional expression, or to avoidance of and minimising of attachments and attachment-related thoughts and memories (Bowlby, 1977; Gumley et al. 2014; Bucci et al., 2014). These, it is argued, may be functional strategies in the context of an individual's development, and important in the development of interpersonal functioning, resilience, and constructive adaptation to threatening life events (Fraley, 2002; Van Bakermans-Kranenburg, 2009).

Insecure attachment styles may confer significant vulnerability to a wide range of mental health problems for many people, and indeed it has been argued that the majority of those with serious mental health problems do display insecure attachment styles (Ma 2006; Berry et al., 2007; MacBeth et al., 2010; Berry and Drake, 2010). Insecure and disorganised attachments have been implicated in, for example, suicidal behaviour (Van Bakermans-Kranenburg, 2009; Lizardi et al., 2011) and psychosis (Pickering, Simpson, and Bentall, 2008). A range of early interpersonal traumas have been associated with insecure attachments and subsequent onset of psychotic symptoms, including abandonment or early separation from parents (Morgan et al., 2007), postnatal bereavement stress (for offspring), especially following the suicide of a close family member (Abel et al., 2014), being raised in institutional care (Bentall et al., 2012), and physical, sexual and emotional abuse and neglect (Fonagy 1996; Bebbington 2004; Varese et al., 2012). Evidence increasingly suggests that exposure to serious adversity in childhood influences the development of psychosis in later life by increasing

sensitivity to stress (Lataster et al., 2012; Lardinois et al., 2011), potentially by affecting neurodevelopmental changes to the brain (Read et al., 2001; 2014).

A recent systematic review of research into the relationship between attachment and psychosis in adulthood found small to moderate associations between greater attachment insecurity (as reflected in anxiety and avoidance) and more interpersonal problems, more avoidant coping strategies, more negative appraisals of parenting experiences and more severe trauma, along with more positive and negative symptoms and greater affective symptoms (Gumley et al., 2014). In psychological terms, attachment problems are thought to confer vulnerability to psychotic phenomena such as paranoia through interpersonal mistrust, negative perceptions of others or fear of being perceived negatively, and perceptions of being persecuted (Trower and Chadwick, 1995; Pickering, Simpson, and Bentall, 2008). Additional factors considered to mediate the relationship between attachment insecurity and paranoia include seeing others as more powerful (Kaney and Bentall, 1989; Lasar, 1997), negative self-esteem (Barrowclough et al., 2003), anticipation of threatening events (Bentall et al., 2008; Corcoran et al., 2006), and shame and self-criticism (Gilbert, 2009). The severity of and distress caused by hallucinatory experiences such as hearing voices have been associated with attachment anxiety in particular, while the degree of intrusiveness and 'hearer distance' has been associated with attachment avoidance, along with perceived rejection, criticism, and threat (Berry et al., 2012; Robson and Mason, 2014).

In recent years compassion-focused therapy (CFT; Gilbert, 2009) has sought to address attachment issues in particular with a focus on internal attachment and affect regulation systems, which are believed to underlie feelings and perceptions of safeness, well-being, and reassurance. The CFT approach suggests that for people with serious psychological difficulties, these systems may have come to be dominated by threat-related affect regulation. By exploring perceptions of threat, shame and self-criticism, and by encouraging self-compassion, it is thought CFT may positively affect attachment systems and experiences, and in turn, improve an individual's ability to cope with and recover from serious psychological difficulties such as psychosis (Gilbert, 2009; Gumley et al., 2014b).

Finally, it is important to recognise the role of attachment in the general treatment of psychosis. A number of studies have shown that while those with secure attachment styles may engage with and adhere to treatment more successfully (Dozier, 1990; MacBeth et al., 2010), insecure attachment styles may lead to poorer engagement with mental health services (Tait, Birchwood and Trower, 2004; Gumley et al., 2014), and therapeutic relationships (Berry et al., 2007). Bucci et al. (2014) suggest that those with severe mental health problems may have attachment needs that should be met in general mental health services, and that services should evaluate the extent to which they meet such needs.

1.2.3.2 Family models

The role of family relationships has also been identified as important in the psychodynamic approach to psychosis, especially the effects of 'expressed emotion'

(EE) (Brown, 1985). Emotional over-involvement, critical comments, hostility, positive remarks, and warmth have been identified as important components of EE, and measurement of these can serve as an indicator of the 'emotional temperature' of relatives' responses to psychosis and to the individual experiencing psychosis (Brown, 1985; Bhugra and McKenzie, 2003). Certain elements of EE may have the most negative effects, including critical comments, hostility, and emotional over-involvement (Kuipers, 1992). It is argued that from a psychodynamic perspective, high EE and critical family behaviour may be seen to act on an affected individual's low tolerance of internal painful affect, which may trigger the need for psychotic defences and may exacerbate psychotic symptoms (Hingley, 2006).

High EE has been found to be a significant and robust predictor of relapse in psychosis/schizophrenia for both genders (Kavanagh 1992; Bebbington and Kuipers, 1994; Butzlaff and Hooley, 1998). High levels of contact with a high-EE relative have been shown to confer significantly higher risk of relapse compared with contact with low-EE relatives (Bebbington and Kuipers, 1994; Linszen et al., 1997). The strongest relationship between EE and relapse may be seen in individuals with more severe or chronic psychoses, while EE may be less reliably predictive of relapse during the early course of psychosis (Butzlaff and Hooley, 1998). Recent findings from comparison of 'established-disorder' versus 'prodromal' (pre-psychosis) samples suggest that EE may emerge largely in reaction to deterioration observed in the person developing a psychotic disorder, rather than being a trait of family members (McFarlane and Cook, 2007). It has also been noted that findings for the role of EE across different cultures have not been consistent, and that in

some cultures (eg., in parts of India), emotional over-involvement may be more normal than in Western cultures (Bhugra and McKenzie, 2003).

1.2.3.3 Psychodynamic theory

Psychodynamic theory has also been applied to research and treatment for psychosis, and may be helpful for understanding the types of vulnerability that underlie psychotic symptoms (Hingley, 2006). It has been argued that a psychodynamic approach to psychosis enriches the stress-vulnerability model, and may be helpful in informing individualised psychological formulations, resolving the issues involved in relapse prevention, and making sense of reactions to treatment (Martindale, 2007).

A central feature of the psychodynamic approach to psychosis is the idea that psychotic phenomena such as delusions and hallucinations serve a protective function. Martindale (2007) argues that from a psychodynamic perspective, it is important to identify emotions that had previously overwhelmed the individual and to pay attention to the content of delusions and hallucinations, which may share meaningful relationships with emotional experience.

Psychodynamic therapy for psychosis has a long history and continues to develop. For example, the Scandinavian family-oriented open-dialogue approach to treatment routinely incorporates psychodynamic and systemic understandings of psychosis (Alanen, 1997; Cullberg et al., 2006; Seikkula et al., 2006). Psychodynamic theory is also thought to share important features with other psychological approaches such as cognitive behavioural therapy, including the central importance

of the therapeutic relationship, and not being overtly challenging or confrontational (Hingley, 2006). Evidence for the clinical efficacy of psychodynamic therapy for psychosis however is not clear, as there have been few methodologically rigorous trials of psychodynamic psychotherapy (Roth and Fonagy, 2006). Malmberg and Fenton (2001) conducted a meta-analysis of evidence from randomised trials of psychodynamic therapy, but reported that such evidence was sparse (only three trials were included), and concluded that psychodynamic therapy confers no additional benefit when combined with medication, and is less effective than medication when offered alone (Malmberg and Fenton, 2001). It was also noted that potential adverse effects of psychodynamic therapy seemed not to have been considered, despite evidence that the emotional intensity of psychodynamic therapy may be harmful for at least some individuals (eg., Mueser and Berenbaum, 1990).

In contrast, Gottdeiner (2004) and Gottdeiner and Haslam (2002) concluded from a different meta-analysis of psychotherapy for schizophrenia (including psychodynamic treatments), that psychodynamic therapy and cognitive behavioural therapy produced similar therapeutic benefits, and that psychodynamic therapy was associated with significant improvements in functioning. However, this latter review included non-randomised and other trials whose methodological quality is thought to fall short of current standards (eg., 17 of 27 trials antedate DSM-III diagnostic criteria), and whose outcome measurements vary widely (Roth and Fonagy, 2006). Nonetheless, Gottdeiner (2006) reaffirmed meta-analytic support for the use of psychodynamic therapy in the treatment of schizophrenia,

and Martindale (2007) highlights recent research suggesting such therapy may be effective in improving functioning (Rosenbaum et al., 2005).

1.2.3.4 Dissociation

Experience of traumatic events, especially in childhood or when associated with PTSD in adulthood, has consistently been associated with an increased likelihood of experiencing psychotic phenomena (Read et al. 2001; van Os et al. 2010; Moskowitz et al., 2009 Varese et al., 2012; Arseneault et al., 2011; Scott et al., 2007). Among psychological explanations for the relationship between trauma and psychosis, the role of dissociative processes is well-established (Moskowitz and Corstens, 2007). Dissociation following traumatic events is common, even for those who don't experience psychosis (van Ijzendoorn and Schuengel, 1996), and those who do experience psychosis are more likely to have greater dissociative tendencies than people with no history of trauma (Goff et al. 1991; Dorahy et al. 2009). Dissociation is thought to confer vulnerability to psychotic phenomena by interfering with discrimination between internally and externally generated events (Bentall, 1990), or 'loosening the moorings in inner and outer reality' (Allen et al., 1997, p327), and therefore impairing reality testing. For example, hallucinations may arise from the misattribution of internally generated cognitive events such as inner speech to external sources (Bentall, 1990; Ditman and Kuperberg, 2005), and dissociation is increasingly thought to be related specifically to hallucinations (Kilcommons and Morrison, 2005; Moskowitz and Corstens, 2007). These associations between trauma and dissociation, and between dissociation and hallucinations therefore

suggest that the increased vulnerability to hallucinations common among those

who experience trauma (especially in childhood) is mediated by dissociative

tendencies (eg., Moskowitz and Corstens, 2007; Varese, Barkus, and Bentall, 2012).

1.2.3.5 Recovery style

Attachment, as discussed above, has also been identified as an important factor in

recovery from psychosis, particularly for the development of different recovery

styles, and differences in responses to treatment (Tait, Birchwood, and Trower,

2004; Berry and Drake, 2010). Evidence suggests that individuals recovering from

psychosis tend to adopt either an 'integrative' or 'sealing over' recovery style.

Integration is thought to reflect greater curiosity about and recognition of links

between life experiences and psychosis (resulting in greater flexibility in attitude),

while sealing over is seen as a lack of desire to explore or understand psychotic

experiences, or to consider them in the context of life experiences, and is

associated with more fixed, negative views of psychological difficulties (McGlashan,

Levy, and Carpenter, 1975; McGlashan, 1987; Berry and Drake, 2010). Recovery

style may change over time, for example with integration changing to sealing over

during adjustment to psychosis, or vice versa (Tait, Birchwood, and Trower, 2004),

and may change in line with improved or reduced insight, though it is argued that a

sealing over recovery style is not necessarily indicative of poor insight (Drayton et

al., 1998; Tait et al., 2003). It is thought that people with a diagnosis of

schizophrenia more often use sealing over or avoidance recovery styles and

strategies, and evidence suggests that in comparison with integrative approaches,

these are associated with greater risk of relapse, reduced social functioning and quality of life, and higher levels of depression (McGlashan 1987; Jackson et al., 1998; Drayton et al., 1998; Thompson et al., 2003; Tait, Birchwood, and Trower, 2003).

The relationship between recovery styles and attachment has been explained particularly in relation to findings that sealing-over recovery styles are associated with more negative early childhood experiences, more insecure adult attachments, negative self-evaluative beliefs and a more insecure sense of identity (Drayton 1998; Tait, Birchwood, Trower, 2004; Berry and Drake, 2010). It has been argued that individuals who 'seal over' may not have a sufficient sense of internal security or the psychological resilience to explore and understand their psychotic experiences without being overwhelmed (Drayton 1998), and that this may be caused by the anomalous developmental trajectory conferred by poor attachment experiences (Birchwood, 2003). As with insecure attachment styles (see above), sealing over recovery styles are also associated with poorer engagement with mental health services (Tait, Birchwood, and Trower, 2004; Gumley et al. 2014).

1.2.3.6 Coping styles and strategies

Looking more widely at the ways people cope with psychosis or schizophrenia, a wide range of 'natural' coping strategies along with treatment-based approaches to coping have been observed. A review of research into coping strategies for hallucinated voices reported that at least 70% of individuals identified at least one coping behaviour, with some individuals identifying many more (Farhall,

Greenwood, and Jackson, 2007). Most coping strategies overlap considerably with those used for other disorders (Breier and Strauss, 1983) and with those reported by non-clinical populations for other stressors (Romme and Escher, 1989; Farhall and Gehrke, 1997). Coping strategies are not usually 'culture-bound', with sample groups in India and Taiwan (Ramanathan, 1984; Singh et al., 2003; Tsai and Ku, 2005) reporting similar approaches to those in Western cultures, though there may be different emphases in strategy use across cultures (Wahass and Kent, 1997).

Coping strategies are diverse and include behavioural, cognitive and physiological elements. Various approaches to categorising coping have identified strategies or styles such as: fighting back against or accepting symptoms (Cohen and Berk, 1985), active acceptance, passive coping, and resistance coping (Farhall and Gehrke, 1997) and competing auditory stimuli, vocalisation, and distraction (Carter et al., 1996). 'Auditory competition methods' (eg., listening to interesting and boring speech or music) have been found to reduce auditory hallucinations compared with sensory restriction or non-aversive white noise (Margo, Hemsley, and Slade, 1981; Johnston, et al., 2002). Addressing hallucinated voices as possible 'subvocalisation' (Slade, 1994), a number of strategies that aim to control subvocalisation such as humming or counting have been found to be moderately effective in inhibiting voices (Nelson, Thrasher, and Barnes, 1991; Dinan, and Baker, 1995). Distraction strategies typically aim to divert attention away from hallucinations (Tarrier et al., 1993; Buccheri et al., 1996), though a Cochrane review of distraction treatments for hallucinated voices (Crawford-Walker, King, and Chan, 2005) could offer no conclusions on the evidence for the efficacy of such treatment.

Enhancement of coping strategies has become an established feature of many psychotherapeutic approaches, particularly in CBT (Tarrier et al., 1990; Kingdon and Turkington, 1994; Fowler, Garety, and Kuipers, 1998). As natural coping strategies are identified by individuals themselves, and as engagement in coping enhancement should require no confrontation of psychotic beliefs, therapeutic support of natural coping may also be experienced as empowering (Farhall et al., 2007). Though more recent theoretically-driven CBT research has emphasised the role of cognitive factors (Beck and Rector, 2003; Morrison, 2001), it has been argued that behavioural aspects of therapy such as work on coping strategies may be as effective as cognitive elements, and possibly sufficient for clinical change (Gaudiano, 2005). Meta-cognitive approaches to coping have also been developed within the context of psychotherapy, including mindfulness and acceptance. As resisting voices, for example, can have emotional costs (Gilbert et al., 2001), adopting an alternative approach of accepting them may be an adaptive form of coping (Farhall et al., 2007). Shawyer et al. (2005) argue that in order for acceptance to be adaptive it needs to include some degree of disengagement from the psychotic experience, as in the practice of mindfulness. Farhall and Gehrke (1997) found that 'active acceptance' was associated with perceived control of voices whereas resistance and passive coping were not. Acceptance and Commitment Therapy (ACT) has been found to reduce levels of voice believability, and hospitalisation (Bach and Hayes, 2002; Gaudiano and Herbert, 2006). A recent qualitative study of ACT for psychosis reported that though symptom frequency may not change with ACT, the intensity and distress associated with symptoms

were reduced; both mindfulness and acceptance were among the most useful

components of therapy identified by participants themselves (Bacon, Farhall, and

Fossey, 2013). Overall however, though natural coping strategies are widely used,

and though various therapeutic interventions focus on coping enhancement, there

is little clear evidence for the efficacy of specific coping strategies (Farhall et al.,

2007). In part, this is because coping has rarely been the primary focus of published

treatments, and more generally the effectiveness of any coping strategy may vary

greatly between individuals (Hustig et al., 1990).

1.2.3.7 Cognitive behavioural models of psychosis

Garety et al. (2001) suggest that early adverse life experience (childhood loss, social

marginalisation, or severe childhood trauma) may contribute to an enduring

cognitive vulnerability, characterised by negative schematic models of the self and

the world. Prior emotional distress may also influence the content of delusions,

with delusion content in turn influencing levels of emotional distress (Freeman et

al., 2001). Among people who hear persecutory voices, perceived power

imbalances between the individual and their persecutor/s may be linked to

subordination and marginalization in other social relationships, and in the

individuals appraisal of their social rank and sense of group identification and

belonging (Birchwood et al., 2000). Morrison (2001) notes a 'striking congruence'

between early experience and life events and the content of psychotic

symptomatology: "It seems indisputable that previous experience (traumatic events

in particular) is implicated in the development of psychosis, and it appears likely

that such experiences influence belief formation, which will in turn influence the nature of intrusions into awareness… the nature of the misinterpretation that is made by a person will be determined by a combination of their experience, beliefs and knowledge" (p.265).

Morrison (2001) argues that psychotic phenomena can be conceptualised as cognitive intrusions into consciousness, and that it is the interpretation of these intrusions that causes the associated distress and disability. The interpretation of such intrusions (eg., 'This voice must be the devil' vs. 'I must be tired') may be central to an understanding of psychotic experience (eg. Kingdon and Turkington, 1994). It is suggested that interpretations or misinterpretations of cognitive intrusions are affected by faulty self and social knowledge, and that both cognitive intrusions themselves and interpretations of them are maintained by mood, physiology, and cognitive and behavioural responses (including selective attention, safety behaviours and counterproductive control strategies) (Morrison, 2001; Chadwick and Birchwood, 1994). Freeman et al. (2002) similarly suggest that persecutory delusional beliefs are maintained through processes that lead to the receipt of confirmatory evidence and processes that prevent the processing of disconfirmatory evidence (for example, using safety behaviours). Particular types of beliefs or appraisals about hearing voices may also cause greater distress and severity, such as believing that voices are malevolent (intending harm), that they are more powerful than the voice-hearer themselves, or that voices are those of people with whom the voice-hearer is personally acquainted (Mawson, Cohen, and Berry, 2010). Interestingly, Mawson et al. (2010) suggest that trials of CBT with

people who hear voices have not consistently achieved significant improvements in voice related distress, and that this may be because mediating variables such as social schemata (highlighted by Garety et al., 2001, above) have not been targeted in CBT trials.

1.2.3.7.1 Cognitive biases

Studies have found that particular cognitive biases including data-gathering bias (Garety et al., 1991), an externalising attributional style (Randall et al., 2003; Bentall, 2003), and deficits in understanding social situations and the intentions of others ('theory of mind'; eg., Corcoran et al., 2008), are common among those who experience psychosis. Garety and colleagues have conducted considerable research into the 'jumping to conclusions' (JTC) and belief inflexibility biases in particular. JTC, it is argued, involves gathering limited information in appraising psychotic experiences, leading to the formation of delusional beliefs, while belief inflexibility mediates the relationship between the JTC bias and the strength of delusional conviction (Garety et al., 2005; So et al., 2012). JTC may be also associated with impairments in working memory (Garety et al., 2013).

These cognitive biases may directly influence the maintenance of psychosis, and may be worsened by negative emotional states such as anxiety, depression, or anger (Bentall and Kaney, 1989; Kinderman, 1994), though it is worth noting that Garety and et al. (2005) found that anxiety but not depression contributed to delusional conviction. In addition, attentional bias has been implicated in paranoia, particularly selective attention and confirmatory biases which may create or

reinforce a preoccupation with potentially threatening events, possibly in relation to threat-related memories (Blackwood et al., 2001). Meta-cognitive bias has also been identified in the development of psychosis, especially the tendency to hold strong beliefs in the uncontrollability and danger of thoughts, and positive beliefs about worrying (Baker and Morrison, 1998; Morrison and Wells, 2003).

1.2.3.7.2 Self-concept and self-esteem

Poor self-esteem and negative schemas or self-concept are often significant difficulties among people who experience psychosis (Trower and Chadwick, 1995; Kinderman and Bentall, 1996; Freeman et al., 1998; van Os et al., 2000). Negative self-concepts, for example, may contribute to the negative content of hallucinations and delusions (Close and Garety, 1998), while pre-existing negative schemas may influence content in psychotic attributions (Bowins and Shugar, 1998; Fowler et al., 1998).

Negative schemas involving social humiliation and subordination may be most commonly influenced by childhood experiences of social adversity, and may in turn fuel voice-hearing and paranoia (Birchwood et al., 2000). Bentall and Fernyhough (2008) argue that early adverse experiences, especially when occurring repeatedly, increase the likelihood of negative self-esteem, an externalizing attributional style, and problems understanding others' intentions because of difficulties with theory of mind skills (where a person may be unable to attribute the negative actions of others to situational circumstances). Over time these factors may lead to a tendency to anticipate social encounters as a threat, especially when

influenced by jumping to negative conclusions, or preventing contextual updating of information ('reality testing').

Perceiving others' attitudes towards oneself as negative, often in relation to subjectively experienced social defeat, may be an early feature of psychotic development (Selten and Cantor-Graae, 2005), and distorted interpretation of interpersonal relationships "may be located at the core of psychotic experience" (Salokangas et al., 2009, ps234). Indeed, a recent study found that high levels of social defeat ('feelings of a failed struggle and losing rank') influenced negative evaluations of the self and others among a group of participants considered to be at high risk of developing psychosis, and that negative beliefs mediated the relationship between social defeat and early symptoms (Stowkowy and Addington, 2012). The onset of psychosis can in turn threaten an individual's sense of self and identity, their valued goals, roles, and social status resulting in tendencies for negative appraisals or beliefs involving loss, entrapment, and worthlessness (Birchwood et al., 1997). Roe (2003) emphasises the importance of helping those with psychosis to sustain positive self-esteem, and psychological therapies (eg., CT) focused on improving self-esteem for those with psychosis have been developed (Lecomte et al., 1999; Hall and Tarrier, 2003; Knight et al., 2006).

1.2.3.7.3 Safety-seeking behaviours

In attempting to ameliorate the confusion and distress that may emerge with the onset of psychotic phenomena, attempting to exert control over their experiences, or to prevent some feared catastrophe, people with psychosis may adopt 'safety-

seeking behaviours' (types of distraction, drug or alcohol abuse, or social withdrawal, for example) (Nayani and David, 1996; Romme et al., 1992; Morrison, 1998). Defining safety behaviours in the context of a cognitive behavioural model of mental health, Salkovskis (1996) identified three main categories: avoidance of situations, escape during a panic attack, and behaviours carried out to prevent a feared outcome. Wells and Matthews' meta-cognitive S-REF model (1994) suggests that the choice of coping mechanism (ie., safety behaviour) is mediated cognitively through compensatory beliefs about psychotic experiences. Indeed, Chadwick and Birchwood (1994) found that behavioural responses chosen by people who experienced auditory hallucinations appeared to be driven by underlying beliefs about voices, and asserted that "affective, cognitive and behavioural responses evolve together and are always meaningfully related" (p.200).

Nothard et al. (2008) found that participants who heard voices frequently reported catastrophic interpretations about these experiences, and undertook corresponding safety behaviours that served to prevent feared outcomes. Nothard and colleagues report examples of such interpretations and behaviours. A participant believing that "He (the voice) is watching me and knows exactly what I am doing", who also holds the mediating belief that "If I do not let him see in the flat or read my mind, he will not be able to do this", may act to "keep curtains closed, relax, lie down, sing in head, try not to think about what I am going to do beforehand" (p.356).

Freeman et al. (2007) argue that using safety behaviours is a common form of acting on persecutory delusions. They found that greater use of safety

behaviours was associated with a history of suicide attempts or violent behaviour (ie., acting on delusional beliefs), and that greater use of safety behaviours was associated with higher levels of distress, suggesting that safety behaviours may cause more harm than good. Undertaking safety behaviours may also be fundamentally unhelpful as they may maintain delusional beliefs, or misinterpretations of otherwise understandable phenomena such as hearing voices (Morrison, 1998). Social withdrawal and isolation, in particular, are very common among people who experience psychosis and can contribute to the development and maintenance of psychotic symptoms by reducing individuals' opportunities for interactions with others that could provide alternative, more acceptable, or 'normal' explanations for the psychotic experiences (Garety et al., 2001; Morrison, 2001; Freeman et al., 2007). Indeed, the onset of psychotic symptoms may often be related to an inability to generate alternative explanations for them, frequently due to a lack of trusting or supportive relationships that would facilitate the normalisation of such interpretations (French and Morrison, 2004).

1.2.4 Psychosis and stigma

Psychosis and schizophrenia are highly stigmatised conditions in many societies (Haghighat, 2001). Cultural stereotypes perpetuated through dramatic representations of people with psychosis in films and on television, or media reports of violence attributed to people with psychiatric diagnoses, for example, reinforce inaccurate beliefs related to the perceived dangerousness of those with psychosis (Ion and Beer, 2003; Anderson, 2003; Hewitt, 2008). A notable recent

example of this was seen in the UK in October 2013, when The Sun newspaper published a front page article drawing on published statistics relating to homicides committed by people with serious mental health problems (Appleby et al., 2103): "1,200 KILLED BY MENTAL PATIENTS. Shock 10-year toll exposes care crisis" (The Sun front page, 7 October 2013). The Sun story continues, stating that: "disturbing failings in Britain's mental health system… have allowed high-risk patients to kill 1,200 people in a decade". This statement is inaccurate for two main reasons. Firstly, the statistics reported by Appleby et al. (2013) relate both to those receiving mental health treatment, and those with mental health difficulties who were not engaged with services (ie., not all relevant homicides were committed by 'high risk patients'). Secondly, the description of "disturbing failings in Britain's mental health system" misrepresents the actual findings of the report the newspaper quotes, which show that rates of homicide committed by mental health service users has fallen substantially, with rates for the most recent confirmed years (2009-2010) being the lowest since data collection began in 1997 (Appleby et al., 2013). In other words, the 'disturbing failings in the mental health system' described by the tabloid are not evident in the reported data, which in fact suggest that the opposite is true. Given the likelihood of newspaper reporting alone to contribute significantly to stigmatising beliefs among the general public about those with mental health problems (Thornton and Wahl, 1996; Angermeyer and Matschinger, 1995; Torrey, 2011), widely-read mass-media reporting such as the Sun front page article described above may have been particularly unhelpful.

Beliefs among the general public regarding perceived links between risk of violence and psychosis specifically have often been shown to be inaccurate and disproportionate. For example, recent studies have reported that up to 70% of public survey respondents expect people with psychosis to be violent towards others, with only 30-40% of the same respondents believing people diagnosed with nonpsychotic disorders are likely to be violent (Penn et al., 2005; Martin et al. 2007; Yang et al., 2013). The actual relative risk of violence towards others among those with psychosis has been well-studied. A systematic review and meta-analysis conducted by Fazel et al. (2009) found that though schizophrenia and other psychoses may be associated with increased statistical risk of violence and homicide, most of the excess risk (relative to non-psychotic individuals) appears to be mediated by substance abuse comorbidity (ie., similar levels of risk are found among those with substance abuse problems without psychosis) (Fazel et al., 2009). Recent research examining risk of violence among people with psychosis has focused on, for example, the relationship between delusional beliefs and violent behaviour. Coid et al. (2013) and Ullrich, Keers, and Coid (2013) note that though people with psychosis who commit violence may explain their violence as being due to delusional beliefs, this has not been confirmed in research to date. However, anger caused by delusions may be a key factor in violent behaviour, and was seen to mediate links between delusional beliefs implying threat (being spied upon, followed, or controlled) and subsequent violence (Coid et al., 2013; Ullrich, Keers, and Coid, 2013).

Stigma associated with psychotic conditions is pervasive, both in general society and among healthcare workers, and as such forms a real barrier to recovery for service users (Hocking, 2003). It has been argued that professionals in the field of psychosis research and treatment can often contribute to the negative stigma experienced by service users (eg., Repper, 2000; Wilson, 2001; Hocking, 2003). Tee et al. (2007) suggest that stigmatising and paternalistic approaches to care can also inhibit service user involvement in service delivery.

The stigma associated with psychosis or schizophrenia can contribute to problems with discrimination (in housing, education, and employment), and can contribute significantly to diminished self-esteem, feelings of shame, social unattractiveness, low personal worth (eg., Birchwood et al., 1993), and hopelessness (Hocking, 2003). Stigma can contribute to increased depression (Birchwood et al., 1993) and social anxiety, especially related to the shame, social marginalisation and low social status associated with a diagnosis of psychosis or schizophrenia (Birchwood et al., 2006). Salokangas et al. (2009) argue that subjectively experienced negative attitudes of others may be associated with a heightened vulnerability to and risk of psychosis, highlighting the harmful effects of self-stigmatising beliefs.

Birchwood et al. (2006) suggest that culture-wide stigmatised beliefs about psychosis or schizophrenia are often internalised even before people experience psychosis, and so with onset, service users may fear being seen and judged by others according to the stigmatising stereotype. Concerned that outward displays of their psychological problems (speech, nonverbal behaviour) will 'give them away'

as being 'mad', and fearing shame or rejection, many people with psychotic

experiences make continual efforts to conceal their problems and try to present

themselves well. This concealment of psychological difficulties can lead to delayed

help-seeking (Henderson et al., 2013) which in turn can contribute to longer

durations of untreated psychosis (DUP) and less favourable outcomes (Birchwood,

1992; Falloon et al., 1996).

McGlashan (1996) argues that the denial, fear, confusion, and stigmatisation

that influence concealment of psychotic experiences and delayed help-seeking

need to be faced and dealt with (to reduce DUP), while Hocking (2003) argues that

health professionals have a responsibility to improve their own attitudes and

behaviour towards people with psychosis or schizophrenia, and that educational

campaigns aimed at the general public and media personnel could help to

demystify psychological disorders and reduce the portrayal of offensive

stereotypes.

1.2.5 Normalisation of psychosis

Traditionally, psychiatric treatment of psychosis has emphasised the perceived

abnormality and pathological nature of such experiences. Contemporary

psychological and psychosocial approaches on the other hand (eg., Kingdon and

Turkington, 1994; Morrison, 2001) highlight the fundamental normality of psychotic

phenomena when considered in the context of difficult and traumatic life

experiences, and in light of the prevalence of such phenomena across non-clinical

populations (Romme and Escher, 1989). The normalisation of psychosis may be an

important strategy for helping those with such experiences (eg., Berry and Hayward, 2011), and for reducing the negative impact of stigmatising beliefs and behaviour among the general public (eg., Read et al., 2006). Therefore, it is important to evaluate how common psychotic experiences are in the general populations and in specific groups, such as those who have experienced particular traumatic events (eg., Morrison, 1998). Hallucinations, for example, can occur during organic confusional states (eg., induced by drugs like LSD and cocaine, or during alcohol withdrawal; Kingdon and Turkington, 1994), and various other types of lived experience have been associated with increased incidence of hallucinations in non-psychotic populations. Examples of such experiences include bereavement (Grimby, 1993), being held hostage (Siegel, 1984), sleep deprivation (Oswald, 1974), sensory deprivation (Vernon, 1963), and solitary confinement (Grassian, 1983). It has also been found that among the general population, between 10 and 15% of people have experienced hallucinations at least once (Slade and Bentall, 1989), while studies of college students have found that up to 39% had experienced verbal hallucinations (Barrett and Etheridge, 1992). Romme et al. (1992) report that almost 40% of voice-hearers assessed were not involved with psychiatric services; that is, their auditory hallucinations were not seriously problematic, or were not problematic at all. In addition, large proportions of the general population, with no psychiatric history, endorse delusional-type ideas (Verdoux et al., 1998; Peters et al., 1999; van Os et al., 1999).

Sharing this information with service users and with the general public, as mentioned above, may be valuable for helping to reduce the distress associated

with psychotic experiences, and for reducing the stigma associated with psychosis. In therapeutic practice, normalisation of psychosis may be highly valued by people experiencing psychosis, and psychological therapies such as CBT and alternative therapeutic approaches such as Hearing Voices groups may be particularly well-suited to offer this approach (Newton et al., 2007; Ruddle, Mason, and Wykes, 2011).

1.2.6 Recovery

Focused on re-conceptualising psychoses or schizophrenia in more positive and realistic terms, the 'recovery movement' is developing through the efforts of both mental health professionals and service users. One of the most pervasive and stigmatising beliefs about psychosis or schizophrenia is the idea that these conditions are usually permanent. In fact, evidence shows that half to two-thirds of people diagnosed with schizophrenia and other serious psychological disorders significantly improve or recover (Harding and Zahniser, 1994), while up to 85% of individuals may achieve full remission within 6 months following a first episode of psychosis (Lieberman et al., 1993).

Recovery research to date suggests that professional treatments and interventions that focus on recovery, rather than on pathologising unusual experiences, may be inherently preferable to service users, and therefore that a focus on enhancing holistic recovery (eg., functional and social recovery) may be more likely to encourage engagement with services than interventions focused only on the treatment of positive psychotic symptoms, which are not always prioritised

by service users themselves (Deegan, 2005; Pitt et al., 2007). Indeed it has been suggested that improving vocational outcomes should be a central aim of the recovery process (Birchwood et al., 2007).

Pitt et al. (2007) identified a wide range of psychological, psychosocial, and practical factors important for service users during the process of recovery that include rebuilding the self, rebuilding life, and maintaining or generating hope for the future. Pitt et al. (2007) also report elements of professional care valued or hoped for among service users that enhance recovery and these include more collaborative approaches to care, more continuity in care, protection from harm by professionals, a wider choice of treatment, more emphasis and guidance on recovery, alternatives to the medical model, more service user involvement, and an end to stigma and discrimination. The value of increased collaboration between professional mental health staff and service users in particular has been highlighted in a number of similar studies (O'Toole et al., 2004; Lawn et al., 2007). These findings have been supported by recent quantitative research among a large sample of service users. Beck et al. (2012) found that judgements of recovery in people with psychosis were predicted by mood, optimism and self-esteem, while subjective judgements of recovery were seen to be idiosyncratic, with people appearing to have different thresholds for perceived recovery. Thus, the conclusions of the existing qualitative research and first-person accounts appear generalisable to larger samples.

1.3 Treatment of psychosis

There are numerous evidence-based treatment interventions for people with psychosis, some of which are recommended within national treatment guidelines. These include antipsychotic medication, cognitive behavioural therapy (CBT), and family interventions (FI), which have been shown to offer benefits in symptom reduction, distress reduction, quality of life gains and relapse prevention. These treatments may be most effective when delivered in combination, though in practice medication is offered far more frequently than psychological or family therapies. Recent clinical guidelines recommend informed choice in treatment decision-making, so that service users may judge for themselves the relative benefits, limitations, or potentially harmful effects of the different treatments available (National Institute for Health and Care Excellence, 2013; 2014), and summaries of these factors will be discussed below.

1.3.1 Antipsychotic medication

The primary treatment for psychosis or schizophrenia worldwide is the prescription of antipsychotic medication. In the UK antipsychotics are recommended as a first-line treatment for all individuals experiencing psychosis or given a schizophrenia diagnosis (NICE, 2014). The palliation of the positive symptoms of psychosis conferred by antipsychotic medication is often an effective and welcome intervention for service users (Schizophrenia Commission, 2012). It is, however, also an intervention that often fails to effectively treat the positive symptoms they are designed to diminish (Brown and Herz, 1989; Kingdon et al., 1994; Leucht et al.,

2006; Morrison et al., 2012). This may in part be due to the fact that psychotic phenomena such as hallucinations and delusional beliefs are qualitatively distinct, and not necessarily equally affected by antipsychotics. Nonetheless, recent meta-analyses have demonstrated that antipsychotics are on the whole superior to placebo for treatment of acute psychosis (Thomas et al., 2012), relapse prevention (Leucht et al., 2012), and treatment of schizophrenia (Leucht et al., 2013). It is not yet clear however which antipsychotics work best for which individuals, or to what extent each type is tolerable; for example Tiihonen et al. (2006) examined data from a large national cohort (Finland) of individuals hospitalised with schizophrenia spectrum disorders and found that the effectiveness of prescribed antipsychotics varied greatly. Support for the continued administration of antipsychotics was found in data showing that 'excess mortality' (including suicide) was seen mostly in patients not using antipsychotic drugs (Tiihonen et al., 2006). However wider evidence for the long-term efficacious continuation of antipsychotic medication is neither clear nor conclusive (Schizophrenia Commission, 2012). For example, Wunderink et al. (2013) recently reported findings from a seven-year follow-up of remitted first-episode trial participants. Those assigned to a dose reduction or discontinuation treatment strategy were found to have achieved twice the rate of functional recovery compared with participants assigned to maintenance treatment (ie., continued-dose medication).

Importantly, despite the inconsistent efficacy of antipsychotics described above, service users themselves may derive or at least perceive considerable benefits from these medications. A recent large-scale consultation process in the

UK (the Schizophrenia Commission, 2012) found that antipsychotic medication was

rated by a large majority of respondents (approximately 75%) as the single most

effective treatment for managing psychosis or schizophrenia. It may be important

to note though that antipsychotic medication is also the *only* active treatment

offered to a larger majority of eligible service users. The same report stated that

only around 10% of people who could benefit from the next most popular

treatment (CBT) were actually offered an appropriately delivered CBT intervention

(Schizophrenia Commission, 2012).

The issue of tolerability of antipsychotics, as measured by Tiihonen et al.

(2006; above), is also very important, as these medications are known to be

associated with serious adverse effects, which in themselves may be considered

more harmful than psychotic disorders themselves by service users, and

discontinued for this reason (see eg., Lieberman et al., 2005; discontinuation rates

of 74% over 18 months). Some argue that with the substantial reductions of

duration of untreated psychosis (DUP) now seen in many early psychosis services, it

may be possible that the immediate introduction of antipsychotic medication may

not be necessary for all first episode cases. It may be that safer interventions which

confer fewer serious adverse effects, and which may be more acceptable to many

service users (eg., psychological therapy), could be effective treatments for a

subgroup of patients (Francey et al., 2010). Indeed recent treatment guidelines in

the UK recommend offering service users who are experiencing a first episode of

psychosis the choice to try psychological interventions (family therapy or CBT)

without medication first, though service users should also be informed that these

therapies have been found to be more effective when delivered in conjunction with antipsychotic medication (NICE, 2014).

1.3.1.1 Adverse effects of antipsychotic medication

The risk of experiencing unwanted side-effects when taking antipsychotic medication are well-documented and include disorders of movement which may be permanent, such as tardive dyskinesia, and some which on rare occasions, may be fatal, such as neuroleptic malignant syndrome (NMS) (Tarrier, 2005; Langan et al., 2012). The extent and prevalence of common adverse effects of antipsychotics have been evaluated in increasing detail in recent years (Morrison et al., 2012). For example the risk of unwanted weight gain associated with antipsychotic medication is now well-established (Álvarez-Jiménez et al., 2008; Leucht et al., 2013). A recent meta-analysis found that almost all antipsychotics result in weight gain (Bak et al., 2014). While significant weight gain was commonly observed following prolonged use, it was also more pronounced in medication-naïve individuals (ie., weight gain was seen soon after first administration of antipsychotics) (Bak et al., 2014). The UK-based Schizophrenia Commission (2012) reported that negative impacts on quality of life and physical health from long-term antipsychotic medication including weight gain, diabetes and heart disease, drowsiness, sexual dysfunction, and restlessness were identified by 53% of service user respondents as the key treatment problem they experienced. Such side effects, it was found, often led to abrupt discontinuation of medication and for some individuals, subsequent relapse. It has been established that a significant proportion of all people prescribed

antipsychotic medications for treatment of psychosis or schizophrenia reject them and discontinue their use (eg., 40-74% discontinutation rates reported in Kingdon and Turkington, 1991 and Lieberman et al., 2005, respectively)**.**

Antipsychotics have also increasingly been associated with structural abnormalities in brain volume. Moncrieff and Leo (2010) found evidence that antipsychotic drugs reduce the volume of brain matter and increase ventricular or fluid volume, and concluded that antipsychotics may contribute to the genesis of some of the abnormalities usually attributed to schizophrenia. Similarly, Ho et al. (2011) found that longer duration and greater intensity of antipsychotic treatment was associated with smaller brain tissue volumes, larger cerebrospinal fluid volumes, generalised and specific brain tissue reduction, smaller grey matter volumes, and progressive decrement in white matter volume. More recent studies have similarly identified structural or progressive changes in the brain associated with antipsychotic medication (Fusar-Poli et al., 2013; Torres et al., 2013). A recent study evaluating the relative harm caused to the brain by antipsychotic treatment intensity and duration of relapse in psychosis interestingly found that both factors were related to significant decreases in particular cerebral regions (Andreasen et al., 2013). This study suggests that antipsychotic medications, while conferring negative effects on the brain, may also serve a protective function when administered early in the course of relapse by preventing disorder-related damage. However, this hypothesis has previously been questioned (Moncrieff, 2011), and is not clearly supported by other research into the effects of antipsychotics on the brain. For example Fusar-Poli etal. (2013) observed no similar effects associated

with the duration or severity of psychosis. Andreasen and colleagues conclude that while antipsychotic medication is important for the prevention of acute relapse, it should be prescribed at the lowest possible effective dose (Andreasen et al., 2013). The Schizophrenia Commission (2012) found 'persistent deficiencies' in medication prescribing practices, with too many people prescribed drugs above the maximum prescribing guideline limits, and argued for 'much better' prescribing and for an individual's right to a second opinion on decisions regarding medication (Schizophrenia Commission; 2012). It has also recently been argued that, given the severity of the side effects described above (including cardiovascular and metabolic difficulties), clinicians should offer informed choice in the decision to take such medications or not (Bailey et al., 2012).

1.3.2 Hospitalisation

Psychiatric hospitalisation can be a necessary, valuable intervention for treatment of acute psychosis, and may be valued by many service users as such. However hospitalisation, especially involuntary admission, may be perceived by some service users as a traumatic experience (McGorry et al., 1991), contributing to stigmatisation, dislocation from the community, and an increased likelihood of future hospitalisation and dependence (Kiesler, 1982). Coercive psychiatric treatment including physical restraint or involuntary medication may exacerbate existing trauma, alienate people from seeking treatment, and damage self-esteem (Swartz and Monahan, 2001). Indeed, as mentioned above, coercive or unwanted psychiatric treatment may be experienced as traumatic and lead to the development of post-traumatic stress disorder (PTSD) (Morrison et al., 1999), as

can the experience of psychosis itself (Morrison et al., 2003; Kessler et al., 1995).

Meyer et al. (1999) assessed PTSD symptoms related to psychosis and acute

involuntary hospitalisation among individuals with delusional or schizophrenia-

spectrum disorders and identified PTSD in 11% of participants, with 69% of

traumatic symptoms associated with psychosis and 24% with hospitalisation.

Another study has found that hallucinations and delusions were identified as

traumatic for 60% of individuals with schizophrenia (Kennedy et al., 2002).

It is important however to acknowledge the limitations of the research that

has been conducted in this area. For example, although perceptions of trauma

during psychiatric hospitalisation are common, they may not actually be related to

treatment (Paksarian et al. 2014). Similarly, despite the reciprocal occurrence of

secondary psychosis in PTSD and PTSD in primary psychosis, the assertion that

psychosis itself may directly lead to PTSD (eg., Morrison et al., 2003) is not yet well-

evidenced as empirical data for such associations are sparse (Seedat et al., 2003).

Seedat et al. (2003) note that clinicians often fail to assess trauma exposure and

PTSD symptoms in individuals with serious psychological disorders, and that this

may in part be due to clinician concerns that individuals whose disorders are

characterised by distortions of thought and perception are not capable of rendering

accurate or reliable trauma histories, though evidence suggests that trauma

exposure among such groups tends to be under- rather than over-reported

(Goodman et al., 1999). However, although trauma exposure is well-documented in

people with psychotic disorders, with up to 98% of individuals experiencing at least

one traumatic event in their lifetime (Mueser et al. 1998), accurate trauma rates

have not been adequately determined because of the nosologic, psychometric, and sampling difficulties often present in this population (Rosenberg et al., 2001; Seedat et al., 2003).

The most recent research into associations between psychosis, hospitalisation and trauma present equivocal findings. For example Paksarian et al. (2014) found that 69% of individuals hospitalised with psychotic reported perceived trauma associated with their treatment, though it was unclear how accurate these perceptions were. Interestingly the same study found modest evidence that coercive treatment (eg., forced medication) was associated with reduced time in treatment. Berry et al. (2013) conducted a literature review of the associations between experiences of psychosis, hospitalisation, and PTSD symptoms and concluded that while there is evidence of high rates of PTSD in people with psychosis, the influence that symptoms or hospitalisation have on PTSD is less clear. Across 24 studies reviewed, the prevalence of actual PTSD resulting from treatment-related traumas was inconsistent, varying from 11% to 67% (median 39%). Associations between PTSD and severity of positive and negative symptoms were found to be inconsistent, though there were consistent associations between affective symptoms (anxiety and depression) and PTSD. Finally it was reported that there was evidence that psychosis-related PTSD was associated with trauma history, and some emerging evidence that psychological variables (eg., appraisals and coping style) may influence psychosis-related PTSD (Berry et al., 2013). These findings support earlier research suggesting that post-psychotic PTSD is moderated by levels of affective, behavioural, and cognitive disorder, and that these

comorbidities may in turn have influenced experiences and responses to treatment (Seedat et al., 2003). Meyer et al. (1999) suggest that, in general, psychotic symptoms are more traumatic than coercive measures used to treat them.

1.3.3 Psychological and psychosocial interventions

"Psychosocial treatments have a fundamental place in early treatment, providing a humane basis for continuing care, preventing or resolving secondary consequences of the psychosis, and promoting recovery" (International Early Psychosis Association Writing Group, 2005). Psychological and psychosocial treatments for psychosis include psychological therapy such as CBT (Kingdon and Turkington, 1991), supportive counselling (Lewis et al., 2002), befriending (Sensky et al., 2000), and family and group therapies (Barrowclough and Tarrier, 1992). These interventions aim to reduce the frequency of psychotic symptoms or the distress and disruption associated with them, and may also address associated conditions such as depression, anxiety, or drug or alcohol abuse, and through social and vocational support, may offer significant improvements in quality of life, and social and functional recovery (Lam, 1991; Falloon et al., 1996; Birchwood et al., 1997). The strongest research evidence to date for psychological or psychosocial interventions for psychosis supports individual CBT and family therapy (Burns et al., 2014; Pharoah et al., 2010), and these have been recommended treatments for some time (eg., NICE, 2002; 2014). As FI and other psychosocial treatment approaches are discussed elsewhere in this review, the following section will offer only a brief review of the most commonly delivered psychological treatment (CBT).

1.3.3.1 CBT for psychosis

Individual cognitive behavioural therapy (CBT) has been recommended for the treatment of psychosis and schizophrenia in the UK by the National Institute for Health and Care Excellence (2009; 2013; 2014). Kingdon and Turkington (1991) note that until relatively recently, the prevalent psychiatric approach to treating delusional beliefs common in psychosis, other than noting such beliefs for diagnostic purposes, was essentially to ignore them, and they cite Slater and Roth (1969), who suggested that "it is a waste of time to argue with a paranoid patient about his delusions". However this view has evolved, and indeed a growing number of research trials have now demonstrated the effectiveness of CBT as a treatment for medication-resistant psychosis or schizhophrenia (Kuipers et al., 1998; Turkington et al., 2006), acute psychosis (Drury et al., 1996), and first-episode psychosis (Tarrier et al., 2004). Indeed, several meta-analysis have confirmed this efficacy (Wykes et al., 2008; Bird et al., 2010; Burns et al., 2014). It is worth noting that different meta-analyses suggest that CBT may not be more effective than other psychotherapies (Lynch et al., 2009; Newton-Howes and Wood, 2011), though these have recently been challenged (Hutton and Taylor, 2013). The potential effectiveness of CBT in preventing transition to psychosis has also been shown in several recent meta-analyses of Early Detection trials (Stafford et al., 2013; Hutton and Taylor, 2013).

As CBT for psychosis is a collaborative, flexible, and problem-orientated approach, it often also encompasses treatment of, for example, depression,

anxiety, self-esteem, or social functioning, all of which are regularly found to

prefigure or accompany the onset and development of psychosis (Trower et al.,

1998; Rooke and Birchwood, 1998). As such, CBT treatment often offers a more

holistic intervention than strictly psychiatric treatment, and is often more

acceptable to service users (O'Toole et al., 2004), with greater rates of sustained

engagement. In a recent meta-analysis of 'drop-out' from psychosocial intervention

trials, the average rate of drop-out was just 13% (Villeneuve et al., 2010), which is

significantly lower than rates of discontinuation in trials of antipsychotic medication

(eg., 74% discontinuation reported in Lieberman et al., 2005). A more general set of

pragmatic and humane attributes of CBT for psychosis often identified by service

users themselves reflect the principals of therapeutic engagement originally

outlined by Beck et al. (1979). Describing key elements of CBT provision, Beck

highlighted interpersonal engagement, collaborative development of problem lists,

and establishing goals to be aimed for through therapy, all of which reflect central

elements of expressed preferences of service users with psychosis (eg., O'Toole et

al., 2004; Byrne et al., 2010).

1.3.3.2 Adverse effects of CBT

Empirical evidence shows that psychosocial treatments for psychosis or

schizophrenia are far more acceptable to research trial participants than

pharmaceutical interventions (Villeneuve et al., 2010; Lieberman et al., 2005).

While participants' reasons for discontinuing psychiatric medication are relatively

well-understood (usually due to inefficacy or intolerable side effects), the possible

negative attributes of psychosocial interventions have been less thoroughly

assessed, perhaps owing to an assumption that these are inherently less harmful.

Recent years have seen increasing attention paid to this question. For

example, CONSORT guidelines for the reporting of clinical trials have urged

'completeness, clarity, and transparency of reporting', including adequate recording

and reporting of adverse events occurring during such trials (Schulz et al., 2010).

However, it is argued that there is currently a lack of theoretical concept or

standardised measurement with which to adequately evaluate possible negative

effects of psychotherapeutic interventions (Linden, 2013; Parker et al., 2013).

The most serious negative events that may occur during the course of a

treatment are recorded as Serious Adverse Events (SAE's; eg., severe symptom

exacerbations, suicide attempts, or completed suicide), and examination of these

may offer useful insight into the relative safety of various interventions. While it is

important to distinguish adverse effects directly attributable to a given treatment

from adverse *events* that may or may not be attributable to the treatment, it is also

important to record and report all such effects and events. Klingberg et al. (2012)

examined the frequency and extent of SAE's recorded during a randomised trial of

Cognitive Remediation (CR) compared with CBT for negative symptoms of

schizophrenia. Interestingly, more SAE's were recorded among the CBT group than

the CR group, though the differences were not statistically significant. Such a

finding, though inconclusive, certainly suggests that greater attention should be

paid to the risk of exposing CBT recipients to negative effects that may contribute to

SAE's.

Along with the most serious negative events experienced by individuals receiving CBT for psychosis, researchers are increasingly evaluating less severe adverse effects, as these are also important to understand. As noted above, there is currently a lack of evidence and consensus concerning potential adverse effects of psychotherapy (Linden, 2013; Parker et al., 2013), though evidence elicited from qualitative studies of CBT indicate a number of areas of interest.

At least one participant in an early qualitative study of CBT for psychosis (Messari and Hallam, 2003) found CBT unhelpful ("Umm, there wasn't, I, I, I didn't get any help from it", p176). Although this was a single case, and although inefficacy may not be considered an adverse effect of CBT, inefficacy may contribute to disillusionment with treatment as a whole, and to disengagement.

Studies evaluating both individual and group-based CBT for voice-hearing have reported short-term increases in either general distress or the perceived power of voices during or following CBT sessions. However in both circumstances, for the majority of participants, short-term negative effects reduced or were mitigated by improved coping ability (attributed to CBT). Nonetheless, some individuals may find it more difficult to cope with increased distress if their experience of CBT has not been perceived as effective (Goodliffe et al., 2010; Hayward and Fuller, 2010).

Another qualitative study has explored participants' experiences of case formulation, a common approach utilised in CBT for psychosis (Morberg Pain et al. 2008). Though the process of formulation can be appreciated by CBT clients as enlightening and normalising (Byrne and Morrison, 2013), Morberg Pain and

colleagues (2008) reported that while many participants valued formulation, a significant number experienced negative emotional responses during the process. Although the majority of those individuals reported positive changes over time (after 2-3 weeks: "Certainly, it's not so painful now when I look at it''; p.133), a minority continued to experience a 'change for the worse', and the potential for this finding to be common among those receiving CBT for psychosis should be considered.

It is also important to recognise that for some individuals, delusional beliefs could be constructed to defend aspects of the self from a sense of insecurity or alienation (Bentall et al., 1994; Trower and Chadwick, 1995), and that powerful emotional investment in such beliefs may impede progress in CBT (McGowan et al., 2005). In the context of considering the potential for adverse effects in CBT for psychosis, it is important then to acknowledge that ostensibly positive changes such as reducing participants' conviction in holding beliefs considered to be delusional could in fact cause adverse effects if the loss of protective delusional beliefs led to increased depression, distress, anxiety, or hopelessness. Indeed a recent study found that while generic, non-specific aspects of CBT for psychosis were positively associated with successful therapeutic alliance and change strategies, particular CBT skills such as guided discovery actually had the potential to negatively affect the therapeutic relationship (Wittorf et al., 2013).

1.3.4 Additional and alternative treatment approaches

As discussed above, current mainstream treatments for psychosis or schizophrenia (antipsychotic medication, CBT) are not always effective, and are not always acceptable to service users. A range of alternative and complementary approaches to care have also developed alongside these standard psychiatric treatments. In some cases alternative treatment approaches have arisen directly from evident dissatisfaction with standard care (eg., the Soteria initiative), while others are delivered as supportive adjuncts to routine psychiatric treatment (eg., vocational rehabilitation). A number of the most prominent of these alternative or complementary approaches will be discussed below.

1.3.4.1 Residential alternatives to psychiatric hospitalisation (the 'Soteria' paradigm)

Therapeutic residential alternatives to hospitalisation for people experiencing psychosis or schizophrenia have developed since the 1960s and 1970s, particularly in Europe and North America (Cooper, 1967; Warner, 1995; Burston, 2000). These alternative approaches have arisen as traditional psychiatric inpatient wards have been found to be unpopular with service users (Quirk and Lelliott, 2001; Rose, 2001; Johnson, 2009), and may fail to address individuals' needs, or to provide a safe and therapeutic environment (Muijen, 1999; Barker, 2000; Lloyd-Evans et al., 2009). A key feature of alternative residential treatments lies in addressing psychosis and schizophrenia in non-medicalised ways, treating such experiences instead as important aspects of an individual's life history (Jenner et al., 1993).

Rather than prescribing antipsychotic medication as a first course of treatment, alternative approaches have emphasised the therapeutic value of supporting individuals with psychosis with minimal medical interference (Pullen, 1999). Notable examples of such initiatives have been described in the UK (eg., Cooper, 1967), and in the US, where the 'Soteria paradigm' was developed by Mosher and colleagues (Mosher and Hendrix, 2004). Central features of the Soteria approach include providing small, well-staffed (usually with non-psychiatric staff), community-based residential facilities, adopting a phenomenological relational style which aims to help develop an individual's understanding of their experiences by 'being with' and 'doing with', using low-dose or no antipsychotic medication (according to individual choice), and preserving each person's personal power, social networks, and communal responsibilities (Mosher, 2001; Mosher and Bola, 2004; Calton et al., 2007).

Mosher (1999) argued that the Soteria treatment approach could be as effective as antipsychotic treatment in reducing psychotic symptoms within 6 weeks, and that in a modified form of the approach suited to individuals with longer-term needs, clinical improvements and longer-term social adjustment were similar to those seen in traditional psychiatric inpatient treatment. More recent reviews of the evidence for the effectiveness of the Soteria approach have been less conclusive, though encouraging nonetheless. For example Calton and colleagues (2007) found that there was a lack of high-quality studies from which to draw findings, but that the available evidence suggested that the Soteria paradigm may be as effective as conventional, medication-based mental healthcare, and in

specific areas, may yield specific advantages over conventional treatment, including fewer medication-related adverse effects. A different systematic review of residential alternatives to acute psychiatric hospital treatment (Lloyd-Evans et al., 2009) similarly found that the quality of research was insufficient to provide conclusive evidence for Soteria-type treatment. However from this review of twenty-seven studies, Lloyd-Evans and colleagues concluded that no clinical outcomes from community-based alternatives were worse than those from standard ward-based treatment, and that the few differences that were found tended to show increased effectiveness in the community-based models (Lloyd-Evans et al., 2009). These findings, it is argued, suggest no contraindications for community-based residential crisis services, and that these may provide a feasible, acceptable, and less costly alternative to hospital admission for some people with acute psychological difficulties.

1.3.4.2 Peer support services

Earl of Gloucester: Now, good sir, what are you?

Edgar: A most poor man, made tame to fortune's blows,

Who, by the art of known and feeling sorrows,

Am pregnant to good pity. Give me your hand;

I'll lead you to some biding.

(Shakespeare, King Lear, IV, 6)

Davidson et al. (2012), discussing the history of peer support in mental heathcare,

note the striking early example shown by Jean-Baptiste Pussin (1746–1811) and

Phillipe Pinel (1745 - 1826) in their care of psychiatric inpatients. Pussin, supervising

a hospital in Paris, hired as many staff for the hospital as possible from among

recovered patients; Pinel (a chief physician) described these former patients as

'gentle, honest, and humane', and crucially 'averse from active cruelty' and

'disposed to kindness' toward the patients in their care. This early 'peer support'

approach, it is thought, significantly contributed to the abandonment of more

brutal treatment of inpatients (eg., being held in shackles), and the emergence of

the 'moral treatment' era. Davidson et al. also note a similar approach undertaken

by Harry Stack Sullivan in the US in the 1920s (hiring people who had recovered

from psychotic episodes to staff his inpatient unit) (Davidson et al., 2012).

Contemporary peer support initiatives have flourished in recent years. Having been

widely advocated internationally by service user researchers (Clay et al., 2005;

Deegan, 1996; Faulkner and Basset, 2012) and professional organisations

(Bradstreet and Pratt, 2010; Halvorson and Whitter, 2009; The Royal College of

Psychiatrists, 2009; NICE, 2014), peer support approaches have become well

established within mainstream mental healthcare (Repper and Carter, 2011). There

is no single definition of the aims and roles of peer support services and workers, as

these may vary widely, though various useful descriptions have been offered.

Mead, Hilton, and Curtis (2001) described peer support as "a system of giving and

receiving help founded on key principles of respect, shared responsibility, and

mutual agreement of what is helpful" (p.135). NICE (UK) recently adopted

Solomon's (2004) definition of peer support, which highlights the importance of a

non-coercive and informal approach to offering social, emotional, and instrumental

support, mutually offered or provided by people with mental health conditions to

others with similar conditions to bring about a desired social or personal change

(Solomon, 2004). NICE (2014) highlight the importance of offering informal peer

support as people with psychosis or schizophrenia often find engagement with

standard mental health services difficult and may avoid contact, and suggest that

peers with similar lived experiences may help others to overcome these barriers, as

well as challenging attitudes of clinical staff, and contributing to culture change

within mental health services (Repper and Watson, 2012; NICE, 2011). Peer support

workers may also directly promote hope and self-efficacy through role modelling

(ie., demonstrating recovery) (Salzer and Shear, 2002), and may themselves benefit

from the therapeutic value of helping others (Skovholt, 1974).

Davidson et al. (1999) identified three broad types of organised peer-

provided interventions: mutual support groups in which relationships are reciprocal

in nature; peer-support services in which one or more peer support worker offers

support to one or more participant; and peer worker services where people with

experience of using mental health services are employed by a service to provide

part or all of the service's standard care. The range of functions fulfilled by PSW's

may include offering understanding, acceptance, and empathy, role-modelling,

providing practical information and supporting others in accessing community

facilities, and offering ideas for coping strategies and problem solving (Davidson et

al., 2006, 2012).

Although peer support is seen as a valuable addition or alternative to

professional mental healthcare, empirical evidence for the efficacy of such

approaches is currently inconclusive (Solomon, 2004; NICE, 2014). While Davidson

et al. (1999) found that peer-support self-help groups seemed to improve

individuals' symptoms, quality of life, and social networks, the studies from which

these findings were drawn were largely uncontrolled. Repper and Carter (2011)

reported that only seven relevant randomised control trials met the inclusion

criteria for their review, and that those studies offered inconsistent findings and

used varied outcome measures. Indeed, the wide variety of peer support

programmes for those with psychosis has been noted by NICE in the UK (2014) as a

considerable limitation in large-scale reviews. Nonetheless, recent positive research

findings (eg., Sledge et al., 2011) and continued calls for peer support among

service users prompt further high-quality research, especially in key areas such as

the role of peer support in improving engagement with services, and helping to

reduce hospitalisation, along with improving service users' quality of life through

increased hope, sense of control, self-care, social involvement, and reduced

depression and psychosis (Davidson et al., 2012).

1.3.4.3 Hearing Voices groups

One of the most notable examples of successful peer support for those who

experience phenomena associated with psychosis is the group-based approach to

coping with hearing voices. International organisations and their local chapters such as the Hearing Voices Network (HVN) and Intervoice have become increasingly common over the last 25 years or so. Originally developed by Romme and Escher in 1988, the HVN and other hearing voices groups (HVG) offer voice hearers opportunities to meet others with similar experiences in non-medical, non-stigmatising therapeutic settings, and are often viewed by participants as desirable alternatives to standard disorder-based psychiatric treatment (Davidson, Hammond, and Maguire, 2009; Ruddle, Mason, and Wykes, 2011). HVG are typically run by people with experience of hearing voices alongside a professional clinician, and are thought to provide a 'safe space' for participants to talk about and hear others' experiences of hearing voices. As such experiences are highly stigmatised, HVG may help participants feel understood, and 'normal', and also provide a forum for testing out beliefs and coping strategies, along with other group processes that may enhance wellbeing (eg., helping others, instilling hope) (Yalom and Leszcz, 2005).

There is wide variety in the structure and content of HVG, with many such as those run under the auspices of the HVN offering open, unstructured support groups (Meddings et al., 2006), while others provide more structured contexts for the delivery of CBT, mindfulness, or skills training (Ruddle, Mason, and Wykes, 2011). Early evidence for the effectiveness of unstructured HVG was provided by Pennings and Romme (1997), who reported that those attending HVG found it easier to talk to other voice hearers than non-voice hearers, and that they often accepted their voices more after participating in HVG. In addition, HVG were seen

to help improve coping strategies, reduce the perceived power of voices, and in

adopting a different attitude to voices. Importantly, it was also reported that while

attending HVG was associated with increases in voices hearing for some, these

increases were manageable (Pennings and Romme, 1997). A more recent study by

Meddings et al. (2006) reported statistically significant improvements in

participants' ability to live with and control their voices, along with qualitative

evidence of the social benefits of attending HVG such as reduced isolation,

increased self and social confidence, increased self-esteem, and reduced

hospitalisation. However, as Ruddle, Mason, and Wykes (2011) argue, the scientific

quality of many studies such as those described above is not strong; for example

there have been no controlled evaluations of the HVN or skills-training groups. The

strongest evidence for HVG has been reported for CBT-focused groups, where

findings have been generally positive (Newton et al., 2005; McLeod et al., 2007;

Penn et al., 2005), though inconclusive. Ruddle and colleagues conclude that

though current evidence for the clinical effectiveness of HVG (ie., for reducing

'psychotic' phenomena) is not convincing, it is still clear that HVG do successfully

engage participants in helpful discussion of their experiences, that these

approaches are more often acceptable than standard treatment, and that

successful group contexts share certain key ingredients that help reduce personal

distress, such as providing a safe context for sharing experiences and coping

strategies (Ruddle, Mason, and Wykes, 2011). One of a number of notable

qualitative studies of group CBT identified just such key ingredients (Newton et al.,

2007): safety, normalising, and 'learning from and helping others' were commonly highlighted by participants as important benefits of group attendance.

Ruddle, Mason, and Wykes (2011) suggest that as CBT has become a widely recommended treatment for those with psychosis-related difficulties (including hearing voices), it may be as effective and more cost-effective to offer this approach in groups, and that these may be preferred by service users. Indeed Wykes et al. (2008) found that outcomes from group CBT for schizophrenia were comparable to those for individual CBT. However, the evidence for the effectiveness of HVG in general is not clear, especially with regard to mechanisms of change particular to such group contexts (Ruddle, Mason, and Wykes, 2011).

1.3.4.4 Vocational rehabilitation

The UK-based Schizophrenia Commission recently estimated that the rate of employment for people with psychosis and schizophrenia is around 8%, compared with an employment rate of 71% in the general population (Schizophrenia Commission, 2012). Unemployment is thought to be the largest contributor to indirect costs of psychotic disorders (Wu et al., 2005; Carr, Lewin, and Neil, 2002; Killackey, Jackson, and McGorry, 2008). Negative effects of unemployment are well-evidenced and have been associated with increased general health problems including the development of mental health problems (Warr and Jackson, 1987; Warner, 1994), reduced self-esteem and increased psychosomatic symptoms (Paul and Moser, 2009), social isolation (Rinaldi et al., 2008), increased risk of suicide (Stuckler et al., 2011) and premature death (Smith, 1985). For those with

mental health difficulties who do work, the benefits of being employed may

include, along with usually receiving wages, positive changes in self-identity,

improved quality of life and reduced symptoms (Arns and Linney, 1995; Bond,

2001a; Mueser et al., 1997; Van Dongen, 1996; 1998), and enhanced general

recovery (Repper and Perkins, 2003). A recent study of employment among people

with early psychosis reported significant differences between those with and

without employment, suggesting underlying reasons for these differences, along

with a number of positive associations between employment and mental health

(Drake et al., 2013). Drake and colleagues found that 'workers' had better

educational and employment histories, were more likely to have substance-induced

psychoses but less likely to have drug dependence, and had fewer negative

symptoms and better psychosocial adjustment. Over the two-year study period,

workers used fewer medications and mental health services, and received fewer

disability or welfare payments (Drake et al., 2013).

However, despite the strength of evidence showing that work may confer

significant benefits for people with psychosis and schizophrenia (Schizophrenia

Commission, 2012; The Work Foundation, 2013), the likelihood of employment for

these groups remains extremely low (NICE, 2014). It has been suggested that this

may be caused in part by negative, pessimistic attitudes among some mental health

professionals leading to reduced aspirations for service users and the subsequent

provision of services (Hansson et al., 2013). In addition, problems for some service

users with cognitive impairment (Wexler and Bell, 2005), along with the wider

prevalence of societal stigma and discrimination, negative effects of diagnostic

labelling, lack of skills among professionals for implementing employment support, and fear among service users of loss of benefit payments, have also been found to contribute to the problem of low employment (Marwaha and Johnson, 2004; The Work Foundation, 2013; NICE, 2014).

The effectiveness of initiatives to help those with serious mental health problems find or return to work (vocational rehabilitation) has been reviewed in depth in recent years. Traditionally, approaches such as sheltered work schemes have been assumed to help people develop the skills and confidence necessary to move forward into paid employment, but such schemes may not be effective and may actually lead individuals to believe that they are only capable of working in a sheltered environment (Rinaldi et al., 2008). More assertive, evidence-based approaches known collectively as 'individual placement and support' (IPS) or supported employment have now been developed, and have been shown to be more effective than traditional vocational rehabilitation in helping people gain and sustain employment (Crowther et al., 2001; Twamley, Jeste, and Lehman, 2003; Rinaldi et al., 2008; NICE, 2014). For example, Killackey, Jackson, and McGorry (2008) evaluated the effectiveness of IPS with an early psychosis group, and found that along with promoting significantly better outcomes on level of employment, hours worked per week, jobs acquired, and longevity of employment, the IPS intervention also significantly reduced reliance on welfare benefits (as with the 'workers' in Drake and colleagues' 2013 study above). Killackey et al. conclude that the IPS (supported employment) approach has the potential to effectively improve

vocational outcome for people with first-episode psychosis, as it has for those with longer-term difficulties.

1.4 Early Detection and Intervention for psychosis

There is a growing literature regarding the rationale for, and effectiveness of, early intervention for psychosis and the possibility of early detection and prevention of psychosis. These will be considered below.

1.4.1 Early Intervention for psychosis

As outlined above, the biomedical illness model approach to schizophrenia has dominated our understanding of psychosis for the last century, and so identification and treatment of psychosis or schizophrenia have traditionally been focused on acute stages of psychosis, treatment-resistant positive symptoms and long-term interventions (Birchwood et al., 1997). McGorry (1995) argues that best-practice treatment for such later stages of psychotic disorders may not constitute best practice for early psychosis. The early stages of psychosis and stages of psychological disturbance that may pre-figure the onset of a first episode have only recently received significant attention in research and clinical practice, despite having been advocated more than 80 years ago (Sullivan, 1927; Cameron, 1938).

The most frequently cited rationale for increased provision of Early Detection (ED) and Early Intervention (EI) strategies for psychosis is evidence for the relationship between the length of time for which an individual experiences

psychosis before being identified as psychotic (duration of untreated psychosis, or DUP), and the early and long-term course of their condition (Johnstone et al., 1986; Loebel et al., 1992; Marshall et al., 2005). For example, Johnstone et al. (1986) reported that for individuals with a DUP greater than a year, there was a threefold increase in their rate of relapse during the following two years, while Loebel et al. (1992) found that following a first episode, the time to remission of the psychotic episode and the degree of remission were closely related to DUP.

Considerable delays before receiving effective treatment are common, and as treatments for well-established psychosis or schizophrenia are often limited in their success and only palliative in nature (McGlashan and Johannessen, 1996), lengthy DUP and late treatment reduce an individual's chances of a timely and full recovery (Loebel et al., 1992). Birchwood and MacMillan (1993) have described a 'critical period' following a first episode of psychosis within which vulnerability to relapse and the potential for disabling development of psychosis are greatest. It is within this critical period within the first two to three years after onset that Early Intervention practitioners aim to offer effective and holistic treatment and support.

An additional rationale for early treatment of first episode psychosis is the heightened risk for suicide following a first-episode (Jablensky, 1995). Birchwood et al. (1993) suggests that this may be due in particular to a sense of entrapment (perceiving oneself as trapped in a psychotic condition), loss of valued social goals and roles, and loss of social status. It has been found that the risk of suicide following a first episode of psychosis is greatest within the first 6 years (two-thirds

of suicides will have taken place within this time-frame) (Westermeyer et al., 1991;

Mortensen and Juel, 1993).

In contrast with chronic or long-term psychoses or schizophrenia, the first

episode is considered to be a highly treatment-responsive phase (Lieberman et al.,

1993), and indeed in the UK, the Department of Health (1999) recommended and

invested in the development of 50 EI teams, developing another 200 during a

secondary phase. The National Institute for Health and Care Excellence (NICE) has

issued guidelines for treating first episode psychosis that include timely referral to

secondary mental health services and the provision of specialist interventions

(pharmacological, psychological, social, occupational and educational) (NICE, 2002;

2009; 2013; 2014). Current evidence for the value of specialist EI services indicates

that they can achieve improved engagement, reduced relapse rates, and better

social relationships and vocational recovery (Petersen et al., 2005). For people with

early psychosis, early intervention services appear to have clinically important

benefits over standard care; delivery of CBT and family interventions within such

services have been shown to contribute to improved outcomes including reduced

hospital admission, relapse rates and symptom severity, and improved access to

and engagement with treatment (Bird et al., 2010). Quantitative and qualitative

research has also shown that early intervention services are highly valued by service

users and engage users effectively after 12 months (Lester et al., 2009; NICE, 2014).

Although evidence for the effectiveness of EI services remains positive, and

the EI approach continues to be recommended (Marshall and Rathbone, 2011;

Nordentoft et al., 2013; NICE, 2014), the most recent substantial reviews of EI offer

more equivocal conclusions than earlier reports. For example, while the most

recent Cochrane review of EI treatment recognises evidential support for EI

services, it suggests that further, more conclusive trial research would be desirable,

and it questions whether initial clinical gains are maintained after EI involvement

(Marshall and Rathbone, 2011). Similarly, Nordentoft et al. (2013) conclude that

while the evidence available supports the continued recommendation of

specialised EI, this evidence needs to be strengthened through replication in high-

quality trials. NICE continue to recommend EI for psychosis services in the UK

(2014), though the most recent NICE guideline acknowledges that it is not yet well

known which individuals or groups benefit most from EI treatment. As with

Marshall and Rathbone (2011), the NICE guideline also suggests that initial gains

may be diminished when EI clients leave those services, and all three of the reviews

described here recommend extending EI treatment periods or conducting research

to evaluate the benefits of extending treatment. Evidence for the cost-effectiveness

of the EI approach is more clear (Hastrup et al., 2013). Recent analyses demonstrate

significant cost savings associated with EI services in reduced treatment costs

(Mihalopoulos et al., 2009), reduced length of hospital admissions (McCrone et al.,

2013), and improved employment and reduced suicides (Park et al., 2014).

1.4.2 Early Detection of psychosis

The early identification and treatment of people considered to be at risk of

developing psychosis has become a viable and desirable focus for research and

clinical practice (Falloon, 1992; Yung et al., 1996; French and Morrison, 2004).

Identification is achieved through assessment of sub-clinical or brief, limited psychotic symptoms in help-seeking individuals, or through identification of help-seeking close relatives of people with established psychosis. Yung et al. (1996) found that approximately 40% of individuals identified as being at high risk of experiencing a first episode of psychosis will make transition without early clinical intervention. However, recent meta-analyses have suggested that transition rates may not be as high as previously reported (18% of identified at risk individuals after 6 months of follow-up, rising to 36% after 3 years; Fusar-Poli et al., 2012).

Offering treatment or care aimed at preventing transition to psychosis, or to minimise the impact of onset if it should occur (reducing DUP, treating psychological difficulties quickly), Early Detection (ED) services have now been established in a number of centres (eg., Melbourne, Manchester). ED interventions have offered at risk clients either antipsychotic medication alone (McGlashan et al., 2006), medication and cognitive-behavioural therapy (McGorry et al., 2002), or cognitive therapy alone (Morrison et al., 2004). Evidence for these three approaches showed that cognitive behaviour therapy (CBT) alone offered the most effective treatment for at risk clients, significantly reducing the likelihood of transition to psychosis at 12 months (with a 6-month course of CBT) (Morrison et al., 2004). Data from across ED studies suggests that CBT is also the most acceptable treatment for at risk individuals (shown by comparison of 'drop-out rates' for the three study types cited). Several recent trials have confirmed the benefits of CBT for prevention of psychosis (van der Gaag et al., 2012; Bechdolf et al., 2012), as have several meta-analyses (Stafford et al., 2013; Hutton and Taylor,

2013), though the effectiveness of CBT for ED has not been consistently shown (Morrison et al., 2012).

1.4.3 Potential adverse effects of Early Detection and Intervention

Ethical concerns regarding ED for psychosis centre on the risk of conferring harm by involving individuals with mental health services unnecessarily (Warner, 2005), or potentially stigmatising or inappropriately treating service users, especially those 'false positive' individuals who would not go on to develop full psychosis without intervention. However, as Falloon et al. (1996, p280) argue, the risks of failing to offer any professional help to those seeking it or of delaying treatment are well documented and can be seen as "an indictment of the laissez-faire attitudes of many psychiatric services", where professionals have ignored the expressed needs of service users and their families. In addition, recent research has shown that provision of CBT for people at risk of psychosis decreases internalised stigma, rather than increasing it (Morrison et al., 2013).

McGorry et al. (2008) highlight the establishment of effective operational criteria for identification of those at risk of psychosis (Yung et al., 2006; Yung et al., 1996) and argues that all clients identified are seeking professional help, with a strongly predicted risk of psychosis, and a need for immediate clinical care. Along with particular psychosis-like experiences such as hallucinations or delusional thinking, conditions including anxiety and depression frequently accompany the onset of early psychotic phenomena (French and Morrison, 2004), as do a wide range of other personal and practical difficulties (drug or alcohol abuse, the effects

of traumas, self-harm, poverty, homelessness, interpersonal stressors). Therefore, even 'false positive' clients may benefit significantly from the age- and stage-appropriate professional care offered by ED services. Suicide risk is also high in people at high risk of developing psychosis, which further suggests that they are an important group to prioritise (Hutton et al., 2011).

Specific treatments delivered by ED services can include both pharmacological and psychosocial interventions, or a psychosocial intervention alone. The ethical concerns regarding the prescription of antipsychotics for treatment of a first-episode of psychosis apply equally to treatment of at risk individuals (Bentall and Morrison, 2002). Falloon et al. (1996) suggest that the use of antipsychotic medication with those at risk of psychosis may not be justified when only nonspecific symptoms of psychosis are present and before accurate diagnosis, and if prescribed, should be administered to supplement and support the psychosocial management. Treatment guidelines in the UK state that antipsychotics should not be used to prevent psychosis (NICE, 2013).

1.5 Qualitative research and subjective experiences of psychosis

Three of the five studies included in this body of research utilised qualitative research methods as a means to explore areas of interest where few similar studies have done so previously. The background and rationale for this approach will be discussed below.

1.5.1 Overview

Subjective first-person accounts of lived experiences of psychosis or schizophrenia are the most direct source of evidence of the nature of such conditions; psychiatric diagnoses are fundamentally based on an individual's subjective description of their psychotic experiences or 'symptoms'. Strauss and Carpenter (1981) argued that detailing subjective experience is a cornerstone of clinical enquiry, particularly valuable to hypothesis development. Despite this, there have been relatively few substantial studies of psychosis based on qualitative research methods**.**

Qualitative research conducted with service users has increasingly been advocated to inform the provision of mental health services and the conduct of research trials (Powell et al., 1996; Morrison and Bentall, 2003; Geekie, 2004), and it has been suggested that "experiential evidence is essential for a service evaluation to be meaningful and complete" (O'Toole et al., 2004, p320). The British Psychological Society (2000) have recommended that service users should be acknowledged as experts on their own experiences and that "services must respect each individual's understanding of their own experiences" (p58). Among service users themselves, increased conduct of qualitative research is commonly called for as it is considered to offer a more respectful pathway for inclusion in research participation than other types of research routinely offer (May, 2007).

Conduct of qualitative research may improve researchers' understanding of how subjective and socio-cultural perspectives shape an individual's psychological experiences (Wilkinson et al., 2004, p39). This can help to enrich exploration of differing perspectives held by different individuals, along with improved

understanding of the ways in which individuals make sense of their experience, and

the processes used to shape meaning from experience (Geekie, 2004; Charmaz,

2006). In addition, the conduct of qualitative research can empower research

participants through their involvement as partners in the research process, and this

may be the only genuine way to accurately explore individual experiences

(Davidson, 2003).

1.5.2 Qualitative studies exploring Early Intervention for psychosis

Qualitative studies in this area have focused most often on experiences of Early

Intervention services, for example by evaluating treatment preferences or valued

outcomes of treatment (O'Toole et al., 2004; Theuma et al., 2007). It is important

that we also improve our understanding of the subjective experiences of early

psychosis itself along with early or developing at risk states (Yung and McGorry,

1996; Møller and Husby, 2000; Hardy et al., 2009) in order to examine such issues in

greater detail. Huber (1995) argues that 'precursor syndromes' in the prodromal

phase of psychosis are characterised by dynamic and cognitive basic deficiencies,

experiential rather than behavioural in nature, and typically only recognisable by

self-report. While qualitative interviews have demonstrated that many young

people value many aspects of EI services, a significant minority reported that the

sustained engagement based on the assertive outreach approach was overly

intensive and intrusive (Lester et al., 2011).

1.5.2.1 Qualitative research in Early Detection for psychosis

Hardy et al. (2009) conducted the first qualitative study with at-risk individuals, providing valuable insight into participants' journey into and through an Early Detection service. This study identified three central themes in participants' accounts: their perceptions of the need for help and identification of help-seeking priorities; participants' subjective journey; and their orientation to the future. Hardy et al. (2009) also found that young people at-risk of developing psychosis often found it difficult to make sense of and talk about their experiences, and this may have led to delayed help-seeking (consistent with Møller and Husby, 2000). Therefore, improved qualitative understanding of at-risk individuals' experiences and concerns will be important to facilitate successful help-seeking, early referral to specialist services, and recovery.

1.5.3 Qualitative research into CBT for psychosis

A recent review of the qualitative literature on this topic reported eight such studies (Berry and Hayward, 2011), with five studies of individual CBT, and three studies of group-based interventions. Of those that focused on individual CBTp, two focused on very specific aspects: homework (Dunn et al., 2002) and formulation (Morberg-Pain et al., 2008). A qualitative study (Messari and Hallam, 2003) that interviewed 5 service users who received individual CBT for psychosis (CBTp) about their experience identified several central themes from their analysis of clients' experiences, including: 'CBT as an educational process', 'CBT as a respectful relationship between equals', and 'CBT as a healing process'. Another study

interviewed 8 service users and 4 practitioners, and focused more directly on factors that affect outcomes of CBTp, with both users' and therapists' accounts describing both deficits and skills, with a central theme of 'understanding, holding and engaging with the therapist's model of reality' (McGowan et al., 2005).

Of the three studies exploring group-based CBT, Abba et al. (2007) examined a mindfulness-based approach, and found that the group therapy was experienced primarily as a process of learning to relate differently to difficult psychotic experiences. Goodliffe et al. (2010) investigated experiences of group CBT for distressing voices, and summarised their qualitative findings in two thematic areas; the role of the group context for reflection and change, and the acceptance of voices and self, and the changing sense of self. Newton et al. (2007) also reported qualitative findings from a study of group CBT for young people hearing voices, and found that voices groups were appreciated by the young participants as sources as effective therapy, information, and support, with safety, normalising, and 'learning from and helping others' highlighted as valued attributes of the group context. Newton et al. (2007) also suggested that such groups may have helped the young people to moderate their beliefs about hearing voices, which in turn may affect coping strategies and the young people's emotional reactions to hearing voices. Findings from these two latter studies share important common features with qualitative research into other hearing voices groups (HVG). The perceived safety (or safe space) provided by such groups has been consistently reported as a valued feature of such groups, as has normalisation (Martin, 2000; Jones, Hughes, and Ormrod, 2001; Morland, 2004). As Ruddle, Mason, and Wykes (2011) argue, group-

based approaches to delivering structured interventions such as CBT or
unstructured support may be more acceptable to service users than standard
treatment, and offer context-specific factors that can effectively reduce personal
distress (for example, providing a safe context for sharing experiences and coping
strategies).

1.5.4 An overview of qualitative methods

There are a variety of methods for the collection and analysis of qualitative data
from interviews with participants. The selection of specific research methods is
dependent upon the research question, the epistemological stance of the
researcher and pragmatic issues such as resource limitations. Common approaches
include thematic analysis, interpretative phenomenological analysis and grounded
theory. Each of these approaches has a number of advantages and disadvantages.

Thematic analysis (TA) is used to search for repeated or significant patterns
in the data that emerges from qualitative interviews. The 6-phase thematic analysis
procedure described by Braun and Clarke (2006) involves becoming familiar with
the data through transcription, active repeated reading of transcripts, and note-
taking. Manual, inductive 'data-driven' coding is then performed, where all
potentially meaningful responses to the research questions are noted. Following
basic organisation of all coded data extracts, the potential emerging themes are
noted and refined. These initial themes and selected coded data extracts are
collated into a 'thematic map' (for visual organisation). Review and refinement of
suggested themes then involves naming, re-naming, collapsing or expanding

specific themes until there is confidence that candidate themes, sub-themes and codes form coherent patterns and are accurate representations of the data set as a whole.

Interpretative Phenomenological Analysis (IPA) methodology is often chosen to evaluate people's experiences and perceptions. IPA uses a 'double hermeneutic', which refers to the two way interpretative process of this methodology. Investigators have an active role in aiming to make sense of the participant trying to make sense of their world, and to obtain an 'insider perspective'; a core concept of IPA is that the analyst should become immersed in the data (Smith et al., 2009). Given the potential for bias in this process, awareness of the researcher's own biases during analysis is important. The analysis involves an iterative process of repeated reading of interview transcripts, extraction of themes, discussion between researchers and comparisons across transcripts. As researcher interpretation of data is the central analytical mechanism in IPA research, it is important to recognise this as a possible disadvantage; that the emphasis placed on interpretation could lead to unfounded conjecture of topics or themes not well-grounded in the available data.

Grounded theory (GT) is considered most useful when applied as an exploratory methodology used to generate understanding of a topic directly from participants' perspectives and experiences, "collecting and analyzing qualitative data to construct theories 'grounded' in the data themselves" (Charmaz, 2006, p.2). This approach aims to avoid imposing researchers' pre-existing aims or biases on the interpretation of participants' experience through an iterative process designed

to identify categories and concepts within text that are then linked into formal theoretical models (Corbin and Strauss, 2008). A key feature of GT is the flexible nature of interview schedule or topic guide design, where data collection and analysis is carried out simultaneously throughout the study so that new areas of interest suggested by participants' narratives may be further explored in subsequent interviews (Strauss and Corbin, 1998). Data analysis in GT methodology is usually undertaken through a constant-comparison method, where units of text are reviewed as they are collected, with ongoing memo-writing and coding leading to the re-iterative creation of emergent codes and themes until data collection is complete (Guest et al., 2013). GT methodology however may be limited where the sampling of participants interviewed is constrained by practical considerations. For example, while qualitative researchers are often encouraged to employ purposive or theoretical sampling to increase the scope of data exposed, including deviant cases (Lincoln and Guba, 1985), recruitment and sampling for a GT study may be limited considerably where potential participants comprise a small, finite group (service users at a specific service, for example). Nonetheless, GT may still be the most appropriate methodology for a new study in an area with a lack of existing research.

Another research methodology that may be described as a qualitative approach to assess opinion and establish consensus about particular issues is the Delphi method. The Delphi method is a systematic, interactive method which relies on a group of independent experts or representatives answering questionnaires in two or more rounds, with feedback from each round provided to help achieve

consensus. The process is stopped after a pre-defined stop criterion is reached, such as the number of rounds. Several studies have used the Delphi method to seek expert consensus in various domains of treatment for people with psychosis or schizophrenia (Fiander and Burns, 1998; Burns et al., 2000; Marshall et al., 2004; Langlands, et al., 2008; Morrison and Barratt, 2010). The majority of such studies have included only professional participants (such as psychiatrists or psychological therapists), though Langlands and colleagues also invited service users and carers to contribute to their study, which aimed to develop consensus regarding mental health first aid (Langlands et al., 2008). This is an important development, since surveys or Delphi studies designed and completed only by professionals are likely to exclude elements of treatment that are important from a service user perspective. For example, Fiander and Burns (1998) failed to ask their psychiatrist participants to rate the relative importance of pharmacotherapy in the treatment of schizophrenia. The most substantial disadvantage of using the Delphi method perhaps lies in the limitation described above; although the approach aims and claims to represent expert consensus, Delphi researchers may be constrained by practical barriers to recruiting or including an appropriately broad, or appropriately specific participant group.

1.6 Service user involvement in mental health research

While those with lived experience of mental health difficulties and treatment have traditionally been the subjects of research in this area, with little say in the nature and conduct of such research, increasing efforts have been made to include people

with lived experience in the development, design, and practice of research and clinical service provision. The following two sections will outline some important factors in the rationale, background and practice of service user involvement.

1.6.1 Background and rationale for service user involvement

Rush (2004) argues that through the history of mental health services, service users have been perceived in various different ways, from being dangerous and irrational, to being considered equal partners with mental health professionals. It is through this variety of perceptions that an unresolved tension has arisen, which Rush suggests will only be resolved with acknowledgement of conflicts between perspectives and open dialogue to explore these. While these are essentially political aspects of the general picture of service user involvement, in more particular terms, and locally, service user involvement aims to help improve the delivery of services and conduct of research, both for the benefit of other service users, and to help improve the quality and validity of service provision and research.

"Consulting service users is of utmost importance when developing mental health services" (Agar-Jacomb and Read, 2009, p109). In the UK, mental health services must now involve service-users in the planning and delivery of their care (National Service Framework, Department of Health, 1999). It is recommended that professionals should work in partnership with service users, offering care in an atmosphere of hope and optimism (National Institute for Health and Care Excellence, 2002). Many would argue however that current user involvement still

falls far short of an ideal level of inclusion (eg., Hansen et al., 2004). Although there

is now an increasing expectation, even at governmental level, for service users to

be offered opportunities to be actively involved in all aspects of their own care,

there has still been little exploration of the extent to which this expectation has

been realised (Lammers and Happell, 2003).

The British Psychological Society (2000, p.58) recommends that "service

users should be acknowledged as experts on their own experiences" and that

"services must respect each individual's understanding of their own experiences",

and that users' self-reporting should be central in the move towards evidence-

based practice (Faulkner and Thomas, 2002). Morrison et al. (2004) argue that

service-user defined outcomes should be included and measured in future trials of

interventions for at-risk (of psychosis) clients. Similarly the International Early

Psychosis Association (IEPA) suggests that clients or family members with recent

experience of early psychosis should be encouraged to participate in the

development and monitoring of early psychosis services (IEPA Writing Group,

2005). Tee et al. (2007) suggest that service user participation in the clinical practice

decisions of mental health nurses is considered essential for good practice, by

helping staff to develop reflective and reflexive ability so as to avoid disempowering

professional practices, or practices that may even harm users' recovery.

1.6.2 The role of the user-researcher

Those with lived experience of mental health problems have increasingly been

acknowledged as experts by experience, with valuable knowledge of living with

such problems and of using mental health services (May, 2001; Chief Medical Officer (UK), 2001; Rose et al., 2006). It has also been acknowledged that service users and mental health professionals often have very different perspectives and priorities (Lindow, 1999; Bailey et al., 2012). Therefore those with lived experience may contribute significantly to the relevance of research designs and strategies by ensuring the questions being asked by researchers are meaningful, helping to choose appropriate outcome measures, enriching other researchers' understanding of psychological difficulties, and preserving a focus on the meaning of the research to participants. They may additionally help to improve recruitment to research, elicit more open responses from participants, and offer new insight in the interpretation and dissemination of results (Staley and Minogue, 2006; Szmukler, 2009; Sweeney and Morgan, 2009; Gillard et al., 2010). It is further suggested that user-researchers may be more interested in conducting research related to empowerment and functioning in everyday life (Rose et al., 2003; Trivedi and Wykes, 2002), and that they may bring an ecological or 'real world' validity to research (Faulkner and Thomas, 2002).

Considering the highly subjective and idiosyncratic qualities of psychosis, qualitative researchers in this area should ensure that research questions and interview schedules are unbiased and attempt to learn from service users' own experiences and insight into the effectiveness of professional treatment. User-led research in particular may offer essential contributions in this domain (Geekie and Read, 2009). Service users often report that only those with similar types of experience can truly understand their perspective (eg., Hardy et al., 2009). It has

been suggested that user-led interviews for example gain a more accurate picture of services and experiences (Rose, 2001), and this may be enhanced by ensuring that service users are included in the design of research. The involvement of user-researchers can change the focus of a study (including both design and content), with users raising new research questions, ensuring interventions are kept 'user friendly' and influencing the selection of outcome measures (Trivedi and Wykes, 2002). It has also been shown that clients are willing to report being less satisfied with services when interviewed by users (Simpson and House, 2002), which should facilitate more accurate and reliable feedback about such issues.

When working in the field, interacting directly with research participants, user-researchers may offer a valuable and personal experience during the research process (Powell et al., 1996; Lammers and Happell, 2003). Pitt et al. (2007) argue that "service users need more access to other people's stories of recovery. This can be inspiring and a great source of hope" (p.23). A recent study by Bengtsson-Tops and Svensson (2010) explored the role of user-researchers conducting qualitative research, and found that being interviewed by user-researchers in a research project was experienced as both giving and receiving a sense of empowerment, and that interviews, through a mutual sharing of experiences, led to feelings of reciprocity and trust. Rose (2001) reported that participants in user-led interviews visibly relaxed and opened up once they realised the interviewer had 'been through the system' and understood their own situation. These non-specific aspects of engagement may be important for the disclosure of private and sensitive information (Riphahn and Serfling, 2005). For example, enhanced openness and

trust could improve the validity of research findings (Kvale and Brinkmann, 2006). It has been suggested that in line with a social distance model, people tend to disclose more honestly and in greater detail to people with whom they share similarities and with whom they feel emotionally comfortable (Catania et al., 1996). User-researchers may also elicit more critical feedback than non-user interviewers when investigating participant satisfaction with their treatment (Clark et al., 1999; Simpson and House, 2002; Gillard and Stacey, 2005). It seems clear that being interviewed by a user-researcher can be a positive experience, however it is worth noting that being interviewed by another user may also generate feelings of insecurity (Bengtsson-Tops and Svensson, 2010).

Some research has indicated differences in the ways in which service user and conventional researchers analyse qualitative interviews. User researchers may be more likely to code interview transcripts in terms of interviewees' experiences and feelings, while conventional researchers may code the same transcripts largely in terms of processes and procedures related to treatment (Gillard et al., 2010).

1.7 Service users' priorities and preferences for treatment of psychosis

To provide the most effective, helpful and acceptable treatment for psychosis, it is increasingly argued that service users themselves should be consulted to determine the treatment outcomes they themselves prioritise and the elements of treatment they find most helpful. This may be particularly important because there are often significant differences in the priorities of service users and the professionals treating them (Crane-Ross et al., 2000; Hansen et al., 2004).

As described above, a wide range of lived experiences and psychological difficulties are consistently found to influence the emergence and maintenance of psychosis. For example, very difficult or traumatic childhood experiences are often reported by service users (Read et al., 2005), as are negative self-concepts and poor self-esteem (Bentall, 2003). Psychosocial factors rather than psychopathological symptoms may affect service users' subjective quality of life (Ritsner et al., 2000), and sociocultural conditions (such as financial, educational, or vocational status, or geographical location) appear to influence the long-term course of psychotic experiences (Harrison et al., 2001).

When eliciting service users' own preferences and priorities for treatment and outcome, it will be important to recognise that for many, addressing any of the factors mentioned above may be as or more important to them than seeking reductions in positive psychotic symptoms (Haaster et al., 1994). This reinforces the need to give greater consideration to service users' individual needs, and to their own priorities and preferences when conducting research and providing professional help.

There is a lack of published research, and especially qualitative research, specifically concerned with eliciting service users' own priorities and preferences. It is also evident that service users receiving different types of treatment may express differing priorities based on the parameters of their treatment experience. For example, within qualitative studies conducted primarily in terms of a biomedical approach (eg., Forchuk et al., 2003), service users may more often express priorities reflecting this approach; that is, primarily identifying outcome priorities that include

improvements in positive psychotic symptoms or continued effectiveness of

pharmaceutical treatment. In contrast, service users treated with more holistic

interventions more often express outcome priorities that include, for example,

improved social and functional ability, improved housing or financial status (eg.,

Lawn et al., 2007). A detailed review of qualitative research exploring service user

preferences and priorities for treatment delivery and valued outcomes will follow in

Chapter 2.

1.8 Summary and rationale for this thesis

Recent developments in the understanding and treatment of psychosis have

included an increased recognition of the value of psychological approaches to

treatment, and to early detection and intervention treatment strategies. These are

both relatively new areas for research and empirical studies can offer only limited

understanding of how these approaches might be experienced and perceived by

research participants or mental health service users. It is important to explore the

experiences of those at the 'receiving end' of therapeutic interventions or research

participation as individuals' perceptions and preferences related to these may

determine their willingness to engage with such processes, and may influence

relevant clinical outcomes. In an assessment of psychological treatment, for

example, while large-scale quantitative research methods such as clinical trials may

elicit evidence of effectiveness, they may not explain *why* the treatment was

effective, or why it wasn't. Qualitative research on the other hand is well suited to

the study of process, rather than outcome alone (Rubin and Rubin, 1995), as it aims

to improve understanding of lived experience of a treatment (Elliott et al., 1999; Hammersley, 1992; Medical Research Council, 2000). Conduct of qualitative research also recognises the value of participant perspectives in evaluations of mental health services (Department of Health, 1999; 2005). As O'Toole et al. (2004) argue, "experiential evidence is essential for a service evaluation to be meaningful and complete" (p320).

Recent years have seen increasing recognition of the need to consult with service users to determine their individual priorities for treatment (eg., Schizophrenia Commission, 2012), and their subjective experiences of research trials (Morrison and Bentall, 2003). The use of qualitative methodology may enhance the degree to which participants are included as partners in these processes, especially through acknowledgement of participants' status as experts through lived experience (Davidson and Heinrichs, 2003). The methodological flexibility inherent in qualitative methods (reflexive, hypothesis-generation) may also be particularly useful when exploring research areas that are not yet well understood (Britten et al., 1995). Qualitative methods may be the most effective way to investigate particular questions in psychotherapy, for example (McLeod, 2000), and qualitative research into CBT for psychosis has been acknowledged as an important priority for the enrichment of existing evidence (Thornicroft et al., 2002).

As Jones et al. (2001) suggest, research participants or service users may have unique knowledge of what does or does not work in such treatments, and qualitative methods may be particularly useful for gaining insight into factors such as the therapeutic alliance, engagement with treatment, and the motivation

involved in undertaking difficult homework tasks (Bevan et al., 2010). While the types of quantitative self-report measures traditionally used in psychosis or therapy research may provide very useful information to inform clinical outcome measurement, they may not be sufficient to adequately explore these areas of treatment, or the factors prioritised by individual participants, and they may fail to discover new and important aspects of participants' experience as the questions asked in such measures tend to be fixed and standardised. In contrast, qualitative methods are often inherently flexible, with open-ended questioning employed to explore participants' views naturalistically, and this may allow important new or unforeseen areas of interest to be uncovered (Denzin and Lincoln, 2000; Asher and Gask, 2010).

1.9 Aims and objectives of this thesis

The preceding literature review has offered an introduction to the background research literature for understanding and treatment of psychosis and qualitative research into psychosis and CBT, along with the rationale for the studies conducted within this thesis. Subsequent chapters will report these studies in detail. Each of the five studies conducted will be presented in their published or pre-publication format. The aims of the five studies are as follows:

Study 1 aimed to summarise current qualitative evidence about service users' priorities and preferences for overall outcomes and treatment processes for psychosis. A narrative review and qualitative synthesis of the literature regarding priorities and preferences will be described.

Study 2 aimed to assess the relative priorities and preferences for mental health service treatment among people with experience of psychosis using a Delphi method.

Study 3 aimed to explore subjective experiences of young people included in an Early Detection for Psychosis clinical service, and interpersonal experiences in particular, such as interpersonal problems prior to seeking help, and interpersonal dimensions of their experiences of therapy (CBT). A qualitative Grounded Theory (GT) study will be described. As this study was conducted in a new research area with very little existing qualitative research evidence, it was considered appropriate to employ GT methodology to allow for the data-grounded generation of new theoretical avenues in this area (Glaser and Strauss, 1967). GT was also considered an apt methodology as the study was to be user-led; as Grounded Theory methodology facilitates a social constructivist approach through which a researchers' observations and involvement in data generation and collection play a part in shaping the process and the findings of the research (Charmaz, 1990), it may be particularly well-suited to facilitating a user-led approach to exploring and reporting participants' experiences.

Study 4 aimed to explore experiences of CBT for psychosis; in particular, non-specific aspects of psychological therapy were explored (such as interpersonal dimensions). A qualitative Interpretive Phenomenological Analysis (IPA), will be described. IPA was considered a suitable methodological approach for this study as it prioritises gaining an 'insider perspective' of individual participants' experiences and the meaning they ascribe to these (Smith and Osborn, 2003). It was hoped that

as the study and all interviews were to be user-led, the likelihood of successfully

eliciting and understanding participants' perceptions of CBT from their point of

view would be enhanced (Rose, 2001). Similarly, it was hoped that an IPA approach,

where researchers acknowledge the active role they play in the interpretation and

analysis of data, would be well-suited to a user-led evaluation given the increased

likelihood of shared understanding of psychological distress and mental health

service use (including CBT) between user-researchers and participants.

Study 5 aimed to elicit participants' perceptions of both the control and treatment

arms of a randomised clinical trial of specialised CBT for the prevention of

psychosis. A qualitative study of subjective experiences of involvement in the trial

using a Thematic Analysis (TA) approach will be described. TA was selected for this

study as the two-arm clinical trial context of interviews was likely to require a

broad, semantic-level analysis of findings and an analytic approach that would

facilitate the identification of areas of thematic consistency across multiple

interviews, for which TA may be more suitable than alternative qualitative

methodologies (Boyatzis, 1998). Similarly, it was intended that interview data

would be analysed with an inductive, data-driven approach to reflect as directly as

possible the expressed perceptions of participants' trial involvement, and TA

methodology is also considered particularly well-suited for this aim (Frith and

Gleeson, 2004).

Chapter 2: Priorities and preferences for the outcomes of treatment of

psychosis: A service user perspective

Priorities and preferences for the outcomes of treatment of psychosis: A service user perspective

Rory Byrne*[a,b], Linda Davies[b] and Anthony P. Morrison[a,b]

a Greater Manchester West NHS Foundation Trust, Manchester, UK;
b University of Manchester, Manchester, UK
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2.1 Abstract

Background: It is increasingly argued that mental health service users should be

consulted to determine the outcomes of treatment they prioritise, and the

elements of treatment they find most helpful. Qualitative research may allow for

more complete explorations and expressions of service users' own perceptions of

this topic.

Aim: To summarise current qualitative evidence about service users' priorities and

preferences for treatment of psychosis and overall outcomes.

Methods: Narrative literature review methods were used to identify qualitative

research to obtain service user personal priorities and preferences for valued

outcomes in relation to treatment of psychosis.

Results: A notable finding was that qualitative evidence about the priorities and

preferences directly identified by service users was remarkably scarce. The most

relevant articles found presented several central outcome priorities and treatment

preferences. Priorities for treatment outcomes included improved social and functional ability and satisfaction, and reduced symptomatology. Treatment preferences included person-centred, collaborative approaches to care and for adjuncts or alternatives to the traditional medical model of psychosis (eg., psychological therapy or psychosocial interventions).

Conclusions: The implications of these findings are considered for research and practice.

Keywords: qualitative, psychosis, outcome priorities, treatment preferences

2.2 Background

Treatment for psychosis: Service users' priorities and preferences

To provide the most effective, helpful and acceptable treatment for psychosis, it is increasingly argued that service users themselves should be consulted to determine the treatment outcomes they themselves prioritise and the elements of treatment they find most helpful. This may be particularly important because there are often significant differences in the priorities of service users and the professionals treating them (eg., Crane-Ross et al., 2000; Hansen et al., 2004).

Traditional biomedical approaches to psychosis have been concerned primarily with positive psychotic symptoms and biopharmaceutical treatment as central to research into and treatment of psychosis (Lieberman, 1998). This traditional understanding is increasingly being challenged, both by mental health professionals, and by service users themselves. Although positive symptoms of psychosis may be distressing for many service users seeking treatment, positive

symptoms are not always distressing and are not always the primary concern of all service users (Anthony, 1993; Foulds, 2006; Kelly and Gamble, 2005; Brundtland/World Health Organisation, 2000).

A wide range of lived experiences and psychological difficulties (eg., depression, anxiety) are consistently found to influence the emergence and maintenance of psychosis. For example, very difficult or traumatic childhood experiences are often reported by service users (Read et al., 2005), as are negative self-concepts and poor self-esteem (eg. Bentall, 2003). Psychosocial factors rather than psychopathological symptoms may affect service users' subjective quality of life (Ritsner et al., 2000), and sociocultural conditions (such as financial, educational, or vocational status, or geographical location) appear to influence the long-term course of psychotic experiences (Harrison et al., 2001).

When eliciting service users' own preferences and priorities for treatment and outcome, it will be important to recognise that, for many, addressing any of the factors mentioned above may be as or more important to them than seeking reductions in positive psychotic symptoms (Haaster et al., 1994; Klein et al., 2007). Service users may need help with anxiety or depression, or drug or alcohol problems, financial deprivation or homelessness, before they can engage meaningfully with treatment aimed specifically at reducing positive symptoms (French and Morrison, 2004; Maslow, 1968). This reinforces the need to give greater consideration to service users' individual needs, and to their own priorities and preferences when conducting research and providing professional help.

Conducting qualitative research may be particularly important for such evaluations, especially considering the highly subjective and idiosyncratic nature of service users' priorities and preferences for treatments and outcomes. Qualitative research conducted with service users has increasingly been advocated to inform the provision of mental health services and the conduct of research trials (Geekie and Read, 2009; Powell et al., 1996). Importantly, qualitative research may offer service users valuable opportunities to express their concerns in their own terms, rather than within the pre-defined parameters of a professional appraisal (May, 2007).

2.3 Method

The objective of this review is to identify qualitative research that evaluates service users' priorities for outcomes and preferences for professional interventions in treatment for psychosis. Studies published in a refereed journal, including qualitative service user feedback concerning treatment or outcome priorities or preferences for treatment of psychosis, experience of treatments for psychosis, or experience of recovery from psychosis were included in this review. Studies were excluded if they were not published in a refereed journal, if they did not use qualitative methodology, or if they were not concerned with direct service user feedback or involvement, priorities or preferences for treatment or outcome for psychosis. The PubMed and PsycInfo electronic databases were searched using the following terms: (psychosis OR schizophrenia) AND (treatment OR outcome) AND (priorities OR preferences OR experience OR recovery) AND (qualitative OR

subjective). In addition, reference lists from included articles were also searched for further relevant studies. Approximately 300 titles were identified. Studies that were judged to meet inclusion criteria were obtained and reviewed, and studies considered likely to meet inclusion criteria were also obtained (39 studies were assessed in full). Eight studies were included in the final review: Forchuk et al., 2003; Lawn et al., 2007; O'Toole et al., 2004; Phillips and McCann, 2007; Pitt et al., 2007; Rogers et al., 2003; Shepherd et al., 1995; Theuma et al., 2007.

2.4 Results

2.4.2 Outcome priorities and valued outcomes of people with psychosis

Perhaps the most notable finding in this literature review is the *lack* of published qualitative research specifically concerned with eliciting service users' own priorities and preferences for psychosis treatment and treatment outcomes (that is, no studies were identified that solely focused on user priorities and preferences). The eight articles that were included for review were, instead, primarily focused on experiences of treatment interventions for psychosis (Lawn et al., 2007; O'Toole et al., 2004; Phillips and McCann, 2007; Rogers et al., 2003; Shepherd et al., 1995; Theuma et al., 2007), and experiences of recovery from psychosis (Forchuk et al., 2003; Pitt et al., 2007). From these studies, participants' expressed outcome priorities for treatment were identified and are shown in Table 1.

Table 1. Outcome priorities and valued outcomes of people with psychosis

Treatment outcome priority	Reported by study
Improved social activity and inclusion	Forchuk et al., Lawn et al., O'Toole et al., Phillips & McCann, Pitt et al.
Improved functional ability/'participation in life'	Lawn et al., O'Toole et al., Pitt et al., Rogers et al.
Improved self-management/control/coping ability/self-efficacy (related to psychotic symptoms)	Lawn et al., O'Toole et al., Phillips & McCann, Rogers et al.
Effective professional treatment of hallucinations & delusions (including medication & monitoring)	Forchuk et al., O'Toole et al., Shepherd et al.
Independence (including from services)	Lawn et al., O'Toole et al., Rogers et al.
Self-confidence	Lawn et al., O'Toole et al., Rogers et al.
Improved understanding (of psychosis/of self/from others)	Lawn et al., O'Toole et al., Pitt et al., Theuma et al.
Empowerment	Lawn et al., Pitt et al.
Improved thinking and sleeping	Forchuk et al.
Reduced depression & mood problems	Forchuk et al.
Regained dignity and achievement	Lawn et al.
Increased hopefulness	Lawn et al., Pitt et al.
Increased structure (of daily life)	O'Toole et al.
Improved physical health	Shepherd et al.

It is evident that service users receiving different types of treatment may express differing priorities based on the parameters of their treatment experience. For example, it was noted that within studies conducted primarily in terms of a biomedical approach (eg., Forchuk et al., 2003), service users expressed priorities reflecting this approach primarily expressing outcome priorities that include improvements in positive symptoms or continued effectiveness of pharmaceutical treatment. In contrast, service users treated with more holistic interventions more often express outcome priorities that include, for example, improved social and functional ability, improved housing or financial status (eg., Lawn et al., 2007).

The most common finding was that service users prioritised social and functional outcomes and social support and practical help more than they prioritised the treatment and monitoring of positive psychotic symptoms (Lawn et al., 2007; O'Toole et al., 2004; Phillips and McCann, 2007; Rogers et al., 2003; Shepherd et al., 1995). Pitt et al. (2007) argue that the medical approach, relying primarily on pharmacological interventions, can be seen as limiting and disempowering because it does not address the wider personal, psychological and social dimensions central to the broader conceptualisation of recovery from psychosis. Pitt et al. (2007) highlight the importance of service users developing coping skills to manage and live with symptoms, rather than focusing on their complete eradication.

In the study reported by Rogers et al. (2003), participants' valued outcomes included increased self-efficacy, greater autonomy and confidence, empowerment, increased sense of control, and improved coping strategies. Similarly, the participants of Lawn et al. (2007) valued outcomes such as improvements in confidence, dignity, practical self-management, and achievement. For Shepherd et al. (1995), participants placed greater emphasis on outcome priorities concerned with practical issues (eg., housing, finance) than psychiatric treatment, highlighting potential significant differences between professional and service user priorities. O'Toole et al. (2004) identified valued outcomes of treatment such as increased independence and increased confidence, which was "coupled with a reduction or elimination of psychotic symptoms". Theuma et al. (2007) reported valued outcomes as including being understood and not being stigmatised.

Forchuk et al. (2003) report qualitative findings regarding service users'
experiences of recovery from psychosis. In contrast to similar studies where
participants highlighted a wide range of issues, their participants discussed
concerns primarily focused around their psychotic symptoms, and around
pharmaceutical treatment.

2.4.3 Preferences for treatment of psychosis

All of the included studies reported data describing participants' preferences for
treatment or valued experiences of treatment. In all cases, these reports related
directly to participants' hoped-for or experienced outcome priorities (eg., "to
establish specific elements seen as effective to help inform future service planning
and provision"; O'Toole et al., 2004; p319).

Throughout the literature reviewed, service users expressed preferences for
collaborative treatment approaches that offered opportunities for communication
and partnership in decision-making with mental health professionals (Lawn et al.,
2007; O'Toole et al. 2004; Phillips and McCann, 2007; Pitt et al., 2007; Rogers et al.,
2003; Theuma et al., 2007). These aspects were explicitly preferred to previous
experiences of traditional biopharmaceutical treatment based on the
predispositions of professionals (eg., O'Toole et al., 2004; Rogers et al., 2003).
Similarly, service users often highlighted the importance of greater prominence and
value to be given to their own active role during treatment and through the
recovery process (eg., Rogers et al., 2003; Lawn et al., 2007).

O'Toole et al. describe key elements in the recovery process identified by service users, and first among these is the "human approach" offered by particular professionals, along with being involved in treatment decisions. Additional preferred elements of treatment identified included flexibility of appointments, high nurse to patient ratio, and personalised care and attention. Rogers et al. (2003) found that their participants prioritised and valued communication and contact with the researchers involved, and that positive experiences of helpful communication and contact were "formulated and compared with more usual contact with psychiatric services". Phillips and McCann (2007) focused on service users' experiences and perceptions of the role of Community Mental Health Nurses (CMHN) in providing care, and found that service users considered interactions with CMHN's to have therapeutic value, with emphasis given to the value of these relationships as a forum where both clinical and psychosocial issues could be addressed, and where service users felt they had opportunities to influence the delivery of their care.

Pitt et al. (2007) found that service users prioritised the importance of more individualised recovery care plans, along with continuity of care, access to stories of recovery and encouragement, and greater choice in treatment approaches. The participants in the study by Lawn et al. (2007) valued opportunities to share their experiences and relieve burdens while working with professionals. Valued outcomes of this preferred treatment process included participants feeling more empowered to become an equal partner and expert in the management of their health: "I always thought the doctor and social worker knew everything and that

my opinions weren't important. After being asked these questions, I feel I can talk better about my illness and more openly now with my key worker. It would have been good to have been asked these questions years ago when I first got unwell" (p.70). Similarly, Theuma et al. (2007) reported that people valued a collaborative, non-stigmatising approach: "For them to understand what I was going through and having someone to talk about it" (p.125).

2.5 Discussion

Although there has been an increased emphasis on incorporating service users' preferences into the development of treatment interventions and clinical decision making (Shepherd et al., 1995), there is still an evident scarcity of research literature from which to elicit service users' expressed preferences and priorities. This lack of qualitative research specifically concerned with users' priorities and preferences, and the general dearth of other relevant literature from which to extrapolate such concerns, fundamentally limits our understanding of key elements of mental health service provision. We do not know, for example, if or how users' preferences and priorities may be related to particular treatment models they have experienced, or how they may change over time or across cultures. Continued reliance on predominantly professional evaluations of treatment needs and outcome priorities will remain an ineffective basis for providing the most effective and acceptable treatments, without a substantial and meaningful recognition of users' own priorities and preferences. Our findings are consistent with the literature regarding recovery from psychosis, which suggests that highlighting

concepts of recovery and resilience shift clinicians' attention away from disease processes and onto the whole person in the life context (Deegan and Drake, 2006), addressing the wider personal, psychological and social dimensions, which can include the negative impact of using mental health services, experiences of stigma and discrimination, social networks, unemployment, and ability to participate equally in society (Pitt et al., 2007).

The present study identified a very small number of relevant research articles. The central limitation of both the existing evidence and the present review is, therefore, a lack of qualitative evidence for service users' priorities and preferences for treatment of psychosis. The studies identified and reviewed for the present study focused on a range of topics (eg., recovery, experience of services or research trials) and had a range of different objectives. This made it difficult to directly compare and evaluate users' specific priorities and preferences. Of note is the indication that the priorities and preferences expressed differed according to the treatment experiences of participants, and the objectives of the research. For example, the participants interviewed by Forchuk et al. (2003) discussed concerns primarily focused around their psychotic symptoms and pharmaceutical treatment, which may have been influenced by the priorities of the fourth author, a marketing consultant for Johnson&Johnson.

The literature reviewed suggests that positive impacts on symptomatology, social and vocational functioning, self-efficacy and self-esteem are all enhanced with more collaborative and psychosocial treatment approaches that respect the individual's right to be involved in treatment decisions and care-planning. As noted

above, users' priorities are often different from those of professionals, and among themselves (as members of heterogeneous populations) service users will often express differing personal priorities and preferences. It is also important to recognise that users' priorities may change over time. For example, as acute psychotic symptoms are reduced, other concerns may rise to the top of an individual's agenda for professional treatment or support. Future research and clinical practice, it is hoped, will recognise these concerns and endeavour to consult service users more regularly and consistently to evaluate their priorities and preferences for treatment of psychosis (especially in light of an evident collective failure to do so previously). It would be possible to focus clinical service provision more specifically on outcomes that are valued by service users if outcome measures were chosen to reflect this; for example, using measures of recovery (e.g. Neil et al., 2009) rather than more traditional symptom-focused assessments.

User-led research, in particular, may offer essential contributions (Geekie and Read, 2009). It has been suggested that user-led interviews, for example, gain a more accurate picture of services and experiences (Rose, 2001), and this may be enhanced by ensuring that service users are included in the design of research. Importantly, user-researchers may also offer personal insight and positive interpersonal experiences for participants they work with. Pitt et al. (2007, p23) argue that "service users need more access to other people's stories of recovery. This can be inspiring and a great source of hope".

Chapter3: Service users' priorities and preferences for treatment of psychosis: A user-led Delphi study

Service Users' Priorities and Preferences for Treatment of Psychosis:

A User-Led Delphi Study

Rory Byrne, B.Sc.

Anthony P Morrison, Clin.Sci.D

The authors are with the Department of Psychology, Greater Manchester West Mental Health National Health Service Foundation Trust, Prestwich, Manchester, United Kingdom (e mail: rory.byrne@gmw.nhs.uk).

3.1 Abstract

Objective: Service users may have different priorities and preferences for treatment compared with mental health professionals. Few studies have explored these potentially important differences. This study sought consensus from a sample of service users regarding priorities and preferences for treatment of psychosis.

Method: A three-stage Delphi study exploring treatment priorities and preferences was conducted with a sample of mental health service users ("experts by experience"). After generation of an initial statement list (stage 1; n=6 participants), sixty-four diverse elements of mental health treatment were rated during a two-stage online survey process (stage 2, n=32; stage 3, n=21).

Results: Fifteen of sixty-four treatment-related statements were endorsed as important or essential treatment priorities or preferences by more than 80% of participants during stage 2. Two further statements were similarly endorsed during stage 3.

Conclusion: This study is among the first of its kind and highlights the importance of assessing individual treatment priorities.

3.2 Introduction

Recent UK government initiatives affirm that the perspectives and preferences of service-users should play an important part in mental health decision making (Department of Health, 1999; National Institute for Health and Care Excellence, 2014). However, people seeking help for psychosis- or schizophrenia-associated difficulties may find that their personal priorities and preferences differ from those of clinicians or that these factors are not adequately considered (Greenwood et al., 2010).

Clinicians and researchers in this field have primarily focused on the positive symptoms of psychosis (such as hearing voices or experiencing paranoia), and antipsychotic medication is often the only active treatment offered (Warner et al., 2006). While antipsychotic medication is helpful for some, it is ineffective for others, and is associated with significant adverse effects which may outweigh perceived benefits and lead to discontinuation (Lieberman et al., 2005; Bailey et al., 2012). It has been suggested that there is an excessive reliance on antipsychotic medication in the treatment of schizophrenia and related disorders, and that there

is "little or no choice offered to service users who meet criteria for such diagnoses, despite policies that actively promote patient-led care, collaborative decision-making and provision of choice" (Morrison et al., 2012, p.83).

Although there is a need, therefore, to consider service users' priorities and choice of treatment, research assessing these factors is limited. A number of studies have compared the priorities of service users, caregivers, and mental health professionals (eg., Fischer et al., 2002; Shumway et al., 2003), and have reported differences between these groups. Differences between individual service users have also been found in ratings of treatment priorities and preferences (Rosenheck et al., 2005), although the most recent research in this area suggests it may be possible to identify areas of consensus among a large group of service users (Sterk et al., 2013).

Several studies have used the Delphi method to seek expert consensus regarding treatment for psychosis or schizophrenia (Langlands et al., 2008; Morrison and Barratt, 2010). However such studies tend to include only professional participants such as psychiatrists or psychologists, who may not prioritize elements of treatment that are important from a service user perspective. This study aimed to address this potential source of research bias by conducting a user-led Delphi method evaluation of user-defined treatment outcome priorities and treatment preferences.

3.3 Methods

Delphi-method studies are consensus-seeking surveys of expert opinion, often conducted in three stages (Langlands et al., 2008). We sought to recruit a sample of individuals with experience of receiving treatment for psychosis or schizophrenia ("experts by experience") to complete a Delphi method survey examining treatment priorities and preferences. Appropriate ethical approvals were gained from local university and National Health Service research ethics committees. During the first stage of the study, a literature search was conducted to identify treatment factors of potential importance to service users. Relevant research surveyed included quantitative studies of service users' treatment priorities and preferences, and qualitative studies of service users' experiences of treatment and recovery. A diverse range of treatment factors were identified and listed until 'thematic sufficiency' was achieved (ie., until no new items were identified). These items (n=77) were listed in a numbered series of statements (for example, "It is most important for me to get help with depression") alongside a Likert rating scale (1, essential, to 5, not required). This statement list was then sent to members of a local Service User Reference Group for consultation (n=6, each with experience of treatment for psychosis or schizophrenia). Following group rating and discussion, 13 items were removed from the statement list, and a final statement list comprising 64 items was organized into four sections: current treatment priorities, long-term priorities, treatment preferences, and additional treatment preferences.

The second and third stages of the study were conducted online between January and August, 2012, and recruitment was achieved with the help of the

Rethink Mental Illness charity, which advertised the study through e-mail and online social networks (eg., Facebook, Twitter). Online study material consisted of a participant information sheet and a consent form, along with the four-part statement list and accompanying Likert rating scale. Before they could progress to the survey section, participants were required to complete the consent form (online "tickbox" format), and were asked to provide an e-mail address to which we could send the next stage of the survey. Among the 32 stage 2 participants, 50% were female and 59% were between the ages of 20 and 39. Among the 21 stage 3 participants, 45% were female and 55% were between the ages of 20 and 39. Race-ethnicity was not recorded for this study. Participant characteristics are shown in Appendix 1 (p.284).

At the prespecified end date for completion of stage 2 of the study, responses were analyzed by calculating percentages for the group (n=32 participants). Statements rated as 'essential' or 'important' by at least 80% of participants were included in a final statement list. Statements rated as essential or important by between 70% and 79% of participants were included in the stage 3 survey for rerating. Statements that did not meet either of these conditions were excluded. Participants were then e-mailed a direct link to the stage 3 survey Web page. The same rating criteria as above were used to analyze stage 3 responses (n=21 participants).

3.4 Results

Sixty-four treatment-related statements were generated during stage 1. During

stage 2 of the study, fifteen of these items were rated essential or important by at

least 80% of participants and included in the final statement set. Twelve statements

were rated essential or important by 70-79% of participants and re-rated at stage 3,

after which two additional statements were included in the final statement set

(Table 2). Participants' ratings for these statements and for statements not included

in the final set are shown in Appendices 2 and 3 (p.286 and 287).

Table 2. Statements about treatment priorities and preferences endorsed by service users in a Delphi study

Statement	Stage included
What I most want help with	
Feeling paranoid	2
Stress	2
Anxiety or feeling nervous	2
Feeling confused or unable to control my thoughts	2
Concentration or memory problems	2
What I want for the long term	
Understand my psychological problems	2
Learn to cope with ongoing "unusual psychological experiences"	2
Improve my emotional well-being	2
Improve my energy and motivation	2
Feel better about myself	2
Improve my concentration and memory	2
Remain out of the hospital (for my mental health issues)	3
What I would prefer when I receive mental health help	
Offer help based on my individual problems (rather than help based on a clinical diagnosis)	2
Inform me about different types of help available	2
Allow me to play a part in making decisions about what kind of help is best for me	2
What I prefer when meeting with mental health staff	
In private (between myself and staff)	3
Offer help that's appropriate for different age groups	2

Strong consensus was noted for particular treatment factors in a number of areas. The most frequently endorsed current treatment priorities included paranoia, stress and anxiety, confusion and concentration/memory. Long-term priorities included improved understanding (of mental health), coping ability, emotional well-being, and staying out of the hospital. Frequently endorsed treatment preferences included individualized care and collaborative decision making, greater information and treatment choice, privacy (when meeting with mental health staff), and age-appropriate care.

3.5 Discussion and conclusions

There are few existing studies with which to compare our findings, and it is difficult to compare these directly as methodologies in this topic area vary. Nonetheless it is worth highlighting a number of general similarities. Rosenheck et al. (2005) reported that among a large sample (n=1,200) of individuals with schizophrenia diagnoses, the most common treatment priority was reducing confusion (Rosenheck et al., 2005), which is echoed in this study, as it is in a number of studies in this area (Sterk et al., 2013; de Haan et al., 2001). Fischer (2002) found that service users and their family members more often prioritized social support, housing and medical services, compared with service providers. Shumway et al. (2003) found that across groups of service providers, users, policy makers, and family members, participants valued social and functional improvements more than reductions in psychotic symptom. Although our participants prioritized social and

functional improvements less clearly, they prioritized treatment of psychotic symptoms less frequently than more general psychological and emotional improvements (such as reduced confusion and stress and improved understanding).

The clearest limitation of this study was our small sample size, because analysis of data drawn from a larger sample may have enabled the identification of differences between groups of participants. In addition, online social network-based recruitment may have excluded some potential participants. People with psychosis or schizophrenia may be economically disadvantaged (Lester et al., 2011) and therefore may not have private access to the internet, whereas older people may be less likely to access social-networking media in general. It is also possible that some people in our target population may not have been comfortable participating in this kind of study over the Internet. The option to request paper copies of study materials was offered in our advertising information in order to reduce the risk of excluding potential participants, but none were requested. The validity of our results is also limited by the inclusion of several participants who identified as having primary diagnoses other than psychosis or schizophrenia (for example, bipolar disorder). Control of inclusion was limited by the open-access nature of our recruitment strategy. This could be addressed in similar studies conducted online with more effectively targeted recruitment strategies. It may also have been desirable to collect more detailed information about participants' current difficulties and self-defined recovery status, as treatment priorities may change over time.

Our results identify a number of commonly valued treatment priorities, suggesting these as important areas for clinical attention (eg., confusion, anxiety,

and stress). The most highly valued treatment preferences we identified reflect a desire for more information, choice, and collaboration in treatment decision making, suggesting that participants are not routinely satisfied in these areas. It is also worth noting that among the survey items most frequently endorsed as unnecessary, the use of medical terminology and attending appointments at mental health service premises were identified, suggesting that some aspects of routine psychiatric care may not be considered helpful by service users.

The relatively low levels of group consensus for many elements of treatment reinforce the need to evaluate the individual's personal priorities in clinical practice. It is reasonable to suggest that greater concordance between an individual's priorities and preferences and the treatment he or she is offered will enhance continued engagement. As Bailey and colleagues suggest in a recent article addressing the risks of general medical illness among people with serious mental health problems, especially those prescribed antipsychotic medication, "it is perhaps now worth reflecting on what might most trouble the young person facing you in the consulting room - the weight gain or the reduction in mental health symptoms" (Bailey et al., 2012., p376)**.**

3.6 Acknowledgements and disclosures

Chapter 4: Young people at risk of psychosis: a user-led exploration of interpersonal relationships and communication of psychological difficulties

Young people at risk of psychosis: a user-led exploration of interpersonal relationships and communication of psychological difficulties

Rory Byrne and Anthony P. Morrison

4.1 Abstract

Aim: The aim of the present study was to qualitatively explore experiences and perceptions of interpersonal relationships and interpersonal communication among young people at risk of psychosis.

Method: Semi-structured interviews were conducted using a qualitative grounded theory approach. Participants had entered into a service providing psychological interventions for young people assessed to be at a high risk of developing psychosis (Northwest UK). Our sample comprised one female and seven male participants (n = 8), ranging in age from 16 to 28 years, with a mean age of 22.4 years.

Results: Analyses identified three central themes: difficulty with interpersonal relationships and reduced opportunities for helpful communication, difficulty talking to others about psychological problems, and experiences of talking to others about psychological problems.

Conclusions: Individuals at risk of psychosis may have experienced significant difficulties with interpersonal relationships. Such difficulties may contribute directly to the development of unusual psychological experiences, and to an inability or

reluctance to communicate these to others. In addition, commonly held

stigmatizing ideas associated with unusual psychological experiences may

contribute to a fear among at-risk individuals that they are 'going mad', and this

may lead to concealment of their difficulties, and to delayed help-seeking. For at-

risk individuals, helpful communication of psychological distress offers significant

benefits, including improved psychological and emotional wellbeing and reduced

risk of psychosis. Thus, while concealment of distress may directly impact on the

development of unusual psychological difficulties, communication of such

difficulties may be central to recovery.

Key words: at-risk mental state, interpersonal relationships, prodrome, psychosis.

4.2 Introduction

Recently established approaches to the treatment of psychosis focusing on Early

Intervention (EI) and Early Detection (ED) aim to offer timely help for those

experiencing a first psychotic episode, or to intervene a stage earlier, identifying

people *at high risk* of experiencing psychosis and offering interventions aimed at

preventing the first episode, or reducing the impact of onset if it should occur

(Falloon, 1992; Birchwood, 1992; McGorry, 1995; Yung et al., 1996; French and

Morrison, 2004).

The identification of people considered to be at high risk of developing

psychosis has been pioneered by Yung, McGorry and colleagues in Melbourne

(McGorry et al., 1996). Defining operational criteria for such identification has

centred around three pathways considered to most accurately identify an 'at risk'

mental state. Firstly, experience of attenuated, sub-clinical positive psychotic

symptoms, present at least once a week during the month prior to assessment;

secondly, experience of transient psychotic symptoms (Brief Limited Intermittent

Psychotic Symptoms (BLIPS) lasting less than 1 week and resolving without

treatment); or thirdly, vulnerability defined by first degree relation to a family

member with a diagnosis of psychosis or schizophrenia, along with a recent

deterioration in functioning, or previous diagnosis of schizotypal personality

disorder.

Yung et al. (2003) found that approximately 40% of individuals identified as

being at high risk of experiencing a first episode of psychosis made transition within

12 months. Early Interventions aimed at preventing or delaying transition to

psychosis have now been offered at a small number of sites internationally. These

interventions have offered at-risk clients either antipsychotic medication alone

(McGlashan et al., 2003), medication and cognitive-behavioural therapy (McGorry

et al., 2002), or cognitive therapy (CT) alone (Morrison et al., 2004). It is important

to note that the three treatment types described here reflect research-based

interventions; 'real-world' clinical services for the at-risk population may be based

on any of these. Evidence available to date suggests that CT alone may offer the

most effective treatment for at-risk clients, significantly reducing the likelihood of

transition to psychosis at 12 months (with a 6-month course of CT). Data from these

studies suggests that CT is the most acceptable treatment for at-risk individuals

themselves, having a noticeably lower dropout rate.

The cognitive-behavioural approach to treatment of at-risk individuals described by French and Morrison (2004) suggests that the initial onset of psychotic symptoms seems to be related to an inability to generate alternative (more acceptable) explanations for unusual experiences, frequently because of a lack of trusting or supportive relationships that would facilitate the normalization of such interpretations. Unfortunately, the onset of mental health problems often leads to increased social withdrawal and isolation (Repper and Perkins, 2003) reducing opportunities for helpful communication of distress. In addition, widely held stigmatizing ideas about mental health problems may contribute to at-risk individuals' reluctance to disclose their worries to others or to seek professional help (fearing negative reactions from others, unwanted professional interventions, or involuntary hospitalization or medication, for example).

It is important that we improve our understanding of the subjective experiences of at-risk individuals in order to examine such issues in greater detail (Yung and McGorry, 1996; Møller and Husby, 2000; Hardy et al., 2009). Qualitative research conducted with service users has increasingly been advocated to inform the provision of mental health services and the conduct of research trials (Powell et al., 1996; Morrison and Bentall, 2003; Geekie, 2004). Importantly, conduct of qualitative research may offer service users valuable opportunities to express their concerns in their own terms, which, it can be argued, is a more respectful approach than trying to fit each person's experiences into a diagnostic category (May, 2007).

User-led research, in particular, may offer essential contributions. Service users' own priorities and preferences often differ from those of mental health

professionals (Shumway et al. 2003; Rosenheck et al., 2005), and it has been suggested that user-led interviews, for example, gain a more accurate picture of services and experiences (Rose, 2001). Importantly, user-researchers may offer personal insight and positive interpersonal experiences for participants they work with. Pitt et al. (2007) argue that "service users need more access to other people's stories of recovery. This can be inspiring and a great source of hope" (p23). With these considerations in mind, the present study was conducted as a user-led qualitative exploration of at-risk individuals' social relationships and communication, or concealment, of their psychological difficulties.

4.3 Method

A qualitative method was used to explore participants' experiences and perceptions of social relationships and communication or concealment of psychological difficulties. A grounded theory (GT) approach was used to best facilitate user-led data collection and theory generation. GT methodology, developed by Glaser and Strauss (1967) aims to facilitate the generation of new theories, rather than basing new research on existing theories, through interviews and analyses which 'ground' emerging theories and hypotheses in a foundation of rich qualitative data. Charmaz highlighted a 'social constructivism' that aims to further enrich GT methodology, whereby researchers' observation of and involvement in the data collection shape both the 'process and product throughout the research' (Charmaz, 1990)**.** This approach allows for theory generation and empowers participants in giving voice to

their experiences, so that any theory developing from the research can be said to

be grounded in the participants' perspective.

4.3.1 Participants

There were eight participants interviewed: seven male and one female.

Participants' ages ranged from 16 to 28 (mean age was 22.4 years). All participants

were white British. Participants were recruited through an Early Detection and

Intervention Team service in the UK. Clients who had entered this service were all

seeking help and had met criteria for inclusion through one of three assessment

pathways, as measured by the Comprehensive Assessment of At Risk Mental States

(Yung et al., 2006): experience of attenuated positive psychotic symptoms

(experienced at least once per week in the month prior to assessment); following a

Brief Limited Intermittent Psychosis (BLIP, experienced for 1 week, resolved without

medication); or through the 'family route', where along with having a first degree

relative with a psychosis or schizophrenia diagnosis, such clients had also shown a

recent deterioration in functioning (measured with the Global Assessment of

Functioning Scale; American Psychiatric Association, 1994). Service exclusion

criteria include current or previous use of antipsychotic medication, moderate to

severe learning disability and organic impairment assessed by the service's clinical

psychologists.

4.3.2 Procedure

Appropriate ethical approvals were gained from the local Research Ethics Committee and governance approval obtained from the National Health Service (NHS) trust where the research was to be conducted; all ethical guidelines were followed during the research process. Participants were recruited through their therapist or the assistant psychologist they met for monitoring appointments. All participants were interviewed individually. In line with general service practice, clients were met for interview at their own home or in a suitable, convenient location (to reduce the risk of stigmatizing clients by limiting meetings to NHS or mental health service premises).

During the interviews, the interviewer employed a reflexive approach to the use of language; as with Hardy et al. (2009) the interviewer didn't use words such as 'psychosis' or 'mental illness' unless the participant did so first. In addition, the interviewer (RB) had identified himself to participants as a former service user (having previously been an at-risk client himself). This was considered valuable for a number of reasons. Firstly, as with Deegan (2005) such disclosure may help participants to feel more comfortable with their own identification as at-risk clients and with disclosure of personal difficulties. Secondly, although the interviewer was employed within the service team, it was stressed to participants that his role was one of relative independence. Participants may therefore have felt more comfortable describing any negative experiences of involvement with the service than if they had been speaking to clinical staff.

Central questions asked during interviews included: *'Have you experienced any very difficult personal relationships in your life?'; 'Do you feel close to others (family and friends)?'; 'Have you been able to reveal or express your psychological problems to anyone other than mental health or other professionals (such as friends or family)?'*

4.3.3 Data analysis

The interviewer recorded preliminary notes after each interview to record initial impressions of each interview's content and to help further develop the interview schedule. Following interviews and initial analysis, line-by-line examination of data (initial coding), was followed by a re-examination of transcripts and initial codes (focused coding) to highlight either the most common or significant themes discussed. This process was continued until theoretical sufficiency of emergent themes was achieved. During all stages of analysis, the interviewer-researcher's active participation in the research process was acknowledged; that is, analysis was conducted with the understanding that data had been collected and analysed from a user perspective.

4.4 Results

Analyses of the data collected elicited three central themes: (i) experiences of difficulty with interpersonal relationships with others; (ii) subjective difficulty

talking to others about psychological problems; (iii) experiences of talking to others about psychological problems.

4.4.1 Difficulty with interpersonal relationships and reduced opportunities for communication

Participants identified significant experienced difficulty with either family or social relationships, or both. Identified problems with family relationships included conflict, separation, childhood neglect and abuse, exposure to domestic violence, lack of parental care and support (for a number of participants, this was seen to have been caused by their parents' own mental health problems, or problems with abuse of alcohol or drugs), difficulty with sibling and other family relationships, and estrangement. For example:

I was born into a violent relationship, my mum, my mum and my dad and, really escalated from there because I was neglected and things happened to me (p5)

Central characteristics of difficulties described included interpersonal conflict and perceived lack of closeness. Three participants had experienced significant emotional and psychological distress following the death of a parent or loved one. Difficulties with wider social relationships, experienced before or during the onset of mental health problems, were most commonly related to friendships and peer groups and included problems with attachments, loss of social relationships, trauma, bullying and social isolation. For example:

Basically it was bullying at school…it's my instinct to run away and be alone instead of being with the group (p1)

Social isolation caused by bullying, for example, was associated with problems with self-esteem, confidence and social anxiety. A number of participants identified experience of traumatic violence as a central source of psychological difficulty (especially social anxiety and paranoia) and subsequent withdrawal. For others, distressing social anxiety had emerged in relation to perception of themselves as different or unusual ('not normal'), and to the fear of being perceived as such by others; this had often led directly to participants' social withdrawal.

I've lost a lot of friends…because I haven't been able to cope (p5)

4.4.2 Reluctance to disclose unusual psychological problems

The second central theme identified in our analysis was the difficulty participants had experienced with communicating their mental health concerns to others.

I'd always really wanted help but I had trouble admitting I had problems…it was hard to admit it to myself, like, it was even harder to admit it to somebody else to get help for it (p6)

Most participants had first disclosed their concerns to a mental health or other professional, rather than to a family member or friend. For some, this was because they lacked adequately supportive relationships; while for others, the potential personal and social costs of disclosure were perceived as being favourably reduced in the context of a professional rather than personal relationship. For example:

I wasn't close to my family or anything so professional help was the only real way to go (p1)

All participants described the particular difficulty of talking about unusual psychological experiences (psychosis-like phenomena such as hearing voices or feeling paranoid). Participants most often identified their central concern as the fear that their experiences meant that they were 'going mad', and therefore, that others would react negatively towards them if they disclosed their mental health problems (with rejection, unkind treatment or ridicule, for example):

I don't bother trying to explain to my family or friends, I just keep it to myself…you feel a bit like, they're gonna think you're going mad (p8)

4.4.3 Disclosure of unusual psychological problems: costs and benefits

Participants all recounted experiences of talking to others about their psychological problems. A number of participants had experienced or perceived negative reactions to their disclosure. For example:

When you're suffering with social anxiety and people are staring at you, when people are looking at me like I'm different, all of a sudden your doctor's doing it as well and it's one of the last people you want that to happen with (p7)

Participants more often described positive experiences of communication of their psychological difficulties. Common perceived benefits of disclosure included reduced anxiety about mental health problems, improved emotional well-being and increased access to professional help. A number of participants had spoken to family members or friends about their mental health concerns and had found valuable outlets for helpful communication and sources of support. For example:

I wouldn't even talk to my Mum and Dad about mental problems but I'll talk to [neighbour] because she seems more understanding and more concerned…like, she's been through mental problems and stuff…it's good to speak to somebody face to face (p2)

The most commonly recounted of participants' experiences of helpful communication were related to involvement with staff from the ED service. Along

with the common benefits of disclosure described above, participants also

identified particular benefits associated with their experiences of CT. For example:

I've been able to understand what is happening and why, why I feel such things in

such a situation, why I get certain images in my head, all sorts, and because of that

I've now got a list of things that I need to work on, either to minimise them, increase

them, or just to accept there's nothing I can do about them (p1)

Along with the treatment of unusual phenomena (e.g. hearing voices or

paranoia), additional valued elements of communication with service staff

identified by participants included the informality and acceptability of language

used (normalizing, generally non-clinical), the collaborative nature of CT work, and

the beneficial nature of interpersonal interactions with staff.

It's a team effort and that's probably the easiest way for me to sum it up, in my

words, it's a team and I'm part of that team you know, I'm just as important, I'm

making decisions, after all I am the only one that knows about what's going on in

my own head (p7)

4.5 Discussion

The aim of the present study is to explore participants' perceptions of their

interpersonal relationships with others and how these may have facilitated or

prevented disclosure of their psychological difficulties. Findings from this study

suggest that difficulties with family or social relationships were common among participants and were often associated with the development of unusual psychological experiences, and to an inability or reluctance to disclose those experiences to others when they emerged.

The kinds of adverse life experiences identified by participants as having contributed most significantly to their interpersonal difficulties and to their psychological problems are often implicated in the development of first-episode psychosis (Freeman et al., 2001; French et al., 2003; Garety et al., 2001; Read et al., 2005; Larkin and Morrison, 2006). Negative self-concepts and poor self-esteem in particular are common among people who experience psychosis and are thought to contribute directly to the development and maintenance of psychosis (Kinderman and Bentall, 1996; Close and Garety, 1998).

All participants described a fear of negative reactions from others as a significant cause of nondisclosure of psychological problems. Distress associated with unusual psychological experiences was often related to participants' fear that they could be 'going mad' and that others would perceive them as such. Morrison (2001) argues that cognitive intrusions (e.g. hallucinations or delusional thinking) become distressing through an individuals' *interpretation* of them. In this context, we may argue that participants' common fear of 'going mad' had contributed significantly to the development and maintenance of their psychological difficulties, and that it had been a common cause of delayed help-seeking.

All participants described experiences of disclosing their concerns to others. For a number of participants, these had occasionally been negative experiences,

though for the most part, participants had appreciated the value of seeking help and communicating their psychological distress to others. Positive experiences of disclosure (interactions which had helped to reduce distress and anxiety, for example) had helped those who had experienced negative reactions to re-evaluate their perceptions of the costs and benefits of disclosure, for both current and future engagement with mental health services. This highlights the importance of normalizing, destigmatizing approaches, and shows the counterproductive nature of catastrophic, pessimistic reactions of health professionals to the disclosure of unusual perceptual experiences and beliefs.

Valued aspects of involvement with the ED service identified by participants in the present study included reduced frequency of distress associated with unusual experiences, reduced anxiety and confusion, improved ability to cope with psychological and emotional distress, improved mood, and improved social ability. These improvements were most often identified in relation to the formulation of psychological difficulties, and recovery, through practical cognitive models of anxiety, depression and unusual experiences like hallucinations (Morrison, 2001; Wells, 1997; Beck, 1976).

The range and extent of valued elements of CT identified by participants in the present study, and the lack of complaints, suggest that it had been perceived and experienced as a widely acceptable and effective therapeutic intervention: future development of services for at-risk individuals may prove most acceptable and effective with delivery of similar clinical practice and practical support.

4.5.1 Methodological considerations

Our analysis generally explored interpersonal and communicative *difficulties* experienced by participants; it could be very helpful to further evaluate the benefits of *positive* interpersonal relationships in future research.

The present study recruited a relatively small sample of participants (n=8); greater sample sizes may be desirable for similar future research. As with Hardy et al. (2009), our sample were self-selected and therefore, may have been more inclined to relate positive experiences of their involvement with the ED service than clients who were not engaged with the service at the time of recruitment; future research may endeavour to evaluate disengaged clients' experiences of ED interventions.

Our sample included only one female participant; future research would benefit from involving both male and female interviewers so that potential participants are offered a choice. In relation to the present study, the gender imbalance described may have had an impact on the results reported. For example, there may be notable differences between genders for experiences of communication of psychological difficulties, or reluctance to do so (World Health Organisation). Therefore, future research into this area will also benefit from investigating such potential gender differences.

All participants were white British. This is not reflective of the service's clients as a whole, though the service is based in a predominantly white-populated geographical area. Similar future studies may benefit from recruiting participants from more diverse populations.

4.5.2 Clinical implications

The emergence of unusual psychological experiences can have a serious negative impact on a young person's social relationships, and can often lead to withdrawal and isolation; withdrawal and isolation may in turn contribute directly to the development and maintenance of psychotic experiences. These concerns strongly suggest a need for greater emphasis to be given to the promotion of social recovery and the provision of social support during the delivery of clinical interventions. Supportive and affirmative relationships may reduce anxiety and depression (French et al., 2003), may reduce experience of unusual beliefs (Myin-Germeys et al., 2003), and may improve overall clinical outcome (Norman et al., 2005). Importantly, treatment that helps to improve self-esteem (eg. CT) may offer significant clinical benefits along with improvements in social functioning (Roe, 2003; Hall and Tarrier, 2003).

Participants' common fear of negative consequences of disclosure of unusual experiences suggests that it is very important to improve general cultural understanding of psychosis. It may be most important to re-evaluate ideas held by mental health professionals themselves, and professionals' use of language when describing psychosis, as professionals may often contribute to the negative stigma experienced by service users (Shumway et al., 2003; Hocking, 2003; Bentall, 2003). The often negative impact of clinical descriptions or diagnoses of psychosis or 'schizophrenia' as biologically engendered, permanent 'mental illnesses' can play a significant part in the development of very harmful anxiety, depression and

hopelessness (*'When I realized this condition was permanent . . . I understood it would eventually destroy the core of my life'*; Møller and Husby, 2000, p.221). A normalizing approach to understanding and treatment (Bentall, 2003; Romme and Escher, 1989) that promotes recovery from unusual psychological experiences and psychosis, may prove more effective for helpful delivery of treatment, increased adherence to treatment and improved relapse prevention. CT may offer particularly benevolent treatment interventions for at-risk individuals, and is already recommended as a first-line treatment for early psychosis in the UK (National Institute for Health and Care Excellence, 2002) and internationally (IEPA Writing Group, 2005). Provision of CT offers an inherently normalizing and pragmatic intervention that provides established benefits not only for treatment of psychosis (Wykes et al., 2008) but also for anxiety (Clark, 1999) and depression (Beck et al., 1979), which are both common and significant concerns among at-risk individuals.

Regular consultation with service users to evaluate their priorities for clinical intervention should help to accelerate the provision of the most effective and helpful treatment, and similarly, increased inclusion of service users in the conduct of research and service provision should be facilitated. The present study found that participants commonly appreciated the interviewers stated role as a user researcher: *'it just makes you feel like you're not on your own . . . it's just nice to know that people get better'.*

4.6 Acknowledgements

Chapter 5: Exploring Service Users' Perceptions of Cognitive

Behavioural Therapy for Psychosis: A User Led Study

Exploring Service Users' Perceptions of Cognitive Behavioural Therapy for Psychosis: A User Led Study

Martina Kilbride, Rory Byrne and Jason Price

Greater Manchester West Mental Health NHS Foundation Trust, UK

Lisa Wood

North Essex Partnership NHS Foundation Trust, Chelmsford, UK

Sarah Barratt

University of Liverpool, UK

Mary Welford and Anthony P. Morrison

Greater Manchester West Mental Health NHS Foundation Trust, UK

5.1 Abstract

Background and aims: This study explored individuals' subjective experiences of Cognitive Behavioural Therapy for psychosis (CBTp) with the aim of identifying coherent themes consistent across individual accounts and any potential barriers to CBTp effectiveness. **Method:** Semi-structured interviews were conducted with nine individuals with experience of CBTp. A qualitative Interpretive Phenomenological Analysis was used to analyze the data collected to identify common themes.
Results: Five super-ordinate themes emerged from our analyses: CBT as a process

of person-centred engagement; CBT as an active process of structured learning; CBT helping to improve personal understanding; CBT is hard work; Recovery and outcomes of CBT for psychosis. **Conclusions:** The theoretical and clinical implications are discussed.

Keywords: CBT, psychosis, service users.

5.2 Introduction

There is increasing evidence that cognitive behavioural therapy is effective in the treatment of psychosis (Wykes et al., 2008), and has been recommended for the treatment of schizophrenia (National Institute of Health and Care Excellence, 2009). It aims to help reduce distress and improve quality of life by evaluating appraisals and modifying behavioural, cognitive and emotional responses (Morrison and Barratt, 2010). To date, the effectiveness of CBT for psychosis (CBTp) has focused on the reduction of psychotic symptoms and associated improvements in functioning (Greenwood et al., 2010); however, psychotic symptoms may not be primary concerns for those seeking treatment (Pitt et al., 2007). Rather than focus on symptoms exclusively, several psychological models of psychosis encompass factors such as beliefs about self and others, emotional difficulties and problematic consequences of symptoms (Bentall, 2003; Chadwick and Birchwood, 1994; Garety et al., 2001; Morrison, 2001). Given the common differences between professionals' and service users' priorities for treatment (Byrne et al., 2010), it can be argued that these psychological approaches allow for greater consideration of

service users' individual priorities, which may prove more effective than treatment approaches focused primarily on the reduction of symptoms.

It has been argued that our limited understanding of the effectiveness of CBTp may be due to the relative lack of studies conducted to investigate service users' subjective experiences (Fowler et al., 1995). A recent review of the qualitative literature on this topic reported eight such studies (Berry and Hayward, 2011), but three of these examined group-based interventions. Of those that focused on individual CBTp, two focused on very specific aspects: homework (Dunn et al., 2002) and formulation (Morberg-Pain et al., 2008). A qualitative study (Messari and Hallam, 2003) that interviewed five service users who received individual CBTp identified several central themes from their analysis of clients' experiences, including: CBT as an educational process; CBT as a respectful relationship between equals; and CBT as a healing process. Another study interviewed eight service users and four practitioners, and focused more directly on factors that affect outcomes of CBTp, with both users' and therapists' accounts describing both deficits and skills, with a central theme being "understanding, holding and engaging with the therapists' model of reality" (McGowan et al., 2005).

While both studies offer valuable insights into CBTp practice and particularly users' understanding of therapy, it may be suggested that similar studies will benefit from greater involvement of service users in the research process itself. User-involvement in mental health research has been recommended by the Department of Health (Department of Health, 2005), and by the National Institute for Health and Care Excellence (NICE, 2009). User-led research may offer

advantages such as increased rapport between interviewers and interviewees, and may reduce interviewees' potential concerns regarding confidentiality and criticism of professionals, and may also offer "a different view of the world of mental health" to that produced within mainstream research (Rose, 2008; Rose, 2001).

The present study has been designed and conducted as a user-led qualitative evaluation of service users' subjective experiences and perceptions of CBTp. The study aims to inform user-oriented perspectives on treatment for psychosis.

5.3 Method

5.3.1 Participants

Participants had experience of CBTp within the last 12 months, and were aged between 18 and 65. Exclusion criteria included not being able to speak English, and not being able to give informed consent. Nine participants took part in the study; five females and four males. The sample had a mean age of 26 years (ranging between 21 and 65 years of age). Eight participants came from Early Intervention Services (EIS) and one was recruited from a Community Mental Health Team (CMHT), all based in or around Greater Manchester. Eight participants were white British and one was black British.

5.3.2 Design, procedure and analysis

Individuals with experience of CBT for psychosis were invited to take part in a user-led semi-structured interview. Interpretative Phenomenological Analysis (IPA) methodology was chosen to evaluate people's experiences and perceptions. IPA uses a 'double hermeneutic', which refers to the two-way interpretative process of this methodology. Investigators have an active role in aiming to make sense of the participant trying to make sense of their world, and to obtain an 'insider perspective'. This aspect of IPA methodology was enhanced by having interviewers who had first-hand experience of psychosis, although it is important to acknowledge that this enhanced degree of shared understanding between interviewers and participants may have increased the likelihood of user-oriented bias in either the tone or content of interviews. Similarly, the collective standpoint of the wider research team as proponents of CBT for people with psychosis may have increased the likelihood that a positive bias towards CBT could have influenced our analysis of participants' accounts. However, we did seek to minimize this risk via discussion of such issues, awareness of our own biases during analysis, and explicitly seeking negative or unfavourable information throughout the interviews and analytic process. The analysis, which was led by user-researchers (RB and JP), involved an iterative process of repeated reading of interview transcripts, extraction of themes, discussion between user-researchers, and comparisons across transcripts. A final set of user-defined themes was produced and organized structurally in response to the research question.

5.4 Results

The research identified five major or super-ordinate areas of thematic consistency throughout the interviews, as listed in Table 3. Each of these thematic groupings had further subthemes, also summarized in Table 3 and discussed below.

Table 3. Qualitative study of CBT for psychosis: Super-ordinate and subordinate themes (including number of participants endorsing each)

Super-ordinate themes	Subordinate themes	N of participants reporting
1. CBT as a process of person-centred engagement	Personal engagement and trust	5
	Partnership and collaboration	2
	Sharing control with clients	7
	Flexibility enabling continued engagement	4
2. CBT as an active process of structured learning	Identifying clients' 'psychological map' through formulation	3
	Re-appraising psychological difficulties through evidence-gathering	5
	The value of practical [written] tools	7
	Carrying on CBT work with homework	3
3. CBT helping to improve personal understanding	Gaining a different perspective	6
	Normalisation as a central active process	4
	The role of improved understanding in long-term coping	8
4. 'CBT is hard work'	'Being ready'	4
	Finding it difficult to engage with or complete work	7
	Emotionally difficult	6
5. CBT and recovery	Acceptance as a part of recovery	5
	Practical, social & functional recovery	8
	Achievement, empowerment & independence in recovery	5
	Gaining or regaining hope	7

5.4.1 CBT as a process of person-centred engagement

The first theme reflects the value participants attribute to experiences of interpersonal engagement with their therapist, and to their therapists' ability to offer person-centred, individualized approaches to therapy.

The importance of personal engagement and trust. The theme of interpersonal engagement emerged as a common element in clients' discussions of valued experiences of CBT, with five of nine clients making specific reference to trust and personal comfort being central to their ability to engage with therapy:

If you don't trust them you aren't gonna tell them what you've been through and you aren't going to go into depth with people. (1)

I think it's just having someone there really…that you can trust and that…that knows what's going on and understands. (5)

Partnership and collaboration in CBT. Partnership and collaboration in CBT emerged as a valued aspect of engagement. The concept of partnership in particular was identified as a respectful recognition of participants' personal worth as individuals capable of contributing meaningfully to the therapy process:

I'm not just a service user, I'm someone on her level you know, really as a service user you get looked down on and you don't get considered at all, your feelings don't get considered at all when you're ill, you know people tend to talk over you or at you, or at someone else for you, but people in [therapist's] position, and people on her level and people such as you don't do that you know. (2)

A number of participants compared previous mental healthcare experiences with CBT, identifying the role of a collaborative partnership as a distinct and even novel aspect of their care:

It was very much a partnership between myself and the psychologist, it was really put to me as team work, which I thought was great. It wasn't that someone else has an agenda…it was centred around me which I'd not come across before in anything really in medicine or psychiatry. (6)

Sharing control with clients. Most participants highlighted shared control of therapy as an integral part of their experience, and identified individualized, client-led agenda-setting in particular, as important:

She puts an agenda down what we need to go through but she'll also ask if there's anything that I need to…if anything's been difficult that I want to talk through or if there's anything else I want to talk about. (5)

For other participants, the issue of control in therapy was framed as a natural process of client-led discussion, or as a 'safe' therapeutic context for self-determined disclosure:

I felt like I've been in control of what I wanted to say and anything I did say I felt you know that no-one's gonna judge me. (4)

Flexibility enabling continued engagement. Flexibility was highlighted as an important attribute of therapy that improved participants' ability to remain engaged. Flexibility was most often discussed as an attribute of the perceived control described above:

…if something wasn't so much of a problem later on we could reduce that, if something else came up we could add that in to the plan. (3)

Flexibility within therapy also meant being allowed to re-evaluate their difficulties and to determine their own priorities for therapy:

We did working out what my main problems were that I wanted to overcome and when you look at it that way you start thinking, well you know, you'd think it was the voice I was hearing nearly all the time but that actually wasn't much of a problem, it was kind of pleasant. It was the thinking people could hear my thoughts on the bus. (2)

5.4.2 CBT as an active process of structured learning

The second major theme that emerged from our analyses reflects participants' perceptions and understanding of specific CBT exercises and techniques, which may best be summarized from our data as individualized processes of 'structured learning'. Participants' accounts of progress through therapy often included references to practical psychological exercises, with common outcomes of these including perceived improvements in their psychological wellbeing and quality of life.

Identifying clients' 'psychological map' through formulation. Most participants referred to experiences of working through psychological formulations with therapists, though only three identified structured formulations in clear terms as a distinct therapeutic technique. The majority of participants' accounts of undertaking formulation exercises were described in broader terms and included common reference to the perceived value of 'writing things down' and 'drawing diagrams' to facilitate understanding:

…like maps of my mood and little things about different parts of your life and how they can fit together, he would just kind of draw little diagrams that to me they would make sense and I'd be like yeah yeah you're right. (8)

For those participants who did identify formulation as a key stage in their progress through CBT, perhaps the most effective element was the normalizing process of re-evaluating psychotic experiences within the wider context of their individual life experiences:

We'd go through various steps of my life sort of thing and break everything down, we'd go through what was good and what was bad, it was really helpful…what you think the cause of the voice hearing and any traumatic experiences, and explain like, me Mam died and stress at work. (7)

Re-appraising psychological difficulties through evidence-gathering. The process of re-evaluating beliefs about psychotic experiences by exploring the presence or absence of evidence was viewed as valuable:

I think the evidence thing's kind of good, sort of is it real and you have to sort of work out well, is it likely to be real. Like if you think, say, people taking thoughts out of my head, and erm, it's sort of well what's the proof that they are. (2)

Re-evaluation, as a means of assessing probability for themselves ('is it likely to be real') was valued as a transferable and independently applicable skill:

*We could test out our predictions, and like look for other explanations like, there
was some exercises in the CBT that I could do…so eventually I'd feel, like I'd get a de-
escalating feeling of anxiety*. (1)

Monitoring progress in CBT. For a number of participants, filling out assessment
measures enabled them to view their experiences in a formalized structured
context, and this in turn enabled them to recognize progress:

*…it's [measuring symptoms] a good idea because you can then look back at stuff
and say, oh right, that's a similar situation and that made me feel like, 10 or
whatever*. (2)

Some acknowledged the value of written relapse-prevention exercises, or
'blueprints' to enable them to act as 'self-therapists' when therapy had come to an
end:

*…this is all my early warning signs I did, that we got out of the sessions, and on a
day to day basis so I could score and I could see improvements in how I was doing*.
(1)

CBT 'homework'. Although most participants' accounts contained references to
completing tasks or exercises outside therapy sessions, just three referred directly
to homework as a distinct element of their experience. For those who did, engaging

with homework tasks such as 'thought diaries' helped to maintain a practical focus regarding their concerns between sessions:

I feel if I hadn't done the homework that I had, then, and showed up to the sessions as well, I think it would have taken me a lot longer. (1)

5.4.3 CBT helping to improve personal understanding

Along with discussions related to structured or practical 'work', all participants offered descriptions of the internal learning processes that characterized their experiences of CBT. Overall, improved understanding was identified as a central valued outcome.

Gaining a different perspective on psychosis through CBT. CBT was seen to offer opportunities to gain a 'different perspective' on psychotic experiences and associated difficulties, and this was identified as an active element and an important outcome:

She explained to me…was there a chance that it could be my thoughts…and I'd never thought of it that way. I always thought that the voice was coming from somewhere else…somebody else should I say. (5)

Normalization as a central active process in CBT learning. Normalization emerged as a significant element in the various CBT processes described by our participants,

and was seen to have played an important part in the re-evaluation of psychological problems:

…all these thoughts, I was thinking when I felt fine, oh my god they're crazy but [therapist] helped me to see that the thoughts weren't crazy, after looking at what happened. (1)

A number of participants also described normalization as a means of re-evaluating their self-image:

I've learnt a lot…erm I guess about mental health it happens to a lot of people and things like…I thought I was abnormal, especially when I was down I thought what is wrong with me erm and [therapist] would always say well would you think somebody was normal if they had green eyes, and you'd be like yeah, and she'd say like… well more people have mental health problems than have green eyes. (8)

Understanding psychosis helping to improve long term coping. Improved understanding was a central factor in participants' perceived ability to cope with their difficulties in the long-term. A central thread within participants' discussions in this area relates to a shift in understanding of psychotic experiences from an expectation that treatment should stop them occurring, to learning to respond to them differently:

I don't think it's [CBT] used to eliminate them altogether it's knowing why you get the voices erm…how to deal with them basically. (7)

Improvements in understanding were also seen by a number of participants to represent improvements in their perceived ability to act independently of mental health services in the future:

It just helped me be a bit more insightful, a bit more logical about it and yeah be more independent just to think yeah I can actually deal with this. (2)

5.4.4 CBT is hard work

The fourth of the super-ordinate themes identified relates to the potential difficulties of engaging with CBT, and was reflected in almost all participants' accounts. Aspects of CBT that were commonly perceived as difficult were identified in terms of personal motivation, practical barriers to engagement, emotionally difficult disclosure and engagement with sensitive areas of personal experience.

'Being ready for CBT'. For some participants, the potential difficulty of engaging with CBTp initially, or over time, seemed related to their readiness:

I don't know if I had cognitive therapy many years ago if it would have helped, as I don't know if I'd be ready you know, but since having CBT I've never looked back. (2)

There was a recognition that the self-examination or cognitive 'work' necessary for effective engagement with CBT was not always possible:

To be honest there would have been times where there was no way I would have engaged with it or benefited from it…think you've got to be ready and motivated for it cos there is quite a lot of thinking and you need to be fairly open minded. (3)

Finding it difficult to engage with or complete CBT work. Almost all participants referred directly to engagement with CBT as 'hard work', where personal motivation and agency were required to achieve progress. For a number of participants, CBT was considered effortful due to concentration on specific cognitive processes:

I couldn't think of the thoughts, I struggled identifying the thoughts, cos I had loads running through my head. (1)

Finding that therapy was more demanding than expected was often related to widely-held cultural understandings of psychological therapy, where clients are most often seen as passive recipients of therapists' professional expertise, rather than as active partners within a more collaborative process:

When I first like you know got told I was gonna have CBT you just expect you get better but it doesn't, there's a lot of like, you got a put a lot in yourself to get a lot out really. (7)

A number of participants found that homework tasks were difficult to complete outside therapy because their ability to undertake them was often dependent on their mood, memory or circumstances:

I think it's hard to get into them at first [thought diaries] because when you're stressed out you don't want to write it down... it kind of passes by and then you remember afterwards. (3).

CBT can be emotionally difficult. Difficulties around personal disclosure of either psychotic experiences themselves or difficult previous life experiences were associated with worries that such disclosures could have resulted in the therapist making negative personal judgements:

I found it hard sometimes as you don't want to write down what was going on in your head because people will think you're a bit weird. (6)

Emotional disturbance and distress was a common difficulty for participants when disclosing personal issues:

I suppose sometimes I had to face up to some of the problems I was having that I was trying to stick my head in the sand about so maybe, I suppose there were times when anxiety was a huge side effect of everything and I suppose it increased it at times. (2)

Participants often described the experience of strong emotions as a necessary prerequisite of achieving progress:

It was hard, it wasn't easy…to go through things that had happened in the past. Erm, I got upset a lot, so it wasn't easy but…I knew it had to be done, just to get past it. (5)

However, it was also evident that for at least one participant this highlighted limitations in therapy:

I think the worst thing is getting upset and being left with it once they've gone. (5)

5.4.5 CBT and recovery

The final super-ordinate theme that emerged from our data is drawn from participants' discussions of recovery. All participants identified particular improvements that followed therapy. Recovery from psychosis through CBT involved reductions in the frequency of psychotic experiences and reductions in

distress associated with these, improved understanding and coping ability, as described above, and improved social and functional ability.

The importance of acceptance in recovery. Acceptance as a part of recovery was most clearly related to participants' recognition that psychotic experiences or serious emotional difficulties could continue after therapy, though with less distressing or disabling effects:

[Therapist] showed me that it's not just going to go away, I've had 10 years of this and yeah I am going to have blips, but the blips that I have had have been shorter and short-lived so I can look back and think yeah it is working. I've never had an episode that was like that first. So we are obviously doing something right. (1)

As well as acceptance of difficulties, acceptance of self was also identified as an important element of recovery:

I like myself a bit which I never did, I disliked myself intensely at one time, I can notice the positive things about myself you know. (2)

Social and functional recovery. Improved social and functional ability was also an important element of recovery. For some this was the result of changes in relation to psychotic experiences:

I can deal with them [voices] a bit better now…cos they used to stop me going out

an…on me own and stuff like that. They used to interfere with me life, they still

interfere but not half as much as they used to. (5)

For others, this was as the result of changes in relation to emotional difficulties:

The biggest impact actually which I didn't realize was anxiety actually, that's what

stopped me doing things, that's what stopped me going out and to the shops and

pubs, things like that. (2)

Achievement and independence in recovery. Another common dimension of

participants' perceived recovery was recognition of personal achievement within

and outside of therapy, and consequential improvements in perceived

empowerment and independence:

I struggled and struggled for the last 20 years and I felt that I wasn't making any

ground, but I felt that in the last 4 years I have really moved forward, that have

been times when I have had bad days, but I've really managed to pull myself round

you know. (2)

The ability to personally employ CBT practices brought a sense of confidence in

their ability to continue effectively on their own:

So once we had worked out that I was actually doing it right I could do it by myself. (1)

Gaining or regaining hope. The importance of gaining or regaining a hopeful attitude for continued recovery was evident, through a change of perspective from negative, 'stuck', or even hopeless, to more positive, future-oriented frames of mind:

The first time I came into contact with the mental health services I couldn't see anywhere forward, didn't want to be here, couldn't see the point of being here, now I've got things to aim for, it's like, okay, I've got things to aim for. (6)

Past experiences of feeling trapped by psychological difficulties were addressed through CBT, where evidence of their ability to affect positive change on their wellbeing had brought about a significant improvement in their perception of their coping ability, characterized by the emergence of a long-absent sense of optimism:

I was without any hope for many years, I would go around thinking I was going to jack it in or not live very long, I would always come up with some negative point, I actually feel now, well more recently, over the last 6, 12 months that there is actually hope, I can move forward. (2)

5.5 Discussion

We interviewed nine people with experience of CBTp and identified five major themes: 'person-centred' engagement; a process of structured learning; improving personal understanding of both psychosis and self; hard work practically and emotionally; and recovery from psychosis. We found that participants most consistently valued: shared control in therapy (ie., through collaboration), gaining improved understanding for long-term coping, and achieving social and functional recovery. In addition, normalization in CBT appeared both as a discrete subtheme within the area of improved understanding and throughout a variety of other discourses such as interpersonal engagement, the role of psychological formulation, and the development of acceptance in recovery. As such, we suggest normalization to be of central importance in CBTp.

A number of the central discourses previously identified (Messari and Hallam, 2003) are echoed in the present study, suggesting a degree of generalizability for these areas. They report that for their clients CBT constituted "an educational process", and "a respectful relationship between equals", while we identified from participants' discussions the role of CBTp as a process of "structured learning" and "improved understanding" primarily conducted within the context of collaborative partnership. However, our findings differ from theirs in a number of ways, including the extent of therapeutic progress reported and in the language used to reflect participants' beliefs about psychotic experiences. In their study (Messari and Hallam, 2003), personal beliefs about psychosis were represented either in psychiatric terms (eg., "I am ill"), or in terms of unresolved delusional

certainty ("this [psychotic experience] is truly happening"). None of our

participants' discussions reflected delusional certainty or continued uncertainty

about the veracity of their earlier beliefs. In addition, few of our participants

explicitly referred to themselves as having been "ill" or "mentally ill". A final

difference between our studies can be seen in their inclusion of the discourse "CBT

participation as compliance with the powerful medical establishment" (reflecting a

minority view among their participants); none of our participants referred to such a

dynamic, perhaps reflecting differences in the delivery of CBT; for example,

different CBT manuals place different emphasis on factors such as diagnosis,

normalization and the amenability of psychotic experiences themselves to change.

Thus, some approaches emphasize adjustment and coping with mental 'illness',

whereas others aim to modify appraisals of and responses to psychotic experiences

in order to create lasting change in psychological functioning.

Comparison of our findings with the study that sought to explore specific

psychological processes implicated in outcomes from CBTp (McGowan et al., 2005)

highlights a similarity regarding "non-model-specific benefits of therapy" (eg.,

personal engagement, or "having difficult experiences listened to and taken

seriously"). Another element identified in both studies is referred to as "a move

from old to new understanding" of psychotic experiences (McGowan et al., 2005)

which is similar to our "gaining a new perspective" of psychosis. The commonality

of this finding suggests that such a shift may be central in effective CBTp.

A notable difference between our findings and those reported in both

studies mentioned above relates to normalization in CBT. For our participants,

normalization represented a highly valued element of CBT experience where, in contrast, neither of the other two studies explicitly identified the importance of normalization, although the review of the eight qualitative studies (Berry and Hayward, 2011) did identify normalization as a theme that emerged. This may reflect a substantial difference in the practice of CBT between therapists related to each research study or a substantial difference in the interpretations our respective researchers have given participants' accounts of their CBTp experience.

A recent study examining user-defined outcomes of CBT for psychosis (Greenwood et al., 2010) reported that the highest ratings of importance were given to goals such as achieving a sense of control, ways of dealing with unpleasant feelings and emotions, and having a positive purpose and direction in life. These goals can be seen to reflect our participants' CBT experiences in terms of achieving control through improved coping with continued difficulties, along with regaining hopefulness. However, unlike Greenwood et al. (2010), our participants highly valued a number of internal change processes (especially improving understanding of psychosis) during therapy and in recovery. This difference may be explained by the fact that the majority of their participants were long-term service-users consulted at the beginning of CBTp involvement, whereas the majority of our participants generally had less lengthy experience of psychosis, and were interviewed following CBTp, where stages of recovery had commonly been achieved.

A study of service-user satisfaction with CBTp (Miles et al., 2007) found that participants' highest ratings of factors were for "therapist attributes", suggesting

that collaboration within CBTp along with "being able to talk to someone" were highly valued. However, they also found that overall satisfaction was best predicted by the extent to which participants believed they had gained specific CBT skills and knowledge in therapy, and that the perceived helpfulness of CBT homework tasks may also predict long-term satisfaction. These findings are complementary to our own, with a number of both specific and non-specific aspects highlighted by our participants.

Research into recovery from psychosis is also relevant to our findings. A study of user-defined attributes of recovery from psychosis (Pitt et al., 2007) reported a number of findings echoed by our own results. For example, their findings included themes of rebuilding self, rebuilding life, and hope for a better future. These factors may constitute central and generalizable aspects of recovery across treatment modalities; thus, CBTp may be a treatment that is likely to be acceptable and likely to address user-defined priorities.

There are several limitations of our research. In common with similar qualitative studies, we included only a small number of participants, and so our findings do not necessarily reflect a generalizable picture of CBTp experience. Our sample was self-selected and evidently satisfied with CBTp involvement; in future, it would be interesting to purposively sample participants who had dropped out of CBT in order to identify a more critical perspective. A combination of qualitative and quantitative analyses, perhaps using nested qualitative studies within clinical trials of CBT for psychosis, may be particularly fruitful in furthering our

understandings of the factors that are most important in influencing engagement and outcome.

Our findings suggest that CBT is an acceptable treatment for people with psychosis, and have implications for clinical practice. Normalization processes (in engagement, re-evaluation of psychotic experiences, and improving self-esteem) emerged as one of the most important aspects of CBT for our participants, and may represent a key 'active ingredient' of successful therapy; thus, normalization should be an essential element of CBT for psychosis, and therapists should have attitudes and beliefs that are compatible with such an approach. This reflects professional consensus regarding elements of CBT for psychosis (Morrison and Barratt, 2010). The 'human' element of CBT, embodied in factors such as collaboration, informality, and use of non-psychiatric language was often favourably compared with participants' earlier experiences of mental health involvement, and may have significantly affected participants' ability or willingness to engage with therapy; again, this is consistent with professional consensus (Morrison and Barratt, 2010).

The collaborative approach, in particular, was often novel to our participants, who were more used to professional-led psychiatric treatment, and this was considered an integral part of the effectiveness of CBT; this suggests that mental health practitioners in general may improve engagement with clients through the adoption of increasingly collaborative approaches to care (eg., offering flexibility and choice in treatment options). Participants' appreciation for the use of written exercises such as diagrammatic formulations and diaries suggests these are important, perhaps especially where cognitive deficits impair clients' concentration

and memory. Similarly, homework tasks, where appropriately negotiated, may help

clients 'hold' therapeutic progress between sessions and following therapy. One of

the clearest themes to emerge from our findings was the value attributed to skills

learned during therapy, both for immediate reductions in psychosis-related

distress, and for long-term ability to live with continued psychotic experiences; this

is consistent with the aim of CBT to teach people to become their own therapist

(Morrison and Barratt, 2010).

Clinical trials of CBT for people with psychosis have focused primarily on

psychotic symptom reduction, rather than, for example, distress or personal

fulfilment. The findings of our study and others (Greenwood et al., 2010; Pitt et al.,

2007) suggest that recovery from psychosis does not necessarily involve the

reduction of psychotic symptoms, and that the most helpful approach may be to

assess treatment priorities and valued outcomes with service users on an individual

and dynamic basis; the collaborative nature of CBT, which involves working towards

shared goals, should facilitate this process. However, it is important that this

approach is also reflected in the design of clinical trials, which could utilize outcome

measures that more accurately capture the diversity of service user preferences

and priorities, including user-defined recovery (Neil et al., 2009). Finally, it is

important to acknowledge that, while participants were positive about CBT, they

also identified difficulties relating to the effortful hard work involved, the

importance of being ready and the possible side effects, such as short-term

increases in emotional distress. CBT practitioners should alert their clients to these

possibilities, and be open and honest in their discussions of them, as well as

problem solving proactively to minimize the potential problems. Similarly, clinical trials of CBTp should consider measuring such adverse effects in order to facilitate a comprehensive cost/benefit analysis.

5.6 Acknowledgements

Chapter 6: Young people at risk of psychosis: Their subjective experiences of monitoring and cognitive behaviour therapy in the EDIE 2 trial

Young people at risk of psychosis: Their subjective experiences of monitoring and cognitive behaviour therapy in the EDIE 2 trial.

Rory E. Byrne[1,2]* and Anthony P. Morrison[1,2]
[1]Greater Manchester West Mental Health NHS Foundation Trust, Manchester, UK
[2]The University of Manchester, UK

6.1 Abstract

Objective: To explore participants' experiences of 'enhanced monitoring' and cognitive behaviour therapy (CBT) within a randomized controlled trial evaluating early detection and prevention of psychosis ('early detection and intervention evaluation [EDIE] 2').

Design: Semi-structured qualitative interviews were conducted with a sample of participants at the end of their involvement with the trial.

Methods: Ten young people were interviewed; six males and four females, with a mean age of 27.5. Nine participants identified themselves as White British and one Black British. All participants had received 'enhanced monitoring' during the trial, and 8 of 10 also received CBT. Interviews were transcribed verbatim and analysed using thematic analysis to identify central themes within and among participants' accounts.

Results: Three super-ordinate thematic areas were identified: 'a chance to talk', monitoring-specific themes, and CBT-specific themes. The central theme ('a chance to talk') was drawn from across all participants' accounts and represents the most consistently valued attribute of participants' experiences of the EDIE 2 trial. Sub-themes of this topic were identified as follows: interpersonal engagement, informality and normalisation, and 'opening up'. Sub-themes related to monitoring include the following: clarity and reassurance, 'a therapeutic process', and challenges. CBT experience was most consistently conceptualised as 'rethinking things', and two additional CBT-specific sub-themes were identified: hard work and moving forward.

Conclusions: Our findings suggest that for young people at risk of psychosis, a normalizing psychosocially oriented assessment and monitoring process may have benefits for many, while CBT may help to reduce the negative impact of unusual psychological experiences for both the short- and long-term.

Practitioner Points

- Young people considered at risk of psychosis highly value normalizing, collaborative and flexible approaches when engaging with research or clinical staff.

- All of our participants highlighted the primary value of their engagement with staff as having a 'chance to talk' about their experiences and difficulties.

- CBT seems to be widely acceptable among 'at-risk' participants, though further research is required to establish the 'key ingredients' of effective CBT for 'at-risk' individuals.

- Valued CBT-related outcomes highlighted by participants included improved psychosocial understanding of their difficulties, improved coping ability, and greater optimism for the future.

6.2 Introduction

The last ten years have brought significant developments in research into early detection (ED) and prevention of psychosis. Criteria for the identification of individuals at high or ultra-high risk of developing psychosis have been established (Yung et al., 2005) and a number of clinical trials have been conducted to evaluate interventions to prevent or delay the onset of psychosis. The interventions offered to trial participants have included antipsychotic medication (McGlashan et al., 2006; McGorry et al., 2002; Yung et al., 2011), cognitive-behavioural therapy (Addington et al., 2011; Bechdolf et al., 2012; Morrison et al., 2004; van der Gaag et al., 2012), and omega-3 (fish oil) supplements (Amminger et al., 2010).

Among the 'first-wave' of such clinical trials, Morrison and colleagues found that cognitive behaviour therapy (CBT) alone significantly reduced the risk of transition to psychosis (Morrison et al., 2004). This trial also reported significantly lower drop-out rates in comparison with similar trials that included antipsychotic medication in their active treatments. These findings suggest that for participants,

CBT alone was the most acceptable intervention. More recent trials of CBT to prevent psychosis have produced varying results; while Bechdolf et al. (2012) reported that CBT significantly reduced transition in comparison to supportive therapies, Addington et al. (2011) and Yung et al. (2011) failed to find a significant effect.

Morrison and colleagues have now completed a large-scale multi-site randomised controlled trial of CBT for the prevention of psychosis ('early detection and intervention evaluation [EDIE] 2'). Findings from this trial are reported in detail elsewhere (Morrison et al., 2012); although no significant difference in rates of transition were found between treatment (CBT) and control groups (possibly due to low transition rates in both groups), there was a significant reduction in the severity of psychotic experiences for those who received CBT.

It is important to consult participants in such trials as preventative interventions raise ethical issues such as labelling, stigma, or risks associated with medication (Morrison and Bentall, 2003). Similarly, it is important to conduct qualitative research in particular to help inform our interpretation of quantitative analyses of efficacy. For CBT, qualitative studies may be important to help identify key cognitive, behavioural, and therapeutic mechanisms involved in successful CBT, to assess the tolerability of CBT, to determine which aspects of CBT are most valued by participants, and especially to evaluate difficult elements of CBT for participants, as these are rarely highlighted in standard research practice.

There is a growing body of qualitative research focused on CBT for psychosis (eg., Berry and Hayward, 2011; McGowan et al., 2005), which includes studies conducted with individuals who have been treated in early intervention (EI) services following a first episode (eg., Lester et al., 2011; O'Toole et al., 2004). A smaller number of studies have been conducted with young people considered to be at risk of developing psychosis (eg., Byrne and Morrison, 2010; Hardy et al., 2009), but to date no qualitative studies have evaluated subjective experiences of participants in a clinical trial in this area. The present study is therefore the first of its kind and unique, in that it is user-led (the first author was a participant in the original EDIE trial), and we aim to explore participants' experiences of involvement in the EDIE 2 trial, particularly 'enhanced monitoring' assessments and CBT.

6.3 Method

6.3.1 Participants

Ten young people included in the EDIE 2 trial (Manchester site only). Participants in the EDIE 2 trial were aged between 14 and 35, were identified as being at high or ultra-high risk of developing psychosis, and were help-seeking. Included participants had been assessed using the Comprehensive Assessment of At-Risk Mental States measure (Yung et al., 2005), and met primary inclusion criteria with either attenuated (subclinical) psychotic symptoms, transient psychotic symptoms ('brief limited intermittent psychotic symptoms'), or a recent deterioration in functioning plus either a first-degree relative with a history of psychosis or a pre-

existing schizotypal personality disorder. Six participants were male, four were female; nine were White British, one Black British. Participants had a mean age of 27.5 (ranging from 22 to 35). All participants were interviewed for this study at the end of their active participation in the trial; none had made transition to psychosis. Of the ten participants included in the present study, eight had received CBT and monitoring, two had received treatment as usual plus monitoring. Monitoring during this trial was considered to enhance routine care by providing "warm, empathic, and non-judgemental face to face contact and supportive listening" (Morrison et al., 2012), along with ensuring contact with a general practitioner (GP), signposting to other services, and crisis management when necessary. Monitoring assessments were conducted by EDIE 2 research assistants, and were scheduled once a month for the first 6 months of a participants' involvement in the trial, and once every 3 months afterwards, for up to a maximum of 18 months follow-up. CBT was based on a specific cognitive model (Morrison, 2001), and sessions were offered on a weekly basis for up to a maximum of 26 weeks, with an average of 11 sessions being delivered within the trial. CBT incorporated a process of assessment and formulation, and the specific interventions used were dependent on individual goals and formulations, but common elements of the approach were the development of a problem and goal list, a focus upon normalizing psychotic-like experiences, and an active therapy stance utilising behavioural experiments and evaluation of appraisals (the approach is described in detail in the treatment manual (French and Morrison, 2004).

6.3.2 Procedure

Appropriate ethical approvals were gained from local university and NHS research

ethics committees. A convenience sampling approach was undertaken to recruit

participants. Manchester-based EDIE 2 research assistants informed trial

participants towards the end of their involvement about the qualitative study being

conducted, unless participants were no longer in contact with the research team or

were not considered to be suitable to approach (eg., due to acute distress or ethical

considerations regarding withdrawal of consent). In line with similar qualitative

studies it was intended that we would recruit between ten and twelve participants.

Participants were informed that taking part was entirely voluntary, that it would be

a single-occasion meeting with a formerly 'at-risk' service-user researcher,

conducted either at their home or at a mutually convenient location (eg., GP

surgery, college counselling service). Participants were also informed that they

would be reimbursed with £10 to compensate for any travel or other expenses

incurred. A formal Participant Information Sheet which detailed these factors was

provided, and verbal consent to be contacted by the qualitative researcher was

sought.

6.3.3 Interviews

Semi-structured qualitative interviews were conducted by a user-researcher

working with the EDIE 2 research team. This approach was considered valuable as it

was expected to enhance rapport and engagement with interviewees. All

participants were asked about their experience of the monitoring arm of the trial,

and those who also received CBT were asked about their experiences of therapy. Interviews lasted between 40 and 80 minutes, were recorded electronically, and transcribed verbatim by the first author. Our interview Topic Guide addressed the following topic areas: background to inclusion in the trial, perceptions of interpersonal engagement with trial staff members, recollections of monitoring assessments, recollections of therapy, trial-related difficulties or challenges, post-trial changes, long-term outlook (the complete Topic Guide is shown in Appendix 14, p.317).

We acknowledge that participants may have been reluctant to offer negative appraisals about their experience of the EDIE 2 trial. However, every effort was made to emphasise to participants that negative or ambivalent appraisals of any aspect of the EDIE 2 trial could be very helpful. Additionally, the authors recognise that our user-led approach demands active reflexivity throughout the research process to guard against potential user-oriented biases.

6.3.4 Analysis

Thematic analysis was used to search for repeated or significant patterns in the data, and the 6-phase thematic analysis procedure described by Braun and Clarke (2006) was followed. The first author became familiar with the data through transcription, active repeated reading of transcripts, and note-taking. Manual, inductive 'data-driven' coding was then performed by the first author, where all potentially meaningful responses to our research questions were noted. Following basic organisation of all coded data extracts, the first author noted potential

emerging themes, and through periodic discussions with the second author, refined these initial themes and selected coded data extracts into a 'thematic map' (for visual organisation). Review and refinement of suggested themes then involved naming, re-naming, collapsing or expanding specific themes until we were confident that candidate themes, sub-themes and codes formed coherent patterns and were accurate representations of the data set as whole.

6.4 Results

We identified three super-ordinate thematic areas. The first is an over-arching theme drawn from all interviews, which represents the most consistently valued attribute of participants' experiences of the EDIE 2 trial: 'A chance to talk'. Sub-themes are identified as: Interpersonal engagement, Informality and normalisation, and 'Opening up'. We identified discrete themes within participants' accounts of both monitoring assessments and therapy sessions, and have divided these into two super-ordinate areas. Experiences of Monitoring are described in the following sub-themes: Clarity and reassurance, 'A therapeutic process', and Challenges. Sub-themes drawn from discussions of Therapy (CBT) include: 'Rethinking things', Hard work, and Moving forward.

6.4.1 'A chance to talk'

A central theme emerged from participants' accounts of their involvement in the EDIE 2 trial: 'A chance to talk'. This theme reflects a range of interpersonal and

therapeutic processes highlighted by participants from both the control (monitoring) and treatment (CBT) arms of the trial. All participants reflected positively on their experiences of meeting regularly with members of the research team, and staff members were most consistently characterised in terms of their informality, empathy, and professional understanding. We identified three discrete dimensions within this thematic area, and these are described below. It's important to note that these dimensions are inter-related; for example, interpersonal engagement often played an important role in the process of disclosure.

Interpersonal engagement

Interpersonal engagement with research staff was consistently highlighted as a valued element of participants' involvement with the trial, and in many cases was considered integral to continued engagement with assessment and therapy processes. Many of our participants had experienced social withdrawal or isolation, and EDIE 2 staff may have been the only people with whom they were communicating meaningfully about their mental health concerns, or at all. In this context, staff continuity was important for most participants, and in some cases was considered crucial in helping participants to maintain engagement and openness:

"I saw [Research Assistant 1] and [RA2] to start with and then, that was the first session, and then I just saw [RA2] the rest of the time and you do build up a little bit of a relationship with them and I think that's good because you feel, you feel more

reassured seeing the same person because you feel they understand you and

they've got to know you and em…when I first met her I couldn't stop crying cos I felt

so weird, talking about it was really difficult whereas towards the end it was a lot

easier" (monitoring-only [m] participant 2)

The befriending aspect of personal engagement alluded to in the quote above was very important and highly valued for a number of individuals interviewed:

"It wasn't like you was in a study, it was like you was sitting in your living room

having a conversation with a friend and have a brew with you or whatever, so,

without being a friend they was as close to it, you know for a while, and like

[therapist] came and visited me when I was in hospital and stuff like that, so, it just

helped me at the time to feel, felt like I belonged to somewhere… even if it's just one

person who cares you know it gives you something to fight for" (therapy [t]

participant 8)

Informality and normalisation

Our participants frequently identified the informal interpersonal approach of EDIE 2 staff as an important factor in their ability or willingness to maintain engagement with ongoing assessment and therapy processes. Participants most often characterised staff members' informal approach in terms of their use of 'everyday' language (rather than psychiatric terminology), non-catastrophic reactions to disclosures of unusual psychological experiences, and a flexible, collaborative

approach to making practical arrangements for meeting. The normalising effect of

staff members' empathic, understanding reactions to difficult or distressing

disclosures is reflected here:

Interviewer: "So if you felt that something you were saying was stupid or was

embarrassing or something, how did you find [therapist]'s reaction to those things?"

Participant: "She didn't, she wasn't like really shocked or anything…it's nice to have

someone, who gets it, you know like [therapist], like when you, to not be shocked

and to know why you're saying it and just, to feel normal" (t4)

'Opening up'

All participants described positive experiences of disclosing their personal concerns

in confidence with research assistants or therapists. For some participants, 'opening

up' primarily involved the disclosure of unusual or distressing psychological

experiences, while for others it involved the disclosure of very difficult life

experiences such as bullying or childhood trauma. Disclosure was commonly

described as difficult, but also as a crucial stage in the process of recovery:

I: "When you didn't get therapy, was that a bad thing for you? Were you

disappointed with that?"

P: "Er, no, no, not really"

I: "You weren't? Ok"

P: "No, I think it was more about, I just needed to, like, talk things through, really,

about myself, cos pretty much all my life I've kept things bottled up basically and…

think I just needed to talk about stuff and get stuff out of me" (m1)

In many cases participants were disclosing their primary concerns for the first time,

either because they had been unwilling to disclose those to family or friends for

fear of being seen as 'weird', or because they had habitually 'kept things to

themselves' over many years:

"The EDIE 2 people were the only people I felt like I could talk to, because I thought

like, I thought if I went to a doctor and said that, I always thought it was like what

you saw on Eastenders and that and that I was going to get arrested and put in a

padded call and I was never gonna get out again, and stuff, and I thought if I admit

that I'm going to be locked away and I'm never gonna see my family and friends

again, so the EDIE 2 people have been the only people I've felt like I could talk to"

(t7)

6.4.2 Monitoring

All participants had regularly met with a research assistant for monitoring

assessments and all described those experiences in generally positive terms, with

research assistants frequently referred to as personally supportive and practically

helpful (eg., by 'sign-posting' participants to relevant external agencies).

A therapeutic process

Although the monitoring arm of the trial functioned to offer a control condition comparison with the active treatment (CBT) group, a variety of therapeutic benefits for participants in the monitoring group were identified. Along with the non-specific therapeutic benefits of interpersonal engagement and assessments with staff mentioned above, both monitoring group participants interviewed also identified additional valued outcomes, such as improved mood, optimism, and perceived coping ability. For one participant, engagement with the monitoring process had contributed to a highly valued reduction of social anxiety:

I: "Do you think that the EDIE involvement and talking about these things, do you think all that has helped with the going out type stuff?"

P: "I think, yeah, I think it has improved, even just talking about it made me realise that…how stupid it sounds really"

I: "How do you mean, stupid? Stupid to say you were nervous outside or…"

P: "Yeah, like to people that don't know you, you're thinking that they're talking about you and stuff like that and when I started going out I just didn't think about it anymore I just like, carried, carried on doing what I was doing" (m1)

Clarity and reassurance

Many of our participants had worried that they were 'going mad', and the normalising effects of research assistants' calm, empathic responses to disclosures

of unusual psychological experiences were thought to have helped reduce this fear

(even among participants who also received CBT):

I: "Is there anything you kind of remember about those [monitoring] sessions that

was either helpful or unhelpful?"

P: "It was helpful with the trail of questions like, like I said, like the yes or no criteria

about what you were experiencing, feeling, and, then again it was getting that

realisation out and, stepping into normality a bit, you know, which, constantly being

asked about how you feel, like that, with somebody who is really supportive at the

same time, it does help" (t4)

For a number of participants, the fear of 'going mad' was also reduced with the

reassurance they gained from recognising that they had not reached the diagnostic

threshold for serious psychological conditions (such as psychosis or schizophrenia):

"I never expected it to be a wondercure, and that EDIE 2 at the end of it I was going

to feel normal again, but in terms of looking at the horrible side of mental health, I

feel as though they've confirmed that I'm not going down that road, and that's

helped me feel better inside I guess" (m2)

Challenges

The most frequently identified difficulty for participants during monitoring

assessments was the initial disclosure of their concerns (common to participants in

both arms of the trial). Finding the courage to discuss distressing psychological

experiences, often for the first time, was a significant challenge for many:

I: "Did you also mention when you started with EDIE about hearing things or feeling

unusual when you saw things, did you mention those as well?"

P: "Yeah, after a couple of weeks"

I: "It's interesting when you say em 'a couple of weeks', is it true to say that you

found it a bit difficult to talk about those things at first?"

P: "Yeah" (t3)

The primary challenge identified by one of our two 'monitoring-only' participants

was accepting and coping with the disappointment of not receiving therapy:

I: "How did you feel about not getting it? [CBT]"

P: "I was I suppose disappointed that I didn't get it because em I think because it

was linked to EDIE 2 and I felt they understood what I was going through, I felt that

any other therapy wouldn't be as good because they kind, they you know I felt they

were educated to know how maybe I could work through it" (m2)

6.4.3 CBT

Eight of the ten participants interviewed for this studied received CBT during the

EDIE 2 trial. While some participants were able to offer rich, detailed replies to

interview questions, others found it difficult to recall specific therapeutic processes

in detail, but all were able to describe aspects of CBT that had been helpful for

them, and these most frequently included collaborative agenda-setting, normalising processes, and re-appraisal of distressing experiences and beliefs.

'Learning to rethink things'

The primary value of receiving CBT for our participants may be characterised as 'learning to rethink things'. This theme draws from all CBT participants' accounts, and encompasses elements of common CBT-specific processes such as case formulation and reappraisal of distressing beliefs. 'Rethinking things' was usually based firstly on therapist-led formulation of difficult psychological experiences within either longitudinal or maintenance formats, usually in written diagrammatic form. These were frequently considered to be very helpful and normalising exercises, where psychological problems could be viewed as fundamentally understandable in the wider context of difficult life experiences (such as bullying, trauma, or social isolation) and personal beliefs about the self or others. An example of a helpful reappraisal following an analysis of a recent distressing situation is shown here:

I: "Can you remember if [therapist] did any kind of diagrams or wrote stuff down to explain thinking and"

P: "Yeah she did, yeah, behavioural patterns"

I: "Did you find any of that useful?"

P: "Yeah, I mean, like I was saying, that one, that one about that car following me, she went through it on a piece of paper, and then as soon as I left I thought well fair

enough you know what I mean, half of me could be right, and the other half could

be, just paranoid, and then I just, I settled down after that" (t1)

Secondary stages of 'rethinking things' were described as collaborative problem-specific evaluations of participants' difficulties. A number of CBT techniques were consistently highlighted by participants as the most useful, and these included 'evidence-gathering' and subsequent reappraisal of negative, unusual, or paranoid beliefs (along with reappraisal of potentially unhelpful 'safety behaviours' such as social withdrawal):

"I was able to start looking at myself, and start looking at that em, people weren't

necessarily thinking what I thought they was thinking and I can't read minds and

there could be a million and one other answers to the answer I've got in my head to

what people were possibly thinking you know, and that's what helped, what

[therapist] helped me to deal with" (t8)

'Hard work'

For most participants, some aspect of engagement with therapy proved to be difficult. One of the most frequently highlighted difficulties was the disclosure and discussion of unusual psychological experiences or difficult life experiences that continued to cause distress, embarrassment, or emotional pain:

"There were times when I spoke to [therapist], you know, and it's, you know, I was speaking about things from the past, and you know it brings it all back to you again, and there was times I left the session and you know my mood felt a bit low, but that's just because, you know bringing sh-t from the past, it's like a reminder" (t1)

However, as described above ('Opening up'), almost all participants recognised the importance of such disclosures and discussions for their therapy to be effective. In a number of cases participants also found engaging with home-work difficult because it meant continuing the difficult process of self-examination:

"I think what I struggled with was the fact that I was having to look at myself and em, and then there was like homework that came with it you know, and I struggled with that for a while purely and simply because I was having to look at myself" (t6)

'Moving forward'

The most consistent post-therapy change that our participants identified was an improved sense of understanding how or why their psychological difficulties had come about, and improved understanding of how they could cope with remaining difficulties for the long-term:

"Generally I think if I do have these problems again in the future em, like I say I am fairly sure I'll be able to deal with them, but again I know if, I've had enough sort of experience in them to know when I won't be able to deal with them but I think

generally it feels like the hard part's over now, I've got the, for lack of a better

phrase I've got the tools to fix the problems in future" (t5)

Participants also frequently identified improved social functioning as a valued

outcome of CBT involvement. In some cases this meant feeling more able to spend

time with family and friends, while for others it meant feeling more able to go out

into public spaces (including school, college, or work-places) when this had

previously been extremely difficult:

"It does help, it does help, that you're trying to rationalise it…when I'm out on the

streets and I'm getting paranoid, which I still do sometimes, don't get me wrong,

nowhere near as bad, at least I actually try and get out now, whereas at one point I

wouldn't even leave the house, but I think to myself, there's no reason for you to be

paranoid, it's the middle of the day, no-one's gonna jump out and get you, I'm just

using that to train my thoughts, and it does help definitely" (t1)

6.5 Discussion

This study explored subjective experiences of a group of participants in the EDIE 2

trial. We identified an over-arching theme evident in all interviews: 'A chance to

talk'. This represents the value participants attributed to interpersonal engagement

with trial staff, which was usually characterised in terms of informality, the use of

normalising, non-clinical language, and empathic, non-judgemental responses to

difficult disclosures. Further important themes emerged in relation to experiences

of Monitoring and Therapy in the trial. Monitoring assessments were most commonly valued for helping to clarify the extent of psychological difficulties, and for reducing the fear among participants that they were 'going mad'. A central theme, 'Learning to rethink things', emerged from discussions of Therapy (CBT). The most frequently valued CBT processes included individualised psychological formulations, normalisation and the evaluation of alternative appraisals of distressing beliefs and experiences. We also identified 'Hard work' as a common theme among therapy participants, usually related to the emotional cost of disclosing unusual psychological experiences and distressing life events. Finally, a range of recovery-related themes emerged from participants' accounts, and these included: improved psychosocial understanding of mental health difficulties; improved coping ability; improved social and occupational functioning; and improved optimism.

6.5.1 Comparison with existing research

There are no relevant qualitative studies with which to directly compare our participants' experiences of monitoring assessments in the trial. However the general importance of person-centred engagement is highlighted throughout qualitative research into Early Detection (ED) and Early Intervention (EI) for psychosis. Byrne and Morrison (2010) previously reported that participants from an ED service highly valued interpersonal interactions with service staff, especially their informality, use of normalising language, and collaborative approach to treatment. O'Toole et al. (2004) found that their EI participants primarily valued the

'human approach' to engagement and treatment, which was characterised as feeling listened to, understood, supported and cared for, and being involved in treatment decisions. Lester and colleagues' (2011) participants frequently described EI staff as having 'very positive personal qualities', such as being supportive, warm, and trustworthy. This study also highlighted the importance for service users of a youth-centred approach to engagement, and being offered frequent visits in low-stigma settings. Grealish et al. (2011) interviewed young clients from a Child And Adolescent Mental Health Service (CAMHS) with experience of psychosis, and also found that non-specific interpersonal factors in treatment were highly valued and likely to be clinically meaningful, and that engagement with sympathetic clinicians was often held to be a core element of recovery.

Central elements of CBT experience identified by our participants (formulation, normalisation, reappraisal) have also been highlighted in similar qualitative research. Hardy et al. (2009) found that CBT in an ED service was characterised in terms of normalisation, learning to rationalize negative thinking patterns, and improving coping strategies. Berry and Hayward (2011) synthesised eight qualitative studies of individual and group CBT for established psychosis and identified improved understanding of the onset of psychosis as a 'key ingredient' of CBT in five of the eight studies reviewed, while improved understanding of coping strategies was an important outcome for participants in seven of the eight studies reviewed. Processes of considering alternative explanations for psychotic phenomena were identified as important for participants in six of the eight studies. Normalisation was also identified as a key ingredient of CBT for psychosis, though it

was explicitly identified in only a minority of the studies reviewed. Importantly, non-specific factors in CBT for psychosis were also highlighted as beneficial in a number of the studies reviewed by Berry and Hayward (2011). For example McGowan et al. (2005) reported that for their participants, having difficult experiences listened to and taken seriously was very important.

Our findings have notable similarities with the quantitative outcomes of relevant CBT trials and studies examining therapeutic processes that mediate such outcomes (eg., Dunn and Bentall, 2007; Dunn et al., 2012). For example, several of the trials of CBT for at-risk participants have found an impact on psychotic symptoms, which may reflect the improved understanding, coping and optimism outlined here. EDIE 2 participants also identified notable benefits of the monitoring process, such as problem clarification, normalisation and reduced fear of impending 'madness'. This reduction in fear of psychotic experiences may explain why some of the trials have failed to show an effect on transition to psychosis, since catastrophic appraisals of unusual experiences are highlighted as an important factor in the development of psychosis in several cognitive models (Morrison, 2001; Garety et al., 2001). The evaluation of appraisals of psychotic experiences resulting from CBT that was identified as important by our participants supports quantitative research demonstrating that change in such appraisals within a clinical trial is associated with clinical outcomes (Morrison et al., 2012). The non-specific benefits highlighted in 'a chance to talk' clearly support the quantitative research showing the importance of the therapeutic relationship in the outcomes of CBT for psychosis (Dunn and Bentall, 2007).The emotional 'hard work' of CBT for psychosis has rarely been

described in the literature, though Morberg Pain et al. (2008) report that a number

of their participants experienced negative emotional reactions following case

formulations. McGowan et al. (2005) also report problems among participants with

understanding or remembering therapy (eg., inability to recall what elements of

therapy had worked or why) and Dunn et al. (2002) found that homework tasks in

particular were considered difficult due to problems with recall, motivation and

insight.

6.5.2 Methodological Limitations

There are several methodological limitations to our study, including a small sample

size, which clearly limits the generalisability of our findings. Although

generalisability is not usually the aim of qualitative research, this study would have

benefited from a more purposive sampling approach and greater recruitment of

participants from the monitoring arm of the trial, participants who left the trial

early (from either arm), and participants who made transition to psychosis. We

recruited only two participants from the monitoring condition and no participants

who had 'dropped-out' or made transition to psychosis, which suggests that

participants in those groups were either less inclined to volunteer for a further

interview, were no longer in contact with the research team or were not considered

to be suitable to approach (eg., due to acute distress or ethical considerations

regarding withdrawal of consent). This study would also have benefited from wider

recruitment in geographic terms (our participants were all drawn from the

Manchester trial site) and greater ethnic and cultural diversity among participants;

a qualitative study of CBT developed for individuals from minority ethnic

backgrounds (Rathod et al., 2010) suggested that it is important to recognise the

fundamental role that cultural background may play in shaping opinions about

psychological problems and mental health services, treatment priorities, and the

acceptability and likely success of a treatment like CBT.

6.5.3 Clinical Implications

There are several clinical implications that arise from our findings. Interpersonal

engagement is a crucial factor in the delivery of effective treatment for young

people at risk of psychosis. Disclosure of unusual psychological problems can be

very difficult, especially due to perceptions and experiences of psychosis-related

stigma (Birchwood et al., 2004; Hardy et al., 2009; Byrne and Morrison, 2010; Lester

et al., 2011). Clinicians and research staff should therefore aim to respond to such

disclosures with empathy, patience, and whenever possible, a normalising

approach to assessment and treatment. Many of our participants also disclosed

very distressing life events for the first time with EDIE 2 staff (including childhood

abuse, bullying and other traumas). Again, empathy and understanding may be

crucial for effective engagement in such cases, and there should be flexibility in

therapy to allow for an appropriate degree of discussion of such issues. Practical

flexibility was also valued by our participants, as it often is by service users in

general (Lester et al., 2011).

Our findings, along with the results of the EDIE 2 trial (Morrison et al., 2012),

suggest that supportive monitoring of young people at risk of psychosis may, for

some people, be an effective intervention in itself. Therapeutic attributes of the monitoring process (supportive listening, structured assessments, normalising language) may constitute active processes by which an individual's risk of developing psychosis can be reduced. One factor that was speculated to have contributed to the low transition rate in the monitoring condition in EDIE 2 (9%) was that it was more therapeutic than envisaged (Morrison et al., 2012); our qualitative findings would support this. CBT has been described by our participants in broadly positive terms; given the high rate of continued engagement with CBT during the trial, this suggests that CBT is a widely acceptable and relatively benign treatment for young people at risk of psychosis. The emotional and cognitive 'hard work' of CBT, along with other potential adverse effects such as stigma, should be more frequently acknowledged and evaluated by clinicians and researchers. For example, although service users often value and benefit from the disclosure and discussion of difficult issues within a therapeutic environment, this is not always the case, and there should be flexibility in the extent to which distressing disclosures are encouraged. In particular, substantial care should be taken by researchers and clinicians when addressing issues like childhood trauma, and follow-up checks should be undertaken to ensure the wellbeing of participants is monitored and where possible, additional support offered. Given that monitoring is clearly identified as having some benefits, and CBT is identified as having costs by some participants, it may be sensible for services delivering interventions to people at risk of psychosis to promote choice, offering monitoring and/or CBT to all.

Finally, our study was user-led, which was widely appreciated by our participants as normalising, encouraging, or inspiring. ED and EI service users may commonly believe that peers with similar difficulties will be more able to understand and empathise with them (Hardy et al., 2009; Tanskanen et al., 2011). Tanskanen et al. (2011) conclude that greater involvement of service users in Early Detection initiatives may be an effective way to normalise psychosis and reduce stigma-driven reluctance to contact services. One such possibility that may be worth exploring would be the involvement of peers in the monitoring process.

Chapter 7: Discussion

The aim of this chapter is to summarise the central findings from each study described, to relate these to the wider research literature, to highlight limitations and strengths of the studies presented here, and to suggest possible implications for clinical contexts and future research directions.

7.1 Summary of study findings

From the narrative review of the qualitative literature regarding preferences for treatment and priorities for outcomes, arguably the most notable finding was that qualitative evidence about such priorities and preferences directly identified by service users was remarkably scarce. However, several central outcome priorities and treatment preferences were identified, including improved social and functional ability and satisfaction, and reduced symptomatology as outcomes. Common treatment preferences included more person-centred, collaborative approaches to care and for adjuncts or alternatives to the traditional medical model of psychosis (eg., psychological therapy or psychosocial interventions).

From the Delphi study, it is apparent that participants most frequently prioritised difficulties with difficult emotions (paranoia, stress and anxiety) and cognitive difficulties (confusion and concentration/memory). The most frequently endorsed long-term priorities included improved understanding of mental health, coping ability, emotional wellbeing, and staying out of hospital. Commonly valued treatment preferences identified by the Delphi study included individualised care

and collaborative decision-making, along with greater information and treatment choice, privacy (when meeting with mental health staff), and age-appropriate care. The lower levels of consensus for other items highlighted the heterogeneity of opinion, which emphasises the need for more individualised approaches in terms of content and process of care delivery. The overlap between the themes identified in the qualitative literature on preferences and priorities and the expert opinion elicited in the Delphi study is striking.

In the Grounded Theory study of young people using ED services, three central themes were identified: difficulty with interpersonal relationships and reduced opportunities for helpful communication, difficulty talking to others about psychological problems, and experiences of talking to others about psychological problems. In addition, it was found that commonly held stigmatising ideas associated with unusual psychological experiences may contribute to a fear among at-risk individuals that they are 'going mad', and that this may lead to concealment of their difficulties, and to delayed help-seeking. Communication of psychological distress offered significant benefits, including improved psychological and emotional wellbeing and reduced risk of psychosis. Thus, while concealment of distress may directly impact on the development of unusual psychological difficulties, communication of such difficulties may be central to recovery.

In the Interpretive Phenomenological Analysis study of the subjective experience of receiving CBT for psychosis, the themes that emerged were 'person-centred' engagement, a process of structured learning, improving personal understanding of both psychosis and self, hard work (both practically and

emotionally), and recovery from psychosis. We found that participants most consistently valued shared control in therapy (ie., through collaboration), gaining improved understanding for long-term coping, and achieving social and functional recovery. In addition, normalisation in CBT appeared both as a discrete subtheme within the area of 'improved understanding' and throughout a variety of other discourses such as interpersonal engagement, the role of psychological formulation, and the development of acceptance in recovery.

In the Thematic Analysis study of participation in the EDIE-2 trial, an over-arching theme of 'A chance to talk' emerged, which showed the value participants attributed to interpersonal engagement with trial staff, which was usually characterised in terms of informality, the use of normalising, non-clinical language, and empathic, non-judgemental responses to difficult disclosures. Further important themes emerged in relation to experiences of Monitoring and Therapy in the trial. Monitoring assessments were most commonly valued for helping to clarify the extent of psychological difficulties, and for reducing the fear among participants that they were 'going mad'. A central theme, 'Learning to rethink things', emerged from discussions of Therapy (CBT). The most frequently valued CBT processes included individualised psychological formulations, normalisation and the evaluation of alternative appraisals of distressing beliefs and experiences. We also identified 'Hard work' as a common theme among therapy participants, usually related to the emotional cost of disclosing unusual psychological experiences and distressing life events. Finally, a range of recovery-related themes emerged from participants' accounts, and these included improved psychosocial understanding of

mental health difficulties, improved coping ability, improved social and occupational functioning, and improved optimism.

7.2 Integration of themes across studies

Over the five studies, a number of recurrent themes emerged. Interpersonal relationships, and the benefits of talking to someone about difficult issues, were clearly highlighted as important factors, both in the emergence and resolution of difficulties. This was less clearly demonstrated in the Delphi study, though participants did express a clear wish to be informed of different treatment options, which should routinely include access to counselling or therapy. Across all studies, the value of improved understanding of psychological difficulties was consistently highlighted. In the qualitative studies, this was evidenced particularly through participants' common appreciation of psychological formulation, suggesting that psychosocial rather than biomedical approaches to understanding psychosis may be valuable for many service users with psychosis-spectrum difficulties. Normalisation of distressing psychological experiences was also a valued theme evident across the three qualitative studies, and was indirectly evident in the Delphi study, with participants prioritising personalised rather than diagnostic treatment. Across studies it was also evident that people valued reductions in distressing symptoms (whether these were psychotic experiences or emotional issues) and social aspects of recovery (such as improved relationships and social functioning).

In terms of service organisation and delivery, several themes also emerged across the five studies. Important factors included collaborative relationships with

professionals, opportunities for involvement in decision making and the facilitation

of choices, and the adoption of an idiosyncratic, flexible and individualised

approach to understanding and care planning. The importance of identifying

idiosyncratic goals and the use of active coping methods to help with the

achievement of these goals also emerged as a recurrent theme. Finally, across the

three qualitative interview studies, there was recognition of the challenges and

hard work involved in the process of engaging in psychological therapy and striving

for recovery.

7.3 Comparison with existing literature

Findings from each study included in this thesis have been discussed in relation to

existing research literature in the body of each finished research article presented

above. A summary of the common themes identified among these findings, and

how they relate to the wider literature is presented here.

Firstly, the topic of interpersonal engagement emerged throughout all studies in a

number of ways. The general value of finding avenues for discussion about personal

distress, whether through participation in research or through clinical service use,

was consistently highlighted. Through the qualitative studies included here, for

example, participants from the Early Detection (ED) service, from the ED trial, and

from the CBT for psychosis study all identified the non-specific benefits of

interpersonal engagement with staff members as highly valued. Previous research

in these areas similarly shows that engagement may be important or even crucial

for effective treatment to be delivered. For example, O'Toole et al. (2004) describe

the importance of the 'human approach' for clients in an Early Intervention (EI)

team. Miles et al. (2007) found that participants' highest ratings of factors related

to satisfaction with CBT for psychosis were for therapist attributes, suggesting that

collaboration within CBTp along with "being able to talk to someone" were highly

valued. Grealish et al. (2011) found that their young participants identified being

listened to and understood as a central component in the process of their

engagement with staff, and with feeling empowered.

An important treatment preference found across studies and reported

directly by participants in three of the studies included here (the Delphi study, and

both Early Detection qualitative studies) is for the use of non-clinical, normalising

language rather than traditionally biomedical psychiatric language to describe and

discuss mental health issues. There are few established research findings in this

specific area with which to compare our findings, but qualitative studies conducted

with EI client groups, for example, have tended to report similar preferences for

informality in engagement with staff members (as above, see O'Toole et al., 2004;

Lester et al., 2011). A synthesis of qualitative studies of CBT for psychosis found

that normalisation of psychosis in general was an important ingredient of therapy

(Berry and Hayward, 2011). Research conducted to evaluate the impact of

psychiatric diagnosis has highlighted the potential negative effect of diagnostic and

biomedical terminology (eg., Pitt et al., 2009). Nonetheless, it is important to

acknowledge that while a preference for greater informality and non-clinical

language is shared among many mental health service users, other service users or

carers can and do prefer the use of medical terminology and clinical diagnoses; such terms and explanatory models may be welcome, and prove helpful for some.

Across studies there has been a common preference among research participants for greater consideration of individual priorities and preferences for treatment. This echoes similar findings identified throughout user-led and user-oriented qualitative research. For example, Pitt et al. (2007) interviewed individuals with experience of psychosis about recovery, and highlighted the importance of more individualised care plans for service users, while Lawn et al. (2007) found that participants valued self-management education tailored to them as individuals. This type of individualised treatment approach was reported to have contributed to a sense of empowerment among participants, where they could view themselves as equal partners and experts in the management of their health: "I always thought the doctor and social worker knew everything and that my opinions weren't important. After being asked these questions, I feel I can talk better about my illness and more openly now with my key worker. It would have been good to have been asked these questions years ago when I first got unwell" (Lawn et al., p.70).

As has been highlighted, a clear preference emerged among study participants for individualised, idiosyncratic formulation of their personal goals for treatment, though it is worth mentioning that some consensus has been identified through the studies included here for particular treatment outcomes. For example, improved social functioning and reduced symptomatology (psychotic and mood-related) were identified as important through the initial literature review included here, and throughout the qualitative studies reported. Among the relatively few

existing research studies concerned with evaluating service users' priorities for treatment, these same outcomes are also frequently identified (eg., de Haan et al., 2001; Rosenheck et al., 2005).

The most distinct findings to emerge from this body of work may be those related to CBT for psychosis. There is consistency in participants' accounts of valued aspects of CBT, and in their identification of CBT as a potentially challenging process. There is also an increasingly substantial body of existing research literature with which to compare the findings reported here. For example, in addition to the value participants attributed to consideration of their treatment priorities across all studies, in the CBT studies specifically, the actively collaborative approach of CBT therapists was highly valued and appreciated, and this appears to be an area with clear consensus across qualitative studies of CBT (Berry and Hayward, 2011), and studies of the EI treatment approach (Theuma et al., 2007).

It is also important to note that while non-specific elements of therapeutic engagement, including collaborative working, were highly valued by participants, a number of specific CBT strategies also emerged across the qualitative studies included here, and these findings are supported by the existing literature in this area, including both qualitative studies and recent research publications examining outcomes of CBT for psychosis in clinical trials. For example, case formulation, active normalisation of psychosis, and processes of generating alternative appraisals of psychotic phenomena have been identified as key elements throughout qualitative research studies into CBT for psychosis (Messari and Hallam, 2003; Newton et al., 2007; Berry and Hayward, 2011). From trial-based, statistical

findings, it has also been shown that while general engagement processes are highly valued (and may in some cases be highly effective), the most successful CBT for psychosis involves the delivery of full courses of therapy which include specific cognitive and behavioural techniques (Dunn et al., 2012). Interestingly however, a study conducted with participants included in a different trial of CBT for psychosis has found that more general therapy skills were important for participants' positive experiences of therapeutic alliance, contentment, and control in therapy; specific technical CBT skills were negatively associated with these factors, and that in fact technical skills, such as guided discovery, could detrimentally affect the therapeutic relationship (Wittorf et al., 2013). This variation in research findings in relation to effective aspects CBT for psychosis, and the continued relative scarcity of established understanding of these factors, certainly prompts further research in this area.

7.4 Limitations of studies

There were a number of limitations in the design and conduct of the Delphi study (Chapter 3). The participant sample size was relatively small, and this limits the generalisability of the results for a number of reasons. Firstly, recruiting participants through online social-network media may have excluded some potential participants. For example, people with psychosis or schizophrenia may be economically disadvantaged (Lester et al., 2011) and therefore may not have private access to the internet. Individuals from older age-groups may be less likely to access social-networking media, while some people in our target population, regardless of

access or age, may not have been comfortable participating in this kind of study over the Internet. Secondly, it is also possible that our participant group, primarily recruited via the Rethink charity, represent a biased sample, as their attitudes and input could have been influenced or enriched in particular ways through their interest or involvement with Rethink. Additionally, had the study recruited a larger, more representative participant group, it may have been possible to identify significant differences in treatment priorities and preferences between groups of participants, or between participants at different stages of recovery.

The use of the Delphi method for this type of research may represent a more fundamental limitation. There may be an inherent difficulty in using the Delphi method to seek consensus among service users, while emphasising the importance of individual priorities and preferences for treatment. A research process that seeks to establish consensus for treatment factors among service users could be very useful as there may be more significant differences between the priorities of service users and mental health professionals than within groups of service users. However, the Delphi method approach of including or excluding individual survey items according to group ratings is problematic in this context, as small differences in group ratings for specific items can lead to their exclusion from reported results, even when those items have been rated 'essential' or 'most important' by many participants. In addition to the established Delphi-method analysis described in Chapter 3 above (ie., measurement of group percentages and ordinal ranking), a secondary analysis of the data was also undertaken by calculating individual mean Likert-scale ratings for each survey item, and this re-

analysis produced small but notable changes to our findings. For example, two treatment priorities excluded from the final statement set (depression, and medication side-effects) were found to have higher mean scores than one item that was included (concentration/memory; see Table 2., p.130). Three statements relating to treatment preferences were similarly excluded in the first analysis, but rated more highly than three included statements when individual mean scores were calculated (meetings with a counsellor or therapist, focus on non-psychosis issues such as depression or anxiety, and choice to speak to either male or female staff). These statistically small but individually significant differences between alternative analyses of the same data set suggest that it is important to consider how such survey data are analysed, as alternative analyses may highlight, or neglect, important treatment factors prioritised by groups of participants or by individual service users.

Each of the three qualitative interview studies included have recruited relatively small samples of participants (between 8 and 10 per study), and this is the clearest limitation for the generalizability of results. However these sample sizes were considered appropriate for the conduct of meaningful studies of the topics investigated, and were designed in accordance with well-established and common practices among qualitative researchers (Strauss and Corbin, 1998; Smith et al., 2009). However it may have been desirable to have more systematically pre-defined and recorded intended and actual recruitment, and the relative representativeness of intended and actual sample sizes in the context of the wider

groups of participants from which interviewees were drawn. In the case of the ED

trial study in particular, although recruitment numbers were in line with lower

estimates of the stated recruitment target ("between 10 and 12 participants"), the

significant imbalance between participants recruited from the treatment and

control arms of the trial (8 and 2 respectively) suggests, again, that a more

systematic and purposive sampling approach would have yielded greater validity for

this study. Nonetheless, qualitative research is not intended to produce widely

generalisable evidence, but rather to explore and illuminate individual lived

experiences. The relatively small numbers of participants usually recruited to

similar studies are not being asked to take part in research in the same way that

participants in clinical trials are, for example. The aim of qualitative research is to

explore topic areas in more depth and with more flexibility than is possible in

quantitative research; the aim is to gain an 'insider' perspective of participants'

lived experience through collection and analysis of subjective accounts and

narratives. This is considered a valuable and complimentary addition to the kind of

population-wide generalisability produced in large-scale research trials, as in-depth

evaluations of phenomena or experience can often help to explain empirical

research findings. As such, while the numbers of participants recruited to

qualitative interview studies were small, study sample sizes were in line with

sample sizes reported throughout similar research in this area (eg., O'Toole et al.,

2004, n=12; Pitt et al., 2007, n=7; Harris et al., 2012, n=8). The clearest limitation of

the Delphi study is also the relatively small sample size. A larger sample would have

improved the validity and generalisability of the results, and would enable the

identification of any important differences between groups of participants (such as the preferences of younger and older individuals, men and women, and different diagnostic groups).

Although sample sizes reported above may have been appropriate for the nature of these studies, there were limitations in the way the respective participant groups were selected and recruited. Across all three studies, convenience sampling was employed, primarily for a variety of practical reasons, and this limits the confidence with which it is possible to infer the validity of participants' accounts as representative of their respective peer-group. For example, in the first study (Early Detection service) recruitment was limited in general to a small group of individuals with experience of a single clinical team, and limited further by the research aim of interviewing those service users who had completed a course of CBT during their involvement with the service. This meant that to attain the intended sample size (8-10) it was necessary to recruit all willing individuals for participation rather than employing a more purposive sampling process to ensure recruitment of a reliably representative sample of the population group.

Recruitment for the second study reported above (CBT for psychosis) was conducted in a similar manner. Recruitment for this study was not limited in the same way as the first study (ie., limited to one clinical service); in practice there was a much larger pool of potential participants from which to recruit (via local EI and Community Mental Health teams), yet as in the first study the study sample size was intended to be small, in order to apply an appropriate methodology (Interpretive Phenomenological Analysis). As the study was intended to be

exploratory, it was not considered necessary to recruit participants through a purposive or selective process. While this consideration was appropriate, and though participants' accounts contributed to valuable findings, it must still be recognised that it is possible that a more deliberate sampling approach could have yielded a more complex understanding of participants' experiences of CBT for psychosis. For example, a number of specific factors and processes involved in CBT for psychosis have been identified as being particularly important in the attainment of good outcomes (eg., completion of homework tasks, completion of longer courses of therapy) so it may have been beneficial to have recruited participants with the aim of interviewing individuals with a range of perspectives and experiences in those areas.

The third qualitative interview study reported here also relied on convenience sampling, and in this case this approach did amount to a substantial limitation of the research design, and substantially limited the validity of research findings. This was a study of subjective experiences of participation in a randomised clinical trial ('EDIE 2') and as such was intended to draw from an appropriately wide range of participant experiences (eg., to explore comparisons between those randomised to the treatment and control arms of the trial). However in practice, a purposive sampling approach was not rigorously applied, and the study recruited a disproportionate number of individuals from the treatment (CBT) arm of the trial. The central implication of this limitation is that participants who received CBT were more willing to take part in an interview about their experiences (as a 'self-selected' sample), suggesting that those who did not were less satisfied with their

involvement, and reluctant or unmotivated to discuss it. While qualitative

investigations of participants' experiences in research 'control groups' are not

addressing the active treatment being evaluated, they are important to consider as

participants in those groups could be exposed to negative effects of being involved

in the research (effects related to mood, or willingness to engage with mental

health professionals).

It is frequently reported in similar qualitative research that the recruitment

of individuals with the most negative experiences is most difficult. The three studies

outlined here share this limitation. The convenience sampling process described

above did not succeed in recruiting significant numbers of participants with

negative experiences of mental health treatment or research involvement, and this

has been acknowledged explicitly. Although the importance of recruiting

participants with negative or critical perspectives was increasingly recognised over

the course of the study period, few references to negative attributes of CBT for

example, were evident in the existing literature, and so were not prioritised as

effectively as would have been ideal. In hindsight it is clear that stronger efforts to

recruit therapy clients or research participants who discontinued their involvement,

or whose condition worsened during their involvement, could have elicited very

important insight into less-than-ideal experiences of treatment or research.

Other limitations in terms of the samples in these studies included non-

representativeness and a lack of diversity in terms of gender, age, ethnicity and

geography. Such qualitative approaches do not aim to be generalizable, and some

specifically aim to recruit homogenous samples to increase the likelihood of

coherent themes emerging. Nonetheless, there is well established evidence that socioeconomic factors can directly influence the development of psychosis. For example there is a greater risk of receiving a schizophrenia diagnosis among individuals from ethnic minority groups (Fearon et al., 2006; Bresnahan et al., 2007), while urban living has also been consistently implicated in increased risk for psychosis (Pedersen and Mortensen, 2001; van Os et al., 2001). A recent qualitative study focusing on the cultural acceptability of CBT for psychosis among individuals from ethnic minority groups reported that African-Caribbean and Black African participants have higher drop-out rates and poorer outcomes from treatment (Rathod et al., 2010). The authors conclude by suggesting that greater attention be paid to the development of culturally-sensitive CBT approaches that acknowledge variety in culturally-based health beliefs, attributions concerning psychosis, attention to help seeking pathways, and technical adjustments.

It is also important to acknowledge the possibility that the interview schedules produced for the three qualitative interview studies included questions that were too directional or leading, and therefore may have been a source of researcher bias. Grounded Theory (GT), for example, is fundamentally predicated on the concept of generating analytic codes free from the influence of any predetermined standpoint or preconceived hypotheses, and on the use of open-ended questioning to allow participants to answer questions fully and in their own terms (Glaser and Strauss, 1967). However some of the questions included in the interview schedule for the GT study included here (Chapter 4), for example, were not open-ended; questions such as - *"Have you chosen not to tell people [about*

psychological difficulties], or has it been too difficult to talk about?" - offer only two

avenues for participants' replies. In addition this question presumes that all

participants have found it difficult to talk to others about their psychological

difficulties, which may not have been the case (in practice though, difficulty

disclosing psychological concerns *was* common to all participants). Although in

practice the directional nature of such questions did not preclude participants from

discussing their experiences openly and in depth, they were not open-ended and

therefore inconsistent with the fundamental principles of GT methodology. On

reflection, it would have been preferable to have reframed the same question in

this way: *"Could you tell me how you have found talking to others or not talking to*

others about psychological concerns or difficulties?". Similarly, other questions in

the same interview schedule such as – *"Have you felt it's been helpful to speak to*

the EDIT people?" – can be seen as potentially leading. The question is, again, not

open-ended, and in this case may also have implicitly directed interviewees towards

a particular response (ie., a positive reflection of their experience with the EDIT

service's staff). An appropriately open-ended, non-directional way of asking this

question might have been worded as follows: *"Could you tell me how you have*

found speaking to the EDIT staff?". Along with the immediate impact these factors

could have had on the tone, depth, and content of participants' interview

responses, the potentially directional or leading nature of questions such as these

may also have affected or influenced the coding of interview data and the resultant

themes generated from this process. While it is necessary to pre-determine at least

a basic focus for GT interview questions (Charmaz, 2006), it is also possible for

interview schedules to 'force' the data they elicit (Glaser, 1998), thereby resulting in findings in line with the researcher's implicit expectations. It is possible that this occurred to some degree in the conduct and analysis of the GT and other qualitative studies reported here.

7.4.1 Potential researcher bias

Researcher bias is another issue that may limit the generalisability and validity of the findings. For example, within the IPA study, having interviewers who had first-hand experience of psychosis and CBT may have increased the likelihood of specific biases in either the tone or content of the interviews. In particular, it is possible that a user-researcher with positive personal experience of CBT may have conducted interviews and analysis differently than, for example, a user-researcher with negative experiences of CBT. It is also important to acknowledge that user-researchers for this study were white Irish or British males, and this may also have impacted on research conduct and on personal interactions between interviewers and interviewees. It is possible, for example, that female interviewees would have preferred to speak to female interviewers and may have engaged differently with the interview process if offered the choice. Likewise, participants from ethnic minority backgrounds might prefer to speak with interviewers with shared cultural identities, and again, may engage differently with interviews given that opportunity. As Rathod et al. (2010) argue, culturally-bound factors may influence the way individuals perceive or respond to therapeutic processes. This suggests that cultural influences and the presence or lack of shared cultural identity may also

impact on the way individuals from different ethnic or cultural backgrounds engage with interviews about therapy. Callard and Rose (2010), discussing user-involvement in research, affirm that it is essential to attend to the heterogeneity among service users (ie., differences in gender, ethnicity, age, sexuality). In the present body of work then, it is important to recognise the specificity, personal nature, and relative homogeneity of the potential user-oriented bias described.

The collective standpoint of the wider research team as proponents of CBT for people with psychosis may have increased the likelihood that a positive bias towards CBT could have influenced our analysis of participants' accounts. However, we did seek to minimise this risk via individual and team discussion of such issues, awareness of our own biases during analysis, and explicitly seeking negative or unfavourable information throughout the interviews and analytic process. For example, interview schedules incorporated specific prompts for unwanted effects of CBT, any negative memories or experiences associated with the therapeutic process, and for participants' suggestions for improving the therapy process. Similarly, participants were reminded that their responses were confidential and would not be shared with their therapist.

The question of potential personal bias arises due to the lived experience of the author, who has in the past sought mental health treatment (including CBT) for psychosis-like experiences and related difficulties. As has been highlighted above, mental health service users are a widely heterogenous group, with a wide range of opinions related to research and treatment. An individual service user cannot adequately represent the personal priorities and preferences of even one sub-

group of service users, and may in fact hold personal opinions that other service users directly dispute. As such, it's important for the author to disclose that in his case, personal experience of CBT to prevent psychosis preceded employment as a user-researcher working within the context of a psychosocially-oriented team of research and clinical psychologists.

The author has been and remains a member of several research teams conducting clinical trials of CBT for psychosis or the prevention of psychosis without the use of antipsychotic medication (the EDIE 2 and ACTION trials; Morrison et al. 2012; Morrison, et al., 2014), and supports increased delivery of CBT to mental health service users. It is possible that this standpoint could mediate the degree to which critical or negative appraisals of CBT or other psychosocial approaches have been analysed and/or reported in this body of work. However, it is equally true that throughout the research process, the author has been encouraged (through academic supervision) and has endeavoured to focus on potentially negative aspects of CBT (including inefficacy) as much as possible, and to elicit participants' perspectives in an open, inquisitive way. This has been considered important as insight into aspects of CBT perceived by participants as unhelpful or harmful may be crucial in the ongoing development of such treatments. Adopting a standpoint of genuine curiosity throughout the research process has also been motivated by a recognition of the need for active reflexivity on the part of qualitative researchers: "the capacity of the researcher to acknowledge how their own experiences and contexts inform the process and outcomes of inquiry" (Etherington, 2004, p31). Researcher reflexivity is particularly important in the analysis and interpretation of

qualitative data, where preconceived ideas and assumptions may influence researchers' roles in the analytic process (Henwood and Pidgeon, 1997; Devine and Heath, 1999; Olesen et al., 1994).

In practice, the author has undertaken an increasingly complex, ongoing process of reflexivity in the development and conduct of this body of research. It is worth noting, for example, that the first of the three qualitative studies presented here used a Grounded Theory method, where there is an expectation for the research approach to remain dynamic and flexible, and so the author became familiar with the need for active reflexivity at an early stage of the wider research process. From the outset, the author's role as a user-researcher has been explicitly acknowledged as a potential material influence in the conduct and outcome of interviews, as has his position as a member of research teams from which interview participants were recruited, both in discussion with individual participants and in the presentation of study findings (ie., in the writing of journal articles and in conference presentations).

These latter discussion contexts have also contributed to the researcher's active reflexivity. Constructive critiques of the research presented here have enabled the author to routinely reflect on the strengths and limitations of both the research produced, and the research context in which it was produced. For example, for each of the three qualitative studies presented here, participant groups have tended to be 'self-selected' (ie., individuals willing to talk about experiences of CBT with a member of the CBT research group), and therefore more likely to have had positive experiences and perceptions of therapy. As this is rightly

considered a limitation of each qualitative study, it has been highlighted

consistently throughout iterative study review processes and conference

presentation feedback. In turn this has prompted the author to increasingly

consider the implications of recruiting self-selecting samples for the validity and

reliability of study findings, and to actively consider ways of addressing this problem

(for example, by asking those who refer participants to stress the value for the

research of eliciting both positive and negative perceptions of CBT). As mentioned

above, the author has been situated within a CBT-oriented research milieu

throughout the process described, so it could be suggested that the wider research

team may have been reluctant to facilitate, record, and publicise negative feedback

about their work; however in practice this has not been the case. Both in local

terms, and in interactions with the wider CBT research community (eg., at

international conferences), presentation and discussion of any negative qualitative

evidence has been welcomed as important and instructive. Most recently the

author, along with his supervisor and a number of colleagues, have endeavoured to

improve our measurement and understanding of potential adverse effects of CBT

for psychosis as these are not yet well understood. This area of investigation has

recently been addressed through, for example, the development of a research tool

to record participants' reasons for discontinuing CBT in the context of an ongoing

clinical trial (the FOCUS trial of CBT for 'treatment-resistant' psychosis), and in a

presentation and discussion of potential adverse effects of CBT for psychosis by the

author at a national conference of behavioural and cognitive psychotherapy

adherents (BABCP, London, 2013). The author notes that to his knowledge this was the first presentation of its type at this well-established annual conference.

Reflecting on the limitations of the research related to potential researcher bias, a more systematic approach to reflexive note-keeping and memo-writing would have been beneficial. For example, making use of the NVivo software programme for analysis of qualitative data would have improved the quality of descriptions of the analytic processes undertaken, including more detailed summaries of memo-writing and coding processes. In practice, these processes were undertaken regularly and under academic supervision, but were not recorded as systematically as would have been the case if the author had employed NVivo or recorded reflexive notes in a single permanent document or journal. Additional approaches to addressing potential researcher bias and validating findings could have included more systematic recording of discussions of findings with a local Service User Reference Group (SURG), and matching of sample interview quotes to emergent themes by independent raters. It is also important to link each of these strategies to the particular methodology employed in each study. For example it would be appropriate to consult the SURG group for refinement of emerging themes in an Interpretive Phenomenological Analysis (IPA) study, but less so for a Thematic Analysis (TA) study, as IPA facilitates an active role for researchers in the interpretation and analysis of data, while TA aims to produce findings directly reflective of the data collected. Without these tasks having been undertaken with sufficient consistency and rigour, it must be acknowledged that the low demonstrable evidence of active reflexivity is a limitation of the findings and

synthesis of findings reported here. Future qualitative research projects should incorporate the approaches to recording and reporting processes of active reflexivity described above.

7.5 Strengths of the research

Perhaps the primary strength of the body of research outlined above is that is has been user-led throughout. As has been highlighted throughout this thesis, there have been increasing calls for the inclusion of those with lived experience of mental health difficulties in research processes for some time, and so each new addition to user-led research in this area represents a step towards greater formal recognition of service users as active and able researchers.

More specifically, it is hoped that a number of the positive attributes of user-led research described in the introductory chapter above, and elsewhere, have been realised in this body of work. For example, given that service users and mental health professionals often have very different perspectives and priorities (eg., Bailey et al., 2012), it is hoped that the relevance to other service users of the research studies included here has been enhanced. In particular, the initial literature review and subsequent Delphi study aimed to establish a user-oriented understanding of the relative importance of service users' priorities and preferences for treatment of psychosis. While these may be exploratory rather than definitive studies, it is hoped that they contribute meaningfully to a more user-oriented understanding of the variety, breadth and complexity of individual priorities in this area.

Similarly it is hoped that the questions asked during qualitative interviews have been meaningfully formulated to capture aspects of lived experience most relevant to participants, while still attending to areas of importance for the wider research question. This may be considered a strength of qualitative research in general; as traditional empirical research aims to test and analyse specific, pre-determined research questions, areas of experiential interest that fall outside the stated hypotheses in question are usually not analysed, and therefore important aspects of the research process may not be well understood.

It is hoped that by exploring subjective experiences of CBT through the current body of research, the researcher has given voice to participants' subjective experiences and perceptions, while also eliciting valuable insight to help illuminate professional researchers' understanding of current and future trial results. Literature in this area certainly suggests that user-interviewers are likely to elicit more open responses from participants (Catania et al., 1996; Szmukler, 2009), and that non-specific aspects of peer-to-peer engagement may be important for the disclosure of private and sensitive information (Riphahn and Serfling, 2005). Importantly for research into the effectiveness of CBT for psychosis, where there is little established understanding of negative aspects of the treatment, user-researchers may also elicit more critical feedback than non-user interviewers when investigating participant satisfaction with their treatment (Gillard and Stacey, 2005).

Overall, the literature review and subsequent studies included in this thesis could be said to embody a 'mixed methods' approach to research, with the varied

attributes of review, quantitative measurement (ie., Delphi study), and qualitative evaluation, each contributing to an holistic examination of the research area. It is suggested that the value of this mixed methods approach can be seen in the clarity of service user/research participant opinion that emerges across studies. In brief, it has been shown that there are common preferences across participant groups for more choice in treatment, including psychologically-oriented treatment approaches for psychosis and schizophrenia, for better information and decision-making ability in relation to varied treatment types, for a decrease in the use of psychiatric language and terminology among mental health professionals, for more normalising language in clinical practice, and for improved and increased provision of psychological therapy to treat or prevent psychosis.

7.6 Clinical implications

Findings from the research presented here suggest a number of implications for clinical practice. Drawing from the initial literature review and the studies identified therein, and from the results of the Delphi study, it is firstly evident that people accessing mental health services for help with psychosis or schizophrenia make up a widely heterogenous group of individuals, with a wide range of individual priorities and preferences for treatment. When individuals among this population have been consulted to assess their personal priorities and preferences, it has been commonly found that rather than collectively endorsing any one treatment approach or model, consulted participants have tended to endorse approaches that respect

their differences and that allow for greater choice in treatment and more
individualised care (eg., Pitt et al., 2007).

A key example of this desire for more individualised care is in the
determination of treatment outcomes. While mental health professionals working
in this area have traditionally focused on psychiatric treatment of the positive
symptoms of psychosis (such as hearing voices, or holding unusual beliefs), many
people who actually experience these phenomena would prefer that professional
attention was directed firstly at reducing, for example, anxiety or depression, or
improving, for example, social functioning or practical difficulties such as distress
related to housing or financial problems. Clinicians working in this area should
therefore consider the relative priorities of their clients or patients when
establishing therapeutic relationships, and allow for flexibility in their decision-
making. For example it may be helpful in practice to acknowledge the limitations of
current diagnosis-led psychiatric treatment (Bentall, 2009) and to explore the
strengths of alternative approaches such as psychological formulation. The Division
of Clinical Psychology (DCP) in the UK has argued that professionals and other
mental health workers "should not insist that all service users accept any one
particular framework of understanding… such as [that] hearing voices and holding
unusual beliefs are always symptoms of an underlying 'illness'… [They] should
respect and work collaboratively with the service user's frame of reference" (DCP,
2001, p.59). The DCP have recently reaffirmed this proposal for more individualised
treatment, calling for a paradigm shift away from psychiatric diagnoses towards a
conceptual system not based on a disease model (DCP, 2013), and psychological

formulation has been suggested as a viable alternative to the existing diagnostic

approach (Johnstone and Dallos, 2006). In brief, psychological formulations treat

individual cases in fundamentally individualised ways by identifying each person's

psychological concerns, how these may be related to the person's lived experience

and the personal meanings ascribed to these experiences, and by suggesting a

treatment approach based on the psychological processes and maintenance factors

identified through this process (Johnstone and Dallos, 2006).

It is recommended that prescribing clinicians consider the relative costs and

benefits of prescribing powerful antipsychotic medications, as these may impact

negatively on their clients or patients without offering valued benefits. For example

such medications may impact harmfully on an individual's physical wellbeing, or

reduce their motivation for social interaction, while also failing to reduce distress

related to positive symptomatology (Morrison et al., 2012; Bailey et al., 2012).

Given the considerable risk of harmful side-effects conferred by prescription of

antipsychotic medication, it is also worth reiterating the established

recommendation that clinical teams in the UK more routinely offer access to

psychological therapy for psychosis, especially CBT (NICE, 2013; 2014). This is

already recommended as a first treatment for young people at risk of psychosis,

and indeed a recent clinical study, the first of its kind, has shown that CBT may be

an effective treatment for established psychosis among people not taking

antipsychotics (Morrison et al., 2014).

Additionally it is recommended that mental health services more regularly

and routinely consult their clients to evaluate the effectiveness of these decision-

making processes, as tailoring treatment to individual preferences should enhance engagement with services and regular re-iterations of such audit processes should yield valuable insight into the relative value of the treatments offered. Further, as researchers have increasingly included those with lived experience of mental health difficulties in the development and conduct of research, so clinical service commissioners and managers should increasingly involve service users in the planning and development of their services. Considering the benefits of user involvement highlighted throughout this thesis (eg., enhanced insight into subjective experiences of psychosis and treatment, greater consideration for user-oriented priorities), it is clear that greater consultation with and inclusion of service users in commissioning and clinical teams is likely to yield valuable benefits, not least of which would be the message delivered to the wider service user community that our voice is being heard and respected.

7.7 Future research

The first suggestion for future research conducted in this topic area is for greater inclusion of those with lived experience of psychosis in research design and development. It has been shown throughout this thesis that user-oriented research priorities may differ from and enhance traditionally academic/professional-led research aims, and that user-led research has been empirically evaluated as a valuable addition to mainstream research (eg., enhancing the richness of qualitative data elicited during interviews). There are a variety of avenues for recruitment of user-collaborators and researchers, and readers are invited to consider these in

their own work. For example, for small-scale projects it may be most useful to consider convening user-oriented focus groups or reference groups to generate or refine new research ideas. For larger or longer-term research projects, such as clinical trials, it may be advantageous to employ user-researchers as collaborators, with more wide-ranging roles integrated throughout the research process (eg., overseeing study design, consideration of ethical concerns, staff recruitment processes). Depending on the scale, demands and aims of these types of user-involvement, it will also be beneficial to consider the professional development or training needs of user-partners; while inclusion of user-collaborators in itself represents an improvement on 'business as usual', without adequate relevant training where necessary, user-collaborators may not feel equipped to contribute optimally.

Secondly, it is suggested that more general processes of consultation are conducted more commonly in this area of research (mental health treatment for psychosis). Surveys or Delphi-type studies of service users' priorities and preferences for treatment are still surprisingly rare, when it is clear that improved understanding of individuals' needs and goals is likely to considerably improve effective treatment provision, and engagement with treatment. Indeed the recent UK-based Schizophrenia Commission (2012) recommended "greater partnership and shared decision-making with service users – valuing their experiences and making their preferences central to a recovery focused approach adopted by all services".

In relation to the qualitative dimension of this body of research, it is suggested that further similar studies are conducted to further explore and refine the topic areas and findings described. For example, as the bulk of studies included above have focused on experiences of CBT for psychosis, it would be useful to evaluate the validity of findings reported here through further exploration of effective or valued elements of CBT experience. Although CBT for psychosis has been delivered for over twenty years, the specific mechanisms that effect positive change are not yet fully understood, and similarly it is not well understood if there are particular sub-groups of CBT recipients who are more or less likely to benefit than others. It is especially important to further explore negative experiences of CBT or possible adverse effects of CBT involvement, as these are perhaps the least-well understood area reported to date. It could also be very useful to explore the topic areas discussed here through quantitative means; that is, to test the validity of findings through questionnaire or survey methods. It is likely that such methodologies could also be utilised among much larger population samples, and so enhance the generalizability of findings from qualitative research studies.

Along with future research into CBT for psychosis, qualitative evaluations of other treatment approaches would be valuable. As treatment for psychosis is primarily delivered through antipsychotic medication, and given that findings reported in this thesis demonstrate service users' preference for access to alternative treatments, greater qualitative understanding of experiences of taking antipsychotics including perceived benefits, adverse effects, and decision-making in refusal or discontinuation should be prioritised (Salomon and Hamilton, 2013;

Lorem et al., 2014). Clinicians, researchers, and not least service users may also benefit from further future qualitative studies of psychiatric hospitalisation, along with evaluations of subjective experiences of alternative residential treatment approaches (eg., the Soteria approach), and non-statutory, user-led initiatives such as Hearing Voices groups. As findings from the present body of work indicate common service user preferences for individualised, collaborative care, for talking therapies, and for treatment conducted outside of medical contexts, these latter research areas may prove particularly fruitful.

All studies included in this thesis highlight the value for service users of increased understanding of psychological difficulties, especially 'unusual' or psychotic phenomena, and all qualitative studies identified normalisation of psychosis as a valued attribute of CBT involvement. It could be enlightening and beneficial to evaluate these factors more systematically in future research. For example, future evaluations of effective psychoeducation may be helpful in determining the best way or ways to deliver this to service users (in person, in groups, or online; via professional intervention or 'peer-to-peer'). The impact of causal beliefs on the onset and maintenance of psychosis as well as response to treatment (Freeman et al. 2013) and help-seeking (Yang and Wonpat-Borja, 2012) should be further examined, and the process of normalisation, a potentially key ingredient in successful reduction of psychosis-related distress, should be further explored. This last area may also be useful in efforts to combat psychosis-related stigma, which remains a significant cause of distress and reluctance to seek help among those experiencing 'unusual' or psychotic phenomena.

The importance of interpersonal experiences of qualitative study participants in this thesis (negative experiences such as bereavement, bullying, trauma, and isolation, and positive experiences such as empathic, supportive engagement offered by therapists and research assistants) suggests that it will be important for future research to explore these areas more thoroughly. Firstly, given the prevalence of experienced adversity among the wider population of those who experience psychosis, particularly trauma (Read et al., 2014), it will be important to continue to evaluate in greater complexity the role of negative life experiences in psychological or physiological processes involved in the development and maintenance of psychotic experiences. Secondly, the therapeutic value of successful interpersonal engagement could be more comprehensively examined, as promising approaches in this area (eg., Bucci et al., 2014) suggest that greater recognition and understanding of interpersonal factors may be key to improving mental health service delivery.

7.8 Conclusions

The author of this thesis, drawing on personal experience of psychosis-like phenomena and of various mental health treatment approaches (including CBT), aimed to explore the subjective experiences, and the treatment priorities and preferences, of people with lived experience of psychosis or psychosis-like phenomena, and to contribute original work to the growing body of research literature in this area. The degree to which this effort has succeeded is for the reader to decide. What is clear from the findings reported and discussed through

the body of work above, is that the primary treatment approach examined in this

work (CBT) represents a valued example of an alternative to traditional psychiatric

treatment that is very much welcomed by service users, who have for too long

been considered unable to engage with or benefit from such therapeutic processes.

The author hopes that with current and future developments of the CBT approach,

and psychosocial understanding of psychosis in general, we who benefit from such

advances will continue to find a place in mental health research to voice our

concerns and our hopes, and to be heard.

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Appendices

Appendix 1. Chapter 3: Delphi study of priorities and preferences for treatment of psychosis: participant characteristics

Personal characteristics	Stage 2, n =32	Stage 3, n = 21
Age		
16 – 19	6.3%	5.0%
20 – 29	28.1%	30.0%
30 – 39	31.3%	25.0%
40 – 49	21.9%	20.0%
50 – 59	6.3%	15.0%
60 or older	6.3%	5.0%
Gender		
Male	50%	55%
Female	50%	45%
'I've been in contact with mental health services for…'		
less than one year	6.3%	10.0%
1 to 2 years	6.3%	10.0%
2 to 4 years	28.1%	35.0%
5 to 10 years	12.5%	10.0%
10 to 20 years	34.4%	25.0%
more than 20 years	12.5%	10.0%
'Mental health services call my difficulties…'		
Psychosis	44.0%	42.9%
Schizophrenia	40.0%	50.0%

Bipolar disorder, Schizoaffective disorder, Other	16.0% [n=10]	7.1% [n=7]

Appendix 2. Chapter 3: Delphi study of priorities and preferences for treatment of psychosis: group consensus ratings for items included in final statement set

Statement	Essential %	Important %	Do not know / depends %	Unimportant %	Not required %
'What I most want help with'					
feeling paranoid	**57.7**	23.1	11.5	0.0	7.7
Stress	55.2	27.6	10.3	3.4	3.4
anxiety or feeling nervous	48.3	35.4	10.3	3.4	3.4
feeling confused or unable to control my thoughts	32.1	53.6	3.6	0.0	10.7
concentration or memory problems	24.1	58.6	10.3	3.4	3.4
'What I want for the long-term'					
understand my psychological problems	62.1	31.0	0.0	3.4	3.4
learn to cope with ongoing 'unusual psychological experiences'	48.3	34.5	6.9	3.4	6.9
improve my emotional wellbeing	37.9	51.7	3.4	3.4	3.4
improve my energy and motivation	27.6	55.2	10.3	3.4	3.4
feel better about myself	24.1	58.6	13.8	0.0	3.4
improve my concentration and memory	20.7	62.1	3.4	6.9	6.9
remain out of hospital (for my mental health issues)	27.8	55.6	11.1	0.0	5.6
'What I would prefer when I receive mental health help'					
offer help based on my individual problems (rather than help based on a clinical 'diagnosis')	66.7	18.5	14.8	0.0	0.0
inform me about different types of help available	60.7	32.1	7.1	0.0	0.0
allow me to play a part in making decisions about what kind of help is best for me	60.7	28.6	7.1	3.6	0.0
'What I prefer when meeting with mental health staff					
in private (between myself and staff)	55.6	33.3	5.6	0.0	5.6
offer help that's appropriate for different age-groups	40.7	40.7	11.1	0.0	7.4

Appendix 3. Chapter 3: Delphi study of priorities and preferences for treatment of psychosis: group consensus ratings for items not included in final statement set

'What I most want help with'	Essential %	Important %	Do not know / Depends %	Unimportant %	Not required %	Stage Excluded
2. depression	44.8	27.6	13.8	3.4	10.3	3
4. anger	20.7	27.6	17.2	17.2	17.2	2
5. lack of emotional feeling	24.1	44.8	20.7	0	10.3	3
6. hearing something other people don't, such as a noise or voice	41.4	13.8	17.2	10.3	17.2	2
7. seeing things that others don't see	24.1	27.6	20.7	10.3	17.2	2
9. thinking things that others might think are unusual, such as 'I'm special' or 'there's a conspiracy'	41.4	34.5	10.3	6.9	6.9	3
11. feeling tired or unmotivated	31.0	44.8	20.7	0 0	3.4	3
12. difficulty sleeping	34.5	44.8	13.8	0	6.9	3
14. spending less time on my own	24.1	34.5	13.8	17.2	10.3	2
15. improving my relationships with others	24.1	44.8	17.2	0	13.8	2
16. self-confidence or	27.6	48.3	10.3	6.9	6.9	3

self-esteem						
17. hurting myself	27.6	13.8	20.7	3.4	34.5	2
18. thoughts of taking my own life	53.6	14.3	10.7	3.6	17.9	2
19. alcohol or drug use	24.1	13.8	10.3	10.3	41.4	2
20. side-effects of psychiatric medication	51.7	24.1	3.4	6.9	13.8	3
'What I want for the long-term'						
6. stop having any 'unusual psychological experiences' (such as hearing something or having 'unusual' thoughts that others don't)	41.4	24.1	20.7	10.3	3.4	2
7. improve my social life and relationships with others	13.8	44.8	20.7	13.8	6.9	2
9. feel more hopeful about my future	27.6	51.7	13.8	3.4	3.4	3
11. no longer take medication (for my mental health issues)	17.2	20.7	41.4	13.8	6.9	2
12. no longer need help from mental health services	17.2	27.6	44.8	6.9	3.4	2
13. physical health problems	27.6	44.8	10.3	6.9	10.3	3

14. improving my financial situation	20.7	34.5	24.1	10.3	10.3	2
15. improving my housing situation	17.2	31.0	20.7	6.9	24.1	2
16. continuing or re-starting my education	25.0	25.0	25.0	10.7	14.3	2
17. starting or continuing employment	21.4	39.3	25.0	0	14.3	2
18. physical activities, hobbies and interests	20.7	41.4	27.6	0	10.3	2
'What I would prefer when I receive mental health help'						
1. medication	39.3	25.0	17.9	3.6	14.3	2
2. meetings with a counsellor or therapist	64.3	14.3	14.3	0	7.1	3
3. time in hospital	14.8	11.1	44.4	11.1	18.5	2
4. focus on my 'unusual psychological experiences' (such as hearing something, or having 'unusual' or thoughts)	40.7	22.2	25.9	3.7	7.4	2
5. focus on other issues (such as depression, anxiety, or other personal problems)	48.1	29.6	18.5	0	3.7	3
6. discuss my issues with me in	3.7	25.9	33.3	22.2	14.8	2

medical language (using words such as 'mental illness' or 'diagnosis')						
7. discuss my issues with me in 'everyday' language that I use	42.3	34.6	11.5	3.8	7.7	3
8. give me a clinical diagnosis for my psychological issues (such as 'psychosis')	33.3	29.6	25.9	7.4	3.7	2
'What I prefer when meeting with mental health staff'						
1. and include members of my family	14.8	37.0	29.6	11.1	7.4	2
2. in a group with other people who have similar psychological experiences or difficulties	11.1	33.3	33.3	3.7	18.5	2
4. for brief appointments (half an hour or less)	7.4	33.3	40.7	11.1	7.4	2
5. for longer meetings (up to an hour or more)	14.8	48.1	29.6	3.7	3.7	2
6. frequently (for example, once a week or more)	18.5	25.9	48.1	0	7.4	2
7. infrequently (for example,	7.4	25.9	40.7	3.7	22.2	2

once a month)						
8. in mental health premises (where psychiatrists or psychologists are based)	7.7	23.1	42.3	11.5	15.4	2
9. in other places (such as my GP's surgery or my home)	11.1	25.9	55.6	3.7	3.7	2
10. over the phone or online (for example with emails)	11.1	22.2	48.1	11.1	7.4	2
12. offer the choice to speak to either male or female staff (when possible)	40.7	37.0	11.1	7.4	3.7	3
13. offer the choice to speak to staff from different ethnic or cultural backgrounds	14.8	29.6	18.5	14.8	22.2	2
14. include people in their teams who've also had psychological difficulties	29.6	40.7	18.5	3.7	7.4	3
15. make it possible for me to meet others with similar psychological difficulties	14.8	40.7	25.9	3.7	14.8	2

Appendix 4. Chapter 3: Participant Information Sheet

MANCHESTER
1824

The University
of Manchester

What treatment do Service Users want for Psychosis or Schizophrenia?

(a user-led 'Delphi' study)

Participant Information

You are being invited to take part in a research study. Before you decide please read the following information so that you understand this research. If you have any questions please contact me for further information, or you could ask mental health services staff for advice.

What is this research project about?

This research project is about getting advice from you ('Service users'), as experts of your own experience, to help us improve how we help people with psychosis or schizophrenia. We use the term 'Service user' to mean someone who's had professional help from mental health services (such as a psychiatrist or mental health nurse). We use the term 'treatment' to mean any type of professional help given by mental health services (such as counselling or medication). Mental-health services staff should ask Service users their personal needs and goals for treatment so that treatment is as effective as possible. We should also try to work out which needs and goals are most important for the most people. So, this study is trying to see what Service users think are the most important types of treatment for psychosis or schizophrenia, and the most important results of treatment.

This study will work by asking Service users with experience of psychosis or schizophrenia to complete a survey (on this website), once now and once again in a few months. An example of how the an item in the survey is worded might be: "Mental health services should help to reduce my depression" – Please indicate

whether you think help with depression is 1) essential 2) important or 3) not important 4) not required. At the end of the study, we will collect all those responses to see which treatment needs and goals have been identified by the whole group who take part. We hope to publish our findings, which may help to educate mental health professionals and improve mental health services for the future (though we won't publish the personal information of anyone who takes part).

Who will be taking part?

People with experience of receiving treatment for psychosis or schizophrenia in England will be asked to contribute. This can include people who are currently receiving help from services and also people who have received help in the past.

What will it involve for me?

Your involvement in this project is entirely voluntary, and we expect it should take roughly an hour to complete.

If you decide to take part we ask you to continue through this secure website, where you'll be asked to complete a brief 'consent form', asking you to confirm that you understand the study and what it means for you (below). Then we ask that you enter basic information about yourself (such as gender, age, whether you've experienced psychosis). After giving these details, you will then be able to access the study survey itself and contribute your responses, rating the importance of different parts of professional mental health help. You won't be asked at any time to give us your name, though we will ask that you submit an email address for us to re-contact you the final stage of the study (repeating the same process a second time a few months from now). Email addresses need not have your name in them (though they can if you like), and you can create a new email address without your name free of charge at websites like hotmail or google, for example.

No-one outside the research team will know the answers you've given. We hope that the study is reasonably straightforward, though it could be helpful to have a family member, friend, or key-worker look through the study with you if you're comfortable with them viewing it with you. It is also important to note that a paper copy of the questionnaire can be sent to you or to a key-worker if you'd prefer, though as we'd need a name and address to send it to, this could mean your response wouldn't be anonymous to us (though we'd still never share your details with anyone apart from the authorised persons mentioned below).

If you join the study, the data collected for the study may be looked at by authorised persons from the University of Manchester, NHS Trusts or regulatory authorities to

check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant.

What are the advantages and disadvantages of taking part?

We hope that by documenting a large group of service users' needs and goals for treatment of psychosis, we will be able to help inform mental health professionals about how to offer the best care in the future.

It is possible that thinking about your personal experiences or completing the study may cause you some distress. We hope this won't be a serious problem, as we won't be asking you to say much about private information, and you won't have to discuss any part of the study with anyone, unless you choose to. You are also free to withdraw from the project at any point without it affecting your care or any treatment you are receiving.

If you would like to discuss any concerns that the study could raise, it may be most helpful to speak to a key-worker or other local mental health worker. If you have any worries about the study and would like to speak to us, my details are given at the bottom of the page.

Who is conducting the research?

The study is being led by a user-researcher who has experience of receiving treatment for psychosis-type difficulties (Rory Byrne). In addition, the study is being supervised by an experienced clinical psychologist (Professor Tony Morrison).

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University of Manchester Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to research-governance@manchester.ac.uk.

Harm

Although this particular study shouldn't pose any risk of harm to you, as with all research studies, we must state that if for any reason you find the study distressing

and you think it may have caused you harm, you may have grounds for a legal action for compensation against The University of Manchester (you may have to pay your legal costs). The normal National Health Service complaints mechanisms will still be available to you. The University of Manchester Indemnity insurance offers no-fault compensation. If for any reason taking part in the study did cause some upset, you could also contact The Samaritans at any time, by phone on: 08457 90 90 90, or on email: jo@samaritans.org

Further information

For further information from the researchers for this project, please contact Rory Byrne by email: rory.byrne@postgrad.manchester.ac.uk, or by phone: 0161 772 4642.

For further information from someone who is independent of this research, or to make a complaint, you could contact the Patient Advice and Liaison Service (PALS: www.pals.nhs.uk) on 0800 587 4793, or on email to pals@gmw.nhs.uk.

Appendix 5. Chapter 3: Consent Form

MANCHESTER
1824

The University
of Manchester

"What do Service Users want from treatment for Psychosis?"

(a user-led 'Delphi' study)

Consent Form

You have been invited to take part in a research study. Please complete the following form which will indicate that you understand the information you've been given about the study and that you agree to take part.

1. I confirm that I have read and understood the information for this study.

[tick box]

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

[tick box]

3. I understand that the information I give will remain anonymous and that only members of the research team will have access to personal information that I provide such as my age and gender.

[tick box]

4. I understand that the researchers will present their findings in published articles, or at conference presentations, for example**.** I understand that at no time will any information I give for this study be publically identifiable as information I have given.

[tick box]

5.I understand that any personal information I provide may be accessed by responsible individuals from The University of Manchester (Research and Development department) or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to these records.

[tick box]

I agree to take part in the above study.

[tick box]

Appendix 6. Chapter 4: Participant Information Sheet

Title: User Led Research on Subjective Experiences of people considered to be at high risk of developing psychosis

What is this research project about?

Our project aims to find out more about the aspects of life experience, relationships and how we think about ourselves. Being a user-led project the ideas for the subjects covered have come from personal experience of being at risk of developing psychosis and the areas of life that affect, or are affected by it. The research assistant who will conduct the interviews and analyse them will be a service user.

Who will be taking part?

Participants will be 6 to 10 individuals currently involved in early intervention treatment with teams from BSTMHT. As outlined in the literature describing the work of these teams, participants will be aged between 14 and 35 (considered to be the ages at which someone is most at risk of developing psychosis).

What will it involve for me?

Your involvement will be entirely voluntary. If you decide to take part you will be asked to talk about your experiences of psychological problems and some aspects of your personal life. These will include describing your psychological problems, how you think they came about, your involvement in social life, any past experiences of very difficult personal relationships (no specific or private details will be asked for), and how you think of yourself and others. The interview will last for about an hour and will be audio taped.

All the information you give will be strictly confidential and it will not be shown to anyone outside the research team. The information will also be anonymous; your name will not be quoted in the findings. It is up to you to decide if you want to take part. If you decide to take part you will be asked to sign a consent form. You will still be free to withdraw at any time and you will not need to give a reason. You will also be given £10 to cover any expenses.

What are the advantages and disadvantages of taking part?

We hope taking part in the interview will give you a chance to reflect on your experiences and possibly to help clarify them. We hope that by documenting personal experiences we will be able to inform and influence the practice of mental health professionals in order to improve services for other users.

It is possible that talking about your personal experiences may cause you some distress. The people interviewing you will be sensitive to this as they themselves have personal experience of disturbed life experience and serious psychological problems. You will have the opportunity to discuss any concerns at the end of the interview and you are free to withdraw from the project at any point without it affecting the standard of the care you receive.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

Further information

For further information please contact Rory Byrne on 0161 772 3439 or by email at rory.byrne@man.ac.uk

Appendix 7. Chapter 4: Consent Form

Salford & Trafford Research Consent Form

Title of Project: User led Research on Subjective experiences of people considered to be at high risk of developing psychosis

Name of Researcher: Rory Byrne

(please initial)

1. I confirm that I have read and understood the information sheet dated _____ for the above study and have had the opportunity to ask questions before I participate.

_____

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

_____

3. I understand that my interview will be audio taped and that this information will be kept securely as outlined in the Data Protection Act. It will be deleted once the data has been analysed.

_____

4. I agree to take part in the above study.   _____

_____   _____

Name (Participant)   Date   Signature

_____   _____

Name (Researcher)   Date   Signature

Appendix 8. Chapter 4: Interview Topic Guide

Interview Topic Guide (RB, EDIT, 2007/8)

Background

How are you at the moment?

How long/often (have you felt…)?

Have you felt it's been helpful to speak to the EDIT people?

Was there anything in particular you experienced that led you to look for help?

Can you describe what was happening? What were you experiencing?

How did you feel about seeking help to get better?

Did anything put you off or worry you about seeing someone for help?

Do you think seeking help with the EDIT team has helped you feel any better?

Talking to family, friends and others

How do you find talking to family or friends?

Do you talk about your difficult or unusual issues with any family members or friends?

(do you spend a lot of time alone?)

have you been able to reveal or express your psychological problems to anyone apart from the EDIT team (like friends or family)?

Have you chosen not to tell people (do you prefer to keep your psychological difficulties private), or has it been too difficult to talk about?

(why do you think this is?)

What do others think?

Who understands what you have gone through/your experience?

Do you think there is anyone who could understand?

What do you think people in general think about unusual psychological experiences?

What do you think the attitude is towards people who have had experiences similar to yours? *(family, friends, employers, society?)*

What are the consequences of telling people/ not telling people?

(do you think your experiences have affected the people around you? do you think they see you differently now?)

Has it affected how you relate to people?

Do you know anyone else who has experienced difficulties similar to yours?

Self & Social Comparison

How do you feel about how you are now compared to how you were before any difficulties came about?

How do you feel about how you are compared to other people around you or other people in general?

(worse/better than before?)

(worse/better than others?)

~ these 2 may overlap; expect to evolve ~

Relationships

How do you feel in relation to those around you?

Do you feel close to others (family and friends)?

Do you feel you fit in, or do you feel different to them?

If you are not close to others at the moment, do you think this is because *you* don't want to be, or because *others* don't want to be close to you, or because you feel *unable* to be close with others, even though you'd like to be?

If you are not close with friends and family (or if you fall out with them), do you think this then affects how you are with other people in general (in public, at work, at college)? (*and conversely; ie, in positive terms*)

Do you feel you can trust others?

Difficult relationships

Have you experienced any very difficult personal relationships in your life (eg., involving separation, rejection or trauma - details are unnecessary as this may be very private information; simple, general answers are fine)?

Do you see any connections between your past or current life experiences (especially to do with relationships) and the problems you are experiencing at the moment?

If you have experienced very difficult relationships, has anything happened recently (in the last year or so) that may have 'stirred-up' or reminded you of the original problems?

Ending:

Is there anything else you would like to share with me about your experience?

Can you tell me a bit about what it has been like being interviewed today and what impact it will have on you?

Has there been anything particularly difficult or distressing to talk about?

Is there anything you would like to ask me?

Appendix 9. Chapter 5: Participant Information Sheet

Study Title: Service Users' perception of Cognitive Behaviour Therapy (CBT) in Recovery from Psychosis (User- Led Project)
You are being invited to take part in a user led research study. Before you decide whether to take part it is important you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or you would like more information about. Take time to decide whether or not you wish to take part.

Who is organising the research?
The research is being conducted by several user researchers with experience of psychosis and diagnosis who is employed by GMW Mental Health Trust. They are supported by a research team of clinical psychologists from GMW Mental Health Trust and the University of Manchester. There is also an advisory group made up of several service users from across the trust who are there to help inform the research.

What is the Research Project about?
The project aims to find out more about users' perceptions of CBT in recovery from psychosis. It is a user-led research project, which means that other service users in the advisory group have been involved in deciding the research topic and designing the research. The people who conduct the interviews will be service users who have personal experience of psychosis and receiving therapy.

Who will be taking part?
The participants will be up to 10 current or past service users from within the Bolton, Salford and Trafford area, aged 18 – 65, who have experience of psychosis and CBT within the last 12 months. You have been asked to take part because of your own experience of psychosis and CBT. Sharing this experience with us will help to increase our understanding about the way in which service users' perceive CBT in their recovery from psychosis.

Why have I been asked to take part?
You have been asked to take part because you have experience of psychosis and CBT and you live within Bolton, Salford and Trafford. It is felt that you could make a valuable contribution to the research project by sharing your experiences and talking about your perception of CBT in relation to recovery from psychosis.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given a copy of this information sheet and asked to sign a consent form. If you decide to take part you are free to withdraw at any time

and do not need to give a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will it involve for me?

You will be asked to talk about your experiences of CBT and recovery. You can choose whether you want to be interviewed in your own home or at a local venue of your choice. The interview will last up to an hour and you will be audio taped. You will be asked to talk about your experience of CBT, specifically about your perception of CBT and how helpful/unhelpful it was for your recovery from psychosis. Including your feelings about it and the impact it has on you and your life generally. You will have the opportunity to tell us about any changes you would like to see in the practice of CBT for recovery from psychosis.

All the information you give will be strictly confidential; and the transcript of the interview will not be shown to anyone outside the research team. The information will also be anonymous; your name will not be quoted in the findings. However, extracts from the interviews in the form of quotes will be used to illustrate themes for the Steering Committee and in presentations and findings. They will be entirely anonymous and there will be no way of identifying you from any of the quotes used.

You will be paid £10 for taking part in the interview and your travel expenses.

What are the Advantages and Disadvantages of taking part?

The interview will give you a chance to reflect on your own experiences of mental distress and your perception of the experience of CBT and its effect on your health and recovery from psychosis. We hope that by documenting personal experience of the perception of CBT we will be able to inform and influence the practice of mental health professionals in order to improve psychological services for ourselves and other service users.

It is possible that talking about your personal experience of CBT and recovery may result in some distress. The people interviewing you will be sensitive to this as they themselves have personal experience of mental distress. You will have the opportunity to discuss any concerns at the end of the interview and you are free to withdraw from the process at any point. We will contact you 3 days after the interview, to check if there are any further concerns you wish to raise. If necessary you will be able to talk to one of the clinical psychologists who are a member of the research team.

What do I do if something goes wrong?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, then in the first instance please contact: Kathryn Harney, R&D Manager, GMW MH Trust, Bury New Rd, Prestwich M25 3BL

Tel: 0161 772 3591 email: kathryn.harney@gmw.nhs.uk

What will happen to the results of the research?
If you participate in the study you will be invited to attend an end of project meeting with other participants and the advisory group where the results of the findings will be presented. The findings will be presented to a range of mental health professionals and service users with the aim of increasing the understanding of Users' Perceptions of CBT in Recovery from Psychosis. It is hoped the findings also help improve services and validate the experiences of other service users. The findings will be published in a number of mental health journals with the aim of reaching a range of mental health professionals including psychologists and psychiatrists. As a participant you will be informed of all presentations and publications and advised of any improvements to services that result from your participation.

Further Information
If you want any further information or have any questions, please ask the researcher:
Anthony Morrison
GMW Mental Health Trust
Psychology Services
Bury New Road
Prestwich
Manchester
M25 3BL
Tel: 0161 772 4350
e-mail: tony.morrison@manchester.ac.uk

Appendix 10. Chapter 5: Consent Form

CONSENT FORM

Title of Project: Service Users' Perceptions of Cognitive Behaviour Therapy (CBT) in Recovery from Psychosis (User-Led Study)

Name of Researcher: Martina Kilbride

Please initial box

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

I understand that my interview will be audio taped and that this information will be kept securely as outlined in the data protection act. It will be deleted after 12 months.

☐

I understand that extracts from the interview in the form of quotes may be used to illustrate themes for the, Advisory group in presentations and publications. These will be entirely anonymous.

☐

☐

I agree to take part in the above study.

☐

_____   _____   _____

Name of participant   Date   Signature

_____   _____   _____

Researcher   Date   Signature

Appendix 11. Chapter 5: Interview Schedule

Rec Ref:07/h1011/93   09/11/2007

Interview Schedule: Service Users' Perceptions of CBT for Recovery from Psychosis

Background

Can you tell me what were the circumstances around your referral to psychological services?

    Can you tell me a little bit about you experience of mental health problems?

      Can you tell me what it was you needed help with?

Understanding and Experience of CBT

2)   Can you tell me a little about your experience of CBT?

      Can you tell me what was helpful or unhelpful?

      Can you tell me what you liked or disliked about your experience?

      Can you tell me what is the most important thing you have learnt or taken

      away from your experience of CBT?

      Can you tell me why this is important to you?

      Can you tell me if you experienced any side-effects to your therapy?

Relationship between CBT and Recovery

    3)   Can you tell me if CBT has helped you gain a better understanding of

      yourself?

      If so in what way?

      Can you tell me if it has helped you to have better relationships?

      I f so in what way?

      Can you tell me if it has helped you to make positive changes in your life?

      Can you tell me about these changes?

Can you tell me if CBT has given you better coping strategies?

Are you able to briefly describe what these are?

Can you tell me if CBT has offered you hope for the future?

If so in what way?

Identifying Changes to CBT

4) Can you tell me if there are things you would like to change about CBT?

Can you tell me what these changes would be?

Can you tell me if there are things you would of liked to discuss in CBT,

But you didn't get the chance?

What are the things you would have liked to discuss?

Appendix 12. Chapter 6: Participant Information Sheet

Participant Information Sheet

A qualitative exploration of the experience of monitoring and therapy in a randomised controlled trial for people involved with the EDIE 2 trial.

You are being invited to take part in a research study. Before you decide please take time to read the following information so that you understand why the research is being conducted. If you have any questions please do not hesitate to contact me or ask your key worker.

What is this research project about?

This project aims to speak to people who have had some psychological difficulties, and have received support from EDIE 2, to find out how they've found the experience of meeting EDIE 2 assistants or therapists for monitoring or therapy.

Who will be taking part?

People who have received support from the EDIE 2 team will be invited to take part in the study. The project will require ten to fifteen participants.

What will it involve for me?

Your involvement in this project is entirely voluntary.

If you decide to take part you will be asked to talk about your experience of meeting with EDIE 2 assistants or therapists for monitoring appointments or therapy. The questions you'll be asked will be about how you've found the appointments (for example, whether or not you've found monitoring appointments helpful) and what possible impact they may have on the way you think about and manage any psychological difficulties. You do not have to talk about anything that makes you uncomfortable or is distressing to you. The interview will last for about an hour and will be audio taped. The interview will take place at a location convenient for you.

All the information you give will be confidential and it will not be shown to anyone outside the research team (although in the event that any interviewee discloses harm or potential harm to themselves or others, it will be necessary to breach confidentiality in order to notify

someone in an appropriate position of authority). Only the researchers will have access to the audiotape. The research supervisor will see anonymised transcripts. The audiotapes will be kept locked away and then destroyed after 12 months (which is a standard procedure). Your name will not be quoted in the findings, although direct quotes from interviews may be used in the write-up of the study (with no information to show who has said what in the interviews).

You will be given £10 to cover any expenses.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.
If you decide you do not wish to take part we would like to thank you for taking the time to read this information.

Can I withdraw from the study if I change my mind?

If you decide to take part you are still free to withdraw at any time, without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What should I do if I decide to take part?

If you decide you want to take part inform your key worker of this. I will then contact you to arrange a convenient location and time for the interview to take place. You will be asked to sign a consent form stating that you have read the information sheet and that you agree to take part in the project. If you need more information before making a decision please contact me on the number below.

Who is conducting the research?

The research is being conducted by an EDIE 2 research assistant (Hannah Taylor) and an EDIE 2 service-user researcher (Rory Byrne). Research that includes service-user members will help to gain a better understanding of the way people experience their involvement in the research and treatment process.

What if there is a problem?

Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to research-governance@manchester.ac.uk.

Harm

In the event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against The University of Manchester but

you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you. The University of Manchester Indemnity insurance offers no-fault compensation.

Further information

For further information from the researchers for this project, please contact Hannah Taylor on 0161 306 0430, or Rory Byrne on 0161 772 4350.

For further information from someone who is independent of this research, or to make a complaint, you could contact the Patient Advice and Liaison Service (PALS – www.pals.nhs.uk) on 0800 587 4793, or on email to pals@gmw.nhs.uk .

REC Reference Number: 09/H1013/31

Appendix 13. Chapter 6: Consent Form

MANCHESTER
1824

The University
of Manchester

Consent Form

A qualitative exploration of the experience of monitoring and therapy in a randomised controlled trial for people involved in the EDIE 2 trial.

Name of Researcher: Rory Byrne (Service User Research Assistant and Representative, EDIE 2, University of Manchester) and Hannah Taylor (Research Assistant, EDIE 2, University of Manchester)

Supervisor: Professor Anthony Morrison, Reader in Clinical Psychology, University of Manchester

Participant Identification Number:

(please initial for each point below)

I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions before I participate.

_____

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

_____

I understand that my interview will be audio taped and that this information will be kept securely as outlined in the Data Protection Act.

_____

I understand that the information will remain confidential and that only members of the research team will have access to information from the interview I take part in (only Rory Byrne will have access to identifying information; name and address, for example).

_____

I understand that the researchers will present their findings either in published articles, or at conference presentations, for example. Although direct quotes from interviews may be used in the write-up of the study (with no information to show who has said what in the interviews). At no time will anything I say during this interview be traceable or identifiable to me (in other words, it will be anonymous).

_____

I understand that the personal information I provide may be looked at by responsible individuals from The University of Manchester or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to these records

_____

I agree to take part in the above study

_____

_____ _____   _____

Name (Participant)   Date   Signature

_____ _____

Name (Researcher)   Date   Signature

REC Reference Number: 09/H1013/31

Appendix 14. Chapter 6: Interview Topic Guide

MANCHESTER
1824

The University
of Manchester

Introduction / Background

How are things at the moment (psychological difficulty or life in general)?

Can you tell me a little bit about you experience of mental health problems?

Can you tell me what were the circumstances around your referral to psychological services/Edie?

Treatment needs; at the point of first help-seeking

Can you tell me what it was you most needed or wanted help with?

Were your highest priorities psychological problems or other concerns? (eg, deprivation, risk, employment, etc)

Did you have opportunities before Edie to prioritise your most pressing concerns?

[Did you find that the mental health professionals you saw focused primarily on 'positive symptoms'?] (eg's)

Were these your highest priorities for reducing your distress?

Preferences for treatment for those with experience of services

Have you had help from mental health professionals such as counsellors or nurses, psychologists or psychiatrists that was

particularly helpful?

Particularly unhelpful/harmful?

Do you have any preferences for either medical or psychosocial [explain] treatments and information/language?

Priorities and/or Preferences for/against medication and/or therapy?

Outcome priorities / Valued Outcomes (hoped for improvements, including personal, practical etc)

What would you most like to achieve or improve with therapy?

Are there any other [non-'unusual'] psychological concerns that you hope to improve to improve your quality of life? (eg., depression, anxiety, self-esteem, hope)

Are there any practical difficulties or concerns in your life that you would most like to be able to improve? (eg, finances, housing, relationships, education, employment?)

Monitoring & Edie Involvement 1

How did you feel about seeing someone to talk about your issues? (previous experience of counselling/therapy or much open/in-depth disclosure?)

Compared with previous services?

How was it to complete the measures more than once etc?

Any benefits, personal or psychological, from monitoring? (eg, opportunities for discussion of difficult issues, structure of process for clarity)

Any drawbacks, or suggestions for future improvements?

Practical issues ok (travel/meetings)?

Cognitive Therapy: Edie Involvement 2

How have you found the process of CT?

Have you been able to understand the psychologist and the way CT works (eg psychological model)?

Could you say a bit about how CT may have helped, or not helped, with the issues you most wanted some help with? (pos symps; depression, anxiety, self-esteem, other)

Do you think CT has helped you gain a better understanding of yourself?

Do you think anything in particular has been the most important thing you've learned or gained through doing CT? (eg, for life, work/college, relationships, psychological wellbeing)

Are there any aspects of CT you particularly like?

Are there any aspects of CT you haven't liked?

Cognitive Therapy involvement 3 (long-term & recovery)

Do you think there any coping strategies CT has helped you develop or improve?

How do you think CT has or will work in the long-term?

Compared to other treatments?

Any CT strategies or aspects in particular that may be most helpful for future wellbeing?

Are there any improvements or positive changes in life that you think have come about recently?

Do you think any improvements achieved through CT will also help improve relationships?

Has anything become more difficult since doing CT?

How do think your hope for the future is now compared with before CT?

Could you say a bit about what you think recovery means to you?

Do you think CT has helped you to think of the future more hopefully?

Identifying changes to CT

Is there anything you'd like change about CT? (eg, availability, frequency, methods/models, written info, other resources)?

Were there any issues you didn't deal with in CT that you may like to deal with (eg work/relationships/other)

Treatment needs; current

Can you tell me if there are things you would still want or need help with? (reducing your distress; improving your quality of life?)

Are your highest priorities psychological problems or other concerns? (eg, deprivation, risk, employment, etc)

Have you had opportunities to prioritise your most pressing concerns with any mental health or other professionals recently?

Outro

Is there anything else you'd add to these issues (treatment of unusual experiences, monitoring)?

Are there any other issues you think are important for us to look at in studies like this?

How have you found this interview, and have you any suggestions for how best to conduct these interviews?

Do you have any thoughts on my [interviewer] role as researcher having experience of mental health problems myself?