

VOLUME 1

**Relating to the other in psychosis:
An interpretative phenomenological
analysis**

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1. ABSTRACT

There is little doubt that social and interpersonal processes are key factors in the development and maintenance of, as well as recovery from, psychosis. Many aspects of the social world have been researched in relation to psychotic experiences and much learnt about the impact of early family life, difficulties in social cognition and the importance of social support, rejection and stigma. However, little is understood about the lived experiences of these interpersonal processes from the point of view of those with psychosis themselves. The aim of the following study was to explore how people with psychosis experience other people and make sense of their interpersonal experiences. Semi-structured interviews were conducted with two men and five women experiencing psychosis. Interpretative Phenomenological Analysis (IPA) was used to analyse the verbatim transcripts, from which three master themes emerged. These were: 'Finding a place in society', 'Interpersonal mistrust' and 'Undermined by inner/outer disturbance'. These findings are discussed in relation to the literature on interpersonal processes and psychosis along with the limitations of the current study. Implications and suggestions for future research and clinical practice are also discussed.

2. INTRODUCTION

2.1 Overview

This introduction is concerned with the area of relationships and the experience of the others, as related to psychosis. The chapter begins by providing clarification around terms used to describe and refer to the experiences associated with psychosis. Specific details are then provided as to strategies used to ensure that the literature was reviewed in a comprehensive and systematic way. The main body of this introduction critically reviews the theories and research relating to this area and finally the rationale and aims for the current study are presented.

The literature review itself starts by offering a general explanation of psychosis, what it includes and refers to and some of the current understanding around these experiences. The focus then moves to research relating to interpersonal processes in psychosis, initially looking at literature coming from the quantitative tradition and moving towards qualitative studies. To organise this vast body of literature, research that has looked at early relationships and family factors are first reviewed, followed by that focusing on social cognition and communication and also stigma and social support. A number of theories are presented that focus on the interaction of social and psychotic experiences, some of which have consolidated what has been learned from the body of research reviewed here. A final section focusing on the smaller and more contemporary body of qualitative research reviews studies exploring both interpersonal relationships and more general experiences of psychosis before presenting the rationale for the current study.

2.2 Terminology

2.2.1 'Psychosis' and 'schizophrenia'

Clarity is required regarding the use of both the term 'psychosis' and 'schizophrenia' within the following literature review. The focus of the following study is on individuals who experience 'psychosis', a term used, within this literature review, to refer to a range of experiences that are generally considered to fall outside of reality as most people would experience it, namely, hearing voices, paranoia, as examples. The term

'schizophrenia', on the other hand, is used in reference to the diagnostic category traditionally associated with the experiences of psychosis and often officially given to those who experience 'psychosis' within our current mental health systems. 'Schizophrenia' also provides the focus for much of the historical research on the subject and therefore this term is used here in reference to the samples described in these studies. Elsewhere the term 'psychosis' is used, both in reference to the current sample and also more recent research on the subject, which generally focuses on the experiences of 'psychosis' and pays less attention to diagnostic categories.

2.2.2 'Experience' and 'symptom'

Throughout this literature review, the terms 'experience' and 'symptom' are both used in reference to the various experiences associated with psychosis. These terms are used synonymously to some degree although there are distinctions to be clarified. The use of the word 'experience' over 'symptom' reflects how these experiences can be seen as neutral or as falling within the range of normal human experience and not just as indicative of illness (British Psychological Society, 2014). Both of these terms form part of the language of psychosis and are used both within clinical research and by individuals with psychosis to describe collectively the experiences of psychosis. Effort has been made within the following literature review to use neutral language in reference psychotic experiences, for example, by referring to 'individuals or people with psychosis', rather than 'patients' or 'sufferers' and to 'experiences' rather than 'symptoms'. However, there may be incidences where both terms are used, particularly in reference to previous research where these terms are used to describe the experiences of that particular sample group.

The word 'symptom' is also used in reference to 'positive' and 'negative symptoms', a distinction often referenced in the literature and referring to psychotic experiences that reflect, either, a *change* in experience, such as delusions or hearing voices ('positive symptoms'), or experiences that represents some degree of *loss*, such as withdrawal or flat affect ('negative symptoms'). There is on-going debate as to the usefulness of these terms and/or nature of their cause, i.e., as part of the spectrum of psychosis or as a consequence of living with psychosis (British Psychological Society, 2000).

2.3 Literature Review Strategy

The aim of this introduction is to offer a comprehensive review of the literature relating to the experience of others and psychosis. In conducting this review, a number of stages were followed over the course of a two-year period in order to capture the most pertinent and current literature relating to these areas.

Firstly relevant articles were identified from a systematic search of a number of key databases. This included exploratory searches using *Google Scholar* and more in-depth searches using *PsychINFO*, *Web of Science* and *Pubmed*. Search terms used included combinations of the following: *psychosis, schizophrenia, delusions, voices, hallucinations, paranoia, social, relationships, interpersonal, others, family*. Boolean operators (e.g., AND, OR, NOT or AND NOT) were used to further refine the searches and ensure relevant articles were identified. The abstracts from these searches were reviewed and key or more directly relevant papers were identified, read and followed-up. In addition, books and book chapters relevant to the area were also reviewed and, where relevant, references identified from both articles and book chapters followed-up and reviewed along with particular authors writing in the area.

Important theories and key topics within the area of social relationships and psychosis were also identified and followed-up. In addition, supervisors and colleagues with expertise in the area of psychosis were consulted regarding important topics, theories and papers relevant to the area.

2.4 Literature Review

2.4.1 Psychosis

Psychosis is understood to refer to changes in an individual's state of being, marked by a loss of contact with reality, as most people would normally experience it. It is characterised by a range of experiences and 'symptoms', chiefly, holding beliefs that others do not share, hallucinations and hearing voices and may also include difficulties with thinking, concentration and communication or speech (British Psychological Society, 2014; Cardinal & Bullmore, 2011; Chadwick, 2006;). The term 'psychosis' itself is broad and somewhat general and can include experiences resulting from physical conditions

like delirium. This discussion, however, focuses on psychosis understood to have a psychological cause.

Psychosis is increasingly being seen to exist on a continuum with 'normal' human experience, where many people hold a greater or lesser vulnerability to developing these kinds of experiences (British Psychological Society, 2000). A large body of evidence supports this idea, including research suggesting that 10-15% of the normal population have experienced hallucination at some point in their lives (Tien, 1991). Seeing psychosis as an extension of normal experience helps us to make better sense of such experiences by seeking to understand where these experiences are coming from rather than dismissing them as strange or alien (Fowler, Garety & Kuipers, 1995).

Individuals experiencing psychosis might also be given diagnoses such as *schizophrenia*, *schizo-affective* or *delusional disorder* or their psychotic experiences might be considered part of a mood disorder such as *depression* or *bi-polar disorder*. Schizophrenia is the diagnostic category traditionally associated with the experience of psychosis and provides the focus for much of the historical research on the subject. It is distinguished not just by psychotic experiences but also occupational and social dysfunction and long-term duration (APA, 2013). Historically thought of as an inherited disease of the brain, more recently, biologically-based ideas regarding the cause of psychosis have been incorporated into models that emphasise a more complex picture, where biological, psychological and environmental or experience factors interact to create the conditions necessary for psychosis to develop. Many of these environmental factors relate to experiences with other people, including upbringing and early family life.

2.4.2 Experience of others

Interpersonal and social factors are considered central to understanding the experience of psychosis (Rhodes & Jakes, 2009). Disruption in social and occupational functioning is also one of the main criteria for a diagnosis of schizophrenia, suggesting that, by definition, people with this diagnosis struggle with relationships (Segrin, 2001). The literature exploring interpersonal processes in psychosis, including schizophrenia, has looked at topics ranging from social/family factors as causes and correlates of psychosis (Read, 2013; Segrin, 2001) to research exploring social cognition, support and stigma

(Bentall & Fernyhough, 2008; Macdonald, Hayes & Baglioni, 2000; Switaj, Wciórka, Smolarska-Switaj & Grygiel, 2009). The following sections offer an overview of some of the main aspects of this vast body of literature.

2.4.3 Family and early life experience

Historical theories

Theories focusing on interpersonal processes in relation to the cause or maintenance of psychotic experience have long been a source of controversy, evidently owing to concerns that such a focus would potentially be perceived as blaming and alienating of families (Read & Seymor, 2013). However, in a recent review of 22 studies looking at causal beliefs, Read and Magliano (2012) found that in 16 of these studies, relatives believed their family members experiences were as a result of adverse life events and psychosocial issues rather than biological determinants.

Although no longer considered as valid predictors of psychosis, a number of historical theories warrant mention as key to the development of our current understanding of interpersonal processes in psychosis. One such well-known theory is that of the *double-bind hypothesis* (Bateson, Jackson, Haley & Weakland, 1956). Briefly, this theory references a style of communication found in families affected by schizophrenia, where meanings and expectations are often contradictory. Unable to make correct choices, the child begins to communicate in a distorted and illogical way, such that others can't understand her intentions and so she avoids blame. This strategy is thought to be typical of schizophrenia (Segrin, 2001).

Laing (1965) also wrote about *mystification*, a pattern of communication marked by misunderstandings, ambiguities and misattributions. He conducted intense observations of a small number of families and concluded that such a communication style within a family leaves the individual with schizophrenia confused and with an altered experience of reality.

Mystification and the *double-bind hypothesis* are examples of some of the first approaches to understanding communication anomalies observed in families of those

labelled as having schizophrenia. Both of these theories were borne out of small-sample research and clinical observation and fell into relative obscurity before they could be fully supported or refuted through research. However, they, along with a number of other such classic theories, have formed the foundation for a large body of research focusing on communication and interaction styles within families.

Expressed emotion, affective style and communication deviance

Over the last number of decades, a major research focus in looking at family and social factors and their relationship with schizophrenia has been on three styles of family interaction: *communication deviance*, *affective style* and *expressed emotion*.

Rather than referring to the expression of emotion generally, expressed emotion (EE) is actually a pattern of hostility, criticism and emotional over-involvement on the part of parents towards individuals with the diagnosis (Segrin, 2001). An almost identical concept, affective style (AS), is also characterised by personal criticism, guilt induction and intrusiveness but considered to be more of a behavioural manifestation of EE, with EE being the attitude held by family members about the individual, often in their absence (Diamond & Doane, 1994; Segrin, 2001). Communication deviance (CD), on the other hand, refers to a pattern of peculiar or confusing language, misinterpretation and conversation drift within family interactions (Wynne & Singer, 1963).

CD is thought to facilitate *pseudo-mutuality*, considered an important concept in understanding the development of identity (Wynne, Ryckoff, Day & Hirsch, 1958). In families affected by schizophrenia, it is argued that children are not encouraged to develop their own separate identities. Instead *pseudo-mutuality* is established where differences between people or deviations from a rigid common family identity are ignored in favour of maintaining a false sense of cohesion. CD enables this process, by using vagueness and confusion to passively mask these differences (Wynne & Singer, 1963). In these situations individuation can only really be achieved by withdrawing into an isolated or distorted inner world.

A number of research studies have linked CD, AS and EE with the presence or onset of schizophrenia, including a 15-year follow-up study of 54 families of adolescents

presenting with behavioural problems (Goldstein, 1997). This study investigated all three factors to show that each predicted the onset of schizophrenia, particularly CD where 70% of high-CD families had a child with a broad-spectrum schizophrenia diagnosis.

A number of criticisms have been levelled at the EE, AS and CD lines of research. Particularly in relation to EE and AS, it has been suggested that these factors might be not stable over time and might actually reflect a parent's reaction to dealing with their child's difficulties. CD has indeed been shown to be a stable and enduring trait-like feature (Wahlberg, Wynne, Keskitalo et al., 2001), while EE and AS can fluctuate over time and be reduced with targeted interventions (Kavanagh, 1992). However, high-EE parents do have other more stable trait-like features such as low empathy and inflexibility and, in addition, EE and its relationship with relapse appears to be independent of patient characteristics such as severity of symptoms, history of illness or patient demographics (Hooley & Hiller, 2001; Kavanagh, 1992).

Caution is also advised in taking any one of these variables on their own as a comprehensive explanation of schizophrenia or psychosis and so run the risk of simply shifting blame from one linear cause (i.e., the patient themselves) to another (i.e., the family/parents) (Read & Seymor, 2013). In reality, these variables may only be part of a more complicated picture, where CD, AS and EE along with many other factors interact in a circular way to predict and maintain these difficulties.

Trauma, abuse and adversity

A more contemporary area of research has looked at the impact of childhood adversity, trauma and abuse on the course and development of psychotic experience. This naturally fits with and follows on from research on EE and CD, broadening the focus to include other sources of adversity. 'Adversity' is clearly a broad concept encompassing many types of experiences, measured in various ways and experienced at various stages of development (Fisher & Craig, 2008). Studying this area is also made complicated by a number of issues. For example, some of the experiences studied are clearly understood as abuse, while other, more subtle and insidious experiences might be difficult for individuals to identify as abuse, for example parental antipathy or low level neglect (Fisher & Craig, 2008). In addition there is often overlap between types of abuse, where,

for example, a child who is being physically abused might also be more likely to experience neglect (Fisher & Craig, 2008). Research in this area is vast and complex, and so much of the discussion is beyond the scope of this literature review; a brief summary is, however, warranted to explain how these adverse life events can predict and effect the development of psychosis.

Varese, Smeets, Drukker et al. (2012) published a meta-analysis investigating the relationship between psychosis outcomes and childhood adversity in 41 of the best-designed studies of a total of 736 screened. They looked across six types of adversity: sexual, physical and emotional abuse, neglect, bullying and parental death and found a significant association between psychosis and adversity. Together the 18 case-control studies showed that those experiencing adversity in childhood were 2.73 times more likely to experience psychosis in adulthood. Although it is important to consider that many of these studies did not correct for the influence of possible moderators such as urbanicity, genes or cannabis use and also focused on hallucinations and delusions and not other aspects of psychosis. However, in a similar meta-analysis Matheson, Shepherd, Pinchbeck et al. (2012) also found a similar relationship between adversity and schizophrenia.

In addition, the Varese et al. (2012) review found that likelihood for later development of psychosis increased if the individual reported more severe levels of abuse or experienced multiple adversities. Among those already experiencing psychosis and those considered at risk of psychosis, a history of child abuse was also indicative of poorer outcomes, such as poor engagement in services (Lecomte, Spidel, Leclerc et al., 2008), experiences of alienation, social withdrawal and stigma (Outcalt & Lysaker, 2012) and greater neuropsychological deficits and decline (Campbell, Barrett, Shannon et al., 2013).

Within this research specific forms of adversity have been linked to specific psychotic experiences. After controlling for other aspects of the psychotic experience, Bentall, Wickham, Shevlin et al. (2012) found that childhood rape was associated with auditory hallucinations, while growing up in care and experiencing the associated long-term disruption in attachment was associated with paranoia. Physical abuse was associated with both auditory hallucinations and paranoia (Bentall et al., 2012). This study did

however use conservative definitions of childhood trauma and may therefore exclude more subtle types of childhood adversity that might be important.

2.4.4 Social cognition and interpersonal communication skills

A number of lines of research have looked at the interpersonal and social cognitive difficulties that many individuals struggle with, as well the mechanisms by which these impact relationships. Poorer interpersonal functioning has been found to predict higher levels of certain subclinical psychotic experiences, such as persecutory ideation and bizarre experiences in a general adolescent population (Collip, Wigman, Lin et al., 2013). People with a diagnosis of schizophrenia and schizo-affective disorder also show more significant difficulties in terms of social skills than controls, in particular the ability to accept or initiate contact with others, effective communication and forming friendships (Bartels, Mueser & Miles, 1998), although this study did focus on older adults which may have had a bearing on the results. These social difficulties may, however, impact on how people are perceived by others and, in turn, this may impact on how individuals themselves feel socially and how they perceive others. Salokangos, Heinimaa, Svirskis et al. (2009) for example, found that, among individuals at risk of developing psychosis, for those who perceived other's view of them as 'poor', that risk was increased. This may also link with other risk factors such as self-esteem. However, females were over-represented in this sample, suggesting that this finding has more significance for women who go on to develop psychosis.

Research has also focused on a number of specific social cognitive factors that may contribute or lead to experiences of psychosis. One line of research has explored biased social reasoning and shown that people who experience paranoid delusions are more likely to expect that other people are threatening and that positive events would not likely happen to them, on the basis of little evidence (Corcoran, Cummins, Rowse et al., 2006). Likewise, relying on an external locus of control and choosing attributions that locate the blame for negative outcomes in others rather than situations have also been found to be more common in individuals with paranoia (Kinderman & Bentall, 1997; Rosenbaum & Hadari, 1985). Frith argues that this links with a difficulty recognising and monitoring the mental states of others, termed theory of mind (ToM). ToM has long

been studied as a core aspect of autism (Baron-Cohen, 1995) and early research also shows that people with paranoia experience impairments in ToM (Frith & Corcoran, 1996). This lack of ToM could make negative misunderstandings about what other people are thinking more likely or make it seem that the intentions of others are being concealed. It is this uncertainty and misunderstanding that could lead to paranoid delusions about the intentions of others (Frith, 1992; Frith & Corcoran, 1996).

Other lines of research have looked at receptive and expressive communication skills in people with a diagnosis of schizophrenia specifically. A number of studies have found that people with a diagnosis of schizophrenia exhibit numerous communication disturbances in their speech, including use of ambiguous word meanings, missing information or wrong word references and structural unclarity (Docherty, Cohen, Nienow, et al., 2003; Docherty, DeRosa & Andreasen, 1996). In addition, studies have also found that reduced facial expressiveness and poverty of speech were also pronounced features among patients with schizophrenia compared with clinical controls (Davidson, Frith, Harrison-Read et al., 1996; Ragin, Pogue-Geile & Oltmanns, 1989).

In terms of receptive communication skills, one body of research has looked at social information processing and found that people with schizophrenia have difficulties in facial and emotion recognition and in their ability to recognise interpersonal problems (Addington & Addington, 1998; Bedell, Lennox, Smith et al., 1998). Emotion recognition in particular was found to negatively affect social functioning (Hooker & Park, 2002). Much of the research looking at interpersonal skills and social cognition has however, focused on those with schizophrenia rather than people who have experiences of psychosis more broadly.

2.4.5 Rejection, stigma and social support

Unsurprisingly, stigma and feelings of rejection also mark the experience of psychosis. In a study looking at public attitude to schizophrenia, Angermeyer and Matschinger (2005) found that the desire for social distance from people with this diagnosis had increased since the 1990s, although these findings may relate to the German public alone. Norman and Malla (1983) demonstrated that the more mentally distressed an individual diagnosed with paranoid schizophrenia was perceived to be, the more socially

unacceptable a sample of students judged them. Similarly, social distance was also best predicted by perceived strangeness, which in turn was best predicted by ratings of overall social skill (Penn, Kohlmaier & Corrigan, 2000). In a qualitative study looking at stigma among individuals with mental health problems, Dinos, Stevens, Serfaty, et al. (2004) reported that those with psychosis were most likely to report feelings of stigma and be most affected by such feelings. Additionally, higher levels of stigma were found to relate to lower perceived quality of life and younger age of onset, although this was specific to a non-random, predominately inpatient sample (Switaj et al., 2009).

Feelings and experiences of discrimination are also accepted to be major contributors to the cause of psychotic experiences. Discrimination was found to be longitudinally linked with delusional ideation in a population-based Danish study (Janssen, Hanssen, Bak et al., 2003), although this was measured as perceived discrimination rather than observable acts. In addition, being a member of an ethnic minority in both in the UK and other western countries significantly increases a person's risk of being diagnosed with psychosis, particularly for those living in areas where they are part of a clear minority (Bresnahan, Begg, Brown et al., 2007; Fearon, Kirkbride, Morgan et al., 2006; Veling, Susser, van Os et al., 2008). It is likely that discrimination plays a major part in this relationship (Janssen et al., 2003).

Social support also plays an important role in the development and outcome of psychosis. Individuals with early psychosis typically report smaller social networks, fewer close friends and people to turn to than controls (Erickson, Beiser, Iacano et al., 1989; Macdonald et al., 2000), although this could also be a function of experiencing some degree of psychological difficulty prior to first onset.

In research looking at the social support of adolescents prior to first hospitalisation for a psychotic episode, declining social support was found to relate to negative symptoms and longer duration of untreated psychosis (DeVylder & Gearing, 2013). Moreover, higher levels of support was found to predict better outcomes and quality of life longitudinally (Corrigan & Phelan, 2004; Eack, Newhill, Anderson et al., 2007; Norman, Malla, Manchanda et al., 2005). Of significance also was the nature of the social support people had available to them, with support from friends and acquaintances predicting

five-year outcome while familial support did not (Erickson et al., 1989). On the other hand, for a sample of 40 individuals with a long-term diagnosis of schizophrenia, one study reported that, although social networks were small, they were perceived as adequate and from this it was suggested that withdrawing to some degree could serve a protective function, buffering participants from stressful relationships (Cresswell, Kuipers & Power, 1992). Although further longitudinal research is necessary to better establish if this is in fact the case or if withdrawing is actually a consequence of the negative symptoms of psychosis (Cresswell, et al., 1992).

2.4.6 Models relating social experiences with psychosis

A number of models have been proposed to better understand psychosis and explain the process by which these adverse life experiences and psycho-social difficulties, particularly in childhood, come to influence the later development of psychotic experiences. Rather than focus on psychosis in general or on diagnostic categories such as schizophrenia, many of these models offer a symptom-based approach to conceptualising individual experiences and what might exert an influence for different individuals at different times (Read, Fink, Rudegeair et al., 2008).

Cognitive models

The cognitive understanding of psychosis has built upon the stress-vulnerability model, focusing on psychosocial aspects of onset, particularly early life adversity (Morrison, Renton, Dunn et al., 2004). Cognitive approaches also give consideration to the consequences of living with psychotic experiences such as loss of social roles and stigma and how these might maintain a degree of disability (Garety, Fowler & Kuipers, 2000).

In relation to hallucinations, particularly voices and other auditory hallucinations, theories looking at 'source monitoring' propose that a person's own inner speech is mistakenly attributed to external sources and, likewise, visual hallucinations are a result of mixing up mental imagery with what is actually perceived (Bentall, 2013). As previously discussed the experience of hearing voices is clearly related to earlier experiences of abuse, particularly, sexual abuse and examination of the content of the voices and psychotic delusions draws similarities to earlier abuse experienced (Bentall et

al., 2012; Read & Argyle, 1999). Source monitoring has not been found to relate to childhood trauma (Varese, Barkus & Bentall, 2012) but may be part of a two-factor model that results in the experience (Bentall, 2013).

Cognitive approaches to understanding paranoid delusions have focused on cognitive biases and information processing anomalies, such as having an external locus of control and attributing negative outcomes to the actions of others rather than to circumstances, as previously discussed (Kinderman & Bentall, 1997; Rosenbaum & Hadari, 1985). Taken together these findings led to a proposed model that paranoid delusions serve a self-protective function, allowing individuals to avoid negative views of the self (Bentall, Kinderman, & Kaney, 1994).

Looking at psychosis in general, a number of cognitive theorists have looked at the influence of emotions and beliefs on psychosis. These theories work from the idea that the amount of distress experienced during a psychotic episode and the attributions made about both the psychotic experiences and about negative life events generally serve to exacerbate and maintain these experiences (Fowler, Freeman, Steel et al., 2006; Morrison, 2001). In particular, Morrison (2001) conceptualised hallucinations and delusions as intrusions into awareness. The distress for the individual occurs when he or she interprets these intrusions as culturally unacceptable or when he or she makes interpretations based on faulty and negative views of the self. A lack of trusting and supportive relationships where an individual could discuss and explore more objective explanations can also further exacerbate this distress (French & Morrison, 2004).

Psychodynamic and attachment theory

Psychodynamic approaches also offer a means of understanding psychosis, drawing on a long tradition of working with people with such experiences. A particular concern with the unconscious and with unconscious meaning allows the psychodynamic tradition to look for meaning and reason in the content of an individual's unusual or seemingly meaningless experiences (Koehler, Silver & Karon, 2013). Such experiences are theorised to provide the individual with a defence or a sense of psychological protection against unbearable emotions, memories or experiences by changing how reality is experienced, thus rendering that reality more bearable (Koehler et al., 2013; Martindale & Summers,

2013), drawing similarities to cognitive approaches, discussed above (Bentall et al., 1994).

A driving factor here is how a person views and experiences stress in their lives. This can depend on their level of social support at that time but also the person's attachment style. Early life experiences and adversity can serve to influence the development of a sense of self and also the meaning attributed to such stresses (Koehler et al., 2013). A substantial body of literature, reviewed by Berry, Barrowclough and Wearden (2007), has linked insecure attachment with psychosis, specifically, avoidant attachment with positive and negative symptoms and paranoia (Berry, Barrowclough & Wearden, 2008).

Attachment theory suggests that individuals develop a template or an 'internal working model' of what to expect from others, the future and the self, based on early life experiences and relationships with primary caregivers (Bowlby, 1980). Attachment theory provides a way of conceptualising the transition between early life adversity and psychosis, i.e., that the consequence of an insecure attachment style is typified by problematic interpersonal and emotional adaptation; affect regulation; low self-esteem; sensitivity to interpersonal stress and social withdrawal, all of which may be predictive of psychotic experiences (Gumley & Schwannauer, 2006; Pickering, Simpson & Bentall, 2008).

In a review of 21 studies, Gumley, Taylor, Schwannauer et al. (2014) found moderate associations between insecure attachment and poorer interpersonal relationships, poorer engagement in services, avoidant coping strategies, more severe trauma and more negative appraisals of parenting experiences. Berry et al. (2008) also found an association with difficulties in therapeutic relationships. These studies could be critiqued for focusing on measures of attachment style in adulthood rather than tapping into attachment history or parental attachment in early childhood. However, other research offers corresponding evidence. For example, research suggests that an unwanted pregnancy increases the likelihood for psychosis in adulthood (Myhrman, Rantakallio, Isohanni, et al., 1996). Also, young people and children with a genetic high risk for psychosis are more likely to develop psychosis if they have experienced separation from

their parents in early life (Agid, Shapira, Zislin, et al., 1999) or report difficult parental relationships in adolescence (Schiffman, LaBrie, Carter, et al., 2002).

Phenomenology

Existential concerns such as a person's sense of purpose, personal beliefs and sense of self have long been of interest in understanding psychosis; the field of phenomenology offers another way of conceptualising the experience of psychosis. A number of writers in the area of *schizophrenia* argue that anomalies of self-experience are central to the condition's development and have explored various perspectives on how these anomalies express themselves and impact on the person (Lysaker & Lysaker, 2008; Sass & Parnas, 2003; Scharfetter, 1981). Historically, Laing (1960) referred to an experience of 'ontological insecurity' where an individual feels uncertain about who they are or their way of being in the world. An individual with psychosis may not feel real or comfortable with themselves and assumptions about who they are, who others are and their sense of autonomy or identity cannot automatically be made (Laing, 1960; Geekie, 2012).

Another area of phenomenological uncertainty refers to 'epistemological uncertainty' where the individual may doubt what they know, including how they understand and perceive themselves, as well as others and the world around them (Geekie, 2012). This questioning of basic, existential taken-for-grantedness means that the individual with psychosis will struggle to feel at ease with or trusting of themselves and also of others and, indeed, a fundamental consequence of these existential uncertainties is felt in terms of relationships with others and how that person experiences other people. In turn, Laing (1960) also posits that individuals confirm their sense of who they are through their relationships with others, suggesting that the development of such difficulties as well as consequences is centred around interpersonal and family processes.

2.4.7 Qualitative studies

The above body of literature exploring and understanding social, relationship and family factors and psychosis is clearly both broad and extensive but has mainly developed

within the quantitative tradition. Research explicitly exploring people's experiences of interpersonal relationships within psychosis, and from their own perspective, is more limited. A smaller number of studies have looked at various aspects of such topics using a qualitative design. This includes research looking at the experience of others in related or specific sub-samples, such as early psychosis (e.g., MacDonald, Sauer, Howie & Albiston, 2005) or studies that have looked at other aspects of the experience of psychosis and revealed insights into how people experience being with other people (e.g., McCarthy-Jones, Marriott, Knowles et al., 2012).

Qualitative research on interpersonal relationships

One study exploring social relationships in psychosis focused specifically on young people's experiences in recovery following a first episode. MacDonald et al. (2005) analysed interviews with six young people using an adapted phenomenological method. This involved picking out statements related to social experiences and then clustering based on similar meaning and essence. The resulting key themes included reference to the importance of feeling understood by other service users as well as the reliance on and appreciation of parents and family. A theme entitled, 'spending less time with old friends', made reference to the fear of judgement and lack of commonality with former friends as well as anger at past wrongs, while participants also talked about feeling different following their psychosis and wishing to build new relationships.

This study offers an important overview of how young people, specifically aged 19-25, with psychosis experience their social world. A primary aim of the study was to explore the importance of social relationships at this key developmental stage of early adulthood. The study therefore had quite a specific focus and, further to that, only included individuals attending a particular therapy group. This group focused on social as well as other needs while the main interviewer/researcher was also one of the therapists running the group. These are two factors that may have influenced what participants elected to say in their interviews.

A second key study exploring interpersonal relationships within the context of psychosis focused on young people at clinical risk of psychosis (Byrne & Morrison, 2010). This study was specifically interested in communication, or concealment, of psychological

difficulties. Eight young people, aged 16-28, participated and their interviews analysed using a grounded theory approach. The study's specific focus on the challenges felt in opening up with others may be considered a limitation, particularly as this emphasised problems over positive experiences in relationships. In addition, all but one of the participants were male which may limit the degree these findings may apply to women with psychosis or at clinical risk of psychosis.

Three central themes were elicited from the analysis to address these concerns. Firstly, 'difficulties with relationships and reduced opportunities for communication' included reference to childhood adversity as well as more current difficulties such as conflict and lack of closeness. Secondly, 'reluctance to disclose unusual psychological problems' reflected how individuals chose to first share their experiences with professionals rather than family or friends for fear of stigma or rejection, and a third theme of 'disclosure of unusual psychological problems: costs and benefits' referred to both the positive experiences of sharing and the not so positive.

Another important and relevant paper looked at impact of social relationships on the well-being of mental health services users and the impact of poor mental health on relationships (Green, Hayes, Dickinson et al., 2002). Narratives of 27 service users were analysed using grounded theory approach. The main themes included reference to service user's reliance and sometimes over-reliance on family members, as well as a sense that friends gradually 'drifted away' rather than outright rejecting participants. This was mixed in with social withdrawal on the part of the participants and resulting feelings of loneliness and isolation. A final main theme also highlighted the opportunity for and ease in relationships with other service users.

This group comprised mainly those with a psychotic or depressive disorder although specifics were not noted in the study. While this broader focus highlights the impact of mental health in general, it might also have been important to consider how psychotic experiences might factor in how people experience social interactions specifically and to pay attention to the meaning behind these experiences. This study also has the advantage of a relatively large sample size for a qualitative study but employed an unusual two-tiered approach to recruitment where some participants were recruited 1-3

months following discharge and others were recruited through a Mind drop-in group, up to 5-years following discharge. Differences between these two groups, particularly in terms of social vulnerability or dependence immediately following discharge may have introduced some bias to the study.

A more dated study looked at first-person perspectives on the social lives of people with a diagnosis of schizophrenia (Davidson & Stayner, 1997; Davidson, Stayner & Haglund, 1998). References to social relationships and social functioning were identified from a pool of autobiographical accounts, published over the previous 40 years by individuals reported to have a diagnosis of schizophrenia. This text was then analysed using a phenomenological approach. The study gave an account of the importance of loss of relationships due to experiences of stigma, alienation and rejection, isolation and social withdrawal as well the desire but despair in trying to re-establish a sense of connection with others.

Although dated, this study does provide an important insight into the first person perspective on the social lives of people with schizophrenia. However, it is difficult to make an assessment of the methodology used or of how replicable the study is due to a lack of published detail. Details regarding the nature or purpose of the accounts or the authors themselves are not provided, leaving it difficult to consider any possible bias or limitation. What is apparent is it that this study focused on those with a diagnosis of schizophrenia rather than psychosis generally, in keeping with psychiatric understanding of that time. As such, this may not reflect current views regarding the aetiology and diversity of psychotic experiences and likely excludes many people who have psychotic experiences (British Psychological Society, 2014). In addition, the study looked at perspectives on social life selected from previously published accounts rather than directly interviewing participants about their sense making or how they experience others and then systemically analysing the resulting data.

Qualitative research on the experience of psychosis

There are numerous other areas of qualitative research that do not specifically look at the experiences of relationships but have looked at more general areas such as the experience of psychosis broadly or more specific related areas such as recovery and

coping, relating to voices and other aspects of psychosis and also stigma. While these have either a narrower, broader or different focus, they have invariably offered insights into the impact or importance of social relationships, persistently highlighting their centrality in the experience of psychosis generally. For example, two studies, a review and meta-synthesis, focusing on experience of psychosis from the perspective of those experiencing it highlight key themes centred around social processes, such as achieving identity, the loss of relationships with the associated pain, the rebuilding and reforging of relationships and recovery through these relationships (Boydell, Stasiulis, Volpe et al., 2010; McCarthy-Jones, Marriott, Knowles et al., 2012).

Qualitative studies on stigma

A number of qualitative studies have explored how stigma and issues of discrimination are experienced within the context of psychosis. These studies have highlighted themes relating to public perceptions of dangerousness, limits experienced in access to social roles, including work, feelings of judgement and poor social comparison and reported 'avoidance-social isolation' as a strategy used to cope with stigma (González-Torres, Oraa, Arístegui et al., 2007; Knight, Wykes & Hayward, 2003; Schulze & Angermeyer, 2003).

Qualitative studies on recovery

Recovery is clearly one of the most important aspects of research on psychosis. Many studies exploring what enables recovery highlight themes centred around, for example, social support, detailed as 'collaborative support and understanding' in one study, in addition to the hindering impact of stigma in attaining a sense of recovery (Windell & Norman, 2012; Wood, Price and Morrison et al., 2013). Other significant themes have also included 'emotional change through social and medical support' and 'self-focused recovery', where emphasis was placed on recovery through independence and withdrawal in the context of feeling let down or unsupported by others (Wood et al., 2013).

2.5 Rationale and Aims

A long history of quantitative research and theory have contributed much to our understanding of psychosis in terms of interpersonal processes and have highlighted the range of social difficulties and challenges encountered. It is clear that many people who experience psychosis struggle in terms of social cognitive abilities, accessing social support and stigma (Bentall & Fernyhough, 2008). These factors, along with early experiences of adversity, particularly in the context of family and social relationships, contribute significantly to the cause, maintenance and further complication of their difficulties (Bentall & Fernyhough, 2008; Read, 2013; Segrin, 2001). Qualitative research also highlights how relationships, accessing social support and how people feel and cope with other people are central themes in first person perspectives of psychosis and recovery (Boydell et al., 2010; McCarthy-Jones et al., 2012; Wood et al., 2013). To a lesser extent, previous research has looked at first person accounts of the experience of others and social living in the context of psychotic experiences. As previously discussed, studies have looked at interpersonal relationships in the context of early and clinical high risk of psychosis, in younger people specifically and more broadly in people with mental health difficulties (Byrne & Morrison, 2010; Green et al., 2002; MacDonald et al., 2005). Research has also looked at the first-person perspectives on the social lives of those diagnosed with schizophrenia through analysis of published auto-biographical accounts (Davidson & Stayner, 1997; Davidson, Stayner & Haglund, 1998). However, after reviewing the literature, no published research has been identified that has looked directly at how others are experienced and sense-making with regard to social experiences in the context of the broader group of those experiencing and living with psychosis and at all ages within adulthood.

Such a study would offer an insight into the lived social-experiences of people with psychosis. Rather than just knowing that certain social factors and difficulties are linked with psychotic experiences, we could learn something about *how* other people are experienced from the perspective of the person experiencing it and how that person makes sense of these experiences.

Many writers have called for more qualitative research on the social lives of people with psychosis and mental health (Brunt & Hansson, 2002; Sullivan and Poertner, 1989), with some arguing that research that places the first person perspective as central is

necessary to challenging the apparent marginalisation of the service user's voices within current clinical knowledge and research (Geekie, 2013). As Geekie (2013) suggests, there is a moral case for such an approach, as service users should have the right to author their own experience and may also greatly benefit from the opportunity to express and describe their concerns and experiences in their own terms. It is likely beneficial for service users to know that the personal perspectives of others with similar difficulties have been taken into account in the development of the treatments and interventions that they are receiving and, in fact, many service users may assume that this is already the case.

The general aim of the current study, therefore, is to explore how individuals with psychosis experience other people, interpersonal relationships and their social world.

Specifically, the research questions were as follows:

- ***How do people with psychosis see and experience other people and their social world?***
- ***How do they make sense of their interpersonal experiences, including challenges they encounter?***

3. METHOD

3.1 Overview

The aim of this study was to explore how people with psychosis make sense of their experiences of being with other people. The following chapter will describe the methodology, design and analysis used to meet these research aims as well as the participants, process of recruitment and ethical considerations.

3.2 A Qualitative Design

The aim of qualitative research is to understand and represent the experiences and actions of people based as closely as possible on the perspective of those individuals who are being studied (Elliott, Fischer & Rennie, 1999). Focusing on such perspectives allows for an in-depth exploration of personal experiences, where subjectivity, meaning and interpretation are central (Mawson, Berry, Murray et al., 2011). As such, a qualitative method is considered a more suitable approach to addressing research questions that are less amenable to quantification and require the space for complex and rich information to emerge (Barker, Pistrang & Elliott, 2002). The service users themselves are also afforded the opportunity to voice their own concerns and perspectives, in their own terms, in this case, a group argued to be marginalised from the majority of current clinical and research practice (Byrne & Morrison, 2010; Geekie, 2013). A qualitative methodology was, therefore, considered the more suitable approach in addressing the current research question.

3.3 Interpretative Phenomenological Analysis (IPA)

Interpretative Phenomenological Analysis (IPA) (Smith 1996; Smith, Flowers & Larkin, 2009) was chosen as the most suitable approach for the current project. The primary concern of IPA is with how people make sense of major life events and aspects of their everyday lived experience that take on a particular significance for them (Smith et al., 2009). As such it was deemed consistent with the aims of the current project. It is also considered an established and valued methodology in the social sciences, having been

used in health, clinical, social and educational psychology (Smith et al., 2009) as well as in psychosis related research (e.g., Mawson, et al., 2011; Knight et al., 2003).

Phenomenology, hermeneutics and *idiography* form the theoretical foundations of IPA. *Phenomenology* is concerned with the detailed exploration of a person's lived experience, in particular the person's own "personal perception or account of an object or event, as opposed to an attempt to produce an objective statement of the object or event itself" (Smith & Osborn, 2008, p. 53). Taking account of the person's own perception of their experience, particularly on its own terms, is therefore central. However, being able to access this personal account relies on and is influenced by the researcher and their interpretation as well as on the process of interviewing and on what the individual chooses to share (Smith et al., 2009). Making use of phenomenology is an interpretative process and this brings us to the second theoretical foundation, that of *hermeneutics*. IPA not only acknowledges the active role of the researcher and their act of interpretation, but also requires it. The participant is involved in a process of making sense but to gain an understanding of this process the researcher is also engaged in a process of making sense of the participant's sense making (Smith & Osborn, 2008). This, called the *double hermeneutic*, highlights the need to be able to take the participant's side, to see this process from their point of view but also to ask critical questions (Smith & Osborn, 2008). It also highlights that the researcher brings his or her own set of beliefs, experiences and ideas that could influence or bias these sense-making processes. Transparency and reflexivity are therefore required of the researcher so as to become aware of and acknowledge these possible influences. To aid in the development of this awareness, the researcher engages in a process of 'bracketing' his or her own preconceptions (Smith et al., 2009).

IPA is also an *idiographic* approach, meaning it is more concerned with the particular than with drawing generalizable conclusions about wider groups or populations (Smith et al., 2009). Generalisations may be made but always anchored in the particular and from a more cautious position (Smith et al., 2009). The focus is therefore on hearing the individual story and so a commitment to thorough and detailed analysis is required as well as a commitment to understanding the phenomena of interest from the perspective

of a particular group of people within a given context (Smith et al, 2009). IPA therefore uses small samples that are selected purposely.

3.4 Choosing IPA?

As part of the development of the project, consideration was given to a number of other methodologies so as to confirm that IPA was, in fact, the most suitable approach to answering the research question. These included discourse analysis, narrative analysis and grounded theory.

Discourse analysis refers to a number of approaches to analysis that focus on the use of language and the role language plays in the construction of social reality. These approaches use the close examination of text to theorise on psychological phenomena (Willig, 2013). Discursive psychology in particular, as developed by Potter and Wetherell (1987), is chiefly concerned with how people use language to manage social interaction or position themselves socially, in other words, the performance qualities of discourse (Willig, 2013). While this project was clearly interested in social processes, it was chiefly concerned with the lived experiences of the individuals with psychosis within social contexts, such as understanding what being with other people was like and how they made sense of these experiences. Discourse analysis, on the other hand is concerned with discourse alone and not with meaning making (Willig, 2013) and so was deemed inappropriate to the needs of this project.

A second method that might have been useful was narrative analysis, which is also concerned with how people make sense of their experiences and their world, this time through narrative (Murray, 2003). The main assumption here is that people live and understand their lives through stories or in storied form and that life events are connected temporally following a sequence of beginning, middle and end (Sarbin, 1996). While narrative analysis may prove an interesting and valuable approach, this project was not concerned with the stories people with psychosis told about their experiences with others or about how these developed over time and so IPA was deemed a more flexible approach to accessing meaning making relating to experiences with others in the moment.

Finally, grounded theory is concerned with looking at social processes across cases so as to identify and integrate categories of meaning from the data, with the ultimate aim of developing new theoretical explanations (Willig, 2013). While this study was also concerned with social processes, this was mostly from the point of view of how individuals experienced other people and social interaction in the context of their own difficulties and unusual experiences and so had a psychological rather than a sociological focus. There were also concerns about the logistical demands of gathering enough participants to ensure theoretical saturation, as required.

3.5 Self-reflexivity and epistemological stance

Undertaking qualitative research requires that researchers recognise their values, assumptions and interests in an attempt to acknowledge how these might influence their engagement with and understanding of the data (Elliott et al., 1999). It is also impossible to ignore or set aside one's own perspective or one's previous training and knowledge completely and so a self-reflexive process of 'bracketing' these while analysing helps the researchers access a truer understanding of the participant's lived experiences on their own terms, in keeping with the IPA framework (Elliott et al., 1999; Smith et al., 2009). To do this it is important that I first acknowledge and *own* my own social and theoretical perspectives.

I am a 34-year-old white Irish female. I grew up in a very rural and working class part of Ireland. For a number of years, in my early twenties, I worked in a residential care setting for people with learning disabilities, most of whom had additional mental health problems including psychosis. I worked particularly closely with one service user who was coping with on-going psychotic experiences, which she clearly wished to talk about. As a staff team we often felt at a loss as to how to talk to her about her experiences and although she was really eager to be close to others, it was clear her experiences left her struggling to relate to other people and make friends. At the time, I had limited knowledge of psychosis and relied on what was often conflicting guidance and information from the mental health professionals involved. This guidance mainly centred on distraction or diverting the conversation away and I often felt this left her feeling frustrated and isolated, in what must have been a frightening inner world. Later, as a

trainee, I worked with a number of service users who heard voices and experienced delusions. I was fascinated to learn and see how these experiences were an important insight into what might have happened in the past or difficult conflicts playing out internally but wasn't surprised that much of the therapeutic work I engaged in with these individuals was about trying to help them to reconnect with people and the world around them. It became clear that interpreting the content of people's psychotic experiences could communicate a lot about that person's significant life events and inner conflicts or emotions, both to the person themselves and to important people in their life; yet, it was the strangeness or inaccessibility of these experiences that further isolated people from their social world. When looking for a subject for my final year thesis I was presented with this project but in a slightly different form. I was immediately drawn to it and struck by how important the topics of relating and relationships were for people who might often feel trapped inside a disturbing and distressing inner world and was interested to learn about how people with psychosis themselves understood their experiences with other people and made sense of them.

Although I would consider myself pluralistic in my approach to clinical psychology and clinical work, I would generally describe my personal epistemology as being social constructionist (Burr, 2003) and have approached this research from that stance. I believe that our sense of reality and truth and what we feel we know is co-created between people and within society, heavily influenced by both our culture and history. As such, I feel strongly that all perspectives and points of view have value and that there are many ways of looking at one thing. Some ways are merely more familiar, accepted and privileged than others. For this project I wanted to learn about individuals with psychosis and about their ideas, opinions and ways of making sense of their own experiences. I was also conscious that this viewpoint is often marginalised within the mental health system on which many individuals with psychosis so heavily depend. There, taken-for-granted 'truths' about the nature of their problems or validity of their beliefs, are often privileged over their own voices.

3.6 Study design

The current study utilised a cross-sectional qualitative design, where semi-structured interviews with individuals with psychosis were conducted, transcribed verbatim and analysed using Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2008; Smith et al., 2009).

The study took place as part of a larger study being undertaken by the external supervisor. Although part of a larger study, the current study was considered distinct and separate, with no involvement in the larger study on the part of current author. Within this larger study, entitled 'Exploring the experience of chronic depression', a number of smaller individual studies were taking place focusing on aspects of the experience of significant chronic depression for those with and without psychosis. This included studies understanding the experience of relationships, emotions and also attitudes to self in the context of chronic depression. In developing this study, it became apparent that a study focusing on the social experiences of people with psychosis but without chronic depression would form a useful point of comparison for the purpose of the larger study. More significantly, as a study in its own right, it would offer a valuable insight into the experiences of people with psychosis, where the primary difficulty is coping with psychosis or psychotic experiences rather than with significant on-going depression.

3.6.1 Recruitment

Participants were recruited using purposive sampling. Purposive sampling is used in IPA research to select a reasonably homogenous sample within a specifically defined group, for whom the research question will be most relevant (Smith & Osborn, 2008). For this study that group comprised adults experiencing psychosis. Participants were recruited through a NHS Trust with whom the secondary supervisor on the project worked as a clinical psychologist.

In order to identify potential participants, I contacted clinicians including clinical psychologists and psychiatrists working with the Complex Care, Assertive Outreach and Community Recovery teams. I briefly explained the nature and focus of the research, asking if they could identify service users who might fit the inclusion/exclusion criteria

and who might be willing to participate in the study. If they could identify such individuals, I requested that they speak to them about the possibility of participating and ask if they would be happy for me to contact them by telephone.

I received contact details for nine individuals who were willing to be contacted and telephoned them to explain the study and what would be involved, as well as send them the participant information sheet and consent form, if they were interested. Of these nine, seven agreed to participate and two declined. Meetings were arranged on an NHS clinic site to conduct the one-hour long interview and prior to this we allowed time to go through the participant information sheet, answer any questions or concerns and sign the consent form.

3.6.2 Inclusion/exclusion criteria

The following inclusion and exclusion criteria applied:

- Age 18 upwards
- Male or female
- Has experienced or is currently experiencing one or more symptoms of **psychosis**
- Was **not** currently experiencing chronic or major depression:
 - Does not have a primary diagnosis of depression as per the service users electronic record
 - Does not score in the 'moderate' or 'severe' ranges on the Hospital Anxiety and Depression Scale (HADS) (Snaith & Zigmond, 1994).

The current study excluded those with chronic depression in order to distinguish between those who have a primary diagnosis of a psychotic disorder and those experiencing psychosis as part of chronic depression. Additionally, as this study was also forming part of a larger study, where a similar study was being carried out specifically with those with chronic depression, it was important to exclude those with chronic depression so as to form a distinct point of comparison, in keeping with the aims of the larger study.

As such, each clinician was asked not to include those with a primary diagnosis of chronic depression, as per the service users record (checked by the clinician against their own records or the service user's electronic record prior to selection). In addition, the depression subscale of the HADS was completed with each participant as part of the interview. Those whose scores fell within the 'normal' or 'mild' ranges were included within the study and those with scores that fell within the 'moderate' or 'severe' range were excluded. Considering that those with a primary diagnosis of depression were excluded at the offset, those with a 'mild' score were included to account for people whose primary difficulties related to psychosis but may also experience some low mood, possibly as a consequence of coping with their psychotic experiences, a difficulty demonstrated in previous samples of individuals with non-affective psychosis (Myin-Germeys, Peeters, Havermans et al., 2003).

3.6.3 Participants

The sample consisted of seven individuals who were experiencing psychosis. Two of the participants were men and five were women. All but one were recruited through the complex care psychology service and had or were currently participating in either group or individual therapy. One participant was being seen by psychiatry with the assertive outreach team, having received therapy in the past.

The participants ranged in age between 36 and 55 years, with a mean age of 46.28 years and came from diverse ethnic backgrounds. At the time of the interview, none of the participants were in employment. All lived local to the service in a very diverse area of London. Five of the participants lived independently and on their own, one lived with a partner and one with parents. For two of the participants, English was not a first language although they spoke with a high degree of fluency.

The number of years they had been experiencing mental health problems, including psychosis, ranged from between 8.5 years and 35 years. Five identified themselves as having a primary diagnosis of 'schizophrenia' and two as having a primary diagnosis of 'schizo-affective disorder'. All of the participants completed the depression subscale of the Hospital Anxiety and Depression Scale (HADS). Scores for three of the participants fell within the 'mild' range and scores for four fell within the 'normal' range.

Table 1: Participant characteristics

Name (Pseudonym)	Age	Ethnicity	Problem Length (years)	Diagnosis
Nik	38	Black-European	26	Schizophrenia
Ben	45	White-British	8.5	Schizo-affective disorder
Sara	55	Asian	25	Schizophrenia
Zoe	49	White-British	13	Schizophrenia
Amy	36	White-British	15	Schizophrenia
Lucy	49	Black-British	32	Schizophrenia
Jan	52	White-European/ British	35	Schizo-affective disorder

3.7 Ethical considerations

Ethical approval was granted for the overall study “Exploring the experience of chronic depression” by the National Research Ethics Service (NRES) for Camden and Islington, London, REC reference: 10/H0722/14 (see Appendix 7.1.1). In January 2014, a notice of amendment was submitted to also interview a sample of individuals with psychosis but without depression, as part of the current study (Appendix 7.1.2 includes the notice of amendment with details of the changes). The amendment was approved by the committee in February 2014 (Appendix 7.1.3), amendment reference: *Amendment 2, 14/10/2014*.

At the same time, research and development approval and sponsorship of the study was taken on by the NHS Trust involved and overseen by Noclor, a consortium responsible for providing research management & governance service across a number of London Trusts. An application for a *research passport* and *letter of access* was to submitted to Noclor and granted in April 2014, allowing for my formal inclusion as part of the research

team and for sponsorship for the larger study to be extended to include me (See Appendix 7.1.4). Ethics validation of the NRES REC approval was then granted by the University of Hertfordshire Ethics Committee (Health and human sciences), registration protocol number, LMS/PG/NHS/00192 (Appendix 7.1.5).

3.7.1 Informed consent

Participants were provided with an information sheet at least a week prior to the interview and also in our discussion at the beginning of the interview (Appendix 7.2). This information sheet along with the written consent form was originally developed for the purpose of the overall study. Changes were made to include reference to the current study with people with psychosis/without chronic depression and also the use of the data for the purpose of completing the doctoral thesis. These changes were approved by the NRES as part of the notice of amendment. In the telephone conversation with potential participants, prior to sending them the information sheet, this was explained to the participants and discussed further when we met before conducting the interview.

The participant information sheet explained the purpose of the study, what participating would involve, the risks and benefits of taking part as well as how confidentiality would be maintained. These issues were explained and discussed further, both in the initial telephone conversation with potential participants, and at the beginning of the interview. Participants were also encouraged to ask any questions or raise any concerns. It was emphasised that should they not wish to participate or feel unsure, that they were free to withdraw at any time before, during and also after the interview was completed but before their information had been analysed and used in the write-up. It was made clear that there would be no consequences to withdrawing, including any impact on the care they were currently receiving from the Trust and that they did not need to give a reason. If they wished to participate they were then requested to sign the written consent form (Appendix 7.3).

3.7.2 Confidentiality

Information on confidentiality, how confidentiality would be preserved, as well as its limits was provided to the participants both verbally and in the information sheet. It was

explained that should the participant make statements that suggested there was a risk of harm to themselves or others, that confidentiality would have to be broken and the clinicians responsible for their care in the Trust informed. Based on my clinical judgement, I did not feel that any such concern emerged in any of the interviews or prior discussions with the participants.

It was confirmed that any personally identifying information such as participant's names, contact details and signed consent forms were kept securely and separate to the audio recordings, transcripts or research data. It was also explained that participants would be given a pseudonym to protect their identity, which would be used throughout the research process, including write-up and dissemination and that any identifying information within the interviews, such as names and places would be changed. Participants were also advised that I was completing the research as part of a doctoral thesis and that anonymised transcripts of the interviews would be read by supervisors within the research team, the transcription service and by examiners. Four of the five interviews were transcribed by a transcription service. One individual within that service transcribed all four interviews and completed a non-disclosure and confidentiality agreement prior to the interview being released to them (Appendix 7.5). In the event that this individual would happen to recognise the participant from the recording, they were asked to stop transcribing immediately and contact me.

3.7.3 Consequences of participation

It was important to be aware of any potential distress that the interviews may have brought up for the participants. Some of the questions related to difficult past or current experiences, involving relationships and other people and could potentially evoke some painful memories and discussion. It was also important to be mindful of the vulnerability of this particular group, given the nature of their difficulties. With this in mind, consideration of the participants' well-being was a priority throughout the interview process.

The potential for distress was discussed with the participants before commencing the interview and participants reminded that they could stop the interview, withdraw or take time out at any point throughout the process. It was also explained that, if they wished,

they could decline to answer any question or finish an answer early and ask to move on, nor did they have to offer information that they were not comfortable giving.

Time was allocated at the end of the interview to discuss how the participant found the process and allow space to debrief. Suggested sources of support were shared with the participants, including the clinical psychologists and psychiatrist who had originally identified them for the study. As a trainee clinical psychologist, with experience working with people experiencing emotional distress, I was also able to use my clinical judgement as well as verbal report to assess for any potential risk. I did not feel there was any cause for concern following the interviews. All of the participants reported that they found the experience enjoyable or helpful and reported feeling glad that they had chosen to participate.

3.7.4 Previous involvement in the service

As a trainee clinical psychologist, I had also completed a six-month placement as part of the Complex Care Psychology Service, the service through which most of the participants were recruited. While this was primarily beneficial to the study, as it meant I was aware of how the service operated and knew the clinicians involved in the participants care, it was also important to consider any conflicts of interest. In selection of potential participants, it was important to make sure that I had no previous therapeutic involvement with the participants and also I made the participants aware that I had previously worked with the service as a trainee.

3.8 Data collection

3.8.1 Interview design

A semi-structured interview schedule was developed with input from the supervisory team and drawing on the relevant literature and specialist IPA guidance (Smith et al., 2009). The original ethical approval for the larger study had not included or required an interview schedule. This allowed for the development of a new interview schedule more suited to the intended sample and research questions.

3.8.2 Pilot interviews

In order to gather initial feedback on the interview schedule and gain experience of the interview process, a pilot interview was conducted with another trainee clinical psychologist as well as a section of the interview piloted with my external supervisor. Guidance in conducting a semi-structured interview suggests that a learning process is required to develop clarity and confidence in a researcher's interview style and that the interview schedule needs to be used flexibly to facilitate a detailed and open exploration of the participant's experience (Smith et al., 2009; Smith & Osborn, 2008). Piloting the interviews in this way allowed for opportunity to learn about and reflect on my interview style, while feedback was used to inform the subsequent interviews with participants.

Additional feedback on the relevance and suitability of the interview questions and on the experience of the interview process from the point of view of the participants was gained from conducting a second pilot interview with a potential participant. No changes were made to the schedule following this consultation and the pilot interview included in the sample.

3.8.3 Interviews

Choice of venue for the interview was offered between one of two NHS sites, both of which were local and familiar to the participants. In arranging the interviews, it was explained that the interview could take up to one hour but that extra time was needed to discuss and explain the process and complete the consent form beforehand, and also for breaks and a chance to debrief afterwards. The interviews lasted between 55 and 77 minutes. Before commencing the interview, specialist IPA guidance was followed to help orientate the participant to the interview process (Smith et al., 2009). For example, it was explained that, as the interviewer, I would say very little and instead help the participant to talk, that there were no right or wrong answers and that the main focus of the interview was on their ideas and experiences. At all points throughout the interview process, participants were reminded of their right to withdraw.

Directly following each interview a reflective diary was written to make note of observations, initial ideas, issues of context and process that were important as well as

general reflection on the interview. This was done with the aim of bracketing my own personal feelings about the interview and to aid in reflexivity.

3.8.4 Participant Feedback

Thought was put into how the findings would be fed back to the participants. At the end of each interview, participants were asked if they would like a transcript or audio recording of the interview and also to be contacted with the final results when the study was complete. All gave permission to be contacted although some expressed uncertainty about hearing about the results and, especially, having a record of the interview. It was agreed that I would contact the participants when the findings were published and offer a copy of the final paper, as a more succinct and accessible report on the study. It was also agreed that I would use this same opportunity to offer a copy of the transcript or audio recording, rather than make contact on more than one occasion.

3.9 Data analysis

All of the interviews were recorded via a portable audio recording device and transcribed verbatim. The first three interviews were transcribed by the researcher and, due to time constraints, the remaining four by a transcription service. Transcribing three of the interviews aided in the process of immersing and familiarising myself with the participant and the interview. Although four of the interviews were then transcribed by the transcription service and not by the researcher, time was taken to listen to those interviews through, along with transcript, while also checking for any omissions or errors.

3.9.1 Individual analysis

Interviews were then analysed using IPA as described by Smith et al. (2009) and Smith and Osborn (2008). The process of analysis initially involved an idiographic focus on each interview case-by-case, with each interview being analysed in full before moving onto the next. The transcript for each interview was transferred into a three-column table, one column for the interview and a second and third for the initial or exploratory comments and subsequent emerging themes, respectively. The audio recordings were listened to and transcripts read and re-read. Initial comments were noted down,

including explanations of what was said, important ideas, use of metaphor, contradictions as well as initial interpretations and reoccurring ideas or themes. Comments that were descriptive, linguistic or interpretative in nature were distinguished from one another using textual style, as suggested by Smith et al. (2009). This aided in organising the data and allowed for an increasing interpretative focus with each reading.

Emergent themes were then noted that best captured both the words of the participant and the exploratory comments. This involved a process of going back over the interview to identify what was repeated and also what was new and distinct within the interview, so as to “reduce the volume of detail... whilst maintaining complexity” (Smith et al., 2009, p. 91). At this stage the researcher takes a more central role in “organising and interpreting the analysis” (p. 91), capturing what is significant at one point whilst being influenced by the overall lived experience of the participant and the whole text.

Next, involved the process of organising the emergent themes for each individual and searching across the list of themes for connections. Themes were clustered together in various ways to see which fitted together while also reflecting “the most interesting and important aspects of the participant’s account” (Smith et al., 2009, p. 96). Some of the themes clustered together while others acted as a magnet or an umbrella theme and offered a way of summing up others. These themes became superordinate themes along with the titles given to the clusters that best described the themes within. Throughout this process the transcript was continually referred back to, confirming that the themes were grounded within the original words of the participant. An example of the analytic process for one interview is included in Appendix 7.6.

3.9.2. Cross-case analysis

A table of the clusters or superordinate themes along with the individual emergent themes and corresponding extracts was developed for each individual interview (see Appendix 7.6.2 for an example). The next step in the analysis involved looking across all the individual’s superordinate themes to identify possible patterns. Again the themes for individual cases were listed together and various combinations explored to see what clustered together and also what was most compelling or spoke for the all of the participants. As with the individual clustering process, the iterative focus of IPA was kept

in mind and individual transcripts continually referred back to check for instances of each new superordinate theme (Smith & Osborn, 2008). Smith et al. (2009) also suggests moving to a more theoretical level and exploring “themes and superordinate themes which are particular to individual cases (but) also represent instances of higher order concepts which the cases therefore share” (pg. 101). As with the individual cases, a master table of superordinate and subordinate themes was created for all of the participants together. Appendices 7.6.3 to 7.6.5 demonstrate this process.

3.9.3. Credibility/quality of analysis

Steps were taken to ensure the credibility and quality of the current study and to demonstrate that the following findings have emerged from the data rather than from researcher’s preconceived ideas or beliefs. Guidelines specific to the evaluation of quality and reliability in qualitative research have been developed by a number of writers including Elliott et al., (1999) and Yardley (2008). Elliott et al. (1999) have proposed a number of guidelines that are of specific importance to qualitative research and steps were taken within the current study to ensure credibility in accordance with these guidelines.

For example, Elliott et al. (1999) suggests that owning one’s own perspective in research allows for transparency in terms of the possible impact of a researcher’s “values, interests and assumptions” (pg. 221) thus allowing the reader to more accurately interpret the findings. As well as taking time to reflect on and account for my position within this research, a reflective diary was also kept throughout the interviewing and analytic process to identify and bracket important personal feelings, assumptions and values. In keeping with Elliott et al.’s (1999) guidelines, it was important to highlight the specificity of the findings and limits in terms of generalizability. Effort was also made in the above description of the participants, to situate the sample by providing enough data to allow for the reader to understand the participant’s life and circumstances but not so much as to compromise confidentiality. This helps the reader decide on the range of other people or circumstances to which the findings might also apply (Elliott et al., 1999). In addition, extracts were identified to illustrate each emergent, superordinate and master theme throughout the process and used to illustrate the master themes in the

descriptive account, so as to illustrate both the analytic process and connection between the words of the participants and the findings.

In order to ensure the credibility of the interview and analytic process, supervision was accessed throughout, from both internal and external supervisors, who together have extensive experience in the application, supervision and publication of IPA-related research, as well as research and clinical experience with people with psychosis. Both of the supervisors on the project read through the completed analysis for three of the participants along with the results, aiding in a process of triangulating the analyses (Smith & Osborn, 2008). Discussion took place regarding how well emerging and super-ordinate themes reflected the original data and the overall coherence of the analysis, which allowed for a more rounded understanding of the process and the data. Appendix 7.6 provides a sample of the analytic process for one participant, following that process from interview through to development of the master list of theme and sub-themes.

4. RESULTS

This chapter presents and discusses the findings of an Interpretative Phenomenological Analysis (IPA) of the experiences of seven individuals with psychosis, exploring their relationship with their social world. The following three major themes emerged from this analysis:

1. Finding a place in society
2. Interpersonal mistrust
3. Feeling undermined by inner/outer disturbance

The master and subthemes for the complete analysis are summarised in Table 2, below. Appendix 7.6.5 illustrates the occurrence of each of these themes across all seven interviews.

Table 2: Master themes and subthemes

Master themes	Subthemes
Finding a place in society	Feeling disconnected Doubting my social self Feeling inadequate Struggling for individual identity A society of our own The importance of those that care
Interpersonal mistrust	Expecting the worst from others A need for distance Coping through avoidance
Undermined by inner/outer disturbance	Unusual experiences making it difficult to connect Past intruding on the present

What follows is a detailed account of each of these master and subthemes in turn, along with extracts from the interviews to demonstrate how these themes emerged. The aim is provide a coherent and plausible representation of the participant's experiences.

Owing to the *double hermeneutic* inherent in IPA and the researcher's use of their own sense making in interpreting the words of the participants (Smith & Osborn, 2008), the role of the researcher in the analysis and subsequent emergent themes must be acknowledged. It is impossible to completely bracket and account for the influence of every aspect of the researcher's assumptions, values and interests. As such, the following account offers one possible construction of how people with psychosis make sense of their social world. Analysis conducted on the same interviews by a different researcher at a different time may produce a similar or different set of themes.

It must also be acknowledged that given the level of depth that IPA focuses on, it is not possible to cover or discuss all of the ideas, opinions and experiences that the seven interviewees shared. Instead the focus was aimed at that which was relevant to the research question and particular focus of this study, and, therefore, what was deemed important in capturing the experience of social life for a majority of the participants.

There is also the potential for overlap or commonality among themes as many of the themes reflect different aspects of the same narrative and so are naturally interlinked. In some instances themes may have occurred together or overlapped as differing aspects of a participant's experience or sense making while, at other times they have occurred separately. In addition, many themes may also reflect developments or changes, where one theme may, in part, have resulted as consequence of another. This may be the case for one participant but not the case for all.

4.1 Finding a place in society

This first master theme describes a feeling or process that all of the participants felt or were engaged in in some way. This process moved between a sense of being cut-off from or outside of 'normal' or 'mainstream' society to finding or re-establishing a place for themselves within their social world. Most were socially isolated or felt disconnected and

distanced from others, were lonely or felt alone. All spoke of doubts or difficulties they experienced in terms of their social skills and how to be with or manage other people. There was a strong sense of feeling inadequate, either in their own eyes or in how they thought others perceived them, particularly a doubting of what they could contribute and achieve both socially and occupationally. Within this context, all were engaged in finding a way to express themselves and to assert or protect their sense of individual identity and ways of living. One setting in which the participants did feel a sense of belonging and purpose was in the context of mental health services and with other service users. Here they felt they had something to contribute and felt understood and accepted. The care, support and understanding of important others were also essential in helping people feel as though they had a place among other people.

4.1.1 Feeling disconnected

The sub-theme 'Feeling disconnected' describes the sense of isolation, aloneness and, particularly, disconnection from others that all of the participants were experiencing to varying degrees. There was a strong sense of something missing from their social world. For many, this was having little or no contact with other people or relying on a very small number of family or friends for support. They often felt lonely or alone, with a strong sense of disconnect or distance between them and other people.

When asked about whom he spent time with, Ben talked about one friend that he met to play sports with once a week. Apart from sporadic contact with family, his involvement in mental health services and chats with acquaintances in the pub, this was the only contact he had with another person and the only person he considered a friend.

“...actually, do you know, I’ve only got, I’ve only really got one friend really, or that I would classify as a friend.” (Ben, p.3)

There was very little sense of anywhere for Ben to turn to for comfort, support or a sense of connection with people and with society. There was, however, a strong sense throughout Ben’s interview that being able to adapt to being alone and downplay its impact was an important way to cope with this isolation. As can be seen from his comment, there was a sense that he had just realised how alone he was, as though this

was something he was used to and not really that distressed by. However, Ben also spoke about friends who had come and gone in his life, people that had hurt or disappointed him and who he had 'cut out' from his life. His isolation clearly carried with it anger and memories of hurt and consequently he was left feeling alone and with a sense that he had to resign himself to his situation.

“...my trust in people was much lower when he acted in the way he did and I used to go out to pubs and chat to other people. I used to go and chat to lots of different people and I never relied on the people that I was with. I used to just feel that I was alone even when I was with someone and, consequently, I would socialise, socialise by myself.” (Ben, p.4)

As well as *being* alone, almost all of the participants, like Ben, reported *feeling* alone, regardless of whether they had contact with people. This seemed to stem from feeling unable to build a sense of connection and closeness with those people. It was sometimes a feeling they had always carried with them or a consequence of their past experiences of adversity. Nik, who had grown up in care and reported always feeling alone, described this experience:

“I find it very hard to get close to people. I have attachment issues, as I realise, you know. I keep my distance but I'm open to, to express myself and say things but when it comes to important (pause), to get close to people or let them get close to me and make a bond, it's very hard for me really so I keep a distance.”
(Nik, p.1)

Nik felt confident to talk but the use of the word 'important' suggested that when he wanted to get close to someone, when it was important, he struggled to close that distance and build a sense of connection. Many of the participants talked about barriers that they felt between them and other people, often stemming from feelings of discomfort, vulnerability, fears of being hurt and also voices, confusion or unusual beliefs about people's behaviour.

For others a feeling of aloneness came with acute illness and being in inpatient care, mostly especially as a consequence of other's reactions to them and their difficulties. For

instance, Zoe talked about her friend's apparent discomfort when visiting her as an inpatient. When asked how this made her feel, she responded:

"Eh, a bit lonely. A bit lost. Yeah." (Zoe, p.15)

Seeing her friend's discomfort clearly made Zoe feel more separate from her friend and reminded her that she was alone in dealing with her difficulties. The word 'lost' highlights the consequent lack of direction and hope.

For others, loneliness was a position they feared and felt close to falling in to. Lucy was aware of the consequences of being alone and so worked hard to avoid it:

"...we all need people. We have to admit that if you make yourself lonely you might have a... fundamentally you might have a problem, a bigger problem, than the person that's interacting with people." (Lucy, p.14)

4.1.2 Doubting my social self

All of the participants talked about a sense of doubt and distrust in themselves and in their ability to socialise. Instead of social interaction being natural and free, each of the participants talked about how they questioned what they were doing, what they said and what was happening between them and others. It was clear that, for some, being with others was a chore or a struggle rather than a source of enjoyment and that the outcome was often a sense of uncertainty, anxiety and self-doubt.

Sara talked about how socialising and being with others had become an unpleasant and sometimes frightening experience, especially since she had started to hear voices and to feel that other people were touching her in unusual and confusing ways. She had begun to constantly question both others and herself and found it easier to avoid being with people. She felt that she had lost her natural and warm way of greeting and chatting with people.

"...distant families and all of them, I can't react with them very nicely, you know. I don't know why. Now, before I could but now I'm (pause). The other thing, I've become very quiet and not like before but I don't understand why I became so quiet and not like before." (Sara, p.10)

“I can’t socialise in a good manner like that. I say to them ‘good morning’ and ‘hello’ and ‘how are you?’ and that but apart from that I can’t say much.” (Sara, p.6)

Nik also talked about being aware of how he interacted with people and spoke about shortcomings he felt he had:

“I feel this slowness and that bothers me and the awkwardness and, you know, then not ready, no, then not ready to re-, erm, re-, react, not react, to engage with people in a quiet, normal way... I had to really learn that” (Nik, p.9)

“So, I need to, re-, re-learn, to re-learn myself, re-learn social interactions, you know, social skills again...” (Nik, p.13)

Rather than focusing on the other person/people or on enjoying his experiences with others, it was apparent that Nik had become keenly aware of shortcomings and ways in which he needed to change. He said he needed to ‘re-learn myself’ as though his very way of just *being* with other people was under question and needed to be corrected. It was clear from these comments also that the process of doubting and questioning that Nik was caught up with was likely to contribute to a slowness and awkwardness that others might also feel too and was even suggested in this comment by his struggle to find the right words.

Nik and Sara were explicitly aware and critical of their general social skill and manner of being with people. Others in the group also talked about specific difficulties and skills they felt or suspected were lacking, all contributing to a sense of self-doubt, uncertainty and social struggle. Examples given for two of the participants were around knowing how to build an acquaintance into a friendship, while other examples included coping with anxiety and feeling at ease; knowing where to look while in group; being able to say ‘no’; and knowing what to say and what not to say.

For example, Lucy talked about feeling conscious that she said too much in conversations with others...

“I have a problem. I am telling people my business as well, what I am about to do and I sho... I have to learn not to do this.” (Lucy, p.4)

...while Amy struggled with social abilities that many might take for granted:

“Yeah but I find it hard, like eye contact and everything and, erm, you know and, erm, if I am in a group of people I don’t know where to look basically (awkward laugh).” (Amy, p.6)

Throughout her interview Amy also talked about feeling that she could not make friends or feel comfortable with people. She felt she did not know how to build a friendship or get to know people outside of formally arranged groups:

“Yeah and I don’t really have friends that I speak to on the phone... well people do phone but it’s just... I don’t have like a group of girlfriends or, you know, but I do socialise during the week. I don’t really know how to take it further, like if you have a friend at church, I just don’t seem to be able to say, and start going ‘Oh you know, this or we will see each other after work or...’ it just doesn’t. I don’t know how to even think to take it anything like that.” (Amy, p.22)

Again there was a sense of measuring out each interaction or outcome for Amy, rather than simply going with the flow and enjoying being with people. It seemed there was some inside knowledge that she felt she lacked rather than feeling this was a more organic process that happens when people get on well or have other reasons to become close.

4.1.3 Feeling inadequate

All but one of the participants expressed concern about not feeling good enough, mainly attributed to experiencing significant mental health problems and the subsequent position this left people in. Many of the participants felt they did not measure up to mainstream societal norms, for example, by not having a job, by being on benefits or by not having their own family.

“...I suppose I just don’t see myself as... what do you call a normal life... I am not working and I haven’t got a family and just, you know, these types of things... (Amy, p.10)

There was also a feeling that others were aware and judging of the diagnosis itself or of past difficulties and failures or of the person’s ability to succeed and recover. In some

cases this was just an expectation or a feeling they carried with them, an expression of low-self worth, as Amy again explains:

“Well, I mean to my face everyone seems nice so, erm, I still have an inferiority complex. I suppose there’s, there’s no discrimination.” (Amy, p.20)

In other cases, people experienced overt criticism and discrimination:

“...there was a man... that said to me ‘freedom pass, you’ve never worked a day in your life’ and then he said to me, you know, being on benefits, that I should be locked up and put in Prison....” (Jan, p.7)

Experiencing these problems and having this label seemed to be a defining characteristic for people and more often than not this was *not* a source of confidence or positive affirmation. As Amy explained when describing one of the difficulties she often encountered when out trying to socialise:

“I can socialise, you know, with some difficulty at my church, but you’ll get ‘So what do you do?’, you know, and it’ll be ‘Well, I have mental health problems’” (Amy, p.15)

Amy was not the only participant who talked of her struggle to answer this question. From this comment, it was clear that she had come to see her mental health problems as self-defining, almost as a profession would be and could not think of a response that might have been more relevant to the question or to how she might have described herself. As it did for others, this seemingly simple question, frequently used to make conversation with new people, quickly rendered her encounter into an awkward and even distressing experience.

Many of the participants also talked about the feeling that people lowered their expectations, making assumptions about what they were capable of. As the following extract demonstrates, Lucy even found that people were jealous or begrudging of her unexpected successes:

“In general, they are reasonably jealous... Because I have got a mental health problem and I could do these things. I could achieve these and I should be...to them maybe I should be somebody stupid you know, not really all there.” (Lucy, p.8)

Jan also felt that her lack of achievement and occupation, as well as her ‘label’ was a reason people kept a distance from her:

“Because I feel like I am a nobody. You know I don’t do anything and I have got a label, a mental illness and people have kept away.” (Jan, p.9)

As well as experiencing the emotional distress of the mental health problem itself, it was clear that just having this label had damning and discriminative connotations and so brought an additional burden of social difficulty.

Tied up with feeling inadequate was a concern about not contributing and being a burden, either on society as a whole or on loved ones and those who cared. Zoe talked about the impact her distress and her experiences of voices had on her partner and close friends and the feelings of guilt this left her with:

“Because if I need somebody to help me. Because I am in distress I sometimes feel guilty that I, I’m being too much for them. Like I said, being a burden.” (Zoe, p.10)

Zoe was someone who had clear ideas about wanting to contribute and be valued for the support she gave as well as received from others. She struggled to see her own self-worth and so was left doubting herself and other’s opinion of her when she needed help. She was particularly concerned that her partner might not be willing to stay with her because of her difficulties and worried about his feelings towards her. The catch was however, that the more she berated herself for being a burden, the more distressed she was left feeling and then the more likely it was that she needed more support.

Sara also reflected on what she contributed, not just to her relationships, but to society more generally. She did not work but was keen to keep her mind active and spent her time listening to music, debates and informative programs on the radio. In the following quote, she described her feelings:

“Well I think I’m not wor... sometimes I feel let down and I say to my son that I feel really low and I don’t feel worthy.... Like I’m not used to, any use to so-... in the society, you know... when I see, when I see you and others working and I feel proud, you know, that you can achieve things like that. Where as I feel I’m at home just listening to music and not being able to do things ” (Sara, p.15)

Sara clearly had little sense of her own worth and value, such that having no career or sense of achievement meant she felt ‘low’ and ‘not... any use’. Another person might not worry too much about what they contributed, but for Sara, contributing was clearly important. Her use of the phrase ‘I feel let down’ suggested her disappointment with herself and sense that she maybe once had different intentions for herself. Having work and a sense of purpose and, more generally, contributing and feeling valued within society was, therefore, a central factor in many of the participant’s sense of self as good enough in their own and other’s eyes.

4.1.4 Struggling for individual identity

All of the participants referred to the challenge or wish to be his or her own person and to assert their own individual identity. There was a need for people to get to know themselves and to accept who they were. There was also a need to feel free to *be* that person and be accepted by others as such. The individual’s sense of himself or herself was therefore tied up in what they felt they communicated to others and in what others knew of them. Lucy tried to explain this complex topic in her comments about what helped her to feel at ease during the interview process.

“I felt at ease... there wasn’t pressuring me to behave how I didn’t want to behave or act or (say) things I didn’t want to say... So it really is the behaviour. How you want to act as a person or who you want to be and we all want to be who we are...”
(Lucy, p.26)

Lucy was someone who wanted to reflect on these more complex issues relating to self-identity but her unusual use of language sometimes meant it was difficult to follow what she meant. Put in the context of what she said elsewhere in the interview, it was clear that, for Lucy, feeling like the person she wanted to be depended on behaving in that way and also on others encouraging or even allowing her to be and behave as that

person. She was someone who felt that her family interfered in her life and sometimes did not respect her wish to assert herself and say 'no'. In choosing to reflect on this, when asked about how she felt in the interview, it was clear that needing to express herself as herself and not feeling a pressure to pretend or acquiesce was important. Otherwise, it seemed that becoming the person others wanted or expected could happen all too easily, leaving her feel as though she had let herself down or, more generally, preventing her from living as she wanted.

Each of the participants appeared to be at their own individual stage in a process of trying to get to know and accept who they were and in trying to assert or find a way to express their own sense of identity. For Ben, he looked to the future and talked about a wish to be in a 'permanent relationship' where he could start to trust and open up.

"when I get to know someone then I, then I can be more myself I suppose" (Ben, p.14)

When asked what 'being myself' would be like, Ben responded:

"I suppose, erm, being a bit, maybe, I'm exploring more about my feelings." (Ben, p.14)

Being himself and exploring his feelings clearly required the mutual trust and sense of security he hoped for in a long-term relationship and not something he currently felt that he could do. There was clearly something important about being yourself in the context of a relationship with another person, may be that it might offer him a feeling of being accepted as he was.

Others were in the process of finding ways to express themselves and establish a sense of individuality and identity. Amy, a young woman who lived at home and spent most of her time with family, appeared as someone trying to communicate to those around her that she was an individual with her own ideas, opinions and beliefs. It seemed she had even gone so far as to change religion and at home spoke about her new beliefs, listened to Christian radio and called family members attention to what they should and shouldn't be doing.

“Well because I play my Christian Radio in the house my dad doesn’t like it and... yeah, so I do have problems with my relationships with my dad and my brother. So...” (Amy, p.16)

This put her in conflict with her family, the very people she relied so heavily on, but it was apparent that this was likely her way of asserting who she was and herself as an individual when maybe she felt she couldn’t in other ways. Individuality and self-expression was something she seemed to feel the need to fight for, even when it was likely not going to be accepted by those around her.

For Nik, establishing an individual identity was a current priority and also more of a private endeavour. He was someone who was working hard to manage his emotional well-being and build a better life for himself and part of that was to take time away from his social life to get to know and accept who he was outside of that context.

“I’m just trying to find myself really... I try and spend as much (time) as I can on my own and read my books, listen to favourite music, without being affected by other people’s opinions, not opinions (pause) but I just want to find myself: what I want, that’s how I want to dress, who I want to be, what I want to do and being with other people, I find it very hard to, I, I mean I want to spend my time with myself really, you know. I was preoccupied a lot with caring for other people except myself...” (Nik, p.2)

It seemed Nik viewed himself as someone who was easily led by others and as such would lose sight of doing what he wanted and having opinions that were his opinions. He talked about wanting to ‘find’ himself as though there was a more honest or real version that he had lost. At 38, it seemed that he felt he had spent many years pretending and feeling as though his real opinions, tastes and wishes were not valid or acceptable to others. It was clear this had left him feeling frustrated and led him into situations he did not want to be in.

Similarly, Jan talked about needing to express herself but took a more positive and strong position in putting herself out there socially, as the following extract demonstrated:

“Well you want to...you don’t want to be swallowed up by rubbish. You know, you want to make a comment or say your piece and express yourself wherever you are.

You have got to express yourself.... I express myself through the music I like and the music I play at home. I express myself in my clothes and how I look..." (Jan, p.5)

'Being swallowed up by rubbish' referred to a fear of being talked over in conversation and not getting the chance to show herself as an individual, as intelligent or interesting, with things she wanted to express and talk about. There was a sense that she would be swallowed up or drowned out, but not by good conversation or people that she looked up to or enjoyed but by 'rubbish'. This was a particular struggle for Jan. The fact that she had looked for and found other ways to express herself suggested that she had not always felt as though she got to say what she wanted but it also suggested that there were other important ways to channel feelings, personal tastes and ideas, either for herself or to others.

4.1.5 A society of our own

A majority of the participants reported a sense of affinity or belonging with other service users that they did not often feel more generally. All but two found themselves socialising, living or in therapy and support groups with people who had similar problems and experiences. There was a sense of understanding and familiarity felt in this company as well as a sense of loyalty to or responsibility for other people facing similar difficulties. As with any relationship, spending time and being around other people with mental health problems also brought challenges.

Nik, for example, spoke about a mutual understanding and familiarity that came with having a long history with one friend who also had some of the same experiences as he had:

"I know him twenty years now, you know. But I didn't know him that well before but now we are more close and we support each other. I know where he is; I know where I was and we know where we are right now but I understand. I can see the illness. I can see the illness, the effects of the illness. I know where I was a year (ago)... I had the same (pause) beliefs" (Nik, p.5)

The comment, 'we know where we are', suggested that knowing and understanding each other's difficulties enabled them to support each other better. There was no need for

explanations or need to hide or disguise what might have been going on. Nik felt he could support his friend and also that he could draw on a feeling of shared understanding to help him make sense of his own experiences.

For some, being around other people with similar difficulties was one of the only places they felt a sense of having something in common and the only place they felt comfortable. As Ben said when he explained why he often did not feel 'on a level' with people and why he struggled to maintain conversations with people:

"So, now, the people, the people that I hang around with now, most of them have had a mental health issue and it's quite nice to talk to them because we have something in common." (Ben, p.6)

Amy elaborated on this sense of having something in common when she said:

"I tend to get on with mentally ill people better than I do others.... I feel like (sighs) a bit out of it with mental health problems.... because you know other people my age have got nine-to-five jobs and people with the mental health problems, we are in our own society really.... I just seem to be easier to be friendly with people that have mental health problems.... it's like we all know what it's like to be on drugs. We have all got our own experience of being in the mental health system..." (Amy, p.9)

Amy explained that there were topics that she could talk with other service users about, such as being on medication and being in the mental health system and clearly these were topics that she felt people needed to talk about. There was a sense that having a mental health problem was something that took over, making it difficult or almost impossible to find or have other things to talk about, for both Ben and Amy. Also, as Amy's comment shows, it seemed that getting on better with those with similar difficulties was as much about feeling excluded or outside of mainstream society as it was about feeling included within the service user community. Amy seemed to feel almost pushed out of mainstream society as she felt she could not talk about the things that she thought people generally talk about. Being 'in a society' with other service users therefore meant she could maintain a feeling of equality and of being 'good enough' as well as gain understanding, support and companionship. 'Our own society', therefore,

was not just about having a few extra things to talk about but about finding a place where people feel valued just as they are.

4.1.6 The importance of those that care

Despite the difficulties that the participants spoke about, most also referred to the people in their lives that showed them care and all spoke about the importance of having a person that would care for them in their lives.

Many of the participants experienced and cherished feelings of care, support and understanding from family members, close friends and partners. For Zoe, this network of care was made up of a small number of very close friends, who were there to offer support when she needed it and helped her to feel strong and safe. She spoke about one of these friends in the following terms:

“She’s a rock for me. She has always made me feel very stable.” (Zoe, p.8)

“Yeah she is just very comforting. She is a real comforter.” (Zoe, p.9)

Her use of the word ‘rock’ suggested that this friend was someone who was always there, even if Zoe was being ‘too much’ as she sometimes worried she was for people. Zoe was also someone who struggled to feel confident in her ability to cope, so, while she may have felt unstable and uncertain of herself, she was able to draw on the strength of her close friend and build a sense of security and confidence with this friend as a foundation of sorts.

In the following extract, Sara also talked about the sense of commitment that her husband showed in trying to support her when things were difficult for her and how he tried to understand and accommodate her, even when it was trying for him also:

“...my husband gives me a lot of support because he knows that it effects me and I’ll get wo..., you know, start... If I’m sitting quietly, he won’t trouble me a lot or whatever cause he knows I’m listening to my radio and listening to debates ...he will try and keep calm so that, and I know that he, sometimes everyone gets worked up. He may, might get worked up so I don’t mind that but otherwise, he tries and gives me the support...” (Sara, p.10)

Here, Sara was referring to the time she spent listening to the radio everyday. She saw that her husband was trying hard to support her in what she was doing and when he became 'worked up', she was able to understand his point of view and normalise it, as she appreciated that he was the one who was there *with* her through the difficult times and was bound to feel the stress of these difficulties also.

A consequence of having this kind of support was a sense of reliance on it and, in turn, a worry that it might not always be there. For many of the participants, there was a fear that something might happen to the individuals that cared for them or to the relationships they had. In the following extract, Jan talked about the distress she felt at the thought of something happening to her parents, on whom she felt she relied heavily and who also provided most of the care for her, now adult, son:

"...the most important people in my life, the only people in my life are my Mum, my Dad and my son." (Jan, p.1)

"Every morning I wake up with fear. It like grips me and I am afraid of my Mum and Dad dying.... And I won't see (my son), you know. It will be me and the dog." (Jan, p.7)

Clearly, Jan had an image of the future where she would be alone with just her dog for company and a belief that the success of her relationship with her son depended on her parent's efforts, not hers. Having this kind of support and knowing that it was dependent on the continued ability of a small number of people to provide it, therefore had a price.

As well as receiving care and support from family and friends, many of the participants also spoke about the importance of the mental health professionals involved in their care. Often these individuals were one of the few people that the participants felt safe with or even had regular contact with, as such they had come to occupy some of the biggest places in the participant's social world. An extract from Sara's interview demonstrated this:

"...my care coordinator, I care for her. My support worker, I care for her because they'll come there and then, if I ring them, they'll come quickly I know." (Sara, p.18)

"They are close to me and I love them like my son and husband" (Sara, p.10)

Sara felt she could rely on these support staff, that they were there when she needed them and, as such, she had come to 'care for' and 'love' them. They were not just professionals providing a mental health service but were close to her in a way her family was. Considering Sara's feelings of mistrust and disconnect with people generally, it was not surprising that the people she felt cared for her and that she could rely on became the people she loved.

An important aspect of having people that cared was the opportunity this gave to show care and love in return and also the sense of being valued that this, in turn, offered. Having mutually caring and loving relationships, where people could feel both supported as well as secure enough to express the care and love they felt they had to offer, was central to many of the participants hopes for the future.

"I would like a permanent relationship with someone... so, I can learn about this other person and they can learn about me ...they'd probably learn that I've got a lot of love to give, lot of consideration and attention." (Ben, p.16)

As someone who struggled to believe that people could be relied on and someone who saw himself as very much alone in the world, this comment highlighted Ben's wish to find someone that he could trust enough to open up and be vulnerable with. If he could find that and feel safe enough, he knew that he would be able to offer that person a lot of love, consideration and attention. For Ben, giving care was just as important as receiving it, even though this was not something he felt safe enough to show in his social interactions at that time.

Lucy also talked about how feeling cared for and supported can be central to recovery. Her partner was someone who listened to her and had faith in her even when she was unwell and when, otherwise, she felt alone.

"My guy was there, he was there when I wasn't so good and we're still... he's still there... it means that I had somebody to talk to when nobody wasn't there..." (Lucy, p.34)

She learned from her own experiences of being cared for and talked about how she felt this was important generally for people with mental health problems trying to work towards recovery:

“...for people with mental health, when other people care Maria it’s very helpful. Very very helpful. A person kind of gets themselves back on their feet together. The more people care the better.... Because everybody needs love Maria.” (Lucy, p.34)

Overall, this super-ordinate theme of ‘Struggling to find a place in society’ represents a view that people felt outside of or not valued within ‘mainstream society’. The perceived standards needed to measure up – those of being socially skilled, having a job and something worthwhile to contribute – felt out of reach for many of the participants and, more generally, they felt disconnected from and stressed out by people. This theme also catalogues some of the processes and forums the participants were involved in to re-establish that connection and that sense of having a place in society, those being a sense of belonging with other service users and also looking for ways to express and be themselves. The participants also highlighted the importance of having people in their lives that showed care, love and understanding. This helped them to feel valued as well as safe and able to work towards a sense of recovery.

4.2 Interpersonal mistrust

The master theme of ‘Interpersonal mistrust’ refers to how all of the participants commonly experienced other people and coped with the difficulties that being with others presented. Summed up as a general feeling of mistrust, this included an expectation of dishonesty, unreliability and even threat. Coping with this mistrust usually involved actively keeping others at a distance, becoming selective about whom to be friends with and also by withdrawing or avoiding the company of others.

4.2.1 Expecting the worst from others

For all of the participants there was an expectation that other people would hurt, discriminate or let them down in some way. On another level, many also felt they were vulnerable or under threat, both from other people and their voices and were consequently frightened. Social interaction was often marred by feelings of doubt about other people, their intentions and what they might be thinking of the participants themselves, as Amy summed up in her comment:

“You know. I do sometimes wonder what, what are they thinking and, you know, am I going to experience discrimination, people that don’t understand mental health.” (Amy, p.13)

This template of what to expect from others was more often than not borne out of difficult or painful experiences, either from early life or more recent and recurrent experiences. Many of the participants reported feeling hurt, let down or even confused by people’s words and behaviour, resulting in a loss of trust and what seemed to be a stuck or static assessment of people as untrustworthy. As Sara explained:

“It’s not a nice thing because, I feel now I don’t even trust people like before, you know. I don’t trust people like before.” (Sara, p.6)

Over the previous ten years, Sara had begun to find people’s behaviour confusing and bizarre and also had a sense that some people were judging or patronising her. The result was that she lost trust in them. She repeated this statement as if she is trying to emphasise its full implications, either to me as the interviewer or to herself. There was the use of the word ‘people’; she had lost trust in ‘people’, not just in one or two particular people. The implications, therefore, must have been that with every person she met, she struggled to relax and take them at face value. She would not be able to just talk to them without worrying about what they might be thinking or doing. There was also a sense of loss in her previous social self, where, ‘like before’, meeting people may have been an enjoyable, comfortable experience. This was not a true representation of how she was socially but a function of her more recent confusion and unusual experiences.

Similarly, Ben talks about his experiences of feeling let down by his friends, when he found himself in in-patient care. He felt that they did not show him the support and care he needed:

“...they must’ve lied quite a bit, you know when we were going out. You know all the conversations and communications were, were. Some of it were all lies...” (Ben, p.6)

He was no longer friends with these individuals and looked back and questioned what was said, concluding that ‘all’ or at least ‘some of it were lies’. He appeared to rethink whether it was ‘all’ or ‘some’ but clearly, what he felt was that it was a mistake for him to have believed or relied upon what was said. Ben mentioned a number of similar experiences with friends throughout his interview, from which he drew conclusions about others in general and about what he could expect to happen when he put his trust in people, as the following extract summed up:

“It’s a bit sad really but, but I suppose that sort of paints a picture of my life, that people are unreliable.” (Ben, p.13)

While for Ben there was an expectation of disappointment, for others the expectation was more about harm or exploitation, leaving them to feel more vulnerable with people. Many of the participants spoke about a sense of threat that loomed around relationships and interactions. Lucy spoke about some of her distressing experiences:

“...there is a lot of people that are users out there. They will only use the person for their money, for what they can get and, and sexual things as well... you can’t allow these things to happen.” (Lucy, p.1)

And:

“...the vulnerability of a person with mental health, they are giving them £40, 60, 50, they would be doing this to keep them as a friend, to think the person may like them or that they will be there for them. You know that vulnerability, you know.... Well, it’s happened to me before and I know it has happened to other people in mental health as well. It has happened before.” (Lucy, p.2)

She spoke about being exploited in relationships and also this idea that to keep a friend a person may feel they need to give them money. She added that this had happened to her, concluding that this was something that happens to a lot of people with mental health problems. This may or may not have been the case but what was clear was that these experiences left her feeling vulnerable in relationships and believing that this was likely to happen, not just to herself but also to other people that she felt she identified with, other people with mental health difficulties.

4.2.2 A need for distance

All but two of the participants talked about feeling the need to keep certain people at a distance and to be cautious about whom to be friends with. This theme referred more to friends, acquaintances or distant family than to close family members. While there was a need to have more friends and feel more connected with people, there was also awareness that contact had consequences and having contact with the wrong people had bigger consequences. For these individuals, feeling alone or isolated wasn't just a situation imposed on them but one they partially chose, for fear of what friendship and contact with others might bring.

Certain friends and acquaintances were seen as a distraction or demand on what might be limited emotional resources. This was the case for Nik, who was clear that he wanted to prioritise looking after himself and getting better. He spoke about a tendency he had to choose the 'wrong' friends and to let himself be influenced or affected by these friends in ways he did not want.

"I'm tired of feeling sorry for other people and not feeling sorry for myself... I need to keep distance from people that really upset me or make me feel stressed or upset and not helpful or, or, all negative... I want to spend time on my own and, and have two, three friends, four friends and, and make new friends of course but this time I must be choosy." (Nik, p.4)

Here, Nik was trying to protect himself and protect his recovery from what he perceived as a sort of threat from other people, particularly friends who had significant needs. His view was that feeling sorry for others was at his own expense, that he was maybe too

accommodating of their difficulties while not showing himself that same compassion. There seemed to be difficulty managing the boundaries with others and balancing what he gave with what he had left for himself; keeping a distance and being selective was one solution.

For others, keeping a distance was about managing the sense of threat or distress that other people might bring or a consequence of feeling hurt or let down.

“I felt they just regarded me as some kind of a dirty girl drunk and they let me down. I cut off from them, they cut off from me.” (Jan, p.1)

Jan felt judged and shamed by her friend’s reactions to her illness and difficulties and so it was easier to ‘cut off from them’, keeping a distance that would protect her from being made feel this way. As a result, she had few friends, a situation that was a source of distress but clearly necessary for her.

Sara felt that people were behaving strangely towards her and experienced voices that were intense and threatening. Being with others had become confusing and overwhelming and, over time, she had withdrawn from her once active social life.

“I don’t want to know people much... if they come they come but I don’t, before I used to ring them a lot, you know. Now I just ring two people and not a lot of people. Before, I used to ring my friends and all that” (Sara, p.8)

The phrase, ‘I don’t want to know people’ suggested she was not seeking friendships or contact, even cutting herself off in an effort to keep her contact with others manageable. Trying to maintain a feeling of control in the context of dealing with her confusing and distressing experiences was very important for Sara and it seemed that limiting her social contact to a few people was one way to do this.

For Lucy, being selective was also a way of managing a sense of threat felt from others, although this may seem to have been somewhat displaced onto a more unlikely or sinister outcome. In answering a question about what she would like from her social life she gave the following response:

“More friends but very selective, you know.... I wouldn’t want to meet people that’s killing people and doing all these things.” (Lucy, p.34)

In contrast to Sara, Lucy would like more friends in her life but was clear that she didn’t want to be friends with just anyone. She had clear principles about not wanting to be friends with killers but what was unusual was that she felt the need to think out such an apparently self-evident principle. This comment showed how nervous she must have felt about meeting new people and making new friends, such that she was aware and thinking of even the most extreme outcome. It was as if she was primed to expect danger and encounter dangerous people. Being selective was not a taken-for-granted part of making friends but something she, as well as the others felt they had to consciously and actively do to avoid danger and difficulty.

4.2.3 Coping through avoidance

Many of the participants talked of finding a way to cope that best suited them. By far the most common way of coping and a theme that came up for all of the participants was to cope by avoiding or withdrawing from people. This also brought many consequences, such as problems becoming bigger, a feeling of missing out and a feeling of then being even more disconnected from people. There was awareness that this might not be the best approach but also little sense of other options in the face of difficult situations where people felt they were coping alone.

For some, experiences with other people were difficult, frightening and confusing, often because of the added complication of voices and unusual experiences or beliefs. It seemed that withdrawing offered some way of coping and gaining a sense of control when the alternative, which was often to try to make sense or to speak about these difficulties, seemed impossible. As Sara explained:

“...they also touch me in the wrong manner sometimes and I don’t like that, so when I go out I don’t like to mix a lot...” (Sara, p.1)

Zoe also talked about her experience of not wanting to engage with her partner when she could also hear a negative version of him through her voices:

“When I was talking to my partner last night on the phone I felt like I just didn’t want to speak. I really didn’t... Because I feel like the voices are him in my thoughts so when I talk to him I start feeling resentful and regretful...” (Zoe, p.19)

When asked if she could make sense of this experience she said:

“Not really, that’s why I wanted to get off the phone as quickly as possible and just go to my bed.” (Zoe, p.20)

For both Sara and Zoe, the experience of other people was marred and intruded upon by voices and confusing beliefs. Sara felt she could not be open about her confusion for fear of embarrassing herself and so she coped by avoiding to mix with people and staying indoors, listening to the radio and avoiding sociable activity. As a result she often felt she missed out on life and struggled to maintain a belief in herself as capable and sociable. Zoe was faced with the difficulty of hearing loved ones voices saying hurtful things. For her it seemed as though the separation between what was her mind and other people had broken down and no longer was her mind private or secure in a way most others would have taken for granted. Furthermore, she was aware of this and so found herself untrusting of what she might say in conversation and overwhelmed by a mix of conflicting emotions – feeling angry but also regretful or ashamed. It was understandable that she preferred to avoid talking and to get off the phone as soon as she could. When asked if she could make sense of this, she answered ‘not really’ as if she wanted to avoid even thinking about the experience, preferring instead to escape. She also felt she could not open up about the content of her voices in case she frightened people off. This put Zoe in a difficult position, as the support and comfort of loved ones was the very thing she relied on and treasured.

Others also found themselves avoiding more common and seemingly benign social situations, sometimes in inventive ways. Amy identified herself as suffering from significant social anxiety. She described difficulties making eye contact or knowing what to say to people. Here she talked about her difficulty talking with a group:

“...four people are in a crowd looking at me and it’s like, hmm, where do I look and what shall I do and then I kind of, like, don’t look at them, just look around and pretend not to be there.” (Amy, p.7)

Amy described the conscious effort and thought put into what, for others, might have been a natural and instinctive social skill. Rather than trying and figure out what to do or trying to escape the situation physically, she looked around her and tried to 'pretend not to be there'. This was a strategy that she described frequently in her interview, pretending or imagining to be somewhere else and avoiding the situation and the anxiety, not physically but within her own mind. It followed that she might not have given herself the chance to see how these experiences naturally panned out and might even have appeared distant and vague to others, adding to the general feeling of discomfort. Interestingly, however, Amy also talks about how she was learning to manage her anxiety and had begun to become aware of her thinking and her avoiding in these situations. She began to feel that these situations were becoming more positive and manageable:

“...I thought, first of all, you know, (sighs) oh God, it was just like thinking that the, the worry that no one would speak to me. But actually you know when I was there them people did start to just sit on the table with me and, you know, I saw some familiar people and you know so it wasn't as bad as I thought.” (Amy, p.5)

In summary, this super-ordinate theme of 'interpersonal mistrust' represents the legacy of mistrust and vulnerability that the participants were left with after feeling that others had hurt or let them down or also following the onset of their mental health difficulties. This mistrust often coloured new experiences, leaving people, on one hand, jaded and disinclined to pursue friendship and on the other, precarious and even fearful. To cope with this, people found themselves, actively distancing themselves from certain people and sometimes people generally and regularly fell back on withdrawing and avoiding experiences with others, particularly difficult experiences.

4.3 Undermined by inner/outer disturbance

The final superordinate theme that emerged reflects the difficulties, unusual experiences or *disturbances* that the participants perceived or felt and how challenging the experience of being with people had become with this going on at the same time. This *disturbance* was perceived in experiences with others, in the world around them and also referred to inner distress or confusion that individuals carried with them. All spoke of a

range of difficulties that undermined or interfered with both their enjoyment of people and their ability to connect. These included painful memories that for many appeared raw and powerful and also experiences that might be aspects of psychosis, such as voices, feelings of paranoia and unusual ideas and beliefs.

4.3.1 Unusual experiences making it difficult connect

Five of the seven participants spoke about the impact of voices, feelings of paranoia or unusual beliefs on their experiences with other people. Sometimes these experiences were a result of the anxiety and stress of socialising, for example, feeling *paranoid*; sometimes they were thought of as the cause of interactions deteriorating. Social interaction, it seemed was a challenge to start with but the addition of confusing and distressing experiences meant people were unable to enjoy or relax into social engagement, unable to think and cope when with people or it undermined their sense of self-worth and confidence.

There were various examples of this interference, affecting different aspects of social engagement. Ben spoke about the importance of making an effort to be social. He often went to the pub and felt happy that he could chat to people and hold a good conversation. There were however times, when this was less so the case:

“When I go to the pub, I can hold quite a good conversation with some people most of the time. Sometimes, when there’s, in the pub, if there’s, if it’s very busy, I sometimes get a little bit anxious and eh, feel that, feel that sometimes I feel that, that people are talking about me... So, when I get to that stage I have to leave and go home. I mean part of it is paranoia, I imagine... Well, I get paranoid, I get paranoid quite easily.” (Ben, p.7)

At times, when the pub was busy or in certain pubs, he found that he began to feel anxious and when he felt anxious, he would start to feel people were talking about him. He described this as paranoia, suggesting he was at least somewhat aware that his concerns might not have been completely accurate. Regardless, this effected how he felt and at that point he decided that he would prefer to leave. This use of the clause ‘I imagine’ suggested room for doubt, so even though he said he knew it was paranoia, the

seeds of discomfort, worry or shame had probably already set in when he found himself in these situations and before he became aware of what is going on for him.

Sara on the other hand heard voices, often threatening and 'evil', and also had the unusual experience of people poking her in the abdomen, that she struggled to make sense of. For her, social interaction, especially with people she did not know very well, was felt as confusing and distressing. In the following extract she described some of these experiences and how they left her feeling:

“...I just started not trusting any of my friends and because of my voices, whatever, you know? And it started confusing my mind because I hear so many voices that it effects my mind and then, and then I think, is it my mind or is it the voices or whatever? Can't even think properly, you know?” (Sara, p.8)

Here Sara was explaining why she stopped ringing her friends. The sense of her distress and her feeling of being overwhelmed by all that seemed to be going on was clear to see. She was hearing voices as well as feeling down and then feelings of mistrust set in. On top of all of this there was confusion and doubt about what exactly was going on – were the voices causing this distress or was it her own mind? She talked about her mind as something separate, out of her control and somehow undermining her. The culminating effect was that she could not think clearly and certainly would struggle to enjoy or feel any benefit from being around people. This lack of clarity was also reflected in how she struggled to explain what it was that caused her to stop ringing her friends. She struggled to finish her sentences and to find the right words to describe her distress as though this confusion was also live in the room with her.

Zoe had similar experiences but explained how the content of her voices specifically affected how she felt about herself...

“I find it (being with other people) very distressing at times. The voices that I hear distress me, they make me feel uneasy, unloved and uncared for.” (Zoe, p.3)

...and her perceptions of how others felt about her.

“I go over to my partner's house at weekends and sometimes I don't feel up for it very much actually to be quite honest. Sometimes I feel like, if I hear voices, the

voices are telling me that my partner hates me and his kids hate me and it's very difficult for me. Very difficult." (Zoe, p.1)

Zoe explained that she spent a lot of time with other people and treasured their presence in her life but when asked how she found being with others, said that generally it was a distressing experience. This was mainly owing to the voices and how they made her feel, not to the people themselves. Zoe was someone who presented as being very self-critical and it seemed that her voices also confirmed these views and served to make her feel even worse. What should be enjoyable and much valued closeness with others was spoilt and instead became a source of discomfort and distress, giving her voices even more fodder with which to attack her confidence. As with the others in the group, her way to cope was to withdraw and take refuge in her own company and considering her and the other participant's distress and lack of enjoyment, it is clear to see why they did not feel motivated to socialise or engage freely with the outside world.

4.3.2 Past intruding on the present

For all of the participants there were difficult pasts and memories that appeared to be still quite raw and still impacting on present day experiences with other people. These experiences included painful break-ups, losing or becoming separated from important people, loneliness or conflict in childhood, feeling let down or hurt by other people, guilt at having hurt others and past disappointments or failures. The range was varied and broad but what was common was how these experiences still hurt as though they just happened recently and also still impacted on how people coped with the challenges of their current social life.

Throughout his interview, Ben spoke about the number of times where he felt let down by close friends. He was clearly still angry and hurt and as well talked about the lasting consequences these had on how he now felt about people in general.

"I considered him a really great friend. I considered him nearly as close as a brother. You know I looked up to him, and he, one time, he sort of said 'Ben go away', in a certain fashion and from that time, from the time when he says, when he said 'go away', I've really considered myself quite alone even when I meet up with friends or mates or acquaintances I used to." (Ben, p.3)

Here Ben talked about a time when his friend rejected or dismissed him 'in a certain fashion'. This last comment suggested that this was probably put in a more rude or direct way than simply 'go away'. It is impossible to see what the context of this might have been but clearly Ben felt as though someone he looked up to or felt very loyal to, a friend like a brother, showed him that his loyalty was seriously misplaced and that, as well as misjudging the person, he also misjudged how much this guy liked or respected him. He repeated the phrase 'from that time', which seemed to mark a watershed, that with this abrupt disappointment, he could see this person and the friendship for what it really was. However, he was also left with a lasting uncertainty about other people and his ability to see if they were really his friend or not.

Amy also talked about how her current feelings might actually belong to the past. In the following extract she explained why she felt nervous around people:

"I do (feel nervous), yes. I mean I sort of like worry is anyone going to talk to me and, I mean this goes from probably back in my school days, because at break times at school, sometimes no one would talk to me... Well it's just like, I feel like it sends me back to the school days..." (Amy, p.6)

Amy carried what seemed to be a hard-wired worry that no one would talk to her and that she would be left sitting alone and feeling rejected. School was clearly a difficult time and even though she was now in her late 30s, these memories were the ones that stuck and were so easily reignited in current social situations. It seemed that even after almost 20 years, she was still primed to avoid and protect against a repeat of these feelings of loneliness or rejection. Amy was someone who had struggled to make friends and establish an independent life for herself and in many ways it seemed as if she had also struggled to gain new and more positive experiences to help her change her ideas and expectations of people.

This theme was particularly important for Jan who seemed agonised by mistakes, hurts, and disappointments from the past and talked of 'feeling battered' by the life she had lived so far. As well as living with the memories of how people had hurt and failed her, she also talked about regrets and ways in which she let herself down. Jan felt that people disliked or looked down on her, calling her 'a sponger', judging her on her mental health

status and on not having a job. In the following extract she explained why this was so particularly upsetting for her:

“I get very upset about that because, you know, I wish things had been different. That I had gone to university (tearful) and that I had got exams and got a career and a job. I was going to study youth and community work and French teaching and, erm, my life, I couldn't cope.” (Jan, p.9)

The pain of experiencing this discrimination was felt all the more keenly when she thought of how it should have been different. Jan had a place reserved in university when her problems began and she found she couldn't cope with the pressure of her A-levels. It had been many years since this chance slipped from her but her memory of this alternate life was still noticeably vivid and her emotion as raw as though it was recent.

For Amy and Ben, as with the other participants, it seemed that life had not given them new and positive experiences that could over-shadow these negative memories and, likewise, for Jan, her experiences of discrimination and feeling inadequate have encouraged her to re-hash this disappointment and inhibited her from finding a new dream or standard to measure herself by.

In summary, this final super-ordinate theme represents how the participant's social experiences were made all the more challenging by painful, distressing and confusing aspects of their internal and external world, as they experienced it. Many of the participants wanted and made efforts to engage with people and build closeness but these efforts were often undermined by evidence that other people (and sometimes themselves) were unreliable or hurtful and by the added challenge of having to manage and wade through overwhelming feelings of confusion and disturbing voices and beliefs.

5. DISCUSSION

This final chapter will explore and discuss the findings of the study in relation to the existing literature and theory, attempting to situate these findings within the wider understanding of social processes and psychosis. Owing to the emergence of themes not initially anticipated, I will also include literature not discussed in the introduction, where relevant (Smith et al., 2009). Discussion of the strengths and limitations of the study in terms of methodology will follow, along with exploration of the clinical implications for the study. Finally, ideas for future research in this area will complete this discussion.

5.1 The experience of others and the social world in psychosis

The aim of this study was to explore how people with psychosis experience others and their social world as well as how they make sense of interpersonal experiences, including challenges they might encounter. In the following sections I will explore what these findings tell us about how people with psychosis make sense of their interpersonal experiences as well as how these findings connect with the existing literature base. This discussion will centre on the following areas:

- Feeling outside of society
- Re-establishing a place among others
- Managing mistrust
- The impact of the experience of psychosis
- The impact of the past

5.1.1 Feeling outside of society

The master theme 'Finding a place in society' speaks in part to feelings of being disconnected from people and being outside or in some way not part of mainstream society, as perceived by the participants. Social isolation featured heavily in the participant's descriptions of their social world and relationships, where many spoke of having little or not enough contact with people and feeling alone and unsupported.

A number of quantitative studies have similarly highlighted how individuals with psychosis report smaller social networks, with fewer people to turn to for support (Macdonald et al., 2000; Erickson et al., 1989). Likewise, qualitative studies have tapped into these difficulties, from the point of the view of the individual's themselves, and highlighted this sense of isolation and lacking in social support (Davidson & Stayner, 1997). In a meta-synthesis of 97 qualitative studies on the experience of psychosis itself, McCarthy-Jones et al., (2013) identified a number of themes around the loss of relationships and social isolation, as well as the pain and feeling of loneliness this caused.

The subtheme, 'Doubting my social self' refers to one barrier that the participants felt inhibited their sense of connection with others. This was an uncertainty in how to conduct themselves or *be* with other people, including a struggle to feel confident in one's social skills, ability to manage interactions with others and develop friendships. This sense of doubt may in part be due to a number of difficulties that research has shown people with psychosis and a diagnosis of schizophrenia experience in terms of social skill and social cognition, including the ability to communicate, to initiate contact and form friendships (Bartels et al., 1998), and also poor theory of mind and difficulties in emotion and facial recognition (Addington & Addington, 1998; Frith, 1992; Frith & Corcoran, 1996). As well as contributing to experience of psychosis, it is also likely that these difficulties add to a sense of discomfort and misunderstanding in social situations, possibly also experienced by others sharing in the interaction. Low confidence and poor self-evaluation may also have contributed to this sense of self-doubt, even in the absence of any significant or clearly apparent deficit. Research has long since linked low self-esteem with psychosis and schizophrenia, as well as used low self-evaluation to explain the links between early adversity, family attitudes, such as expressed emotion and criticism, and symptomology (Barrowclough et al., 2003; Bentall et al., 1994; Garety, et al., 2000).

Issues of negative social comparison and feelings of inadequacy in terms of what people had achieved or contributed also had a significant bearing on self-confidence for the current participants. Equally, this left people feeling less inclined to socialise and worried about judgement and discrimination. In many ways the theme 'feeling inadequate' captures the experience of stigma and concerns about discrimination that often

accompanies having a significant mental health problem (Dinos et al., 2004) and in other ways speaks to concerns about not living up to mainstream expectations of success and what one feels they should contribute, to society and relationships. In a qualitative study specifically exploring the various experiences of stigma in schizophrenia, Knight et al. (2003) identified themes relating to both 'judgement' and 'comparison' that highlighted dealing with both negative stereotypes and prejudice as well as the sense of loss of normality and being part of mainstream society. For the current group, loss of social roles as well as occupation was a significant factor in their experiences of not being 'good enough' and this was also felt to be an important dimension of stigma for individuals in previous qualitative research (Schulze & Angereyer, 2003). In addition, participants with schizophrenia who worried about being unfavourably judged or treated as incompetent reported more stigmatizing experiences, which were also found to significantly affect quality of life (Switaj et al., 2009).

5.1.2 Re-establishing a place among others

Part of the process of 'finding a place in society' was to find a way to reconnect with people and re-establish a sense of belonging among others. This reflects the strategies that people personally found helped them feel more validated and cared for within a society often experienced as confusing, scary or judging.

One such strategy was to find ways to express oneself and establish a sense of identity. The subtheme 'struggling for individual identity' highlights the importance of getting to know oneself and being one's own person. This spoke to a process of establishing a clear sense of self or individuality, as well as the struggle to express and assert this with others. A number of studies looking at recovery from both psychosis and severe mental illness, including schizophrenia and schizo-affective disorder, have highlighted the importance of developing a sense of self in participant's narratives about recovery (Davidson & Strauss, 1992; Laithwaite & Gumley, 2007). For the participants in Laithwaite and Gumley's (2007) grounded theory study, two higher-order concepts of 'relationships' and 'changing sense of self' emerged as reciprocally related, where participants spoke about being able to learn about themselves through relationships. This clearer sense of self, in turn, helped in building relationships. Many of the participants in the current

study spoke of getting to know themselves and also feeling able to *be* themselves with others. Davidson and Strauss (1992) also identified a process of developing or accessing a more active or assertive sense of self in enabling better coping and recovery in the context of severe mental illness.

The participants also drew on the support and understanding available among other service users and within the mental health system. They spoke of feeling more comfortable and safe among others who had similar problems and were able to draw on a sense of commonality or *universality* as described by Yalom and Leszcz (2005) in relation to group psychotherapy. Most of the individuals were able to feel understood, accepted as they were and even felt they had something of value to contribute within this group in a way that they did not feel among other, more general social groups. As such, the subtheme 'A society of our own' also emphasises this sense of separateness from mainstream society.

Similar themes reflecting the value of relationships with peers and other service users are common in previous qualitative research (Green et al., 2002; Macdonald et al., 2005). For example, in an exploration of social relationships following first episode psychosis, the findings made particular reference to relationships with other members of a therapeutic group, also recovering from psychosis, and the sense of shared experience, as well as trust and mutual respect, that the participants felt within this company (Macdonald et al., 2005). Also highlighted was the parallel process of feeling less comfortable and secure among previous friends, attributed usually to feelings of shame and worries about stigmatising attitudes and not being understood. Although this study interviewed young people experiencing first episode psychosis and likely facing different social challenges, this sense of feeling distanced from old friends and been drawn instead to the sense of affinity offered amongst other service users are clearly consistent with the experiences of the current sample.

Those that cared generally, including family, partners, close friends and also caring professionals offered an important sense of belonging in the larger context of feeling cut-off. Within the theme 'the importance of those that care' participants talked about how caring individuals helped them feel safe, supported and less alone but also how their

presence and belief in them helped them to hope for the future and work towards recovery. Many of the participants were, however, relying on a very small group of people for this care. They worried about what would happen to them if they lost these precious people and relationships. The literature also clearly emphasises the benefits of social support, identifying that higher levels predict better outcomes and better quality of life for people with psychosis over the longer term (Corrigan & Phelan, 2004; Eack et al., 2007; Norman et al., 2005). In addition, qualitative research in first episode psychosis similarly points to the importance participants placed on the support gained from family as well as from mental health professionals (Macdonald et al., 2005). However, one quantitative study has also identified that having support from family alone was not always as beneficial as the support received from having more friends (Erickson, et al., 1989). This may reflect difficulties within those relationships or/and an increasing reliance on a smaller number of people.

5.1.3 Managing mistrust

Feelings of mistrust towards others characterised the interviews for many of the participants. While the master theme 'finding a place in society' spoke to the sense of disconnection and lack of belonging, as well as the strategies used to bridge these gaps, 'interpersonal mistrust' highlighted how all of the participants, in one way or another, engineered a distance or withdrawal from others. This was largely owing to a sense of mistrust that often coloured their interactions and beliefs about others.

In much of the cognitive understanding of psychosis, mistrust and, in particular, misattributions about the intentions and actions of others, are thought to play a significant role in the experience of paranoia and delusional beliefs. Within this line of research, people with these experiences have been shown to 'jump to conclusions', specifically, expecting that other people would be threatening or are to blame for negative outcomes (Corcoran et al., 2006; Kinderman & Bentall, 1997). Given, also, apparent deficits in terms of theory of mind, it is thought that gaps in an individual's ability to imagine the thoughts and feelings of others might be filled in with these tendencies to expect the worst and so lead to paranoid or unusual beliefs (Frith, 1992; Frith & Corcoran, 1996). French and Morrison (2004) also proposed that a lack of social

support and someone to confide in about their experiences at an earlier stage may mean that a person with early psychosis never gets to normalise their experiences or hear alternative explanations. The current participant's doubt or mistrust of others, as referenced in the subtheme 'Expecting the worst from others', may in part be attributable to these tendencies and exacerbated by the apparent lack of close friends and contact with others. It may also be important to consider the difficult past experiences and histories with others, which participants either alluded to or spoke about directly, discussed in more detail below.

The participants spoke of avoiding or withdrawing from others as a way of managing the mistrust, anxiety and potential for hurt that marked their expectations. The subthemes 'a need for distance' and also 'coping through avoidance' referred to where the participant's disconnect from others was not something imposed on them but rather chosen as a way to manage difficult interactions and keep a distance from other people. This is clearly consistent with Cresswell et al.'s (1992) study of people with a long-term diagnosis of schizophrenia, which found that although small, the participant's social networks were reported as 'adequate' and it was also apparent that withdrawing socially to some degree helped protect them from relationships that were difficult. For many of the participants in the current study, while they wished for more connection and intimacy, they were also aware of the potential for hurt, deception, unwelcome intrusions and their own vulnerability and so were cautious or selective about who they wanted to open themselves up to friendship with. Many preferred not to compromise, choosing to keep their own company or the company of only close family and draw enjoyment from other interests or projects or to wait for a time when they could feel safer. Most also found ways of avoiding contact with others and especially to withdraw to a safety of home or one's own company when things become more difficult.

Another area of research that draws similarities with these themes comes from the phenomenological tradition and anthropological studies carried out to explore coping, recovery and ways of being in day-to-day life among people living with a diagnosis of schizophrenia. Work by Corin (Corin, 1990; Corin & Lauzon, 1992) and Davidson and associates (Davidson & Stayner, 1997; Sells, Stayner & Davidson, 2004) have highlighted through qualitative, ethnographic research how people with this diagnosis have a

tendency to restrict their social interaction and occupy a 'general detachment stance' (Corin & Lauzon, 1992, p.270), for fear of the demands or difficulties that interaction and social involvement with others might entail. Corin (1990) has also coined the phrase 'positive withdrawal' to describe an approach to engaging with the social world that involves largely withdrawing but also retaining a sense of engagement by spending time in public but anonymous or impersonal spaces, such as shopping centres or churches. This offers the person a way of being sociable but also allows for the personal space needed to feel safe. It is also an approach that has been linked with lower rates of rehospitalisation in individuals with a long-term diagnosis, suggesting the potential for coping that withdrawing to a certain degree can allow.

5.1.4 The impact of the experience of psychosis

An important finding from the current study was how experiences associated with psychosis, such as voices, feelings of paranoia and unshared beliefs interfered with the ability to engage with other people and undermined social connections in different ways, as suggested by the theme 'Unusual experiences making it difficult connect'. Hearing voices and/or experiencing other hallucinations and delusions can be clearly overwhelming and distressing experiences, in their own right. Indeed, cognitive models of psychosis propose that psychotic experiences are in fact maintained by the distress experienced *following* onset and negative attributions made about these experiences (Morrison, 2001). In addition, research comparing clinical and non-clinical voices-hearers have found that the main difference is that non-clinical voices hearers feel more in control and don't see the voices as negative (Honig, Romme, Ensink et al., 1998). Having the distress of hearing voices while also trying to socialise or meet new people is likely to add to the distress of what can already be stressful or demanding experiences. This was clearly the case for many of the current participants who, at the very least, reported feeling overwhelmed, confused and unable to think clearly in social situations and often sought refuge in being alone.

Many of the participants also reported that their self-confidence and trust in both themselves and others was undermined by the content of their voices and unusual experiences. As previously discussed, the role of low self-esteem is central to many

theoretical approaches to understanding the development and maintenance of psychosis, particularly cognitive models (Bentall & Fernyhough, 2008; Bentall et al., 1994; Garety, Kuipers, Fowler, et al., 2001). In addition to this, the experience of psychosis itself, along with the experience of hospitalisation, has been shown to lower self-esteem and increase vulnerability to post-psychotic depression (Birchwood, Iqbal, Chadwick, et al., 2000). It is clear that low self-esteem has likely played a role in the development of the current participant's experience of psychosis, but also that the on-going experience of psychosis is taking its toll on their belief in themselves, leaving them to question what people think of them, their ability to fit in socially as well as their view of themselves as a person.

It has also been suggested that command hallucinations can directly challenge trust in other people and may be a factor in the use of social disengagement as a way of coping (Birchwood, 2003). An additional body of evidence also suggests voice hearers relate to their voices in ways that reflect more general social relating and that levels of general distress were significantly associated with perceptions of the voice as dominating and intrusive (Birchwood, Meaden, Trower, et al., 2000; Hayward, 2003). For the current participants it was clear that their experiences of psychosis were also an additional dimension of their social world that, like a close but difficult relationship with a critical person, can set a person against themselves and others.

5.1.5 The impact of the past

For all of the participants there were difficult memories and experiences in the past that were still impacting on the present and, in particular, were clouding or interfering with new social experiences. The theme 'past intruding on the present' reflects difficult memories that still seemed raw and unprocessed and also experiences from the past that were still effecting how other people were experienced in the present or how the participants felt about themselves within the social context. Some of these past experiences were memories from the distant past, such as childhood memories of bullying or they were more recent experiences of hurt and disappointment experienced in adulthood and sometimes as a result of becoming unwell.

The experience and impact of past experiences is clearly evidenced to be significant for the development of psychosis. Numerous studies, including systematic reviews have linked early adversity, including childhood abuse with the later development of psychosis (Matheson et al., 2012; Varese et al., 2012) along with particular styles of interacting in families of origin, such as expressed emotion or high levels of criticism (Goldstein, 1997). As one of a number of models proposed to explain this relationship, attachment theory suggests that it is through the development of an insecure attachment style, marked by difficulties in affect regulation, interpersonal problems, sensitivity to interpersonal stress and compromised resilience generally, that an individual's difficult past can continue to impact on their later experiences and mental health (Gumley & Schwannauer, 2006; Gumley, et al., 2014). This theme referred mainly to the impact of difficult memories from the past, not necessarily from the participant's early childhood but difficulties they could recall and reflect on. These included experiences from late childhood or adulthood, such as bullying in school, the onset of illness and its consequence for their life, losses and let-downs. However, at least four of the participants also directly referenced difficulties in early attachments and current relationships with family and parents, suggesting that a possible insecure attachment may have left them with a negative internal working model regarding themselves and others, along with a compromised ability to adapt and cope with adversity. As a result, the participants have found themselves struggling to cope with or process difficult past experiences, such that these have now become stuck and continue to interfere with the present, affecting how they see other people generally, including new people, their confidence or security in relationships and choices about whether to engage or withdraw socially.

The relationship between difficult or traumatic experience and psychosis is a complex one and research exploring this area is also concerned with looking at this relationship from the other direction, namely at the traumatic impact of experiencing of psychosis itself (Morrison, Frame & Larkin, 2003). It is evidenced that up to 50% of psychiatric inpatients with psychosis also experience symptoms of trauma that would be consistent with a diagnosis of PTSD and that 52% of this variance was accounted for the psychotic experience itself (Frame & Morrison, 2001).

For the current participants, many of the difficult times from that past that still appeared raw, painful and unprocessed were part of the spectrum of consequences of becoming unwell, experiences such as hospitalisation, failures in education attributed to becoming unwell, relationships breakdowns, guilt regarding the impact felt by children, social rejection, feelings of judgement and discrimination as well as the experience of psychosis itself. It is very likely that the prolonged distress and impact of these memories may be part of a trauma reaction and also part of a complex circular interaction between acute mental illness, past adversity, trauma and psychosis.

Overall, this study has offered a first-person insight into how people with psychosis experience other people and their social world. These findings both confirm but also further contribute to the current understanding of social processes in the context of psychosis. Similar to the existing body of literature, themes emerged that reflect the difficulties and challenges encountered by people with psychosis but equally the findings emphasise how the participants were also engaged in a process of trying to cope with and manage difficulties, as well as tap into strengths available to them.

5.2 Clinical implications

The following sections will discuss a number of clinical implications of the current study.

5.2.1 Social connectedness as part of recovery

Numerous studies have highlighted the lack of social support, apparent social withdrawal and feelings of loneliness that are often part of the experience of psychosis (Davidson & Stayner, 1997; Erickson et al., 1989; Macdonald et al., 2000). The current study also highlights this sense of withdrawal and being disconnected but, in addition, offers a detailed insight into the mechanisms and reasons why people felt disconnected, in particular feelings of doubt and distrust in their own abilities and in other people, feelings of inadequacy and negative social comparison and concerns that other people would not understand them. As such, the current study demonstrates the need to address social withdrawal also within a therapeutic context, particularly as social support is considered so important for long-term outcome and quality of life (Eack et al., 2007; Norman et al., 2005). However, it also signals a need to address the reasons why people

might feel alone even when in company or might not be able to gain enough from social interaction so as to motivate them to pursue it more. These would include concerns such as attributions about what other people might think, poor self-esteem and unhelpful expectations about how people might behave as are addressed in a number of cognitive approaches to treating psychosis (e.g., Fowler, Garety & Kuipers, 1995; Morrison, Renton, Dunn et al., 2004). To do this demands listening to the person's individual perspective and beliefs behind why they might not feel or wish to feel connected with others.

In this respect, the study also points to the work that the participants were already engaged in in building their own sense of feeling part of society and finding a place amongst others, work that could potentially be built upon within therapeutic work. This is broadly in keeping with therapeutic approaches to treatment that suggest identifying and working with existing strengths such as those that have incorporated ideas from solution focused therapy (e.g., Rhodes & Jakes, 2009). In keeping with the idea of *positive withdrawal* (Corin, 1991), the current study revealed how this could include less conventional strategies that might look like social withdrawal but, on further exploration, could in fact be seen as manageable first steps towards establishing a place within society, on one's own terms. Examples in the current study included: choosing the company of other service users and withdrawing from *mainstream* society, avoiding potentially difficult social interactions so as to preserve personal integrity and self-esteem or preferring one's own company so as to allow a space to develop a more robust sense of self. Equally, the study has also highlighted the significance of more conventional strategies such as the central role of those that care and the importance of mental health professionals and services.

5.2.2 Addressing stigma and sense of inadequacy

The current study also offers insights into how stigma was experienced by the participants. Although overt experiences of discrimination were a concern for some of the participants, what was also clearly apparent was an expectation that people would be judging and discriminatory, should they, for example, become aware of the participant's mental health status or ask questions about work/career/relationship.

These findings support the need for a focus on improving self-image within therapeutic work and offering space to think about more helpful ideas regarding the beliefs or behaviour of others, thus emphasising the importance of certain aspects of current treatment approaches that work on negative self-schema and core beliefs, as well as attributions about others (e.g., Chadwick, 2006; Gumley & Schwannauer, 2006). Many of the participants spoke of doubting themselves and their abilities within social situations although this may also reflect poor self-image or be a consequence of past experiences of criticism or discrimination rather than reflect actual deficits or deficits beyond what would be considered *normal*.

One strategy that the participants in this study found useful was to find a way of expressing their own individual identity and being themselves. This, along with research carried out by Davidson and Strauss (1992), attests to the importance of establishing a strong sense of self in working towards recovery, which may require taking time and space away from other people or particular people, as it did for a number of the current participants or finding new or creative means of self-expression.

5.2.3 Impact of the past

As would be consistent with the large body of literature evidencing the importance of early adversity in the development of psychosis (Varese et al., 2012), the current study also points to the significance of past difficulties and possibly also attachment and early life difficulties in the current experience of social situations, as well as the need to explore and understand the impact of these experiences better. Equally, it might also be important to consider the traumatic impact of developing psychosis, particularly thinking about the potential distress of having psychotic experiences and the losses associated with becoming acutely unwell. In this respect, these findings also support the value of early intervention in psychosis in order to address and limit the impact of these difficult experiences, particularly as maintaining factors going forward, as well as approaches, such as that of Gumley & Schwannauer (2006), that focus on attachment, trauma and interpersonal factors in recovery and relapse prevention. Psychodynamic approaches also might offer space to explore the impact of past experiences, particularly in terms of current relationships or work on psychological defences individuals may have developed

to help protect their sense of self from the impact of difficult memories (Martindale & Summers, 2013).

5.3 Strengths and limitations

5.3.1 IPA

Selecting an IPA approach allowed for a rich and in-depth exploration of how people with psychosis experience other people and their social world, while also considering for the interpretative role and mutual sense-making of myself as the researcher. As such, it was deemed best suited to the research aims of the current study. We know much from previous research, particularly quantitative research, about interpersonal experiences and difficulties for people with psychosis (e.g., Segrin, 2001). However, using a qualitative methodology that focuses on exploring the participant's lived experience, the current study has contributed to our understanding about the thinking, intentions and sense-making behind these experiences and how the participants have been able to cope with and adapt to these challenges. Using IPA enabled the study to give voice to these experiences in a broad and open way. This has allowed the participants to bring what was important for them in terms of their experience to the research, rather than starting out with a focus that was too specific or preordained.

The current study was exploratory in nature and recruited a small sample of individuals experiencing psychosis. In keeping with the idiographic focus of IPA, the intention of the current study was to offer a representation of the sense making for this particular group, within this particular context and not to make broad generalisations to larger groups of individuals with psychosis who may be different from the participants within this study (Smith et al, 2009). Rather, these findings further contribute to the already existing understanding by giving voice to experiences, previously unheard within the literature and likely marginalised from current clinical knowledge and research (Geekie, 2012; Smith & Osborne, 2008).

5.3.2 Role of researcher

With IPA research it is also important to acknowledge the role of researcher in the process. While the *double hermeneutic* values the interpretative stance of the researcher it also acknowledges the potential for subjectivity (Smith et al., 2009). For example, my position as an *outsider researcher* may have left me limited in how close I could really get to understanding the social world of someone with psychosis, as well as influenced how openly the participants chose to speak. However, writings in the area do point out that both insider and outsider researchers cannot make assumptions about the similarity/dissimilarity of their experiences and also that being an insider-researcher raises different questions about the objectivity of the research (Dwyer & Buckle, 2009). A second concern related to my position as a trainee psychologist who, having worked in the service, was seen as a professional belonging to the service. I was made particularly aware of this during the interview process, when some of the participants commented on this, mainly in reference to me being known to the service and the clinicians involved in their care and, therefore, as someone to trust but also in reference to the fact that I was working and studying at university, while they, on the other hand, spoke of feelings of failure and not having achieved an education or pursued a career. It is possible that this may also have influenced what the participants chose to say and so it was important that I was able to reflect and keep both this and my position as an outsider researcher in mind throughout the interview process.

5.3.3 The sample

In terms of the sample, the current study consisted of two men and five women. It would have been preferable to have a more equal number of men and women, allowing the study to represent a male perspective more fully. This might be particularly important considering evidence of gender differences in terms of prevalence of psychosis, likelihood of relapse and social functioning, with women reported to fair better (Ochoa, Usall, Cobo et al., 2012). Previous qualitative research looking at social experiences in psychosis, particularly early psychosis, interviewed more males than females (Byrne & Morrison, 2010; Macdonald et al., 2005), therefore, it could be argued that the current study offers an alternative perspective by including the views of more women.

The sample was also recruited purposively from the same London-based NHS Trust. Purposive sampling within IPA research serves to ensure as homogenous a sample as possible (Smith et al., 2009). The current sample can be considered homogenous in that all of the participants had long-term experience of psychosis. However, within any homogenous group, there is bound to be some degree of heterogeneity and a number of dissimilarities between the participants were also evident. The participants were at different stages of recovery and undergoing treatment. Some had been an inpatient while others did not have that experience. There was also heterogeneity in terms of specific psychotic and mental health related experiences. All had an official diagnosis of either *schizophrenia* or *schizo-affective disorder* but interviewing these individuals highlighted the diversity of experiences and perspectives within these diagnostic categories and within psychosis generally. Some of the participants reported experiencing differing aspects of psychotic symptomology while others did not or questioned the validity of their diagnosis (although it was apparent that they were experiencing some degree of psychosis).

5.3.4 Language and communication

Finally, the current sample included individuals from a variety of ethnic backgrounds, meaning that such perspectives were included in the study but also adding an additional source of heterogeneity. This may also have introduced a degree of bias, as English was not a first language for two of the participants, although both considered themselves fluent and had lived in the UK for many years.

An additional and related issue was that some of the participants also had unusual ways of speaking that did not appear to be about fluency, vocabulary or understanding but instead appeared to reflect an idiosyncratic or unique way of expressing themselves that often contrasted with colloquial use of language. In some cases this may be a consequence of using a different dialect of English, more likely the case for those for whom English was not a first language but for others it is possible that this could be a function of living a more socially isolated life or living more within one's own internal world. It may also be related to the widely researched concept of communication deviance, where within families of those with a diagnosis of schizophrenia, interaction is

marked by unusual or confusing language and conversation drift (Wynne & Singer, 1963). From a practical point of view, both of these issues meant that it was difficult to accurately transcribe the occasional word or phrase but also, considering the centrality of the participant's words within qualitative research, may have affected how experiences were described or the emphasis of certain meanings, as well as how I might have construed what was said.

5.4 Suggestions for future research

The current findings along with limitations of the study point to a number of lines of research that deserve further exploration. Firstly, a more specific focus in terms of aspects of psychosis might reveal additional insights into how the social world is experienced. Future research could explore the experience of others and the social world specifically among those who experience voices, delusions or feelings of 'paranoia' alone. There is evidence to suggest that the aetiology of each of these experiences is different and it is argued that these experiences should be treated as individual and unique rather than part of a psychosis syndrome (Bentall et al., 2012; Read, et al., 2008). It follows, that how people experience their social world might also differ.

A more specific focus could also explore the quality of particular social relationships rather than looking at the individuals overall social world and social engagement. This might include looking at relationships with parents, children, siblings, partners, friends, acquaintances, or work colleagues. Previous qualitative research has highlighted the specific importance as well as challenges within relationships with parents, loss or difficulties within relationships with children and also friends (Byrne & Morrison, 2010; Green et al 2002; Macdonald et al., 2005). Research has also highlighted the importance of occupational role in recovery (Wood et al., 2013), which may also add to the importance of exploring social relationships in this context.

Future IPA research could address some of the limitations of the current study in terms of homogeneity (Smith et al., 2009). As well recruiting potential participants with similar experiences of psychosis, it might also be important to look at other factors that might

be pertinent in terms of interpersonal process, such as degree to which individuals feel recovered or length of time that people have been experiencing problems.

Specific findings within the current study would also highlight the possible value of exploring the strategies participants used to help manage and cope with the demands of social living. This could involve exploring the role of avoidance and withdrawal, not just as unhelpful coping strategies but as a strategies that might help manage an individual's gradual re-engagement into society, at their own pace and in their own terms. It would also be interesting to explore the role of self-identity and expression in helping people to feel more active and included. This could involve the use of narrative analysis to investigate how individuals adapt or re-negotiate their sense of identity following the onset of psychosis. Along with a large body of previous research, the current study attests to the importance of caring supportive relationships in working towards a sense of recovery (Corrigan & Phelan, 2004; Windell & Norman, 2012; Wood et al., 2013) as well as the specific role of support gained from other service users and mental health professionals. Future research exploring the mechanisms by which these relationships aid recovery warrant continued focus and one suggestion for a future qualitative study would be to explore the experience of positive relationships alone, so as to gain a first person perspective on this topic, as has also been suggested by previous qualitative research (Byrne & Morrison, 2010). Equally, evaluation of programmes to help people with psychosis manage, maintain or develop these relationships, particularly at an early stage before social problems become more entrenched, might offer valuable insights into what can be offered to individuals with psychosis in terms of therapeutic interventions that can increase their social engagement.

5.5 Conclusions

The aim of this study was to explore how people with psychosis experience other people and make sense of their social experiences. It was hoped that in using IPA, the study would offer a unique contribution to our understanding, by allowing for a broad and in-depth exploration of the lived experiences of people with psychosis.

The main findings comprised three master themes. 'Finding a place in society' captures the feeling of being outside or not part of society as well as the efforts, situations, and people that helped the participants feel they did have a place. 'Interpersonal mistrust' reflects the sense that one can expect the worst from other people and the consequent reactions and coping strategies, while, 'Feeling undermined by inner/outer disturbance' reflects how distressing experiences and painful memories were serving to interfere with and undermine the participant's attempts and wishes to connect with other people.

These themes were discussed in relation to the existing literature covering interpersonal processes and psychosis and also in terms of their implications for clinical practice. The findings attest to the importance of exploring and addressing the reasons why people feel socially isolated as well as building on the efforts or strategies that people with psychosis might already be using to feel more integrated. It may also be important to address feelings of inadequacy and low self-esteem in helping people cope with the consequences of experiencing an enduring mental health problem, including experiences of stigma and to bear in mind how well people have been able to process and cope with difficult experiences in the past. Future research looking at social experiences among those with specific psychotic experiences, as well as specific aspects of social living is warranted to help deepen our understanding of the experience of psychosis.

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7. APPENDICES

7.1 Ethical approval documentation

7.1.1 NRES ethical approval for overall study



National Research Ethics Service

Camden & Islington Community Research Ethics Committee

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26 March 2010

Mr John Rhodes
Consultant Clinical Psychologist
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Central North West London NHS Foundation Trust
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NW10 3RY

Dear Mr Rhodes

Study Title: Exploring the experience of chronic depression
REC reference number: 10/H0722/14
Protocol number: Version 2

Thank you for your letter of 09 March 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Committee held on 22 March 2010. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

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

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

This Research Ethics Committee is an advisory committee to London Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

The following are conditions of the REC's Favourable opinion:

- Thank you for confirming at the meeting that the therapists undertaking the therapy, conducted as part of the participant's standard clinical care, would not be yourself or the person conducting the research interviews.
- Further to the discussion at the REC meeting about the participants' perspective of the distinction between research and therapy, the Participant Information Sheet and conduct of the research should make it very clear these are separate and unrelated.

The Participant Information Sheet should:

- be revised to ensure it is written in lay language suitable for these participants.
- state the conditions when confidentiality will need to be breached, i.e. disclosures that require action such as harm to self or others.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

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

<i>Document</i>	<i>Version</i>	<i>Date</i>
REC application		25 January 2010
Protocol		10 November 2009
Investigator CV		25 January 2010
Participant Consent Form		
Student CV		25 January 2010
Reply to Rejection Letter		25 January 2010
Rejection Letter		21 December 2009
Interview Schedules/Topic Guides	2	25 January 2010
Covering Letter		
Participant Information Sheet	3	
Response to Request for Further Information	Cover letter from C.I.	09 March 2010

Statement of compliance

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

An advisory committee to London Strategic Health Authority

Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/H0722/14	Please quote this number on all correspondence
-------------	--

Yours sincerely


Ms Stephanie Ellis
Chair

Email: katherine.ouseley@royalfree.nhs.uk

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

"After ethical review – guidance for researchers"

Copy to: *Sponsor's contact – Lynis Lewis, CNWL*

R&D office for NHS care organisation at lead site – Maria Tsappis, CNWL

Camden & Islington Community Research Ethics Committee

Attendance at Committee meeting on 22 March 2010

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Adedotun Adenugba	Staff Doctor	No	
Professor David Caplin	Emeritus Professor of Physics	Yes	
Ms Heidi Chandler	PA/Administrator	No	
Dr Claudia Cooper	Senior Lecturer in Old Age Psychiatry	No	
Ms Stephanie Ellis	Former Civil Servant	Yes	
Ms Victoria Fox	Lawyer	No	
Dr Angela Hassiotis	Senior Lecturer in Learning Disabilities	Yes	
Mr Matthew Lewin	Journalist and Author	No	
Dr Roshan McClenahan	Retired Consultant Speech & Language Therapist	Yes	
Miss Katherine Ouseley	REC Coordinator	Yes	
Ms Peggy Papada	Clinical Research Officer	Yes	
Dr Frederic Shaw	Sessional GP/GP Appraiser	No	
Dr Charlotte Warren-Gash	SpR Public Health/Academic Clinical Fellow	Yes	
Ms Eleni Yerolaki	Specialist Counsellor	Yes	
Ms Biddy Youell	Head of Child Psychotherapy	No	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Katherine Ouseley	REC Coordinator

Written comments received from:

<i>Name</i>	<i>Position</i>
Ms Victoria Fox	Lawyer
Ms Biddy Youell	Head of Child Psychotherapy

7.1.2 IRAS Amendment form

Notice of Amendment

IRAS Version 3.5

NOTICE OF SUBSTANTIAL AMENDMENT

Please use this form to notify the main REC of substantial amendments to all research other than clinical trials of investigational medicinal products (CTIMPs).
The form should be completed by the Chief Investigator using language comprehensible to a lay person.

Details of Chief Investigator:

	Title	Forename/Initials	Surname
	Mr	John	Rhodes
Work Address	Brent Adult Psychology Service, CNWL Park Royal Centre for Mental Health Central Way		
PostCode	NW10 7NS		
Email	jrhodes2@nhs.net		
Telephone	02089554431		
Fax	02089616339		

Full title of study:	Exploring the experience of chronic depression.
Lead sponsor:	London West Mental Health RND Consortium
Name of REC:	Camden and Islington London
REC reference number:	10/H0722/14
Name of lead R&D office:	London West Mental Health RND Consortium
Date study commenced:	26/03/2010
Protocol reference (if applicable), current version and date:	10/H0722/14
Amendment number and date:	Amendment 2 - 14/01/2014

Type of amendment

(a) Amendment to information previously given in IRAS

Yes No

If yes, please refer to relevant sections of IRAS in the "summary of changes" below.

(b) Amendment to the protocol

Yes No

If yes, please submit either the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the previous and revised text.

Please see attached revised protocol (changes in bold).

Notice of Amendment

IRAS Version 3.5

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

Yes No

If yes, please submit all revised documents with new version numbers and dates, highlighting new text in bold.

Please see attached Patient Information Sheet.

Is this a modified version of an amendment previously notified and not approved?

Yes No

Summary of changes

Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.

If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.

If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

The original study proposed to look at the perceptions of self and others in patients with psychosis and depression. We propose to amend this by also looking at patients with psychosis who are not depressed. This group would be equal in size to that originally proposed, as per the original methodology.

We have realised that it is important to be able to describe and compare the perceptions of self and others of both a) depressed patients with psychosis to b) patients with psychosis who are not depressed.

Our plan is therefore to first analyse the data from the interviews with non-depressed psychotic patients, and also to analyse as a separate group the data from the patients who have psychosis and depression, and then at a later stage make a further analysis comparing the two groups (that is, the psychotic non depressed with depressed psychotic patients). Such analysis will allow us to understand which social difficulties may be due to depression, and which are not. Such knowledge will facilitate the development of better therapies for social problems in these areas. The amendment does not alter the methodology (that being a qualitative thematic analysis using IPA).

Any other relevant information

Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.

List of enclosed documents

<i>Document</i>	<i>Version</i>	<i>Date</i>
Protocol	2	16/10/2013
Patient Information Sheet	2	16/10/2013

Declaration by Chief Investigator

- 1. I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.*
- 2. I consider that it would be reasonable for the proposed amendment to be implemented.*

This section was signed electronically by Mr John Rhodes on 14/01/2014 15:01.

Job Title/Post: Consultant Clinical Psychologist

Organisation:	CNWL
Email:	jrhodes2@nhs.net

Declaration by the sponsor's representative

I confirm the sponsor's support for this substantial amendment.

This section was signed electronically by Ms Angela Williams on 15/01/2014 09:46.

Job Title/Post:	Head of Research & Development
Organisation:	Central and North West London NHS Foundation Trust
Email:	angela.williams9@nhs.net

7.1.3 Confirmation of approval for amendment



Health Research Authority NRES Committee London - Camden & Islington

North East REC Office
Room 002
TEDCO Business Centre
Rolling Mill Road
Jarrow
Tyne & Wear
NE32 3DT

Tel: 0191 4283548

07 February 2014

Luke Bosdet
Assistant Psychologist
Park Royal Centre for Mental Health
Central Way (off Acton Lane)
London
NW10 7NS

Dear Mr Bosdet

Study title: Exploring the experience of chronic depression.
REC reference: 10/H0722/14
Amendment number: Amendment 2, 14/10/2014
Amendment date: 15 January 2014
IRAS project ID: 29462

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

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

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)	Amendment 2, 14/10/2014	15 January 2014
Protocol	2	16 October 2013
Participant Information Sheet	2	16 October 2013

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

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

Statement of compliance

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

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

10/H0722/14:	Please quote this number on all correspondence
---------------------	---

Yours sincerely



pp
Ms Eleni Yerolaki
Chair

E-mail: nrescommittee.london-camdenandislington@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Ms Maria Tsattis, London West Mental Health RND Consortium

7.1.4 Letter of access



Bedford House, 3rd Floor
125-133 Camden High Street
London, NW1 7JR

Tel: 020 3317 3045
Fax: 020 7685 5830/5788
www.noclor.nhs.uk

29 April 2014

Ms Maria Walsh
Health Research Building
College Lane Campus
University of Hertfordshire
Hatfield
AL10 9AB

Dear Ms Walsh,

Employer: Cambridge and Peterborough NHS Foundation Trust
Accountable to: Dr John Rhodes (CNWL)

This letter confirms your right of access to conduct research through the trust(s) identified in the box below, and in the case of multi-project letters of access, in the box(es) in the appendix page(s), for the purpose and under the terms and conditions set out in page 2 & page 3.

<i>For R&D office only: please complete the table below. If the researcher is undertaking more than one project at any one time, please complete the table(s) for the remaining projects in the Appendix page(s).</i>		Project 1 of 1
Study Title: Chronic Depression (Version Two 10/HO722/14) R&D reference: 29462 REC reference: 10/HO722/14		
Letter of access duration:	Start date: 29/04/2014	End date: 29/04/2017
Central and North West London NHS Foundation Trust	--	
--	--	
--	--	
--	--	
--	--	
If any information on this document is altered after the date of issue, this document will be deemed INVALID		

Yours sincerely,

Pushpsen Joshi
R&D Operations Manager

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at **relevant trust(s)** has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to **relevant trust(s)** premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through the **relevant trust(s)**, you will remain accountable to your employer but you are required to follow the reasonable instructions of **Angela Williams, R&D Manager NoCLoR** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance the **relevant trust(s)** policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with **relevant trust(s)** in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on **relevant trust(s)** premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the Trust **relevant trust(s)** prior to commencing your research role at the Trust.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you **MUST** stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

The relevant trust(s) above will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

7.1.5 University of Hertfordshire ethics validation



**UNIVERSITY OF HERTFORDSHIRE
HEALTH & HUMAN SCIENCES**

ETHICS VALIDATION

TO Maria Walsh
CC Pieter Nel
FROM Dr Richard Southern, Health and Human Sciences ECDA Chairman
DATE 13/05/2014

Protocol number: **LMS/PG/NHS/00192**

**The UH protocol number above has now been validated for the study detailed below.
Please quote this number should you need to contact us .**

**Study title: Exploring the experience of chronic depression.
REC reference: 10/H0722/14
Amendment number: Amendment 2, 14/10/2014
Amendment date: 15 January 2014
IRAS project ID: 29462**

7.2 Participant information sheet



Central and North West London **NHS**
NHS Foundation Trust

BRENT MENTAL HEALTH SERVICE

BRENT ADULT PSYCHOLOGY SERVICE
PARK ROYAL CENTRE FOR MENTAL HEALTH
CENTRAL WAY
LONDON
NW10 7NS

TEL: 0208 955 4431
Fax: 0208 961 6339

Participant Information Sheet

Study title: Chronic depression

Reference: Version Two 10/H0722/14 Date: 16th of October 2013

Chief Investigator: John Rhodes, Consultant Clinical Psychologist.

Invitation paragraph

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. We suggest this should take about 10 minutes. Please talk to others about the study if you wish. (Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study). Ask if there is anything that is not clear.

Part One

What is the purpose of the study?

Many patients have chronic depression, that is, depression lasting many years, often 5 years or more. In spite of the large numbers of such patients, there has been, in comparison, little research into such patients.

We wish to interview patients to find out what this sort of depression is like and what effects it has on a person's life in general, that is, on their relationships, their self-image and /or attitudes to self. We do not think the published literature on depression fully answers these questions.

For each participant we wish to carry out a first interview focused on the experience of depression. We will also invite participants to be interviewed a second time after approximately ten sessions of therapy : the particular focus of the second interview will be on how depression influences social relations and how participants perceive and experience themselves, for example, do participants like or dislike themselves? The transcripts will be analysed to summarise themes, that is, the meaning of what was said in the interview. Participants will be invited to meet the chief investigator at the psychology department when the analysis is finished (within three months of the interviews) to discuss the themes suggested in the analysis. The themes will be explained and we will ask the participants how useful and believable they find our results. We hope our results will help to design more appropriate therapy for chronic depression.



BRENT MENTAL HEALTH SERVICE

As part of this research, we are also interviewing some patients who do not have chronic depression. The focus with these patients will be on relationships and attitudes to oneself. If you are one of these patients, then the researcher will be able to tell you. If you are one of these patients, you will only be interviewed once.

A part of the data will first be analysed by a student and used in a dissertation for a MSc/Doctorate. The chief investigator however will be responsible for the publication of the overall findings in peer reviewed journal articles.

Why have I been invited?

You have been invited for one of the following reasons:

- 1) Our assessments suggest that you have suffered from chronic depression or**
- 2) You do not have depression but have been referred to our service for psychological therapy from the secondary care services (that is, the Assessment and Brief Treatment team or the Community and Recovery team).**

Do I have to take part?

It is up to you to decide to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. If you do the first interview, you are free not to do the second interview if you so wish. This would not affect the standard of care you receive.

What will happen to me if I take part?

If you decide to take part you will be given either:

- 1) A first interview about depression and then another interview about your social experiences and experiences of self or**
- 2) You will receive just one interview about your social experiences and experiences of self.**

The interviews will be tape recorded.

What will I have to do?

You will be asked to think about and answer the questions suggested in the interview.

What are the possible disadvantages and risks of taking part?

We do not see any disadvantages, and the only risk is that the questions might sometimes lead to topics which are difficult. These questions however are the same sort that you will be receiving in your therapy for depression.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study might help improve the treatment of people with chronic depression **and also might lead to new ideas for work in the area of self attitudes and social relationships.**

We wish to emphasise that the two interviews (**or single interview**) are not part of your therapy and are not, in themselves, considered to be therapeutic.



BRENT MENTAL HEALTH SERVICE

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You will be able to stop at any stage, and if you wish, your interview data can be deleted within a period of about 3 months: however, once data has been analysed and used in a write up, we will not be able to withdraw any data if used.

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 **[0208 955 4431]**. If you remain unhappy and wish to complain formally, you can do this to the Complaints Officer on 0203 214 5785 (Trust Headquarters, Hampstead Road, London NW1 7QY).

Will my taking part in this study be kept confidential?

All information that is collected about you during the course of the research will be kept strictly confidential, and any information about you, which leaves the hospital/surgery, will have your name and address removed so that you cannot be recognised (if it is applicable to your research). The only situation where confidentiality would have to be broken is where a participant made statements suggesting that they had the intention to harm themselves or another person.

What will happen to the results of the research study?

First one of our team will use part of the data for a dissertation, and then we will use the full set of data in articles to be sent for publication in peer reviewed scientific journals.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Camden and Islington Research Ethics Committee.

Contact for further information

To further discuss this research you can contact John Rhodes on **0208 955 4431**.

Thank you for reading this and taking part in the research.

7.3 Consent form



Central and North West London **NHS**
NHS Foundation Trust

BRENT MENTAL HEALTH SERVICE

BRENT ADULT PSYCHOLOGY SERVICE
PARK ROYAL CENTRE FOR MENTAL HEALTH
CENTRAL WAY
LONDON
NW10 7NS

Study Number 10/H0722/14

TEL: 0208 955 4431
Fax: 0208 961 6339

CONSENT FORM

Title of Project: Chronic depression

Name of Researcher: John Rhodes

Please initial box

1. I confirm that I have read and understand the information sheet dated 16th October 2013 (version Two 10/H0722/14) for the above study. I have had the opportunity to consider the information, ask question and have had these answered satisfactorily.

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 right being affected.

3. I understand that relevant section of my medical notes and data collected during the study, may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I agree to take part in the above study.

Name of Patient:

Date:

Signature

Name of Person
taking consent

Date:

Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to kept in medical notes.

7.4 Interview schedule

INTERVIEW SCHEDULE

1. Can you tell me about your relationships at the present time?
Prompts:
 - *Who do you see on a regular basis; who is important to you?*
 - *Do you spend much of your time with other people; meet other people regularly?*
 - *What do you do?*
2. What is it like for you to be with other people?
 - *How do you feel when with other people?*
 - *What's it like to talk to people?*
 - *How do you feel about other people generally?*
 - *How do you think other people view you?*
3. Can you tell me about some of the difficulties you might experience with other people or in social situations, if any?
 - *Are there difficult things that people do/feelings you have/things you find that you do?*
 - *At home or outside?*
4. Concerning your relationships with others, has there ever been a time or an episode when your relationships became very difficult. What happened?
5. What is being in the room with me like?
6. How do these experiences with other people impact on how you feel about yourself, if at all?
7. When you experience these difficulties or if you find you make a mistake, how do you react? What do you think and feel?
8. What would you like for your social life?
 - *How would you like it to be different for you?*
 - *What would you like to get from relationships and social experiences?*

7.5 Transcription confidentiality agreement

University of
Hertfordshire

Appendix 8: Transcription Agreement

University of
Hertfordshire

Doctorate in Clinical Psychology
University of Hertfordshire

Transcription confidentiality/ non-disclosure agreement

This non-disclosure agreement is in reference to the following parties:
Maria Walsh, Trainee Clinical Psychologist ('the discloser')
And
Louise Breckney, Anglia Transcription Services ('the recipient')

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.

Signed: 
Name: L. BRECKNEY
Date: 21.7.14

 INVESTOR IN PEOPLE
 POSITIVE ABOUT
DISABLED PEOPLE
 THE QUEEN'S AWARD
FOR ENTERPRISE
PERFORMANCE EXCELLENCE

Major Research Proposal Student No:
1.

7.6 Audit trail

7.6.1 Clustered themes for all interviews

NIK:

Needing to keep a distance

- *Limiting social life to a few important people*
- *Distance vs. intimacy*
- *Understanding and support with a few good friends*
- *Coping with friend's mental illness*
- *Maintaining boundaries with others*

Trying to be the person I want to be

- *Not being the person I wanted to be*
- *Relationships with the wrong people*
- *Getting to know and accept myself*
- *Feeling like I'm helping*
- *Importance of relationship with God*
- *Struggling to cope with the prospect of failure*

Still living with the past

- *Lamenting lost love*
- *Learning from and accepting the past*
- *Anger and distress*
- *Feeling alone*

Doubting self and others

- *Distrust and uncertainty about others*
- *Doubting self*
- *Paranoia and heightened awareness of others*

Feeling ready to re-engage with life

- *Needing to focus on recovery*
- *Escaping vs. engaging with life*
- *Control over illness vs. illness in control*
- *Looking towards a better future*
- *Reconnecting with family*

BEN:

Living with a sense of aloneness

- *Limited contact with others*
- *MH professionals key part of social world*
- *Struggle to fit in*
- *Feeling alone*
- *Adapting to being alone*
- *Social anxiety*

Expecting the worst from others

- *Expecting the worst from others*
- *They let me down*
- *Loss of trust*
- *Expecting some give and take*
- *Loss of a friend like a brother*
- *Paranoia*

Feeling safe enough to be myself

- *Understanding and acceptance from other service users*

- *Wish for somebody to trust and rely on*
- *Love and care to give*
- *Wish to open up and be myself*

Engaging vs. withdrawing

- *I cut them out*
- *Dealing with difficulties by withdrawing*
- *Resilience in resignation*
- *Making an effort to engage with life and others*
- *Sense of achievement from being independent*
- *Structure and occupation through friendship*

SARA:

Feeling disconnected

- *I used to be more social*
- *Barriers between me and them*
- *Loss of joy in friendship*

Judgement vs. acceptance

- *People showing care*
- *Feeling judged vs. feeling accepted and understood*
- *Enjoyment in socialising within mental health services*
- *Feeling of little use to society*
- *Giving as much as others give*

Mistrust of self and others

- *Fears of distress I cause others*
- *Feeling not up to task socially*
- *I can't trust people and their behaviour*
- *Is it me or them or illness?*

Sense of threat

- *Doubting experience of reality*
- *If anything happens to them what will happen to me*
- *Sense of threat*
- *Voices and thoughts taking over*

Feeling trapped inside

- *Anger directed inwards*
- *Unable to express true feelings*
- *Returning to the safety of routine*
- *Missing out*
- *Alone with experience*
- *Losing and regaining control*
- *Refuge in withdrawal*
- *A life of my own*
- *Wish to be caring and loving*

ZOE:

Loss of true social self

- *Loss of true self*
- *Loss of pleasure in people over time*
- *Needing for more from others*
- *Fears impeding opportunities with others*

Voices and unusual beliefs are undermining me

- *Causing pain to self and others with thoughts*
- *Visions and beliefs that terrible things could happen*

- *Uncertainty about how to relate to symptoms*
- *Voices are strong than me*
- *Voices rendering other people as a threat*
- *People can hear my thoughts*

Finding a way to cope

- *Learning through talking*
- *Coping by avoiding*
- *Coping and confidence through friendships*
- *Getting over the loss of significant others*

Sense of inadequacy

- *Feeling inadequate*
- *Feeling lonely and lost in context of inpatient care*
- *Fear of being a burden vs. contributing and feeling valued*
- *Pressure in relationships with important people*

Having little faith in myself

- *Distrust of self as well as others*
- *Fear and discomfort in opening up*
- *Feeling vulnerable and unable to cope*

AMY:

Struggling socially

- *Struggling with everyday social situations*
- *Difficult memories intruding on new experiences with people*
- *Official meetings and professionals as frightening*
- *Anxiety takes over*
- *Managing being friendly vs. formal*
- *Limited social world*
- *Difficulty forming friendships*

Trying to be my own person

- *Striving for independence and identity*
- *Difficult relationships with family*
- *Upholding principles despite challenges*
- *Most important relationship is with God*
- *Trying to build the social life I want*
- *Being open about mental health difficulties*

A society of our own

- *In a society of our own*
- *Coping and achievement through involvement in services*
- *Acceptance and ease with other service users*
- *Investing in relationships with those who care for me*

Not measuring up within the mainstream

- *Not measuring up within the mainstream*
- *Beliefs that help me feel like less of failure*
- *Fears of rejection and discrimination*

Coping by avoiding

- *Managing anxiety by avoiding*
- *Passive acceptance*
- *Depending on mother*

LUCY:

Sense of mistrust

- *Rivalry and hostility between me and others*

- *Feeling vulnerable*
- *Difficulty dealing with other's mental health problems*
- *Being selective with people*
- *Latching on to the wrong people*
- *Difficulty dealing with cultural differences*
- *Feeling the need to withdraw*

Trying to be my own person

- *Know and accept me for who I am*
- *Struggle to assert self and boundaries*
- *Retaining sense of self-sufficiency*
- *Self as good and helpful*
- *Disclosing too much*
- *You've got to try and cope*

The importance of those that care

- *Needing support that listens and guides*
- *Importance of those that show they care*
- *Looking to the future with others*

Feeling disconnected

- *Feeling lonely*
- *People come and go*

Feeling inadequate

- *Feeling lower than others*
- *Feeling doubted and unsupported*
- *Feeling under scrutiny*

JAN:

Feeling socially cut-off

- *I'm depending on others*
- *I don't have enough friendships*
- *Comfort with people closest only*
- *Feeling cut off from social media*

Struggling to be accepted as me

- *People don't understand me*
- *I need to be able to express myself*
- *Friends that let me down*

Feeling not good enough

- *Feeling inadequate*
- *The efforts I make are not good enough*
- *Feeling judged and scrutinised*

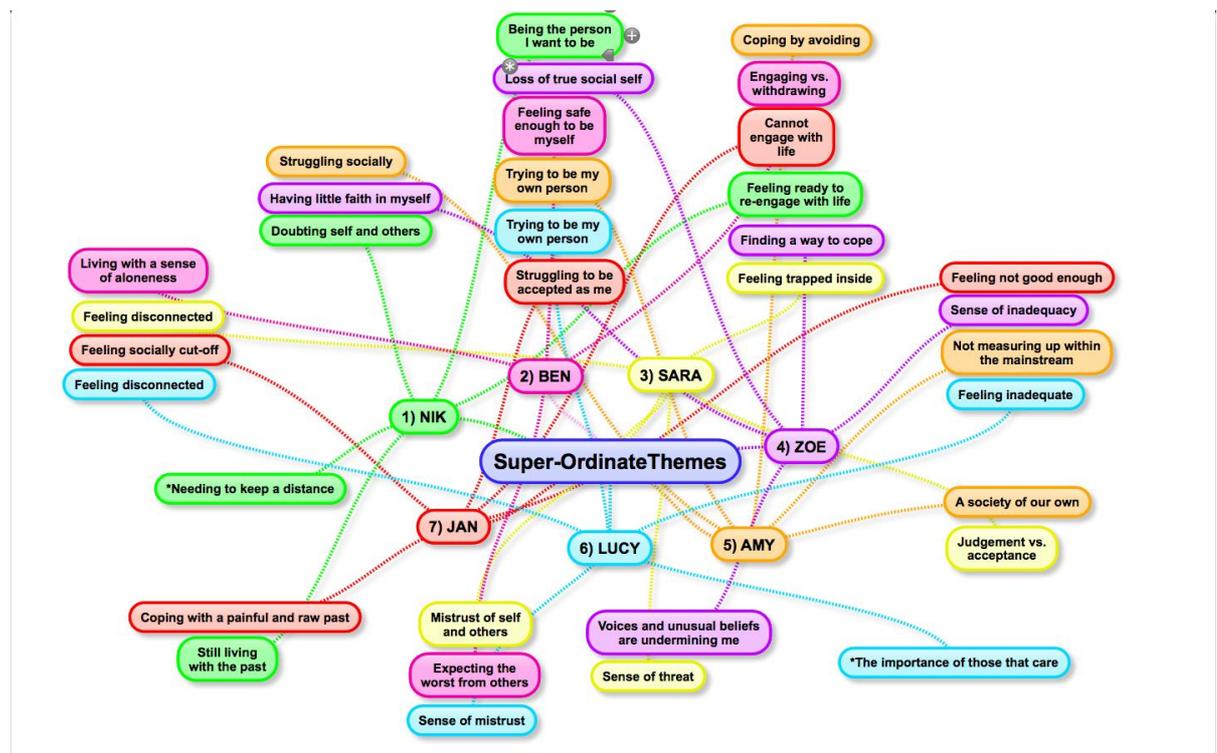
Cannot engage with life

- *Withdrawing*
- *I can't stick at anything or get anywhere*
- *The demands of life are too much for me*

Coping with a painful and raw past

- *I couldn't look after my son*
- *Making my problems worse*
- *Protecting others*
- *A painful and raw break-up*
- *Guilt and blame*
- *Pride and relief at what has worked out*

7.6.2 Diagram to show clustering of superordinate themes into master list



1

¹ Themes that were superordinate themes for one case but on review of all the transcripts were important for all or most of the other participants and represented in the emergent themes.

7.6.3 Table showing clustering of master themes and presence across interviews

Superordinate Themes	Subordinate Themes	Nik	Ben	Sara	Zoe	Amy	Lucy	Jan
Finding a place in society	Feeling disconnected	✓	✓	✓	✓	✓	✓	✓
	Doubting my social self	✓	✓	✓	✓	✓	✓	✓
	Feeling inadequate	✓		✓	✓	✓	✓	✓
	Struggling for individual identity	✓	✓	✓	✓	✓	✓	✓
	A society of our own	✓	✓	✓		✓	✓	
	The importance of those that care	✓	✓	✓	✓	✓	✓	✓
Interpersonal mistrust	Expecting the worst from others	✓	✓	✓	✓	✓	✓	✓
	A need for distance	✓	✓	✓			✓	✓
	Coping through avoidance	✓	✓	✓	✓	✓	✓	✓
Undermined by inner/outer disturbance	Unusual experiences making it difficult to connect	✓	✓	✓	✓			✓
	Past intruding on the present	✓	✓	✓	✓	✓	✓	✓