

**Positive aspects of the experience of psychosis:
An Interpretative Phenomenological Analysis**

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Submitted in accordance with the requirements for the degree of

Doctor of Clinical Psychology (D. Clin. Psychol.)

The University of Leeds

Academic Unit of Behavioural Sciences

School of Medicine

July 2008

**The candidate confirms that the work submitted is her own and that appropriate credit
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ACKNOWLEDGEMENTS

I would like to express my sincere thanks to Dr Anjula Gupta and Dr Carol Martin, for their patience, support and true determination in driving this study forward.

Thanks go also to the participants for their honesty, courage and cooperation. Without them this research could never have taken place; I hope I have done justice to their stories.

Thank you to those who manage the Max Hamilton Fund for making it possible to have the interviews transcribed.

I am grateful to the staff at the rehabilitation services for their energy and encouragement. Thanks to John Thorpe for his genuine interest in the study and his help in recruiting participants.

Thanks to Dr Harry Wood for his encouragement and understanding.

Thanks to Tony and Mona Daly for believing in me and also for their words of wisdom and invaluable advice, and to Linda Stirzaker, Michelle Haigh and Ben Pollinger who were always available to offer practical support.

Thanks to Anne and Michael Speak and to Dominic Richards for their support.

I am eternally grateful to Elaine Richards for her humour in times of despair.

Abstract

This qualitative study is an investigation of subjective accounts of psychosis, with a particular focus on positive aspects of the experience from people who have continuing treatment needs and from those in recovery. The findings offer insight which is applicable to mental health services, psychological understanding and interventions. 15 semi-structured interviews were conducted with 10 participants, four of whom were in recovery and six of whom had continuing needs. Participants welcomed the opportunity to share their stories, and their descriptions were eloquent and valuable. Interpretative Phenomenological Analysis was used to analyse the data. Subordinate themes were clustered around seven master themes in order to explore how positive experiences fit into the experience of psychosis as a whole and to determine the frameworks people used to find meaning in their experiences. Similarities and differences between the two groups were explored. Participants were interested in exploring positive aspects of their experience. They identified 14 positive sub-themes (e.g. enhanced sensory experiences, support and comfort from the voices, accessing an alternative experience), and their implications (e.g. absolution from responsibility, educational and professional opportunities, empowerment through recovery). Only one participant was unable to identify positive aspects of his experience of psychosis.

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CHAPTER 1 INTRODUCTION

Schizophrenia is the worst disease known to man.

(Carpenter and Buchanan, 1995, p899).

It may be that in the sordid quagmire of disease there are genuine flowers to be preserved.

(Chadwick, 1997, p2).

This study is an investigation of subjective accounts of psychosis, with a particular focus on positive aspects of the experience from people with continuing treatment needs and from those in recovery. It aims to enhance understanding of the processes involved in recovery in order to inform clinical interventions and provide direction for further research. The experiences considered are diagnostically labelled as 'schizophrenia' (American Psychiatric Association, 2000). The study will explore how people, whose experiences have been classified under this category, make sense of what has happened to them.

Overview

This chapter provides an overview of relevant research in order to set the study in context. Firstly, consideration will be given to the epistemological and ontological frameworks within which the study was conducted, and all terminology used will be defined. Following this, theoretical approaches which have informed the construction and understanding of people's experiences of psychosis will be introduced. Literature around subjective experiences of psychosis, including first-person accounts inform the current investigation, and will then be discussed. A critique of key discourses in literature pertaining to psychosis will follow, covering stigma, treatment and recovery, and frameworks adopted by people to understand their own experiences. Literature about psychosis, drawing upon empirical research and qualitative approaches will then be explored.

Taking a Constructivist Epistemological Perspective

Particular reference will be made to the construction of psychosis, and the influence of a dominant discourse on perceptions of experiences. A social constructionist model (Gergen, 1977) informs the research aims and overall design of the study. This theoretical perspective permits flexibility in considering:

- Conceptions of the nature of truth and reality: understanding the ways in which individuals or groups contribute to the creation of their perceived reality.
- The construction of reality through language.
- The relationship between power, language and reality.
- The ways in which social phenomena are created, institutionalised and made into tradition by human beings.

Rather than there being one ultimate truth, there are many truths which have been socially constructed. Reality is flexible and dynamic in that it is changed by interpretations and knowledge of it, so that as people act upon their understanding, their common knowledge of reality becomes reinforced (Burr, 1995). Social constructionists would imply that popular discourse about psychosis has been constructed so that possible advantages of psychotic experiences are conceptualised as deficits (Higgins, 2002).

Terminology

Classification of human experience is an inevitable aspect of trying to understand the nature of people's conceptualisations of the world (Bowker and Starr, 1999). Since psychosis is an inherently controversial concept, challenges to the medical classification permeate the literature (Gallie, 1955/56). The debate surrounding the term psychosis is not incidental, accidental or temporary, and has led to a single-symptom approach to research, reflecting a trend to target specific experiences such as delusions or hallucinations, rather than broader conditions (Persons, 1986; Bentall, Jackson and Pilgrim, 1988; Costello, 1992). The academic and medical terms surrounding the experience of psychosis are varied, and for this reason it is useful to be clear about the terminology used in this document and its intended meaning.

Defining Psychosis

The less common, yet arguably less pejorative term (British Psychological Society, 2000), psychosis is used differently depending on which of the psychoses it is used to refer to. In referring to schizophrenia, (which is its usage throughout this thesis) psychosis refers to hallucinations, and disorganised speech or behaviour. The BPS (2000) recommends the use of the term psychosis rather than schizophrenia as, "an umbrella term for unusual perceptions (e.g. hearing voices), or unusual beliefs. In

both cases other people sometimes see the person as, to some extent out of touch with reality” (p.10).

Defining schizophrenia

Medical model

Current psychiatric research into the development of psychosis often focuses on the role of neurobiology, despite the fact that a reliable and identifiable organic cause has not been found. Schizophrenia was classified as a distinct mental disorder by Kraepelin (1896), who first made a distinction in the psychotic disorders between what he called *dementia praecox* and manic depression. Kraepelin suggested that *dementia praecox* was primarily a disease of the brain, and in particular a form of dementia. The term ‘schizophrenia’ has been applied to a set of experiences, namely ‘positive’ symptoms (i.e. hallucinations, delusions and thought disorder) and ‘negative’ symptoms (i.e. poverty of speech and speech content, anhedonia, apathy and attentional impairment) (Bleuer, 1950, in Bentall, 2003).

In the American Psychiatric Association’s (APA) Diagnostic and Statistical Manual of Mental Disorders, DSM IV-R (APA, 2000) schizophrenia is defined as the presence of any two from the following five symptoms: delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour, and negative symptoms (such as affective flattening, or avolition). The two-symptom requirement can be disregarded if the delusions are considered unusual enough, or if the hallucinations are of a particular type (voices providing a running commentary on the person’s behaviour or voices conversing). Importance is given to the duration of the symptoms and any loss of function; some disturbance must be apparent for 6 months (including at least one month duration of the symptoms listed above) before a diagnosis can be made. The manual also lists a range of sub-types of schizophrenia (e.g. paranoid, disorganised, simple), since as an umbrella term, it is less useful for categorising the variety of presentations and experiences which would be subsumed by this category. The above discussion of terminology constitutes the historical medical discourse on psychosis and represents one of many frameworks for understanding and approaching it. Common to these descriptions is a tendency to value existing socially-constructed norms which are employed universally as benchmarks against which human behaviour can be compared and consequently, psychopathology diagnosed.

Epidemiology

There is considerable debate over prevalence rates of schizophrenia since studies have produced inconsistent findings. Some studies rate prevalence of schizophrenia cross-culturally as 1% (British Psychological Society [BPS], 2000; Carpenter & Buchanan, 1995; Sartorius et al., 1986); other reports have suggested different prevalence rates (see Read, 2004), thus it is difficult to report with any degree of certainty. Recent studies have shown that some people who have psychotic experiences remain invisible to formal mental health services (Bak, et al., 2003) which would indicate that prevalence statistics may be inaccurate. Studies suggest that the onset of schizophrenia is often between late teenage years and early twenties, and is often slightly earlier for men than for women (Hafner, Maurer, Loffler & Riecher-Rossler, 1993; Harrop & Trower, 2003).

Usefulness and limitations of the diagnostic criteria

The concept of schizophrenia has been subject to a variety of ethical, scientific and clinical challenges. An obstacle to the utility of the classification of particular behaviors and characteristics is the stigma which inevitably attaches to the term. Evidence suggests that negative attitudes towards individuals with psychosis can have a profound, adverse impact upon their mental health. The diagnostic element of the term implies that the whole person is defined by his/her experiences which can be disempowering (Bentall, 2003). In addition, internalisation of the diagnosis can affect self-image. The hypothesis that the 'heightened sensitivity, unusual experiences, distress, despair, confusion and disorganization' (Read, Mosher & Bentall, 2004, p3) termed "schizophrenia", could be a disorder involving the self has a long history (Freud, 1957; Schneider, 1959). In 1990, Bentall argued that the reliability of diagnosis, and construct and predictive validity for schizophrenia are poor. van Os (2003) claims that "The traditional concept of schizophrenia as a homogeneous disease entity has become outdated and is in need of a more valid and clinically useful successor" (p. 586).

The notion of continuity between psychosis and 'normality' is by no means novel (Bleuler, 1950; Meehl, 1962). Bentall (2003), proposed a continuum model whereby experiences categorised as psychotic, can only be differentiated from 'normal' experiences by careful assessment of the degree of conviction and preoccupation (Strauss 1969). Psychotic experiences, such as delusions and hallucinations, are considered by some to be extreme expressions of traits that are

present in the general population (García-Montes & Pérez-Álvarez, 2003). Tien (1991) maintains that 10% of the general population experience hallucinations. Such experiences have been said to manifest themselves as psychological variations that are observable in individuals who may range from being perfectly well to those who, whilst they may not be considered to be experiencing psychosis, appear to show signs of psychopathology (Claridge, 1972; 1988). Therefore the distinction between the two becomes somewhat blurred and a multi-dimensional continuum approach to understanding psychotic experiences appears more coherent (Krabbendam, Myin-Germeys & van Os, 2004). It is possible, however, that the measures used in these studies are tapping into experiences which are qualitatively different to psychotic experiences in people diagnosed with schizophrenia.

Limitations of a medical framework

Szasz, (1961, 1991) argued that there are inherent ethical problems in applying a medical framework to the classification of mental health issues, since diagnoses mask important ethical responsibilities, such as responsibility for actions and conduct. In addition to ethical dilemmas about the use of diagnoses, the scientific process of identifying a person's mental illness has come under fire. Bentall, (2003), referred to the classification manual as a Chinese menu, where the desired number of symptoms is selected from a set list in order for a diagnosis to be made. Bannister (1968) asserted, "Schizophrenia, as a concept, is a semantic Titanic, doomed before it sails: a concept so diffuse as to be unusable in a scientific context" (p.181).

More recently McGorry, (1995), a prominent psychiatrist, reviewed psychiatric classification over the past century and commented, "It may be sobering to be reminded that "chlorpromazine has turned forty", but it should prompt great concern that the concept of dementia praecox is about to turn 100 without any fundamental change" (p.556) He suggested that the diagnosis of schizophrenia hinders clinical progress, "The binary model has failed to contribute to any significant clarification of the underlying substrates of psychotic disorder. Indeed, it is likely that its rigidity has inhibited progress in helping to create a 'logjam' of confusing research findings" (p.558). Medical conceptualisations of psychosis suggest that experiences can be optimally managed by medications, which at best, can facilitate a functional life with a pervasive, chronic illness. The medical view of psychosis is somewhat pessimistic regarding the possibility of recovery.

THEORETICAL APPROACHES UNDERPINNING THE STUDY

Bentall, Jackson and Pilgrim, (1988) suggested that every factor which affects us as human beings, has been put forward as a potential causal factor of schizophrenia. Consequently, there could be many theories relevant to this study including biological (e.g. Gottesman, 1991; Carpenter & Buchanan, 1995; Johnstone, Crow, Frith, Husband & Kreel, 1979), evolutionary (e.g. Horrobin, 2002), neuropsychological (e.g. Frith, 1994), sociological/anthropological, existential (Sass, 1992), spiritual (Clarke, 2000a; 2000b; 2001) and stress-vulnerability models (Zubin & Spring, 1977).

Four theories underpin this study, namely, Symbolic Interaction Theory, Social Representation Theory, Recovery Model and Rehabilitation Psychology. These models are in keeping with the epistemological stance and are broad enough to encompass the range of possible findings.

Symbolic Interaction Theory

Symbolic Interaction Theory (Blumer, 1938, 1969) proposes that people respond to stimuli in a manner which is congruent to the personal meaning they have for them. Meaning is constructed through social interaction and modified through interpretative processes. It suggests that thoughts and behaviours are inherently linked to past experiences but can be continuously re-evaluated and modified through ongoing interpretation. In clinical terms, problematic interpretations can be identified and modified through interaction with others who can identify with the experiences.

Social Representation Theory

Social Representation Theory (Moscovici, 1973) posits that social and cultural knowledge influences perception, experience and action, and that for people to communicate with each other, there needs to be a shared language within which to locate concepts and ideas which are beyond their own experience. It suggests that social representations are a system of values and practices that allow individuals to orient themselves in their environment, and in so doing, facilitate communication by creating codes for group interactions, social exchange and classifying experiences from collective individual and group histories. This approach provides insight into the influence of socially-constructed, preconceived ideas and social interactions on people's construction of frameworks for understanding their experiences.

The Recovery Model

The recovery model has been created, developed and established primarily through attention to first-person accounts of experiences of mental health problems. In the survivor movement there is an emphasis on ‘celebrating the positive and highly unique creativity of the mentally ill’, and events have been organised to provide a forum for this such as Mad Pride or BonkersFest. A recovery vision looks at the whole person from his/her own perspective; it focuses on strengths, hopes, wishes and achievements, as well as ways of managing difficulties. “For some of us Recovery means learning to cope with our difficulties, gaining control over our lives, achieving our goals, developing our skills and fulfilling our dreams” (Coleman, 1999, p. 103).

The Recovery Model focuses on deconstructing traditional conceptualisations of mental health and advocates a redefining of people’s roles in their own treatment in order to facilitate a sense of personal agency (Walker, 2006). Clinically, this approach suggests that a change of perspective on the part of both clinician and client influences expectation of what constitutes success; by increasing positivity and agency, the possibility of recovery becomes tangible.

Rehabilitation Theory

Some psychological theories have been criticised for being overly-focussed on mental illness rather than mental "wellness" (Seligman, 1990). Recently, theoretical approaches focussing on positive conceptualisations of mental health have begun to appear, and these were pioneered by theorists such as Maslow, Rogers and Fromm (see Snyder & Lopez, 2002). Rehabilitation psychology was initially envisaged as an interdisciplinary, person-centred approach to facilitating optimum rehabilitation and recovery for people with physical health needs. It recommends identification and promotion of positive subjective experience, cognitions about the future, well being and satisfaction. It suggests that people benefit from having an opportunity to identify and enhance their existing positive personal characteristics.

The theory (Brown, DeLeon, Loftis & Scherer, 2008): adheres to a set of four core strengths

- *The somatopsychological relation* – The focus is on learning about a people by finding out about their ability to manage tasks or experiences which are relevant to *their* lives rather than predetermined standards. In relation to psychosis, a person’s presentation would be

evaluated whilst attending to the wider psychosocial and contextual aspects of his/her life experiences and environment.

- *Individuation* – use of first person language. The focus is on treating the person rather than his/her diagnosis.
- *The insider-outsider distinction* – those who experience psychosis have a different understanding of it than those who have not experienced it. The focus is on interacting with people independently of emotional presentation.
- *Existing and potential assets* – psychotic experiences, no matter how severe, in no way diminish or eliminate a person's other assets. The focus is on accentuating real or potential assets rather than deficits. (Dunn & Dougherty, 2005).

In accordance with the biomedical model, mental health problems can typically be framed as the presence of something negative that resides within the individual (e.g., mania or depression). This negative, individual bias in problem framing may explain the ubiquity of some individually focused, negative-eradicating interventions (Wright & Lopez, 2002). Once a problem has been framed as the presence of something bad, its reduction can only be seen as being desirable; indeed, this conceptualization may be adequate in many services and for many service users. However, this one-dimensional conceptualization of problems could be seen as having two potential limitations:

1. The absence of the negative does not ensure the presence of the positive. This model would suggest that by focusing exclusively on eradicating more negative states, there is a risk of overlooking strengths inherent in their experience that may be essential for health and growth.
2. The growth and maintenance of positive characteristics and behaviours may ensure the absence of the negative characteristics and behaviours. This model suggests that maximising strengths can facilitate a reduction in negatives or deficits.

Consideration of the different theoretical perspectives in this section has provided a brief rationale for the shift from exclusively examining negative aspects of the psychotic experience, towards focussing on those qualities that promote positive adjustment.

USER INVOLVEMENT IN RESEARCH - IDENTIFYING A GAP

There is a need to understand the nature of psychotic experiences and the meaning people make of these in order to see the benefits that can be gained from them in terms of recovery. Research has been directed mainly at negative experiences, aspects or consequences of psychosis and investigation of positive aspects is limited, yet The Health of the Nation (HMSO, 1991), the Patients' Charter (HMSO, 1991) and the Research Governance Framework for Health and Social Care (Department of Health, 2001) emphasise the importance of service users' views. There are many indications of the paucity of references to the subjective perspective (Faulkner & Morris, 2003). Jenkins and Barrett (2004) suggest that "The subjective experience of schizophrenia has been a neglected area of research in the latter part of the twentieth century" (p.7).

Benefits of inclusion

Involvement of people with first hand experience is increasingly becoming a political priority (Brunt & Rask, 2005). There are several benefits of inclusion relevant to this study. Offering a different perspective to that of professionals ensures that issues important to individuals, and by implication to clinicians, are identified and prioritized. Those who are marginalized can be accessed and empowered by involvement, which can lead to improvements in quality of life and psychological treatment and to satisfaction with services (Simpson & House, 2002; Sullivan, 2003; Minogue, Boness, Brown & Girdlestone, 2005). Engagement and satisfaction with mental health services can affect the outcome of treatment. Neglecting the voice of service users has had repercussions in terms of perception of patient interests, clinical practice and research focus (Read, Mosher & Bentall, 2004).

A realistic understanding of the experience of psychosis can best be gained through consideration of the accounts of those who have direct experience of it. The following section will outline subjective accounts of psychosis; research that incidentally found positive aspects, and studies which focussed specifically on positive aspects. The discrepancy between the dominant professional narrative and common discourses within subjective accounts will be explored.

Subjective accounts

Chadwick, (1997) talks about enhanced creativity and the concept of ‘creative illness’ and suggests that,

“the access to preconscious and unconscious processes that specifically schizoid and schizophrenic states may permit (Frith, 1979) need not be destructive but an occasion for renewal, enlightenment and insight to a degree where many decades are needed later, to actualise in a disciplined way, the material thus released to consciousness” (p.15).

He documented his own experiences of schizophrenia, (1992, 1997), and used autobiography, biography, psychometric and experimental methods to reveal areas of enhanced functioning. He explored the possibility that people with a diagnosis of schizophrenia have areas of enhanced functioning compared to ‘standard-minded’ people, and asked whether it is possible to construe schizophrenia more positively. He suggested that schizophrenia endows its sufferers with valuable qualities which are worth nourishing, in particular enhanced empathy and sensitivity, of which diagnostic labels take no account. He hypothesised that the psychotic mind can access states of mental clarity and profundity (the value-sensing experiences of Donaldson, 1993) inaccessible to people without experience of psychosis.

Tomecek (1990) describes schizophrenia as an alternative way of living in the world. He acknowledges that the experience can be difficult, but says it involves personal choice and sees his own experiences as an artistic gift. He rejects the idea that schizophrenia is organic in cause and maintains that for him, it is preferable to being normal.

Reflecting on his own experiences of psychosis, May (2006) argues that exposure to others’ accounts of recovery from psychosis can have important therapeutic value by helping to engender hope in those who may be struggling with their own experience, “Meaningful accounts of psychosis that allow us to connect with others and make choices about our lives are essential to any recovery process”.

These accounts do not offer empirical proof that there are positive aspects to experiencing psychosis, nor do they make a scientifically sound argument that concrete, measurable, positive ‘by-products’ exist. They rarely explain how to access or maximise positive aspects which would have direct clinical implications; however they do point to the positive perspective as a potentially undiscovered aspect of the experience of psychosis.

EXPLORING PSYCHOSIS FROM THE INSIDE

Only recently have qualitative methods begun to be accepted as legitimate within psychology (Henwood & Pidgeon 1992; Woolgar, 1997). Proponents of qualitative research methods (e.g., Geertz, 1983; Heron, 1981; Shotter, 1993) argued that conventional scientific methods are not adequate for investigating and interpreting phenomenological topics. Qualitative research methods have made it possible to move from anecdotal accounts to a more systematic study of people's accounts in order to investigate how people construct their own meanings.

Experience of services and treatment

Literature detailing subjective experiences of psychosis forms a critique of the conventional medical and psychopathological models (Harvey, 2004; Coleman, 1999), yet it is exceptional for them to be credited in scientific literature. This section will illustrate the dichotomous relationship between services and consumers, since the experience of services is central in shaping people's experience of psychosis. Epstein (1995) argues, "The suffering of the individual is not, as a pure biological perspective on health may assume, wholly attributable to any putative underlying biological condition, but is shaped also by how the individual makes sense of that condition" (p.19).

Knight and Bradfield (2003) focussed specifically on the subjective experience of being diagnosed with a mental illness. They note that this experience is overwhelmingly negative and people report feeling that their personal identity is taken from them and subsumed by an illness identity. Leventhal and Diefenbach (1991) specified the nature of the influence of diagnosis; "a person who suffers from a set of symptoms will seek to label the symptoms, and a person who is labelled (i.e., diagnosed) as having an illness will expect to experience specific symptoms" (p.260). Knight and Bradfield's participants spoke of the social factors which influenced their experience of being diagnosed, including fear of being rejected by others, and a growing sense of alienation and isolation, combined with a sense of lack of validation from others. This suggests that having personal experiences conceptualised and named by professionals has negative effects, particularly influenced by society's preconceptions about psychosis.

O'Toole et al., (2004) analysed transcripts from focus groups to specify the most helpful elements of a first-episode intervention. They used IPA to explore how participants themselves made sense of and gave meaning to their experiences. An

independent research practitioner analysed transcripts of three focus groups, and identified positive aspects of the service as being a human approach, involvement in treatment decisions, flexibility of appointments, high nurse to patient ratio, reduction in psychotic symptoms, an increase in confidence and independence and the provision of a daily structure.

Cohen (2005) used a qualitative design to interview 220 people about their experiences of the mental health system. Most of the participants described forced medication, electro-convulsive therapy, restraints, seclusion and verbal abuse during their treatment. The four emerging themes were trauma, social control, internalised oppression and recovery. Most participants reported experiences of struggling with abuse in the mental health system, and they concluded that the medical model needed some drastic alterations for it to have a positive influence on service users.

These studies suggest that there is more to learn about the way experience of services influences the broader experience of psychosis, and in particular, the extent to which negative and positive aspects of the experience are influenced by services and the professionals who work within them.

Qualitative Research: Experiencing the influence of society

In investigating experiences of psychosis it is pertinent to consider how negative preconceptions, held by society, influence or determine how people interpret and respond to their experiences (Doherty, 1975). Reference has already been made in this chapter to stigma which has come to be attached to current conceptualisations of psychosis, and hence to those with diagnoses (Link, Struening, Neese-Todd, Asmussen & Phelan, 2001).

Given the research interest in stigma and mental health, it would seem important to ask people about their experiences; however, Wahl (1999), maintains that there is an inexcusable paucity of research into subjective accounts of it, "What is conspicuously absent from these explorations of mental illness stigma is the mental health consumer, the person with the mental disorder who is presumably the recipient of stigma" (p.468).

Knight, Wykes and Hayward, (2003) used IPA to investigate stigma in schizophrenia. They conducted semi-structured interviews with six participants. Service users felt they had been stigmatised by authority figures representing medicine, the police and society in general. Three superordinate themes were drawn from the analysis: judgement, comparison and personal understanding of the mental

issue. They found two elements of stigma: public-stigma and self-stigma. Participants suggested that the source of this prejudice came often from sources of help (such as friends, family, authority figures representing medicine and the police). This qualitative approach emphasizes the extent to which the attitudes, behaviours and interactions of *all* people can influence the experience of those with psychosis.

Stanghellini and Ballerini (2006) used Grounded Theory to explore the values of people with a diagnosis of schizophrenia by investigating the meaning of experiences and beliefs associated with it. Their aim was to reduce social and occupational dysfunction related to the stigmatisation of 'psychotic symptoms'. The authors conducted a minimum of 10 'therapeutic interviews' with 40 of their patients and based their analysis on sentences spoken by the participants, which were seen to exemplify their values. Diaries and personal notes were included in the analysis and were provided by participants themselves, or their relatives. They identified five features in the schizophrenic value system, namely Ego-Syntonic Feelings of Radical Uniqueness, Exceptionality, Metaphysical Concerns, Charismatic Concerns, Refusal of Interpersonal Bonds, Refusal of Common Sense Knowledge and Semantics. They concluded that these values emerged as an overall "crisis of common sense" (p.5) since "persons with schizophrenia convey an appreciation and often an exaltation of their own feelings of radical uniqueness and exceptionality" (p.8). This deficit-focussed view would contrast with the social constructionist and strength-based views and therefore highlights a risk in attempting to make people's accounts of their experiences of psychosis meaningful according to a predetermined deficit-focussed ontological stance. Ritsher and Phelans (2004) suggested that the degree to which people internalise negative stereotypes associated with their experience can influence the extent to which the person feels, alienated, marginalised and excluded and this can mitigate against recovery.

This research illustrates the important role played by society in determining a person's understanding of his or her experience, a theme that will be discussed further in the following section which explores frameworks or 'explanatory models' (Kleinman 1988).

Frameworks to understand the experience

Coinciding with the increased popularity of qualitative research approaches is a small yet significant surge of investigations into people's own attributions for and interpretations of psychosis. These focus on the meaning that psychosis has to those

who experience it, and the contextual influences upon the development, adoption and integration of frameworks within which people conceptualise and explain their experiences.

Angermeyer and Klusmann, (1988) conducted a large-scale study in Germany, asking people how they understood their experience of schizophrenia. They used surveys and interviews to collect data from 200 participants. They found that 74% of participants could identify at least one framework (e.g. esoteric or familial) in an interview, and 93% could identify frameworks when offered a checklist of multiple factors. The findings indicated that people have developed sophisticated understandings of their experience and do indeed strive to make sense of it.

Dittmann and Schuttler (1990) investigated people's explanations for the *cause* of their schizophrenia. Their finding that only 12% of their sample was able to identify an explanatory framework suggested that while some people do strive to find an explanation, asking participants to voluntarily identify causal frameworks can be challenging. Their findings represented the complexity of meaning-making for participants, in that 38% gave multi-factorial explanations (including personal, environmental and endogenous causes). 30% attributed their psychosis to stressful life experiences, and 20% identified external reasons (for example, people in their community).

Practising in medically dominated mental health services can encourage professionals to assume that the majority of those with psychosis would subscribe to illness representations to explain their experiences. In exploring attitudes towards treatment and illness among people with a long history of hospitalisation for schizophrenia (mean 13 years since first admission), McEvoy, Aland, Wilson, Guy and Hawkins, (1981) found that only 13% of their sample identified with an illness model to explain their experiences. This research suggests that incorporating a broad spectrum of possible frameworks is essential.

Social Representation Theory (Moscovici, 1973) posits that frameworks for understanding experiences are not static but can be modified through the environment in which people find themselves and the others with whom they interact. Kleinman (1988, p.55) suggests that forming a framework represents the efforts of a person to take control in finding meaning in a 'wild, disorganised, natural occurrence' and that these are heavily influenced by context and culture. He suggests that the framework

adopted by a person can influence his/her experience in terms of symptoms, and aspects of treatment and recovery.

Jones, Guy, and Ormrod (2003), found three distinct frameworks adopted by the 21 participants they sampled for their q-methodological study, namely, biological, psychological, and spiritual. They reported that those who located their experiences in a spiritual framework were less distressed by what had happened to them, but those who viewed their experiences in a medically informed way were more negative, suggesting that people's explanatory frameworks can influence their response to treatment, their prognosis for recovery.

Romme and Escher (1993) found that people's frameworks for making sense of their psychosis influenced their level of distress in response to their voices. They found that participants drew upon varied frameworks, including metaphysical, mystical, medical, parapsychological and psychodynamic. It would seem, therefore, that attending to an individual's own frameworks for making sense of psychosis is a clinically relevant research endeavour, since some frameworks serve as protective factors. In clinical terms it is clear that people's frameworks influence their beliefs and emotional responses towards psychosis, which in turn influences their response to treatment and attitude towards treatment providers. Caution should be exercised in suggesting frameworks to people, however, since scientific, professional and clinical models may not necessarily be congruent with the frameworks adopted by those who have first hand experience of psychosis.

Recovery

“The goal of recovery is not to become normal. The goal is to embrace the human vocation of becoming more deeply, more fully human” (Deegan, 1996) The studies considered have highlighted directions for recovery from psychosis, such as finding personally meaningful explanatory frameworks (May, 2006), reducing internal and external stigmatization, and rediscovering personal identity. Processes involved in moving towards recovery from psychosis will be considered next.

Corrigan (1999) administered a Recovery Scale on 35 participants in a partial hospitalization program. Analysis of the concurrent validity showed recovery to be positively associated with self-esteem, empowerment, social support, and quality of life, and inversely associated with psychiatric symptoms and age. Markowitz's (2001) findings support this notion that there is a key role for self-esteem in recovery experiences, and suggests that it mediates the effect of life-satisfaction on symptoms.

He used longitudinal questionnaire data from 610 people with ‘severe mental illness’ in self-help groups and outpatient treatment and looked for correlations and variability in the results of the scales he administered to establish relationships between symptoms, life satisfaction, and self-concept. These studies have identified factors which promote and delay recovery and suggest that people in recovery could offer a different, distinct perspective on the experience as a whole, including barriers to and processes involved in recovery.

Vellenga and Christenson (1994) interviewed 15 long term users of mental health services in America. They used a phenomenological methodology to identify four common themes in participants’ accounts relevant to recovery; a sense of stigmatisation and alienation; a feeling of pervasive distress; reaching a form of personal acceptance of the experience, and the desire for this acceptance to be shared by others (family and friends).

Ridgeway (2001) used a narrative method to conduct a document analysis of four published autobiographies about recovery. She noted that while there was variety in the narratives, it was possible to identify common themes, including finding hope, understanding and accepting one’s condition, becoming actively engaged in life, and moving from having a sense of alienation to having meaning and purpose in life. The author noted that recovery narratives are an important resource since they offer, “an alternative “counter plot” that challenges and overturns the master decline narrative, the story of inevitable life-long disability that holds the outmoded “chronicity” or “deficit paradigm” in place. First person accounts amplify the message that a positive life course is attainable for persons with serious and prolonged psychiatric disabilities” (p.342). This study identifies the deeply personal nature of recovery and the value of attending to people’s narratives.

Jacobson (2001) used dimensional analysis on narratives to investigate 30 accounts of recovery. He identified four central dimensions: recognising the problem (*naming and framing*); transforming the self (*to fit with the new circumstances*); reconciling with the system (*making most use of mental health services to aid self transformation and recognising the problem*), and reaching out to others for support (*making connections*). The findings suggested that recovery is a process involving different stages.

These studies suggest that different ways of understanding and relating to the psychotic experience have different implications for issues such as whether or not the

experience will be construed as problematic; what might be considered an appropriate response; attitudes towards recovery and also stigmatisation. They have highlighted and begun to address a gap by refocusing thinking beyond the deficit perspective. Whilst the research studies discussed have provided valuable insight into the experience of psychosis, the clear theme running through these discussions is that psychosis is exclusively problematic for those who experience it – the tone remains remedial. The next sections will introduce the possibility that there may be something in the experience of psychosis, that is in itself valued.

Positive Psychology

Seligman (2002) suggested that the field of psychology has become skewed because it is primarily concerned with the study of disease, weakness and damage; he suggests it should focus more heavily on strength and virtue. By reframing problems to include the absence of the positive, in addition to the presence of the negative, strength-promoting interventions could access and promote more acceptable solutions, and ultimately may be found to be more effective, efficient, or attractive to service users than pathology based, symptom-reduction conceptualizations and interventions. In order for this to become a possibility there is a need for more evidence examining the possibility of positive-focused frameworks and interventions. This would mean a refocusing of research to explore, understand and build upon positive and beneficial characteristics. Studying psychosis from a positive theoretical stance could enable healthcare professionals and therapists to work better with mental health problems by amplifying qualities that help individuals and communities thrive (Snyder & Lopez, 2002).

Following the onset of a disability, some individuals adjust by searching for and finding meaning (Dunn, 1996), seeing purpose in life (Thompson, Coker, Krause & Henry, 2003) or identifying positive by-products (McMillen and Cook, 2003). McMillen and Cook, (2003) suggest that these positive elements should encourage researchers and practitioners to explore the validity of the positive aspects reported by some people. They use the term ‘positive by-product’ to refer to positive outcomes, perceived benefits and post traumatic growth; examples of these include improved relationships; changes in life priorities; and increases in self efficacy.

POSITIVE ELEMENTS OF THE PSYCHOTIC EXPERIENCE

This section will examine empirical research into, and subjective accounts of, the experience of psychosis as a whole including positive aspects.

Empirical Research

Miller, O.Connor and DiPasquale (1993) used a semi-structured interview schedule to study how 50 voice-hearers related to their experience. The methodology is unclear, but they reported that 98% of participants talked of adverse effects of the experience namely financial problems associated with work, emotional distress, reactions of other, feeling endangered or threatened, impact on friendships and self-concept, feeling scared and lonely. They also reported that 52% of participants spoke of positive aspects of their symptomatic experiences, including being relaxing, providing companionship and being protective, self-concept, creativity and performance and relationships. They found that 32% of participants did not want their voices to stop completely. In reflecting on the clinical implications of their findings, Miller et al., (1993) speculated that pre-treatment patient attitude towards the experience, predicts response to treatment. These findings are of critical importance to the current study in that they suggest that investigating the positive aspects of psychosis is valuable. Asking people about the positives of their experience could be useful in identifying issues most suitable for addressing in psychological treatment, so that the needs met by hallucinations could be met by other means.

Williams and Collins (2002) explored the possibility that aspects of chronicity in psychosis are socially constructed, and asked, how much of the poor outcome associated with schizophrenia is the product of external social factors, such as reduced social status, limited employment opportunities and social isolation. Their secondary analysis of data generated from a grounded theory investigation into the subjective experience of schizophrenia (n=15), suggested that family, service users, professionals and society each have a role in shaping a person's perception of worth, competence, and place in society but noted that individuals are not passive recipients of this input. The quality of this research in terms of credibility was limited by secondary analysis of data (Thorne, 1998); applying different research questions to qualitative data gained from a study designed to investigate a different phenomenon could have limited the dependability and validity of the findings (Hinds, Vogel & Clarke-Steffen, 1997). The suggestion that chronicity could be a psychological process influenced by a person's biology, environment, and social interactions may

lay the foundations for research exploring the meaning people make of their experiences and the existence and influence of positive and negative factors.

In their investigation of experiences of stigma among people with psychosis, Knight et al., (2003) incidentally discovered that several participants believed their experience of psychosis afforded them the opportunity for intellectual and personal development and from that, a sense of liberation. The authors suggest that future research should highlight potential positive aspects of experiencing psychosis and ultimately attempt to develop informed coping orientations to assist the person through this traumatic, stigmatising experience.

Can positive aspects be studied?

Chadwick (1997) argued that most of the capacities of enhanced functioning reported by people with experiences of psychosis are, unfortunately for scientist practitioners, often not amenable to standardised research methods. It is suggested that the 'schizophrenic credit' (Claridge, 1988) is made up of mostly intangible qualities, which would account for the dearth of research in this area, and points towards the potential usefulness of qualitative research methods in investigating subjective experiences.

CONCLUSION

It may prove useful to have a clear vision where all aspects of psychosis, be they positive or negative, are noted, understood and publicised so that communities and clinicians can access them (Allott, 2005). In light of the literature discussed so far, it appears that researchers have largely neglected the possibility of positive aspects. Although there is a plethora of literature examining the aspects of psychology and physiology of people with psychosis, that reveals deficits (including Weinberger, Berman & Zee, 1986; Cutting & Murphy, 1988; Morice, 1990; Braun, Bernier, Proulx & Cohen, 1991; Saykin et al., 1991; Baltaxe & Simmons, 1995; Wada, Takizawa & Yamaguchi, 1995; Morice & Delahunty, 1996), the primary focus of the proposed study is to examine positive experiences of psychosis, sometimes referred to as the 'schizophrenic credit' (Claridge, 1985). Positive perspectives on psychosis remain, without exception, a neglected secondary discourse in academic research. Given the emphasis on deficit-laden models of psychosis, and personal accounts which suggest potential positive aspects and capacities that might be advantageous, it would be useful to explore them systematically.

Research discussed has identified positive aspects of the experience of psychosis in terms of voices being relaxing, friendly, and protective. They can positively influence self-image and can enhance creativity, artistic ability and performance. It has been suggested that some people may not want their voices to stop completely, and experience psychosis as a preferred state of being. For some, the experience has provided an opportunity for intellectual and personal development. Whilst the research findings indicate that positive aspects are a possibility in the psychotic experience, there has been no direct investigation into positive aspects per se. Potentially the clinical implications of the existence of positive and desirable aspects of the experience of psychosis are profound and there remains a gap in research which, if explored, could increase knowledge and understanding. The intention of the present study is to explore people's accounts of what McMillen and Cook call "positive by-products" of psychosis. The stance taken on investigating the experience of psychosis for this study is about building on what is right rather than fixing something that is wrong, but without over-romanticising what can be a traumatic and painful psychotic experience.

Research Questions

The four research questions which underpin the study are as follows:

1. What positive aspects of psychosis can people who have experienced it describe?
2. How do accounts of positive experiences fit into the experience of psychosis as a whole?
3. What frameworks do people with psychosis use to find meaning in the experience?
4. What are the similarities and differences between the descriptions of a group with continuing needs and those in recovery?

The next chapter will examine which method was chosen for this initial exploration of subjective experiences and situational meaning of the positive aspects of psychosis.

CHAPTER 2 METHODOLOGY

This chapter includes an introduction to the overall structure of the study; methodological issues and choices between methodological frameworks; procedures integral to the method selected; quality issues and good practice, and procedural aspects of conducting the study. It begins with a reflexive statement.

Personal Reflexivity

Grbich (1999) suggested that reflexivity involves, “a process of self awareness that should clarify how one’s beliefs have been socially constructed and how these values are impacting on interaction and interpretation in research settings” (p.65). The following is my attempt to make my position clear.

I have always been interested in marginalised groups and wanted to find out more about them. As a teenager I volunteered in a homeless shelter and also in a local relief and listening centre for ‘people on the margins of society’. When I took up a post as a Healthcare Support Worker in a women’s forensic unit, I found the patients to be demoralised and powerless – they were locked on a ward which few people were required to visit, (and even fewer chose to do so). I watched them gather together in the smoking lounge during my night shifts and often sat with them. They were awake and calmer for much of the night and found it safe to sit and share their stories at that time. I learned that they had the capacity to articulate and reflect upon their life-experiences, but felt they were not given a voice because the complexity of the problems they faced meant that they were difficult to engage and so, easy to overlook.

The desire to give a voice to marginalised groups stayed with me through my clinical training. I came to recognise a group of people who were continuing with treatment and striving towards recovery after their experiences of psychosis. The fact that I might be able to give them a voice through my research attracted me to them. Although I realised (and was constantly reminded) that recruitment and engagement would be challenging, I was determined to try.

THEORETICAL METHODOLOGY

Qualitative approaches to psychological research

Qualitative methods prioritise the collection of open, reflective, informative responses, in order to explore the meaning people make of their experiences (Edwards & Staniszewska, 2000; Green & Britten, 1998). Adopting a qualitative approach will allow me to explore the rich complexities of the experience of psychosis; “In

qualitative research the researcher attempts to develop understandings of phenomena under study, based as much as possible on the perspective of those being studied” (Elliott, Fisher & Rennie, 1999, p. 216). Qualitative research is appropriate for studying questions of subjective experiences and situational meaning and is recommended for research that requires initial exploration such as this one.

Epistemological Stance

Three different positions will be considered next, each providing a different means of explaining knowledge acquisition and making sense of the world.

Realist / positivist stance

The realist/positivist position proposes that there is an objective reality which can be discovered through processes which are taken to be objective and value free, such as observation and deductive logic. This stance is limited, however, in facilitating an understanding of subjective experiences, the meanings given to experiences, and intersubjective interactions (Fossey, Harvey, McDermott & Davidson, 2002).

Contextual Constructionist stance

The contextual constructionist stance posits that all knowledge is local, provisional and context dependent. This approach contests the idea that there is one objective reality, and instead emphasises the subjectivity of the way the world is perceived (Madill, Jordan and Shirley, 2000). This position is most useful for interpretative methods which are focussed on individuals’ experiences of the world and developing understanding of meanings of experiences and actions (Fossey et al., 2002).

Radical Constructionist stance

The radical constructionist position is aligned with post-structuralism (which contests the idea of there being one ‘self’; instead people are believed to hold multiple identities which are socially and culturally produced and maintained). It calls into question the notion that language can represent reality, as knowledge is considered to be a discursive construction (Madill et al., 2000). This stance is best used for critical research methodologies which examine the cultural and historical construction of discourses and the subsequent confining effect on actions (Fossey et al., 2002).

Epistemological stance taken

The positivist position takes little account of the subjectivity of experience, and for this reason does not seem consistent with research which focuses on the lived

experience of psychosis, where the reality of parts of the accounts might be contested by common sense constructions. The radical constructionist position contests the notion that there can be any absolute basis for knowledge, and examines the way discourses shape notions of self and experience. This emphasis on cultural discourses does not fit with the research aims of the current study. The contextual constructionist position seems to be most congruent with the aims of this study, focussing on the subjective view of participants' experiences of psychosis and is therefore the position adopted for this research. Adopting this stance will allow me to approach people's experiences in the knowledge that I am not attempting to reveal one objective reality. However, it does mean that onus will be on me as the researcher to represent the perspectives of participants, ensuring that findings are grounded in their actual descriptions (Tindall, 1994).

Within the interpretative framework of this study, the meanings which people ascribe to their experience are deemed of central importance,

One cannot understand what people do when one attempts to bypass completely any phenomenological understanding of what the thing means to them.

Mischel, (1977; p.15)

The following section will outline the processes involved in choosing the best methodology.

Methodologies

Several methodological approaches were considered namely Discourse Analysis, Grounded Theory and Interpretative Phenomenological Analysis.

Discourse Analysis

Discourse analysis regards verbal data as behaviour and attends to the context in which the discourse takes place. It involves qualitative reading of text, focussing on variation and contradiction. Consideration is given to the role of language in construction and maintenance of social power structures and to the position the person. It is not focussed on identifying underlying mental states (Willig, 2001).

Grounded Theory

“Grounded theory places great emphasis on attention to participants' own accounts of social and psychological events and of their associated local phenomenal and social worlds” (Pidgeon, 1997; p.76). Grounded Theory is used to identify and explain social processes and the development of theory is a key target. It allows

theories to emerge from the data through a process of induction; however the emphasis on uncovering social processes limits its applicability to more phenomenological research questions. Willig (2001) suggests that when Grounded Theory is applied to the nature of experience, rather than the unfolding of social processes, it becomes a technique for systematic categorisation. Since the focus of this study is exploring experiential accounts, it was felt a different method would be more appropriate.

Interpretative Phenomenological Analysis

The aim of IPA is to explore participants' views of the world in order to access an 'insiders perspective' on a phenomenon (Smith 1996). It is assumed under this approach that there is a chain of connection between what a person says and how a person thinks or feels. The method is phenomenological in that it there is concern for an individual's personal perception of an event as opposed to an attempt to produce an objective statement of the event. It is believed that phenomena can not be separated from the context in which the topic of interest is investigated. It is interpretative in the sense that this dynamic process is complicated by the researchers own conceptions; researchers are required to make sense of participants' personal experiences. There are two interpretative processes- the participants interpret their experience as they give their account and in their reflections on it; the researcher also interprets, both in the interview and in the analysis. The connection between participants' language, thinking and emotional state is complicated since people do not always wish to self-disclose, and some level of interpretation of their physical and emotional wellbeing might be needed (Smith & Osborn 2003).

In employing IPA theory, data generation and data analysis are developed through a dialectical process. This involves the researcher moving back and forth between data analysis and the process of explanation or theory construction. Blaikie (2000) calls this an 'abductive research strategy' and it is associated with moving between everyday concepts and meanings, lay accounts, and psychological explanations. This method is not focussed on employing a theory in the early stages of research, but rather with immersing oneself in the data before drawing on or developing a theory to explain the results.

Methodological approach chosen

IPA underlines the subjective perceptual processes involved when a person searches for meaning in his/her experiences (Smith, Jarman & Osbourn, 1999). As

IPA allows for exploration of the individual's perception of an event or experience, it would appear to be suited to a study of people's experiences of psychosis. The processes involved in applying this method will be outlined later in this chapter.

Data production

Qualitative researchers have at their disposal, a variety of methods to gather data. Three of the most prominent methods are focus groups, structured interviews and semi-structured interviews. Focus groups offer a means of collecting data through a discussion-based interview whereby multiple participants come together to give their perspective on issues raised by the researcher for exploration (Milward, 1995). The dynamics of the group can influence the data generated and group interaction is an important consideration when analysing and interpreting data (Milward, 1995). Structured interviews allow the researcher to decide what data is needed according to predetermined categories (Smith, 1995). These have been criticised for being too constrained and preventing phenomenological exploration of complexity and ambiguity (Smith 1995). Semi-structured interviews allow the researcher to develop broad questions in order to guide the interview (Smith, Harre & van Langenhov, 1995). There is usually a predefined area of interest although the participant is directly involved in developing the focus the interview, and shaping it (Smith et al., 1995). In depth interviews provide a forum for exploration of the experiential perspective; they are appropriate for initial exploration; they add to the theory base for understanding the experiences of psychosis, and give direction for future research.

Group discussions may influence participants' expression of their experiences and responses may be directed by group dynamics so focus groups were ruled out for this study. Since little is known about lived experience of psychosis, it seems important to allow participants flexibility in their answers; structured interviews seem too constraining for this to occur. Since the study intends to examine the meaning people make of their experiences, it requires a flexible data collection instrument which will enhance the main aim of IPA i.e. to enter the psychological and social world of the participant (Smith & Osborn 2003). Semi-structured interviews appear to be the best method of eliciting information about psychosis since they allow greater flexibility, enabling the participant to provide a richer picture (Smith et al., 1995).

The semi structured interview will allow me to approach participants as experiential experts on the topic under investigation and access an 'insider's perspective' (Smith & Osborn, 2003; Denzin & Lincoln, 2000). The semi-structured

interview allows participants to tell their story in their own words (Smith & Osborn 2003), and will allow me to guide the discussion rather than dictate it. I will have greater opportunity to establish rapport with participants, probe interesting areas that arise and follow their interests and concerns (Smith, 1995).

Quality

Quality criteria applicable to qualitative methodologies will be discussed next. The following standards for ensuring good quality qualitative research have been informed by Elliott et al., 1999; Miles & Huberman, 1994. The epistemological stance and the decision making process involved in finalising the research questions meant that reflexive practice was an integral part of the study. I will include a reflexive statement which was formulated as a result of discussions with my academic and clinical supervisors throughout the analytic process. In order to help the reader make an independent and realistic judgement about the generalisability of the research, I have provided description of the context in which I recruited, together with a pen portrait of each participant and his/her life-circumstances. Limitations of generalising the findings to other groups have been specified. In order for the reader to judge my understanding of the data, and to allow him/her to form alternative explanations, I have included an example of each theme which illustrates the analytical procedures used and my subsequent interpretation. Appendix G shows an example of my use of IPA on a specific segment of the data. In order to assure the reader of reliability and validity I asked my field supervisor to review the data and analysis. I took transcripts to a qualitative support research group so that they could offer their perspectives at different stages of the analysis, and compare them with mine.

PROCEDURE

Ethical Approval

The Leeds (East) Research Ethics Committee approved the research in August, 2007. The West Yorkshire Mental Health Research and Development Consortium gave permission for the research to begin in October, 2007 (see Appendix A).

Inclusion criteria

These were:

- Adults above the age 16 years who:

- Have at some time in their lives, been given a diagnosis of schizophrenia and
- Are fluent in English

Exclusion criteria

To avoid the possibility of coercion of participants who were not suitable for the research the following exclusion criteria were put in place:

- People under the age of 16 years who:
- May find an interview too distressing regardless of the flexibility of interviewing times and places
- Were unable to be interviewed (including people who were too acutely affected by their experiences, and people who were unable to give consent, understand or reply to the interview questions).
- Were not fluent in English. This is because the transcripts would be analysed using IPA, where attention to meanings and errors is necessary.

Recruitment and Selection

Selection

The study was conducted in two phases in order to ascertain whether there were positive aspects identified by both groups, and whether these seem to overlap. The first phase involved interviewing people who were recovering from experiences of psychosis and felt they were relatively successful in living their lives. It was anticipated that these people might be more likely to give me a sense of what had been helpful for them; and that they might have had more positive experiences. This group would sensitise me to the ways that people with continuing treatment needs might talk about positive experiences, since I anticipated that there might be fewer positive experiences to report or that their accounts might be confounded by symptoms or situation.

The second phase involved interviewing people who were still engaged with the National Health Service for continuing treatment needs. This group of people were of interest since they were still living with ongoing experiences of psychosis. As a whole, the findings would allow for identification of, and comparisons between a range of experiences.

Recruitment

Phase One – The Non-NHS Group

People who had experienced psychosis at some point in their lives, and who considered that their lives were productive and satisfying were the pool of potential participants for the Non-NHS group. Opportunistic sampling was used whereby my supervisors recruited people believed to be appropriate. This involved approaching people known to my supervisors to ask if they would be interested in participating. This group were no-longer receiving treatment for their experiences of psychosis. Those who had read the Participant Information Sheet specific to their group (see Appendix B), and were therefore familiar with the inclusion and exclusion criteria, would be appropriate.

This phase of the study was intended to explore potential areas of positive experience for those who were recovering from their experiences and living relatively successfully in the community; this group might potentially be more able to describe more clearly positive experience and this would inform the second phase of the study.

Phase Two – The NHS Group

People with continuing treatment needs were recruited for the second phase of the study. Purposive sampling was used whereby I presented the research proposal in team meetings in local rehabilitation units and asked clinical leaders and staff to familiarise themselves with the Staff Information Sheets (see Appendix C) and recommend people they believed met the inclusion criteria. In addition to this, posters inviting people to ask staff about the study were displayed in the units (see Appendix D). Potential participants were given a participant information sheet either in person, or by post. Those who were given it in person had the opportunity to talk through their interest in the study.

It was rightly anticipated that people in this group would be difficult to recruit, and it was felt that the themes generated in the first phase of the study might inform sensitive and insightful interview questions for the second phase.

Sample Size and Recruitment

Qualitative studies vary in how many participants are involved, as emphasis is placed on the quality of the information collected rather than number of participants. The emphasis is on acquiring a sample which will supply an appropriate amount of

data suitable to the method of analysis (Yardley, 2000). Smith and Osborn, (2003) suggest there is no 'right sample size'; the number of participants should be sufficient for the researcher to compare similarities and differences between participants but not so large as to lose detail in the interviews or overwhelm the researcher. Brocki and Wearden, (2006) conducted a literature review of 52 papers using IPA in health psychology. They found a range of 1 to 30 participants and noted that "Small sample sizes are the expected when using IPA" (Brocki & Wearden, 2006). Smith, et al., (1999) suggest that IPA works well with up to 10 participants, and Smith and Osborn (2003) suggest sample sizes of 5-6 people for novice researchers. I aimed to recruit 6-12 participants; this number would provide relevant material, a range of views, and enough data to allow detailed analysis without creating excess which might lead to superficial investigation or wasted data (Malterud, 2001). The intention for each phase of the study was, therefore to recruit between three and six participants. For phase one, four people volunteered and were interviewed. For phase two, around 15 people were identified as being appropriate for the study and 11 gave permission for me to approach them to discuss it further. Six of these 11 participants were interviewed and the five who declined explained that they were either not interested or were not feeling able to participate at that time.

The interviews were conducted between January and April 2008; four were conducted in inpatient units and six in a neutral space belonging to the National Health Service. Of the four people in the Non-NHS Group, three were interviewed once and one requested, and was offered, a second interview. Of the six people in the NHS Group, three were interviewed once, two were interviewed twice (one at her request and the other was invited for a second) and one person was offered three shorter interviews; flexibility was used in order that he might have an opportunity to contribute fully.

Background information on Participants

All participants had experienced psychosis at some time in their lives. All were white British. Exact data on the participants' ages was not collected for every person. Care was exercised in engaging the participants, and it was felt that collecting detailed demographic information about them might threaten consent.

Table 1 – Participant Information

<i>Participant Pseudonym</i>	<i>Group</i>	<i>Number of Interviews</i>	<i>Age</i>	<i>Gender</i>
Ester	Non-NHS	1	26	F
Patrick	Non-NHS	2	35	M
Ivan	Non-NHS	1	34	M
Ron	Non-NHS	1	50s	M
Matthew	NHS	3	60s	M
Lilly	NHS	1	30s	F
Linda	NHS	2	40s	F
Luke	NHS	1	32	M
Jon	NHS	2	30s	M
Stefan	NHS	1	47	M

Consent

Once participants had verbally consented to take part they completed two copies of the consent form (See Appendix E). Consent was gained for recording the interview.

Confidentiality

It was important that information relating to participants' identities was protected throughout the research process and so anonymity was guaranteed. Participants were guaranteed that confidentiality would be maintained through the following procedures:

- All records of interviews would be stored in a locked filing cabinet on secure premises.
- Anonymised interview transcripts would only be seen by a limited number of people, namely my supervisors, and select colleagues who attended a qualitative research support group.
- All digital recordings of the interview would be destroyed upon completion of the study.
- All identifying features would be anonymised in the report.

Data Collection

The Interview Schedule

The interview schedule was designed in two stages. The first stage was designing a topic guide to identify key aspects of the participants' experiences based on literature and research evidence pertaining to positive aspects of psychosis and recovery (Rubin & Rubin, 2005). From this specific questions could be developed. Using the topic guide would allow me flexibility in guiding the discussion, rather than being directed by a set of inquiries; this approach would facilitate the formation of a rapport with the participant. The second stage was designing the interview schedule to maximise the chances of seeing different aspects of the participants' experiences. The schedule consisted of main questions designed to cover the major aspects of the research questions; follow-up questions designed to encourage expansion of themes, concepts and events, and probes designed to manage the interview by keeping it on topic (Rubin & Rubin, 2005).

Having refined the framework of the interview schedule, I conducted a pilot interview with a friend who had experienced psychosis; this allowed me to familiarise myself with the schedule and recording equipment. The Department of Health 'Expert Patient Initiative' (2001) encourages involvement of the expertise of people with first-hand experience and I was fortunate in knowing someone who was happy to advise by identifying areas which would benefit from rewording and restructuring. He commented that the questions appeared sensitive, appropriate and would tap into key aspects of the experience of psychosis. The interview schedule can be found in Appendix F.

Interview Process

Given the plethora of terms associated with the experience of psychosis, each of which is loaded with different meanings and stigmas, I invited participants to offer their preferred terms at the start. This proved to be a discussion which turned out to be key in respecting and retaining their meaning frames for their experience (Holloway & Jefferson, 1997).

Following each interview I kept a written diary of my reflections about how I felt it had gone, to assist in transparency during the write-up of the thesis proper (Yardley, 2000). The written diaries were used to inform potential themes.

After interviews with the second participant I consulted my supervisors to discuss the tone of the questions and to gain their perspective on the outcome of the interviews. This 'checking-out' and debriefing became a regular feature in the interview phase of the study, and clinical supervision was accepted after one interview.

Analysis

There are three main characteristics of IPA (Smith, 2004):

- 1) **Idiographic:** It starts with detailed examination case by case before cross case analysis is attempted and themes from the cases are investigated for convergence and divergence.
- 2) **Inductive:** Techniques are used which are flexible enough to allow unanticipated topics or themes to emerge during analysis rather than through reliance on existing literature or established theories.
- 3) **Interrogative:** Although it differs from mainstream psychology in some of its epistemological assumptions, it shares constructs and concepts with it and results are discussed in relation to the extant psychological literature and can question existing postulations.

Transcribing the first interview gave me insight into the tone, and access to the subtle interactions which could have easily been missed if I had not done this. It increased my familiarity with text so I was better able to make links. After all interviews had been transcribed, it became clear that my concerns about the content of one participant's contribution being entirely focussed on his diagnosis of bipolar disorder, were confirmed and after consulting my supervisors the decision was taken to omit this interview from the analysis. There were four key stages involved in analysing the data using IPA (outlined in Willig, 2001), namely:

- 1) I read the transcript repeatedly to elicit my initial reflections, responses and feelings, and documented these in the margins.
- 2) Then I began to draw sub-themes from the text and noted these in the margins.
- 3) I looked for themes which shared meaning and clustered these together. These were documented in a table relating to each participant. Sub-themes which form the clusters were supported by direct quotations from the transcripts. At this stage, the more peripheral sub-themes were discarded.

- 4) Then I integrated the clusters and formed master-themes which reflected participants' experiences of psychosis. When I reached the stage where my supervisors and I agreed that full integration of themes had been achieved, the analysis is finished.

IPA emphasises the complexities of the interview dialogue, as well as the thoughts and emotional states of both participant and researcher. Participants may be reluctant to disclose information, and Smith and Osborn (2003) recommend a degree of interpretation of his/her emotional state at this stage. In order to remain grounded in interpreting the data, Smith (2004), suggests that the initial analysis should be approached with empathy, and later considered with critical reflection. Smith (2004) warns against approaching the analysis from a pre-ordained theoretical position which could then prejudice the interpretation of the transcript. My attempts to do this will be described next, using my analysis of the first interview as an example.

Analysis of the First Interview

After transcribing the interview, I spent time reading over it and making notes of the idiosyncrasies, indicators of process issues, and emotional tones throughout the account. For example, I noted a sense of anxiety at the start of the interview, and when asked *'erm sorry what was the question again?'* wrote *'so emotionally involved in content she has lost the sense of what was being asked of her'*. My intention was to orientate myself with her experience. I reviewed the reflective notes I had kept after the interview where I had attended to her sense of fulfilment at present which she had regained following a disempowering experience of the psychiatric system and traumatic experiences of psychosis. There was a real sense that she was trying hard to make sure I understood the unfamiliar experiences that she was describing; I wrote comments like *'Careful to be realistic – does not want me to lose the more difficult, complicated parts of her narrative'*. I also noted comments regarding the participant's preconceptions about how her story might be perceived, for example, *'This sounds really freaky'* or *'it sounds a bit strange but...'* and times when she was cautious of my interpretation, *'Don't get me wrong'* and *'I'll rephrase that'* I highlighted descriptive language such as *'horrific'* and *'I sacrificed my sanity'*. Throughout this phenomenological stage of the analysis I aimed to understand her descriptions whilst remaining grounded in the data, which involved highlighting the enormity of the experience in her descriptions, *'I could sit here for a day and not*

really do justice to quite how overwhelming that voice actually was'. In reflecting upon the tone I noted the warmth that ensued as the interview progressed and the collegial temper at the end of the interview. Examining these processes was valuable since it allowed me to become immersed in the rich complexities of the subtle exchanges which could have been easily overlooked and yet were so revealing.

The second stage of the analysis involved noting sub themes in the margin and later linking these, so that, *'[I was] forced to devolve personal power to an unknown professional'* and *'the sort of experience of psychiatry and the resulting disempowerment really and societal disempowerment as well as psychiatric disempowerment was in some ways more distressing and more debilitating'* and *'schizophrenia is entirely frightening and disempowering'* became *'Facing disempowerment as part of the experience'*. In taking an interpretative stance I was considering how themes linked together, why I was linking them together in a particular way and why the participant described them in that way.

As I began to analyse the rest of the transcripts I noted that some of the themes were unique to this one participant and began to reflect upon why these were not present in the narratives of other participants, for example, *'Interpreting the experience and recovery as death and rebirth'* and, *'Feeling special because I belong to an exclusive group of high-profile, leading professionals as a result of my experience'* and, *'Breakdown means loss of identity'*.

Development of Sub-Themes and Thematic Clusters for Interviews

In order to tease out the subthemes and thematic clusters for each interview I constructed a table which grew as more analyses were added. Close attention was paid to areas of repetition and the introduction of different themes (Smith & Osborn, 2003). In total there were around 70 themes and underneath each one, the frequency of reference to it was tallied. The table was reorganised so that clusters became apparent, and eventually there were 10 tables: Society, Friends and family, Process Issues, Cause, Descriptions of the experience, Positives, Negatives, Medication, Illness and Recovery. It became clear that some of the rudimentary themes could be reorganised under a title which encapsulated several themes, for example, Society, Stigma, Cultural Responses and Fear of Response, became *'The Influence of Society'* (see Chapter 3). This process involved revisiting the text to ensure that extracts were being correctly located and clustered. After initial clusters were formed, and printed

on cards, these are reorganised multiple times, whilst revisiting the extracts from which they were formed, in order to refine them. At this stage, the clusters were considered by a colleague also conducting an IPA project, and my academic supervisor; an exercise to increase validity. The clusters were refined repeatedly following this advice in order to form the final Master Themes.

Development of Master Themes

The development of Master Themes involved taking an analytical, abstract stance in order to group themes into overarching categories which brought them naturally together. This stage involved being mindful of the original concepts which were noted in the reflective diary, so for Interview One, these were '*Feeling disempowered by being detained within the psychiatric system*' and '*Finding the experience of psychosis traumatic, distressing, complex, meaningful and external to the self*'. At this stage, four Figures were created which had strands running off them, for example, the master theme read 'Turning Negatives into positives' and from that came 'Making sense of the experience', and from that came, 'I'm not ill', 'I'm ill', 'Internal/External', 'Meaning', 'Identity', 'Doesn't make sense', and 'Spiritual'. When I consulted my academic supervisor to discuss these clusters, it became clear that the groupings were not meaningful to the reader and did not capture the meaning and nuances in the participants' narratives. Again, the clusters were deconstructed to extract the actual essence of what the participants had conveyed to me. Some of the initial themes disappeared because they were subsumed by other themes, and the above were refined into, '*Personal identity is subsumed by the illness*', '*Experiencing psychosis as illness*', '*Breakdown means loss of identity*', '*Breakthrough means rediscovering identity*', '*Struggling to make sense of the dichotomy of realities of self and others*', and '*Recognising a spiritual dimension to the experience which can be either good or evil*'. Throughout this process I reminded myself that it was important not to lose perspective and did this by revisiting my reflexive and reflective notes, discussing preliminary clusters with a qualitative research support group and a colleague. This is one example among many and a significant amount of time was spent on this stage of the analysis. All of the master themes were generated, simultaneously, in the same way. Finally, after having redrafted the tables, and diagrams, the figures presented in Chapter 3 were finalised.

The processes involved in the analysis have been described in this detail in order that the reader can be clear about the complex, nonlinear strategies involved in

generating the master themes. Smith (2004, p.46) suggests that, “A student new to qualitative analysis should be thinking of producing an analysis which is ‘good enough’ rather than feeling forced to produce one which is devastatingly insightful”. In reflecting on the analysis I have found myself asking, ‘How does one know whether ones interpretation is good enough?’

As the analytical process progressed, I found that as a researcher I was an integral part of the process of constructing reality through my interpretation of the participants’ narratives. As a novice researcher, occupying twin roles caused uncertainty. As Patton, (1990, p.128) noted, “The challenge is to combine participation and observation so as to become capable of understanding the program (setting, participants) as an insider while describing the program for outsiders”. Occupying these positions exemplifies the importance of making explicit the involvement of my own position in the research, a process referred to earlier as ‘reflexivity’ (Mead, 1934).

Interpretative agreement

“Triangulation refers to the use of more than one approach to the investigation of a research question in order to enhance confidence in the ensuing findings” (Bryman, 1988). Triangulation has been used to assess the extent to which my interpretation reaches agreement with members of the relevant ‘research community’ (Fish, 1980). For this study, the relevant research community included: a service user network affiliated with the rehabilitation service, clinicians specialising in working with psychosis, fellow researchers familiar with qualitative methodologies, and an academic with a special interest in IPA. Feedback on the interpretation of the data was sought from this community and incorporated into the results.

Quotation Conventions

The following Chapter details the findings. Each major theme is presented through an outline of each subordinate theme which is supported by direct excerpts from participants’ accounts. The themes are grounded in examples from the raw data in order to provide a holistic and narrative account of the experiential descriptions offered. Each participant has been referred to by a pseudonym in order to protect anonymity. The following symbols have been used in the presentation of quotations:

- (.) denotes a pause
- { } denotes the omission of text

- [] denotes text which has been inserted or replaced in order to aid understanding or protect anonymity and confidentiality
- () denotes emotional or non-verbal content

CHAPTER 3

RESULTS

Introduction

This chapter begins with an introduction to each of the nine participants whose interviews were included in the analysis. Following this, the themes generated from analysis of the data are presented. Figures have been used to guide the reader through the development of the seven major themes.

Participant Portraits

The Non-NHS Group

Ester

Ester felt she was well into her recovery from the experiences of psychosis which had first affected her when she was 18 years old. She explained that the voices had initially been a source of comfort at a time in her life when she had felt overwhelmed, and that societal and psychiatric disempowerment had been more distressing and debilitating than the experiences of psychosis themselves. She said that only by chance had she eventually been referred to a psychiatrist who had seen beyond the diagnosis to the person, and had introduced her to other people who provided her with the inspiration to recover. She had changed from believing that the voices were external to her, to believing that they were a subconscious statement about how she felt about herself.

Whilst she suggested that people should be careful not to over-romanticise the experience of psychosis, (which she described as a long and painful process), she identified a number of positive aspects to, and ramifications of, the experience. She described the voices as reassuring at a time when her sense of self was in crisis, grounding her in the reality of what she was doing.

Ester told me that she felt proud to be a voice-hearer and had reclaimed her experience. She said that having had experiences, to which most people do not have access, gave her a sense of privilege. She said the experiences had led to good professional opportunities, and reputation and status which gave her a sense of purpose in life.

She said that the voices now served as a useful barometer for identifying problematic levels of stress, and served as ballast to give her emotional balance. She said the experience had made her a more likeable, mature and empathic person.

Patrick

Patrick suggested that his psychosis had been caused by problems at home, the break-up of a significant relationship, social problems and drug use in his adolescent years. He explained that the consequences of his experiences of psychosis had led to his detention in a variety of secure correctional environments where he had felt victimised, targeted, persecuted, unsupported, unsafe and isolated. He told me that the most disempowering aspect of his experience had been the unpredictability of his future when he was detained against his will.

He described the experiences of psychosis as having been profoundly frightening. He spoke of having been unable to function in the way he would have liked to, which had left him feeling worthless. He said that he suffered as a result of the stigma associated with his diagnosis.

He reported that medication has been his salvation and he has found support and motivation from the encouragement of professionals and peers. He talked about how he now survives from day to day thanks to medication, professional support and the discipline required by holding down a job. He felt that despite occasional setbacks, he is doing 'brilliantly' in terms of recovery. He said that employment is a purposeful way of using his skills and occupying his time and has helped him to rebuild his life. He said that the experience of psychosis had left him more tolerant of others and capable of empathy but that he had a great fear of relapse which was overwhelming at times. He told me that he had found sharing his experiences with fellow inpatients had given him a feeling of inclusion and belonging.

Patrick said that he continues to struggle with residual guilt and feelings of having let people down and having wasted his life. He said he still has problems relating to people and trusting them because he had felt that the world had been against him for so long. Despite this he felt that the experience and consequences of psychosis had left him a stronger, more assertive, confident and all round better person. He felt he had survived.

Ivan

Ivan had lived through two significant experiences of psychosis. He felt that his late-onset psychosis had been caused by traumatic experiences in his youth and drug use in his adult life.

He described feelings of intense terror that his integrity and physical safety were under threat, and that he had felt persecuted and betrayed by the people around

him at the time he was experiencing psychosis. He described a sense of dread that he might have to face the experience again in the future. Ivan was very aware of societal prejudice and preconceptions about people who have experienced psychosis and was careful about communicating his experience to people.

He conceptualised his experience in terms of the impact on the people around him, and was profoundly distressed by thoughts about the repercussions on those closest to him. He described the ongoing difficulties he faces in terms of trusting his colleagues and family members.

Ivan was clear in his belief that there were no positive implications of the experience of psychosis and believed it would be difficult to find people who had found positive aspects of it. He told me that the interview had been difficult because it had reminded him that dissociating from the experience by 'blocking it out' was not as functional for him as he had thought.

The NHS Group

Matthew

Matthew had a learning disability and described having heard voices since childhood. He had felt dismissed and disbelieved when he had communicated the experiences to people, and felt his education had been significantly affected by his treatment. Through his adult life he had found himself detained in correctional facilities where he described feeling disempowered, dehumanised and tortured.

He told me that it was difficult to think of positive aspects to the experience because it had been so frightening and disempowering for him, but said that at times the voices had been comforting and reassuring for him. He was clear that the repercussions of the experience in terms of treatment and detention had been traumatic for him.

Matthew explained that the most important factors in his journey towards recovery had been medication and being listened to. He talked about his hopes for the future and what he would like in order for him to live a good life.

Lilly

Lilly spoke of her experiences in terms of the environment she found herself in, be it an inpatient unit or her flat. She spoke of shutting off from the past and trying to remain constant in the present. She described her confusion that people see her differently at different times. She explained that the voices she hears cause her

pain and distress and have done since she was a baby. She found the interview difficult because she said it reminded her of the difficulties she has faced in her past.

Lilly left the interview after 15 minutes and despite her requesting further opportunities to be interviewed, she declined when these were offered.

Linda

Linda saw her experience as a spiritual journey and believed herself to have privileged access to communication with, and gifts from, God. She said the experience had been extremely useful in some ways and surreal in others and described it as 'peculiar and unexpected'.

She said she suffered as a result of the preconceptions of others, who had pointed at her and humiliated her. She described several times when people had denied her reality, which she had found distressing. Linda felt she had been treated unjustly in inpatient units, where she had lost her dignity. She explained that at times the voices she hears have been frightening for her. She believed that medication made her poorly, and talked about her interest in psychology and alternative therapies as more palatable ways of helping.

She said the experience of psychosis had given her hope and insight into the continuum of life and wishes all people could have the experience of hearing voices at some time in their lives, so that they would be able to empathise with her situation.

Luke

Luke had been experiencing psychosis and intermittently receiving inpatient treatment for 16 years when he agreed to speak with me. He told me that hearing voices and depression were his symptoms of mental illness, which he found difficult to cope with, in conjunction with the physical side effects of his medication. He felt that the whole nature of schizophrenia was defective and said it was difficult to think of any benefit he had gained from it. He spoke of his belief that schizophrenia can invade anybody's life, regardless of who they are, and is part of a person's 'make-up'. He said he felt that he had no choice but to put his trust in his doctor.

Luke had found different ways of managing his distressing experiences. He described having beautiful feelings of being at peace at times when the voices were not there. Luke said the experience had made him more alert to his own capabilities and provided him with creative inspiration. He said he had been able to produce phenomenal works of creativity as a result of the experience, and had become more alert to progression with regards to artistic capability. He said that he felt as though

nobody could understand him or his situation, and so does not talk about his experience with other people.

He explained that he was afraid to hope for recovery for himself because it may not happen, and so lives each day as it comes. He told me he finds inspiration from seeing other people who have shared his experience living in the community. He said he did not think he would ever be completely free from suffering.

Ultimately he said there was nothing that would prevent him from wanting to change to a lifestyle where he could live without the schizophrenia.

Jon

Jon had recently been discharged after a 7 year stay in inpatient services. He believed he had not recovered and told me he was just beginning to come to terms with some of his experiences. He said he did not believe that he was schizophrenic; rather he experienced things which not many people could relate to.

He felt his experience of psychosis had been caused by his use of drugs in his teenage years. When he was a teenager of 16 or 18 years, he had believed he was fine and said that his friends had been the first people to indicate that there was something different going on for him. He said they found it funny and laughed at him. He remembered a counsellor reacting with shock when he told her about what was going on for him. He remembered people telling him to stop being stupid when he spoke of his experiences. He said he remembered the terror of thinking things would never be the same for him again. He said he had felt like a social outcast, a pestilence who would spread sickness, which was overwhelming for him. He said he was most hurt by people whispering about him, undermining him, and excluding him from their world.

He told me that he did not believe there were any positive aspects to his experience of psychosis and described feelings of profound terror at some of the beliefs and experiences he had held, most of which had a spiritual element to them. He said the worst thing about his experience was fatigue and having the sense that he could not do anything. He said that he felt he had become less intelligent as a result of the experience, and was no longer able to earn money through work.

He said he still does not believe that other people do not see the things he does, because it would be too frightening to think that what they tell him about what he is experiencing could be true. He said he felt that the world was totally out of his control.

He said he found other people with psychosis charismatic, creative and fun to be around. He said the interviews had helped him to look for the positives in his experience, and look for something good in it. He said he believed that for some people psychosis was an escape from the terrible reality of their lives. He said that when he speaks to his friends about his experiences he finds they never call him back and then he regrets having shared his story. He told me he believed it was dangerous to speak to people of his experiences. He said he hopes he will get better soon.

Stefan

Stefan had volunteered for the interview after hearing about the study from another participant who was his friend. He told me that the first time he ever experienced psychosis was 27 years ago; it was unbelievable for him and the content of his experience was sinister and focussed around evil entities. He remembered the time when people told him that he was ill, and he was confused about that. Around this time a senior colleague had told him his experiences were caused by his worthlessness when he was born, and this 'got to his heart'.

He spoke of the time he had spent in secure treatment facilities, and the humiliating and debilitating treatments he was subjected to there. He said he felt he had been neglected by his family at the times when he most needed them. Stefan talked about traumatic experiences in his childhood, and throughout his adolescent and adult life and told me that it is because he has been mistreated so badly, that he has been given the gifts of his experiences.

He said he has an ability to see and hear things that other people do not believe in. He told me that he has privileged access to spiritual happenings – he said he misplaces things consciously. Stefan told me he believed that if a person is gifted psychically he/she is gifted naturally, in the physical world as well, and that his Romany Gypsy heritage means that for him, he is gifted in the arts.

He told me that he is weary of talking to people about his experiences, because they might want to take them away from him.

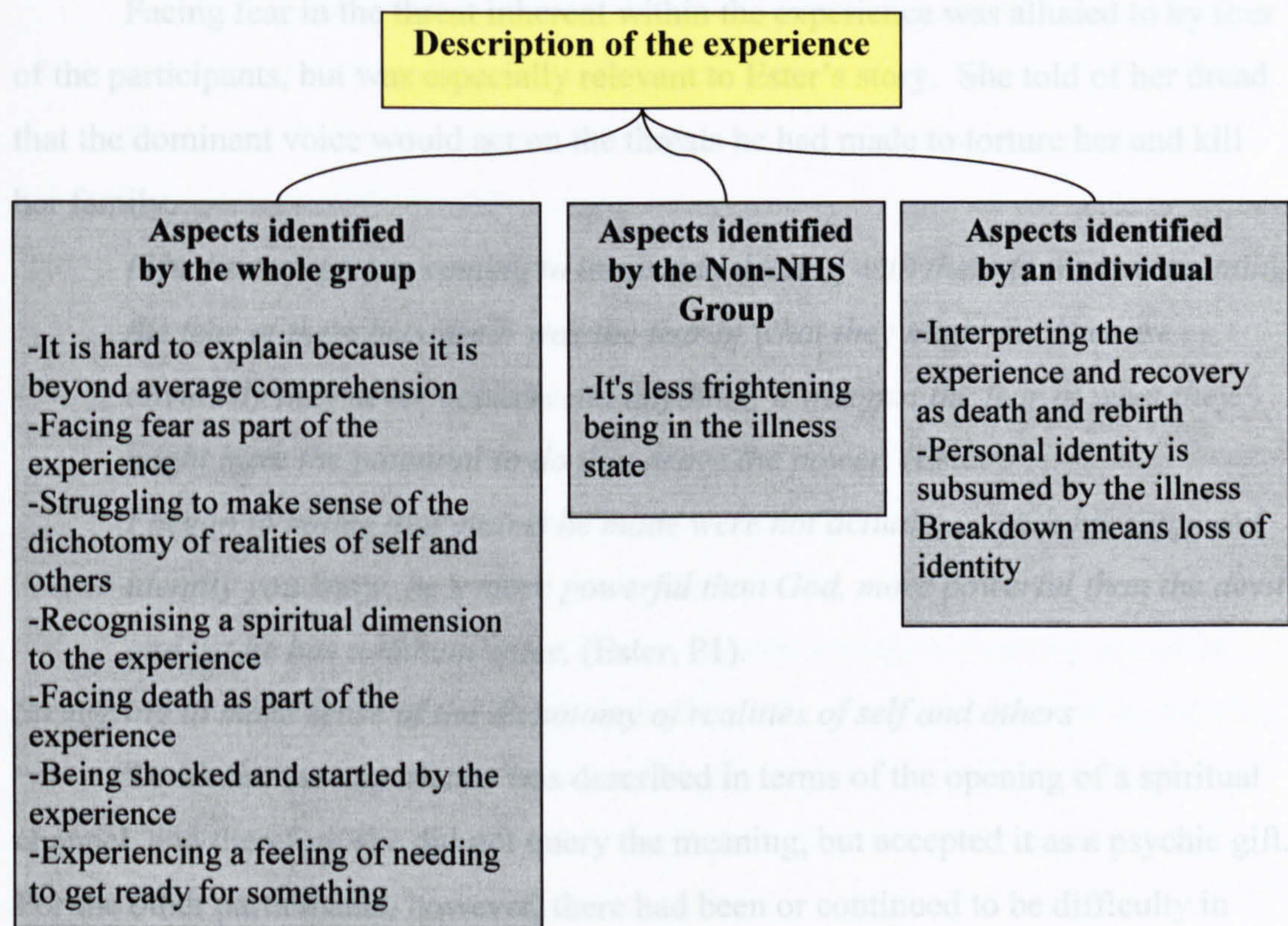
Group analysis

The following section on Group Analysis has been structured according to whether the theme was common throughout the whole group, whether it was specific to either the Non-NHS Group or the NHS Group, or whether an individual participant identified themes not explicitly spoken about by others. Each theme has been

initially represented diagrammatically, and then the identified sub-themes have been discussed.

Descriptions of the experience of psychosis

Figure 1: Diagrammatic representation of descriptions of the experience of psychosis



Aspects identified by the whole group

It is hard to explain because it is beyond average comprehension

Ester, Matthew, Lilly and Linda all suggested that no words exist to explain the overwhelming nature and magnitude of the experience and, because it was outside the experience of the listener, shared ground did not exist which would enable communication that would give complete understanding.

I could sit here for a day and not really do justice to quite how overwhelming that voice actually was, (Ester, P1).

It's hard to explain (.) I find it hard to explain,. (Matthew, P3).

Recognising a spiritual dimension to the experience

Facing fear as part of the experience

Eight of the nine participants spoke of feelings of fear, terror and trauma resulting from the experience.

Yeah, but that was like the beginning, it were funny then, and then it became sort of progressively worse up until being absolutely terrified, and it weren't funny then, (Jon, P8).

Facing fear in the threat inherent within the experience was alluded to by four of the participants, but was especially relevant to Ester's story. She told of her dread that the dominant voice would act on the threats he had made to torture her and kill her family.

[The first stage] in coming to terms and dealing with them {} was overcoming the fear of them because it was the fear of what they might do, because obviously they never actually did anything, it was just the fear of what they might have the potential to do that drove the power, (Ester P1).

I began to notice that claims he made were not actually ... with his supposed identity you know, he's more powerful than God, more powerful than the devil and yet he has a human voice, (Ester, P1).

Struggling to make sense of the dichotomy of realities of self and others

To Linda, the experience was described in terms of the opening of a spiritual channel, and therefore she did not query the meaning, but accepted it as a psychic gift. For the other participants, however, there had been or continued to be difficulty in making sense of the experience. This remained so for the Non-NHS Group.

When I have been ill I've actually thought I was alright. And it's been somebody saying to me, 'No', you know, 'You're not well'. I'm really confused about that, (Jon, P8).

OK so where are they coming from? They're coming from somewhere and the fear I feel is real so how does this make sense? (Ester P1).

It's questions that answers I'm trying to give just don't make sense, (Lilly, P5).

I'm really lost at this point, you know, that's kind of why I'm here, to try and make sense of what's happened to me, (Jon, P8).

Not a lot made sense to me at that time, (Stefan, P9).

Recognising a spiritual dimension to the experience

Ester recognised a spiritual element to her experience, with the omnipotent voice being demonic in nature.

I'd always assumed that he was a demon and what I came to realise was that he was a personal demon, (Ester, P1).

Jon found relief at times in the good spiritual dimension,

In the end it was just like, it were like I were opening the door of heaven and just these spirits coming through and I were just... it were like a machine gun and it were... oh thank god for that, (Jon, P8).

Linda and Stefan also referred to a spiritual dimension but saw themselves as being the recipients of divine gifts.

I do know I'm gifted in some way, but then, what sort of way? do people think I've got a mental health problem as well? (Stefan, P9).

Facing death as part of the experience

Three of the nine participants, (Ivan, Matthew and Paul) spoke of times when they had made attempts to take their own lives, since death was a preferable alternative to living with their experiences of psychosis.

I tried to take my life (...). I went into a toilet and started cutting my wrist with a fork coz I'd no other sharp instruments. I only just handed my bayonet into NCO, you know, non commissioned officer, and if I'd have had that bayonet that would have been it, a different story altogether, yeah (Stefan, P9).

I'd probably go and kill myself if it weren't for the kids (Ivan, P3).

I went to prison and I was slashing up, I was telling everyone I was going to kill myself. I said to the Police, you should have shot me dead (Patrick, P2).

All of the participants made reference to times when they had felt that their integrity was under threat, and Ivan, Jon and Ester had lived with the belief that they would die because of the experiences.

I thought that I could be killed or could be injured and all sorts of stuff, (Ivan, P3).

Being shocked and startled by the experience

When talking about this aspect of the experience, all participants in the NHS Group used words such as 'peculiar' and 'weird' to describe it, '*it was peculiar, not what I'd expected, weird, strange, very peculiar*' (Linda, p6). Their language suggested that they were still on a journey of understanding their experiences. The

Non-NHS Group used 'startling', 'shocking' and 'unbelievable'. The Non-NHS Group used stronger terminology to describe the strangeness of the experience.

Experiencing a feeling of needing to get ready for something

Four participants including the three in the Non-NHS Group spoke of preparation; a sense of expectancy that something was going to happen, but they did not quite know what.

I was wearing everything all the time and getting ready, I just wanted to... just had in my head this idea that I had to get ready for something, (Ivan, P4).

In my experience it's like if you're swimming in the ocean, um and you can't get back. So I just realise that it's like you'll drown, it's weird. And it's a premonition of things, (Luke, P7).

Aspects identified by individuals

Interpreting the experience and recovery as death and rebirth

Ester used the metaphor of death and rebirth to explain her experience of recovery. She said that rather than it having been a breakdown, she now saw it as a break-through.

There was this sense of my family mourning for me as though I actually had died because day by day the person they had known was slipping away and there was nothing anyone seemed to be able to do to bring her back, (Ester, P1).

I went back to, you know, the city where it happened, you know, somebody did die there but somebody else was saved almost, (Ester, P1).

Breakdown means loss of identity

Ester had struggled with being simply the recipient of her psychiatric treatment, rather than being allowed to be proactive in it.

I've talked quite a bit about identity and I think the thing for me what really caused my identity to be in real danger in real crisis and really in danger of destruction, was not my madness but it was psychiatry's refusal to sort of credit me with the wisdom and expertise about my own life, (Ester, P1).

Personal identity is subsumed by the illness

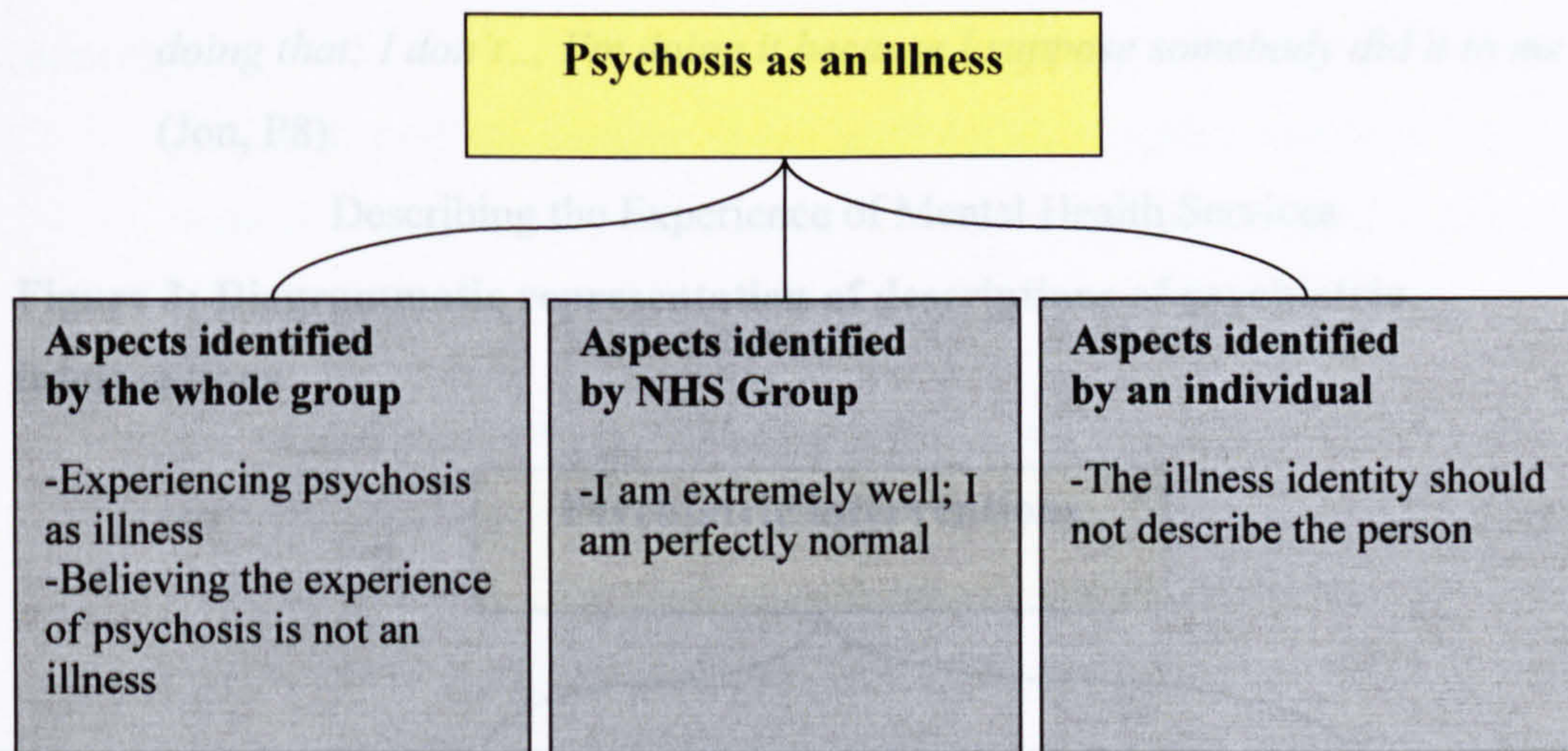
Ester explained that the most debilitating aspect of her experience had been losing her personal identity, and being consumed by an illness identity.

It is your mind that's the component of your humanity, it's who you are. Um, and for that to be compromised is profoundly terrifying and the horror of it is extreme, (Ester, P1).

I found that for the first time I didn't feel like this two legged diagnostic category, (Ester, P1).

Viewing the Experience from an Illness Perspective

Figure 2: Diagrammatic representation of views of psychosis as an illness



Aspects identified by the whole group

Experiencing psychosis as illness

Of the Non-NHS Group, two participants said they had been unwell; of the NHS Group, Matthew said he had been poorly, Lilly that she had stayed unwell for about 10 years, and Luke that he had lost his independence because he was so unwell.

It's just the word 'schizophrenia', it seems an ugly word, and it's all like, it's like cancer I don't want it to happen, (Luke, P7).

Aspects identified by the NHS Group

Believing the experience of psychosis is not an illness

Jon, Linda and Stefan all believed that they were not ill, but that they were alright, gifted, or powerful.

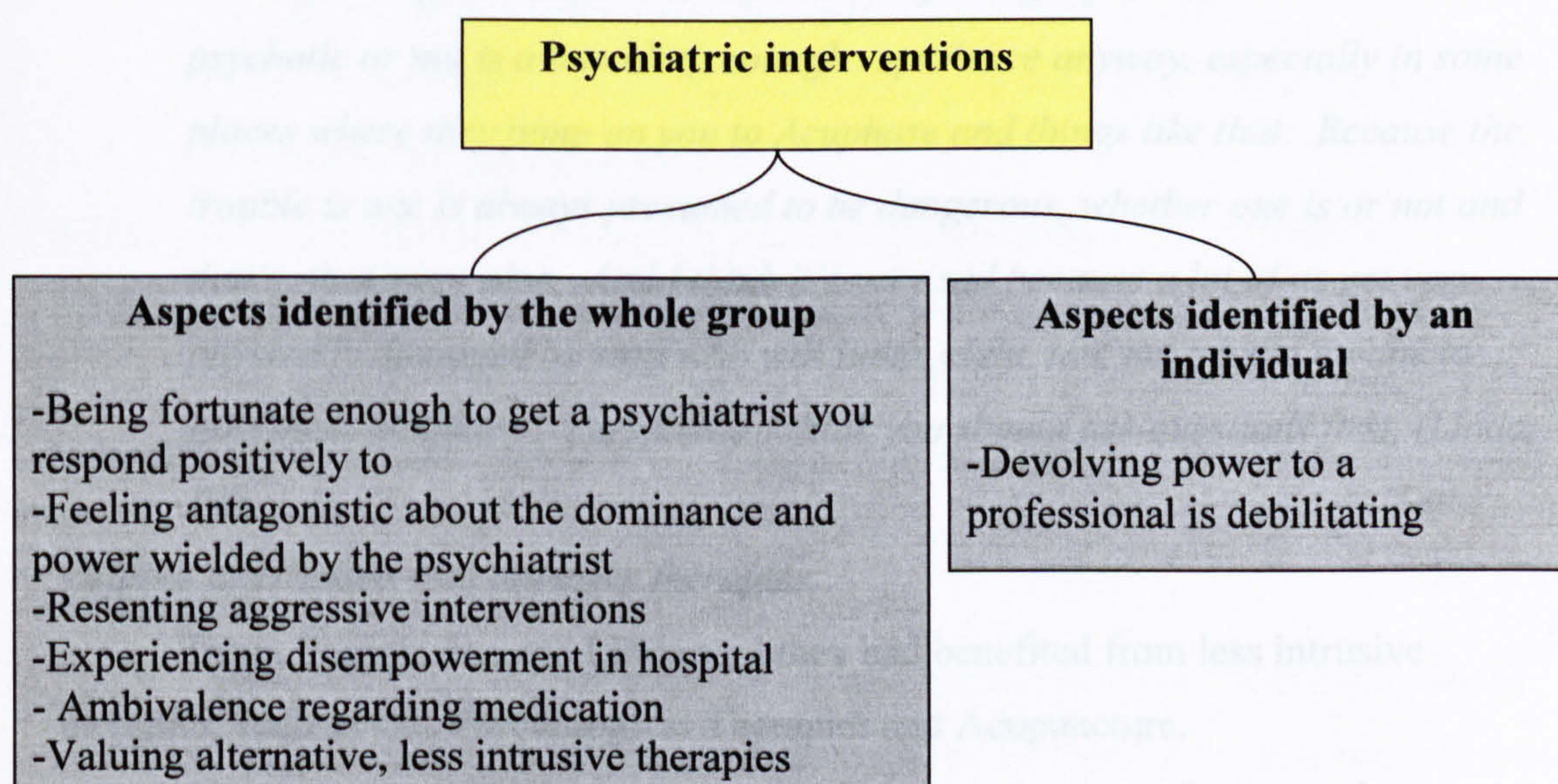
[They] were like me, completely normal (Linda, P6).

Jon was unsure whether he viewed psychosis as an illness.

What if they haven't really got psychosis? What if it's just everybody else that is somehow telling everybody that there's something wrong with them, and looking after them? That's the whole crux of it really, you know. How come you need to be looked after and how much are they sure? I really don't know; I don't know. I'm saying that we should look after people, some people, because they need looking after in my opinion. I really don't understand, but, you know, you only have to watch the Jeremy Kyle show or summat on television and you see people and you think, 'Bloody hell, you can't live like that!' You just have to try and look after a few people, that's all. I mean I'm doing that; I don't... I'm doing it because I suppose somebody did it to me (Jon, P8).

Describing the Experience of Mental Health Services

Figure 3: Diagrammatic representation of descriptions of psychiatric interventions



Being fortunate enough to get a psychiatrist you respond positively to

Ester suggested that she had felt debilitated and violated by her experience of the psychiatric system, where she had been encouraged to take an aggressive stance against her own mind. She went on to say that, by chance, she had been referred to a psychiatrist who she described as 'sensitive and creative'. Patrick had felt that his experiences had been trivialised by his psychiatrist, and Matthew had found his psychiatrist to be extremely empathic, supportive and 'brilliant'.

There was a range again in the responses from the NHS Group. Luke told me he had no other choice but to trust his psychiatrist, which reflected his passivity and sense of hopelessness, whereas Linda equated psychiatry with medication and called it 'a big scam'.

The feeling of antagonism about the dominance and power wielded by the psychiatrist was not confined to one group. Ester, Patrick, Linda and Stefan all made reference to it.

Resenting aggressive interventions

Part of having experienced the treatment as aggressive was the lack of consultation.

They didn't tell me nothing. I was so ill I couldn't give permission either. And none of my family were there so I don't know who give permission to do it, (Stefan, P9).

It's interesting I think just the experience of being a patient, whether one's psychotic or not is a humbling enough experience anyway, especially in some places where they jump on you to Acuphase and things like that. Because the trouble is one is always presumed to be dangerous, whether one is or not and that's, that's not nice. And I think it's very sad because a lot of us get very physically damaged by staff who will jump, eight, ten, ten people on one to give them Acuphase. Personally I think you should ask questions first, (Linda, P6).

Valuing alternative, less intrusive therapies

Ester, Patrick, Jon and Linda said they had benefited from less intrusive therapies, such as OT, Psychological Therapies and Acupuncture.

No one was using acupuncture or herbalism or homeopathy in psychosis, which had all been judged by {} when they had tried it, to work (Linda, P6)

Experiencing disempowerment in hospital

Both groups referred to the boredom in hospital, due to the lack of meaningful activity.

But when you're in hospital nobody really (.) you know, we're not really talking, just sat in the smoke room having a fag and, you know, 'do you want a cup of tea?' and stuff like that. That's basically for me that's what hospital is like, (Jon, P8).

Because when I were upstairs on {} Ward at [Hospital] nobody did owt; they just sat round all day, (Patrick, P2).

So I went there and I thought, I'm not drinking tea all day, you know, (.) so the only time I go to the day centres now is for meetings and interviews for staff. I don't go round drinking tea any more (laughs), (Patrick, P2).

Six of the nine participants referred to the hospital experience as being disabling and disempowering.

More debilitating than the experience itself is the psychiatric disempowerment which occurs when a person is forced to devolve power to a professional, (Ester, P1).

Somebody looking after you makes you worse, (Jon, P8).

Ambivalence regarding medication

Matthew, Patrick, Luke and Jon all identified medication as one, (if not the main) factor in helping them to feel better.

The voices stopped when I was on medication, (Patrick, P2).

It's the medication. I've started sleeping again, um started eating again, um just normal life again, (Ivan, P4).

Despite this, they identified a range of side-effects which they found difficult, including, diabetes, heart problems, weight gain, reflux and gastric problems.

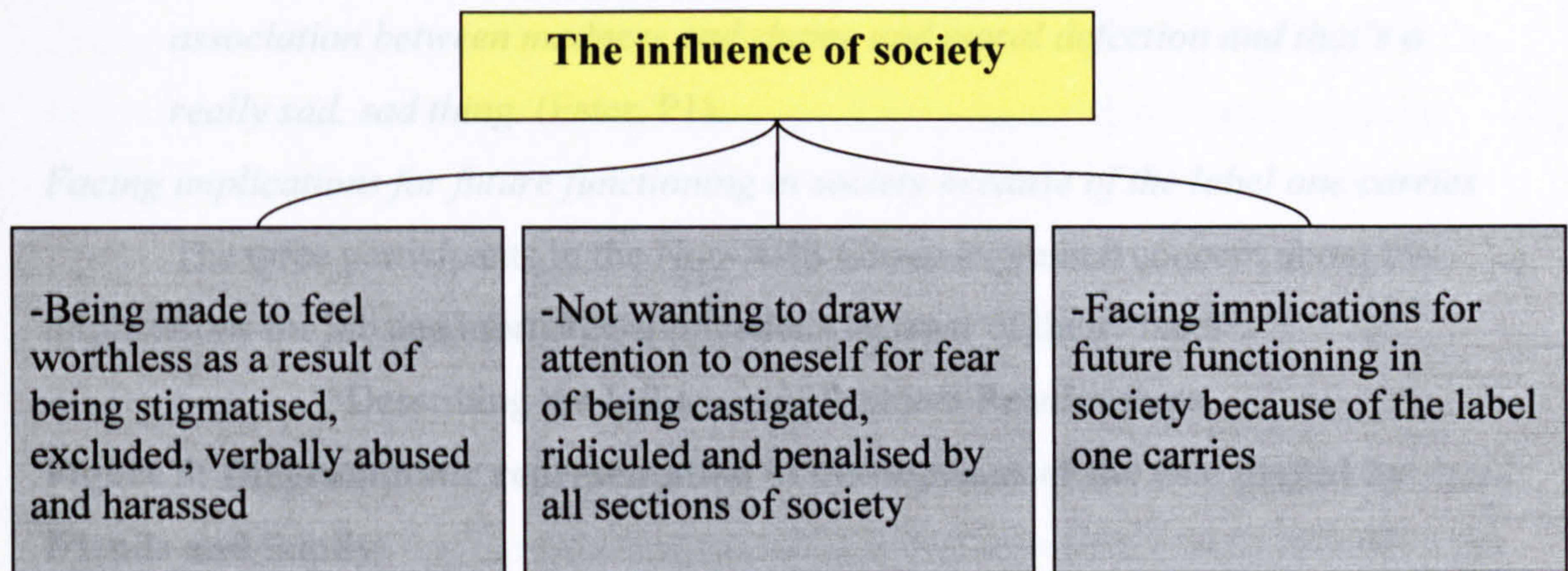
Ester and Linda did not consider medication to have been helpful. Ester believed that it had prevented her from having the clarity of thought she needed to aid her own recovery, whilst Linda believed that medication had itself caused the psychosis.

I think probably the drugs caused the psychotic experience I had at the time because I wasn't having the psychotic experiences until after they injected me. And looking at the long list of drugs I had, um about ten drugs there, then whipped up into a cocktail and bunged in my bum, (Linda, P6).

I needed to sort of have my faculties to do what I needed in words and I couldn't do that on these cripplingly high doses of meds, (Ester, P1).

If the medication just makes people hear more voices, and we are actually hearing them telling us to kill ourselves, then that doesn't help. And if all the psychiatrists can do is put the dose up then that's not going to help, (Linda, P6).

The Experience of Living with Psychosis within Cultural Expectations

Figure 4: Diagrammatic representation of descriptions of the influence of society

Being made to feel worthless as a result of being stigmatised, excluded, verbally abused and harassed

Ester spoke of taunts she had suffered; Patrick spoke of having been victimised; Matthew spoke of having been shouted at; Ivan spoke of having had problems with his neighbours, Linda spoke of people having vacated the bus to avoid her; Jon spoke of times when he had felt marginalised.

Interviewer - *Can you tell me about any of those frightening times?*

Jon - *And just like when I've been like a social outcast and feeling like (.) just feeling like a pestilence, like I were just spreading the sickness and that (.) because I couldn't stand being around people because it were just overwhelming me all the time. But I needed, you know, I were miles away from home and like needed to get home and I had to hitchhike home. And just being awful really and people whispering and saying, 'oh he's awful', that's sort of... that's what hurts.*

Interviewer - *So what other hurtful things have people said or done?*

Jon - *Just little things like just undermining me and sort of letting me... letting me... not letting me sort of into their world. That sounds bad doesn't it? (Jon, P8).*

All participants talked of not wanting to draw attention to themselves, for fear of being castigated, ridiculed, and penalised by all sections of society.

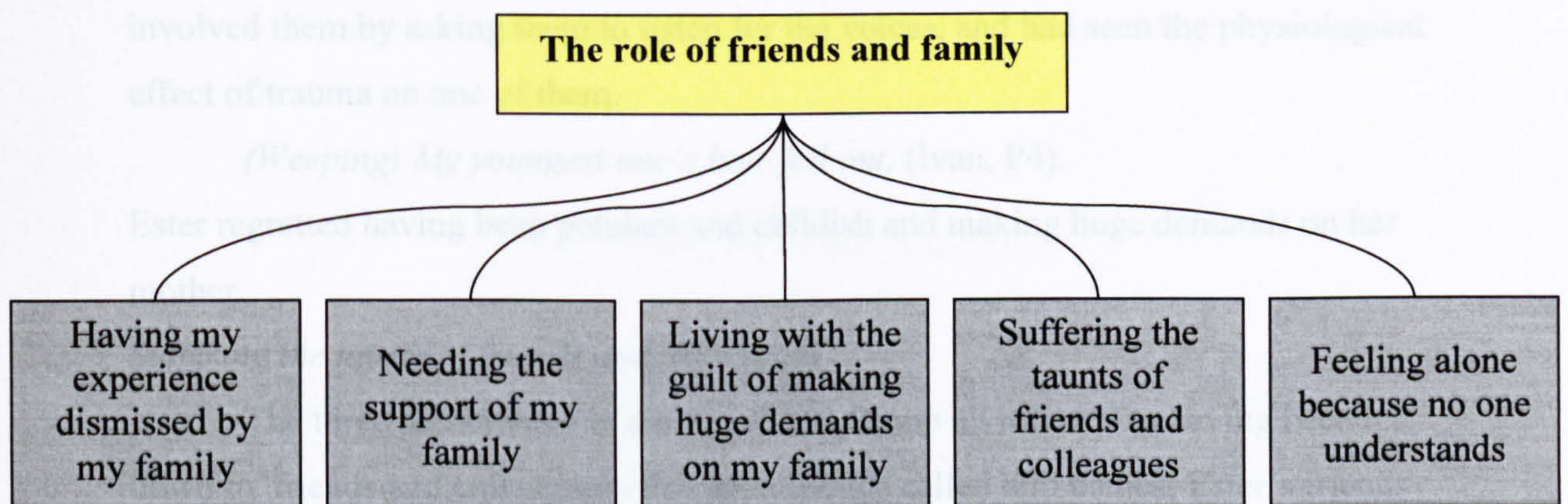
You know, these are patients, they deserve kindness and compassion rather than censure and confinement, but it does blame you because it's blames your mind, it blames your brain, you know, blames you. Um, there is this association between madness and shame and moral defection and that's a really sad, sad thing. (Ester, P1).

Facing implications for future functioning in society because of the label one carries

The three participants in the Non-NHS Group expressed concern about the implications for job and mortgage applications because of their “label”.

Living with the Describing the Influence of Personal Relationships

Figure 5: Diagrammatic representation of descriptions of the role played by friends and family



Having my experience dismissed by my family

There were no differences between the two groups for this sub-theme. Four of the six participants in the NHS Group spoke of their difficulty in communicating the reality of their experience and their subsequent needs to their families.

Matthew - *I were going in care because my mam couldn't cope with me, with hearing voices and that.*

Interviewer - *What did she say to you about that at the time?*

Matthew - *She said I weren't poorly. I said, 'I know I am'. I said, 'Take me to see the doctor'; she said, 'No', (Matthew, P3).*

They just told me, they just told me that it wasn't happening and not to be so stupid, (Jon, P8).

I always knew but my mum wouldn't let me go to hospital, (Lilly, P5).

Needing the support of family (1) *I could've had more support, (1) And tell me what*

Ester said she seeks reassurance from her mother, and wants her to be proud of her. Ivan said that his stable family keeps him going. Jon said that since his discharge he has been attempting to emulate his father's life skills. Luke said that the love of his family has helped him get through. Stefan regretted not having had the support of his family.

It would have been a great help if my family had been there for me, but they never were, not once, never in all those years, 20-odd years, (Stefan, P9).

Living with the guilt of having made huge demands on my family (1) *It's just, it's just*

Two of the three participants in the Non-NHS Group regretted the impact that their experience had had on their families. Ivan talked about being plagued with guilt about the impact his experience of psychosis had on his children, because he had involved them by asking them to listen for the voices, and had seen the physiological effect of trauma on one of them.

(Weeping) My youngest one's hair fell out, (Ivan, P4).

Ester regretted having been petulant and childish and making huge demands on her mother.

Suffering the taunts of friends and colleagues

The three participants in the Non-NHS Group all referred to having been let down by friends and colleagues. Patrick's friends called him names; Ester's friends goaded her, and Ivan's colleagues made judgements and derogatory comments about him.

Out of the NHS Group, Matthew's friends humiliated him.

When I lived with my mate like when I started hearing voices they used to shout, 'schizophrenic's here'. And I didn't like that. They used to call me, 'mental subnormal bastard', (Matthew, P3).

Jon spoke of having felt let down by his friends who thought his experiences were funny, and who used to laugh at him.

Feeling alone because no-one understands

All of the three Non-NHS Group participants had felt alone. Ester felt lost, aimless, directionless and ignored; Ivan felt brushed off and on his own, but Patrick wanted to be left alone and actually shut himself off because he felt people were persecuting him.

I didn't have nobody. {} I could've had more support, {}. And tell me what groups are going on or something like that, you know. How I could get involved with services. They didn't tell me nowt. I were on my own, stuck, (Patrick, P2).

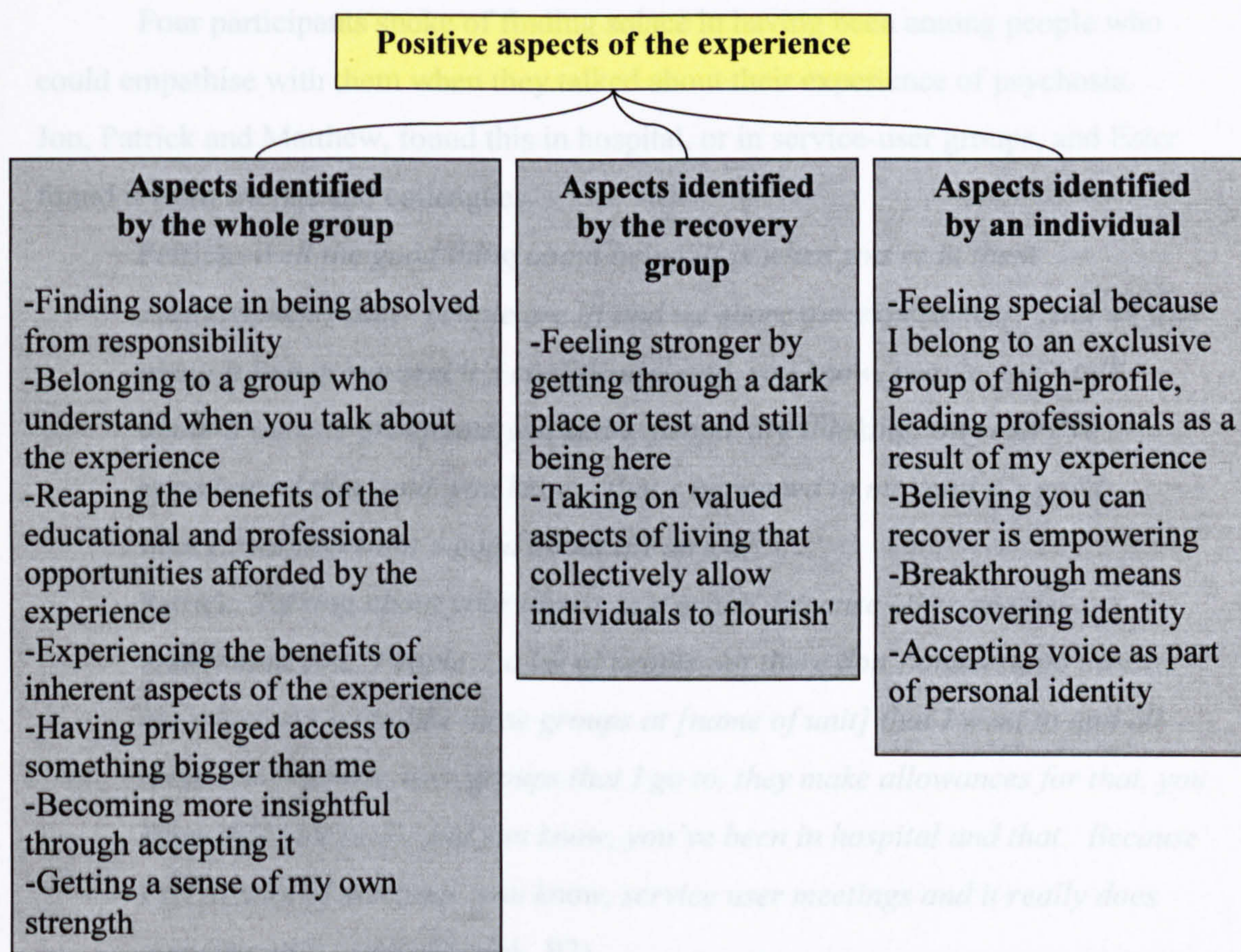
Of the NHS Group, two talked of feeling alone when others did not understand.

Well if you're stuck in a psychiatric system and you actually believe you're a spiritual medium and you've got someone else who believes it too, then it's you're not fighting, battling on your own, you know, (Linda, P6).

I don't think anybody can understand another person really; it's just, it's just impossible, (Luke, P7).

Experiencing Positive Aspects of Psychosis

Figure 6: Diagrammatic representation of positive aspects of the experience of psychosis



Aspects identified by the whole group

Finding solace in being absolved from responsibility

Two of the participants explained that the disempowerment of the experience of psychosis can be seductive in that it relieves responsibility. However, Ester suggested that once seduced by the experience, the disempowerment can be more distressing than the psychosis itself. Jon said that he believed one of the advantages of the experience for some people might be that it provides an escape from the intolerable reality of their lives. They suggested that since power equals responsibility, disempowerment is preferable

At one point I remember being on the Cross with Jesus and I remember having like the power of God but it was no good because there was too much responsibility and I couldn't even remove it. I couldn't even... because of the responsibility. And I came to the conclusion it was so much better to be an innocent puppet than, than a kind of God, (Jon, P8).

Belonging to a group who understand when you talk about the experience

Four participants spoke of finding solace in having been among people who could empathise with them when they talked about their experience of psychosis. Jon, Patrick and Matthew, found this in hospital, or in service-user groups, and Ester found it from friends and colleagues.

Patrick: Well the good thing about being ill is when you're in them establishments other people are ill and we share our experiences. And we talk about it in a group and it's confidential and, you know, people don't talk about it outside group and you know, people are thinking, 'oh yeah I've experienced that' and, you know, 'that's happened to me' and it's good.

Interviewer: So what's good about it Patrick?

Patrick: Talking about your illness in a group, because other people understand you. People... a lot of people out there don't understand illness, but when you go to like these groups at [name of unit] that I went to and all these other service user groups that I go to, they make allowances for that, you know that you're ill, and you know, you've been in hospital and that. Because I go to a lot of meetings, you know, service user meetings and it really does give you a lift, yeah, (Patrick, P2)

Linda said she wishes more people could understand.

A lot of people who have psychotic episodes would like people who don't have them to have them and want a tablet to give people to make them hear voices so that they know what it's like, (Linda, P6).

Matthew said he would not wish the experience on anybody.

I don't wish it on anybody. It's frightening, you get really poorly, you don't know what you're doing, (Matthew, P3).

Reaping the benefits of the educational and professional opportunities afforded by the experience

Patrick spoke of the educational opportunities which had been afforded him during his years as an inpatient, whilst Ester said she has used her experience to further herself professionally and academically.

Experiencing the benefits of inherent aspects of the experience

Three of the participants identified heightened sensations and creative abilities as a result of the experience.

And colours and stuff are brighter, you've got loads of energy, (Ivan, P4).

Ivan - I don't think it's been any real detriment to like, to creativity really, because... in fact it might make it more... maybe it is a benefit, alert to your own capabilities. Might be quite inspirational {} if you're poorly it's sort of like you denounce everything and produce things that you couldn't otherwise {} I like painting and poetry and things like that.

Interviewer - *And you said that schizophrenia can make you more sort of (.)*

Ivan - *More prone to creation (Luke, P7).*

Interviewer - *Are there any things that you can do now that you couldn't do before?*

Stefan - *Artistically yeah, I can act, I can dance, I can sing, I can choreograph; I can do a lot of things, (Stefan, P9).*

Six participants found some aspects of the experience positive. Ester found comradeship; Matthew found support; Linda found guidance, and Jon found relief; Luke found inspiration; and Stefan found empowerment.

The voice I heard was quite a comforting and compassionate {}

People ask me a lot, 'If you could get rid of your voices would you?' and I actually wouldn't you know. Erm well there's possibly some aspects of them I would get rid of; I mean particularly this dominant voice is part of me

almost. You know we've been through a lot together; we've shared a lot of history, (Ester, P1).

Matthew - There are [some good things about schizophrenia] (laughs). If you hear voices they make you feel good.

Interviewer - Tell me about that.

Matthew - They'll say (.) they talk to you good {} and you talk away back to them.

Interviewer - Oh, so you said they talk to you good, how do they talk to you good?

Matthew - Like say nice things to you.

Interviewer – Yeah (.) like what?

Matthew – (.) How are you going on...

Interviewer - Asking you how you're getting on?

Matthew - Yeah.

Interviewer - What other nice things do they say?

Matthew – Um (.) what else? (.) Um, (.) well we hope you soon get better, (Matthew, P3).

Having privileged access to something bigger than me

Ester, Linda and Stefan all spoke of having privileged access to something bigger than themselves. For Ester it was being part of a group of forward thinking professionals.

It's brought out the idealist in me almost, I feel like I'm part of something that's bigger than myself almost, you know. Um, because mental health in some... you know, it is the next civil rights movement, (Ester, P1).

For Linda it was the supernatural and spiritual nature of her experiences which were inspiring. For Stefan, it was the power that resulted from being gifted with his experiences.

Becoming more insightful through accepting it

Two participants in the Non-NHS Group spoke of having become more self aware as a result of accepting their experiences.

I've seen myself really unwell and I've come through it and I look back on it and I think, you know, it were good that I went through that because it's brought me out better.; a better, more confident person, more aware, (Patrick, P2).

But just being comfortable with it really, do you know what I mean, just accepting it and, and not being in denial that that's going to happen, that I'm going to have those sort of feelings. Um, maybe emotionally I'm a bit more in tune with myself now, (Ester, P1).

Getting a sense of my own strength

Three participants in the NHS Group talked about an enhanced sense of personal strength resulting from the experience. Patrick suggested that the experience had left him with a greater sense of his own strength, *'you learn don't you. It's made me stronger'* and Ester said she could now *'thrive rather than survive'*.

Aspects identified by the Non-NHS Group

Feeling stronger by getting through a dark place or test and still being here

The Non-NHS Group recognised that they were stronger after having come through the experience of psychosis, because they had overcome challenging experiences.

I've gone to some of the darkest places that the human mind can go and yet survived that, (Ester, P1).

I'm still here at the end of the day... well they didn't downgrade me, (Matthew, P4).

I didn't like the world, you know, it was a dark place at that time and I've come through it. That's what's made it better, (Patrick, P2).

None of the participants in the NHS Group made reference to this.

Taking on 'valued aspects of living that collectively allow individuals to flourish'

Ester and Patrick identified positive aspects of daily life that contribute to a sense of well being.

You know just things like good food, a good diet you know physical health getting out more having a more stable routine instead of sleeping all day you know just sort of little things that would all cumulatively all start to build up, (Ester, P1).

I used to go to work there, they used to have workshops. I used to go education, I used to go to gym and it set me up to build a life, (Patrick, P2).

Sometimes I go out with my mate. I like going to work, I like going to the gym, I like going to meetings, I like being busy, I like going home, I like going to the football, (Patrick, P2).

Aspects identified by an individual

Feeling special because I belong to an exclusive group of high-profile, leading professionals as a result of my experience

Ester talked about her feeling that she is unique and a novelty since her experience is not common. She believed this had given her a high profile professionally. She suggested that having been an ordinary person who had led an extraordinary life now marked her out as special.

I think that sort of sense of direction really and being part of something that's really important is again really quite special, (Ester, P1).

I still hear voices and I would describe myself as a voice hearer but more than that I would say I'm proud to be a voice hearer because I've reclaimed my experience – I think it's for me there's a sense of real injustice really that more people can't be in this position (Ester, P1)

Believing you can recover is empowering

Ester spoke of the first time she had experienced a professional using empowering language to encourage her to consider the possibility of recovery.

[The psychiatrist] did take a genuine interest in me as a person and again there was something very empowering about that and he broke down that kind of rigid dichotomy between us and them {} the language he used was very empowering, (Ester, P1).

Breakthrough means rediscovering identity

Ester talked about recovery being a time when a person can rediscover his/her personal identity, having had it subsumed by the illness identity.

A kind of holistic assessment of me as a person rather than a person with a mental illness, (Ester, P1).

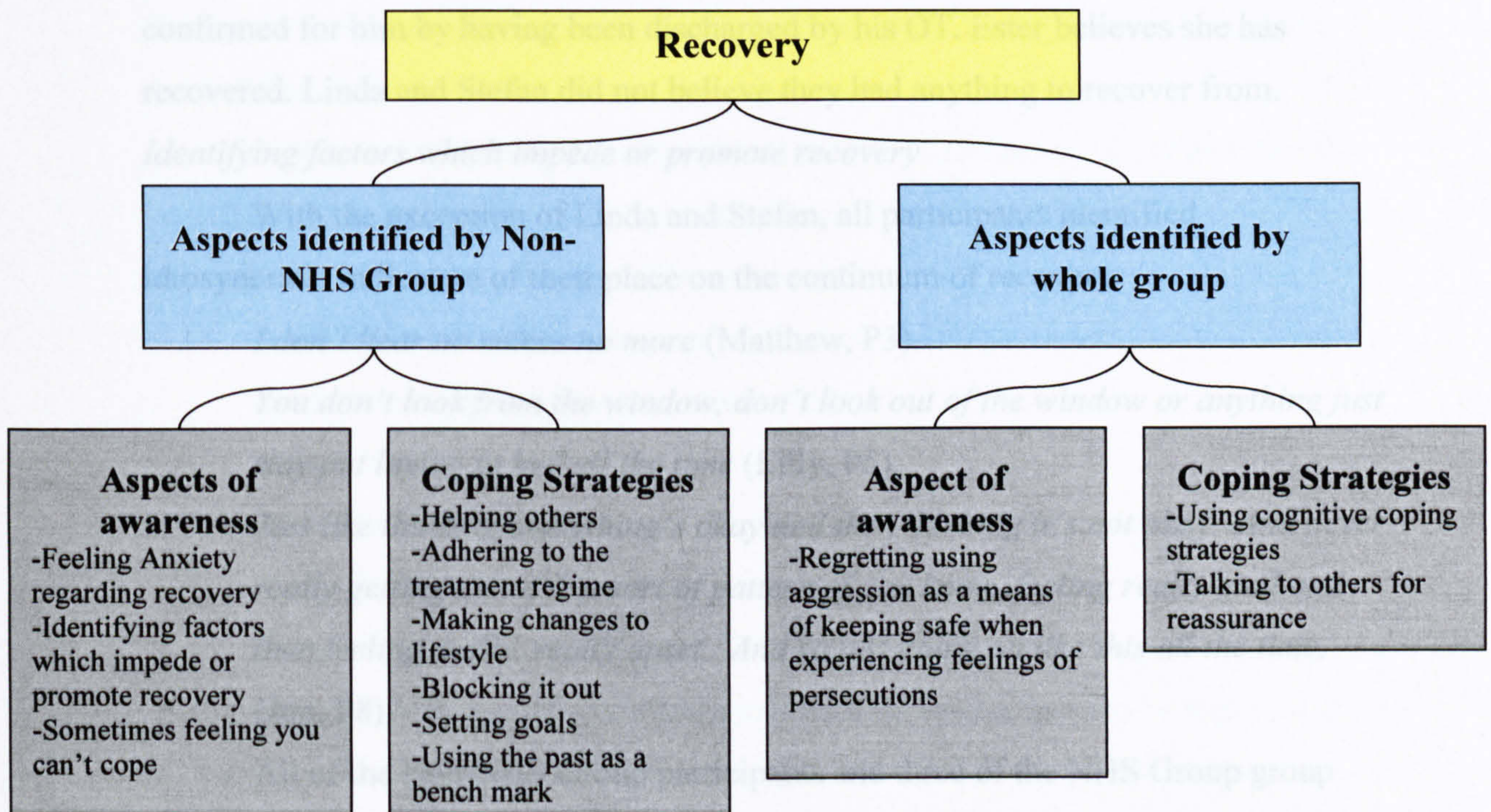
Accepting voice as part of personal identity

Ester spoke of the mind being a component of one's humanity, 'it is who you are', and of being in danger of losing her identity because psychiatry, she felt, refused to 'credit me with the wisdom and expertise about my own life'. She felt able to integrate the identity of the voice with her personal identity in order to make positive changes.

The Experience of Recovery

Linda and Stefan did not talk in terms of recovery because they did not see themselves as having something to recover from. For this reason they contributed little to this section.

Figure 7: Diagrammatic representation of accounts of the experience of recovery



Aspects identified by the Non-NHS Group

Aspects of awareness

Feeling Anxiety regarding recovery

Whilst all of the Non-NHS Group speak of moving on from their experiences of psychosis, two of the continuing treatment needs participants did not anticipate recovery.

I doubt I will ever recover completely. {} I just hope that some day I'll get better. {} I don't think I ever will be completely free of what I'm suffering from at the moment {} I don't think there's really any way you can derail the course, (Luke, P7)

I've got it permanently and I've had it since a child (Lilly, P5).

Ivan, Jon and Patrick, all spoke of fearing the possibility of relapse.

I don't want to relapse again. It's awful relapse, that's traumatic, (Patrick, P2).

I don't think I'd tell anybody if it happened again, (Ivan, P4).

Luke and Lilly did not believe they would recover. Jon said he was only just coming to terms with it and was at the beginning of his recovery. Ivan said he was still plagued by the impact of his experience but felt he was recovering since he was functioning better than he had been. Patrick sees himself as 'well' and this has been confirmed for him by having been discharged by his OT. Ester believes she has recovered. Linda and Stefan did not believe they had anything to recover from.

Identifying factors which impede or promote recovery

With the exception of Linda and Stefan, all participants identified idiosyncratic indicators of their place on the continuum of recovery.

I don't hear no voices no more (Matthew, P3).

You don't look from the window, don't look out of the window or anything just stay put laying in bed all the time (Lilly, P5).

Just like thinking everything's okay and then thinking it's not okay. And never really getting out of this sort of pattern of you know, feeling really glad and then feeling really, really upset. And so just going on like this all the time, (Jon, P8).

All of the Non-NHS Group participants and three of the NHS Group group were able to identify strengths of character that have helped them overcome difficulties.

I think there is probably a sense of luck in some ways almost that I was able to get to the point I am now. Um, but also, you know, credit to myself as well for those qualities that did pull me through. (Ester, P1).

Interviewer - *I was just asking you about what it is about you that's got you through some of those really difficult times?*

Patrick - *Just positive thinking.*

Interviewer *So being able to think positively.*

Patrick - *And rationally. (Patrick, P2).*

Warm and friendly, trustworthy, pretty straight down the line, um, what you see is what you get, warts and all, (Ivan, P4).

Luke - *I don't know, I'm quite gregarious and sociable, maybe that's helped. And sort of like I rely on my introversion too, because I am, it's a dichotomy in a way, I am different to a lot of people {}*

Interviewer - *What might other people say your strengths are as a person?*

Luke - *Well I'm loyal, faithful, sociable, friendly, um I'm passionate about lots of different things. I'm quite a sweet person so... Those are sort of like, you know, like different attributes, (Luke, P7)*

Four participants said that being sociable and friendly helped get them through the more difficult times.

Self-esteem was only mentioned by the Non-NHS Group. Ester and Patrick reported having increased self-esteem as a result of having survived their experiences of psychosis, unlike Ivan whose self-esteem was lower.

Ivan – (Weeping) *I didn't expect to have to evolve from this.*

Interviewer - *Is that how you think of it? (.)*

Ivan - (Nodding).

Interviewer - *So tell me about the things you feel you've lost as a result of it?*

Ivan - *Self esteem. (Ivan, P4)*

I can talk for England if I want [laughs]. But that's what keeps me going, you know, with doing meetings and feedback and you realise you're impor-... I realise that I'm important now and tha-, that builds me up my confidence because I'm thinking, 'Oh I am important because they need me to go to this do, or do this work or these newsletters', (Patrick, P2).

Sometimes feeling you can't cope

Participants from both groups continue to feel, at times, like they cannot cope. *There have been times were I've thought I just couldn't cope with it any more (Ester, P1).*

I don't always feel like I cope with it (Ivan, P4).

Well the symptoms I have really are voices and depression; sometimes they're difficult to cope with, (Luke, P7).

Coping Strategies

Helping others

All three of the recovery participants gain from helping others. Ester tries to give insight which will help change public perceptions of mental health. Patrick reports gaining satisfaction from 'helping others worse off than myself'. He also

regularly interviews and attends meetings. Ivan devotes his life to helping others with mental health problems. Of the six continuing treatment needs participants, only Matthew spoke of his hopes for helping others in the future, through voluntary work to benefit his local community once he is re-housed.

Adhering to the treatment regime

Patrick, Luke, Ivan, Matthew and Jon said they adhere to their medication programmes.

I'm on quite a lot of medication but it works for me (Patrick).

Interviewer - *How have you got to this stage of getting so far along and...?*

Matthew - *My tablets.*

Interviewer - *Right. So tell me a bit more about that.*

Matthew - *I like them because it's helped me a lot my Clozaril (Matthew, P3).*

I probably would have stopped tablets but they've only given me a driving licence for a year so if I stopped taking my tablets they'd just take my driving licence off me. (Ivan, P4).

Making changes to lifestyle

Three participants spoke of the restraints they have now put in place in order to reduce the likelihood of suffering the negative consequences associated with their experiences of psychosis. Patrick said he takes measures to avoid confrontation with the people around him since he knows that the consequences are profound. Ivan said he no longer uses steroids because of their impact on his experience. All three participants who had used drugs (Jon being the third), said they no longer continued to do so.

Every participant in the Non-NHS Group made reference to the benefits of keeping active and busy. Patrick threw himself in to work, meetings and interviews as a means of promoting his recovery. He said that when he had received the letter about this interview, he had felt privileged that the university considered his views to be important. Ester busied herself with study, teaching and presentations which she felt confirmed her positive identity. Ivan concentrated on returning to work and doing the best he could for the people who relied on him.

Blocking it out

Two of the participants from the Non-NHS Group reported actively working to block out their experience of psychosis. Patrick said he blocks out his memory of the experience and puts emotional barriers up in order to keep himself safe.

Ivan said he switches himself off from his memory of it, and three times said he prefers not to think about it but to distance himself from it.

Using the past as a bench mark

As a means of motivating himself, Ivan reminds himself of the consequences of not taking his medication. Patrick grounds himself in the negative aspects of being in hospital. Ester makes comparisons with the past in order to confirm her recovery. All three participants in the Non-NHS Group reported using the past as a benchmark in order to give themselves perspective on the progress they have made.

Aspects identified by the whole group

Aspects of awareness

Regretting using aggression as a means of keeping safe when experiencing feelings of persecutions

Ester talked about injuring herself but now viewing her scars as a talisman. Patrick spoke of his regret at having used interpersonal violence in response to his feelings of persecution. Matthew spoke of feeling bad that he had seriously assaulted a person in the community, and responded to the voices by hitting out at staff when they were trying to put him in 'canvas' (mechanical restraint). Ivan spoke of residual feelings of shock and dismay at the intensity of violence he had used in response to perceived threats to his personal integrity. Stefan remembered a time when he had harmed himself in response to feelings of hopelessness caused by the experience of psychosis. Five of the nine participants had found themselves regretting having used aggression as the most reasonable way of keeping safe during their experience of psychosis.

When I used to hear voices I used to lash out like, you know. I didn't mean to hurt them[staff], (Matthew, P3).

Coping Strategies

Using cognitive coping strategies

Patrick and Luke both talked about listening to music, watching TV and painting as distraction techniques for helping them to manage the intensity of their experiences.

Talking to others for reassurance

Ester and Jon both spoke of benefiting from seeking and being given reassurance from a parent. Jon was in the process of building up a relationship with his family and friends for whom his trust had been destroyed and so he found solace

in talking to other service users. He felt that he had benefited so much from the interview that he encouraged two more reluctant peers to volunteer to participate in this study.

Conclusion

The themes generated have been explored using quotations from the interviews in order to preserve the nuances for the reader. The following chapter will present the meaning of the themes in relation to existing literature in line with the phenomenological approach.

CHAPTER 4 DISCUSSION

The aim of this study was to explore subjective accounts of positive experiences of psychosis in order to enhance understanding and identify implications for clinical practice in psychosis. This chapter explains how the findings fit with existing literature and psychological theory relating to the study of the experience of psychosis. The discussion will consider whether the themes support and/or extend this knowledge base and, any areas of conflict between relevant literature and the findings of the study will be examined. Critical reflections on the study will follow. Directions for future research and theoretical, clinical and research implications will be considered with discussion of the results, and conclusions will be drawn.

Trustworthiness of the analysis

“Perhaps the most vexing problem facing interpretative psychologists is the question of how to evaluate a particular interpretative account” (Tappan, 2001, p45). Fish (1980) suggests that interpretation relies on constructing rather than finding meaning, based on the researcher’s response to the data. He recommends an ‘interpretative agreement’ among the relevant ‘interpretative community’ as a way of minimising the bias that having one interpreter may bring. Dale, (1999, p.58) suggests that, “...the validity of qualitative research rests on transparent methods and the plausibility of the analysis”. The evaluation of this study in relation to these suggestions for good interpretative practice will be discussed next (Elliott, Fischer & Rennie, 1999).

Transparency

In order to maximise the transparency of the study, it is important for the researcher to be clear in terms of declaring his/her personal orientation towards the research, and in particular what he/she might contribute to the interpretation of the data. This informs the reader about the exact process involved in arriving at the final analysis of the data. I have, in Chapter 2, outlined my personal orientation in terms of my approach to the research area. I have discussed the process of analysing the data and have provided details of the interpretation of the interview data.

Coherence of the analysis

Consultation with the interpretative community allowed me to make inferences about the coherence and plausibility of the study. The discussions with,

and feedback from the research community indicated that the analysis was clear and plausible.

Usefulness of the interpretation

The usefulness of the analysis (Michler, 1990), has been assessed through consideration of the clinical implications which are discussed fully below. As yet, I have no way of formally evaluating the usefulness of the findings, other than to say that I have found them helpful and important components of my own clinical practice. Future research could employ a quantitative methodology to investigate the frequency and influence of the positive factors identified in Chapter 3.

Revisiting the research questions

In the planning stages of this study, four questions were identified which would direct the study. These were refined throughout the research in order to address the following questions

1. What positive aspects of psychosis can people who have experienced it describe?
2. How do accounts of positive experiences fit into the experience as a whole?
3. What frameworks do they use to find meaning in their experiences?
4. What are the similarities and differences between the descriptions of the NHS Group and the Non-NHS Group?

DISCUSSION OF THEMES AND IMPLICATIONS

The following section explains the links between the literature, psychological theories and my findings. I will demonstrate by comparison with other studies the range of positives found and will refer to the literature review, to reflect the types of positive aspects identified by other studies. I will illustrate any additional findings which this study has contributed.

Research question 1: What positive aspects of psychosis can people who have experienced it describe?

An important, although at times overlooked, aspect of the psychotic experience, is the extent to which aspects of it are seen to be positive. All but one of the participants described a range of positive aspects, which were either associated directly with the internal experiences or were external benefits resulting from them. This finding was in keeping with the anecdotal accounts introduced in chapter 1 (e.g. Chadwick, 1997).

Internal experiences

Enjoying the benefits of inherent aspects of the experience: Enjoying enhanced sensory experiences which heighten creativity

Increased creativity in music, writing and dance, credited directly to the experience of psychosis, was seen by two participants as a personal attribute beyond the expected normal level of functioning. Horrobin (2002) suggests that genes associated with schizophrenia are of considerable importance in evolution and are associated with increased creativity and imagination, giving rise to the development of artistic and technical skills. Tomecek (1990), in his first person account of schizophrenia acknowledged that whilst having the experience of psychosis can be problematic, it is, for him, also associated with artistic expression and being gifted. This finding supports suggestions referred to by Chadwick (1988) who discussed schizophrenia as a 'creative illness' and described his enhanced skills for photography, which were eradicated as medication was introduced to treat his symptoms. This finding is in line with well documented suggestions of a link between creativity and psychosis (Claridge, 1988). Positive psychology would suggest that enhancing these existing talents develops innate strength and that the focus of psychological intervention should be on building on strengths and talents rather than on repairing damage, in order to promote the resilience critical to recovery. An implication is that people's existing assets can be identified through introducing discussions about strengths into the therapy room, and interventions focussing on these can enhance their psychological well-being. The focus could become part of wider multi-disciplinary interventions with opportunities for the strengths to be cultivated outside the clinic room. A number of interventions are already being developed which focus around hope (Snyder, Rand & Sigmon, 2002), self belief (Maddux, 2002), and benefit-finding (Tennen & Affleck, 2002).

Having privileged access to something bigger than me

Participants talked positively about feeling privileged by having experienced a different dimension of reality which was 'bigger' than themselves and beyond average comprehension. Some spoke of the positive aspects of accessing a reality different from that of most other people, and made reference to the fact that the opportunity had given them greater insight. This in itself was surprising since their alternative reality could have been interpreted as isolating and marginalising in that it was not consensual reality. However, Romme and Escher (1989) found that some people used

a spiritual framework as an anxiety reducing coping mechanism. Clarke (2003) speaks about psychosis as a spiritual experience rather than an illness and refers to different 'manifestations of the mind' and the crisis of dealing with spiritual anxiety. These findings would suggest that some people who experience psychosis within a spiritual framework participate in a different reality which goes beyond conventional scientific conceptualisations of the world, supporting the notion that aspects of psychosis could be socially constructed. The reference made to the 'insider-outsider' distinction in rehabilitation theory, whereby psychological approaches are underpinned by the presupposition that those who have experience of psychosis have a different understanding than those who have not, is pertinent to increasing understanding and introducing discussion about accessing different realities in the clinic room. The inclination to view the experience of psychosis in terms of a framework of meaning relating to how a person views his or her position within the universe has been referred to as 'spirituality' (Geekie & Read, 2008), and is an area which merits future research.

Finding aspects of the experience comforting, compassionate, supportive and guiding

Participants spoke of having found their voices comforting, compassionate, supportive and guiding at times. They also said that when they changed their attitude towards the voices, the voices themselves became more positive. Research suggests that the degree of distress experienced by people who hear voices is influenced by the ways in which they understand and make sense of the experience and their situation, rather than for example, the content of what they are hearing (Romme and Escher, 1989).

Miller et al., (1993) found that hallucinations were sometimes valued by the patients they interviewed (n = 50), and that a sizable minority wished to continue experiencing hallucinations. They questioned whether or not patients adapted to the hallucinations by learning to value aspects of the experience, and further questioned whether this occurred more consistently in people more chronically affected and served as a protective factor against potential distress and trauma.

There are significant clinical implications for approaching treatment since the assumption that patients are inclined to rid themselves entirely of the experience may be misleading and may go some way to explaining different rates of adherence to treatment. Psychological assessment, formulation, and intervention needs to take account of the complexities of the relationship between individuals and their voices.

It is important for clinicians to be aware that voices can be supportive, protective and positive experiences and that by exploring this, clinicians could begin to understand issues such as ambivalence to treatment interventions aimed at eliminating the experience. Participants, however, warned against over-romanticising what is undoubtedly, for many, a traumatic and distressing experience. Indeed, some aspects of the experience of psychosis are negative and psychological therapy aims to reduce them but the findings suggest that complexity lies in preserving the positive aspects simultaneously. This may involve negotiation and balance so that the individual can learn to cope with negative aspects and find reward in the positives. Rehabilitation theory indicates that focussing on positives within the experience will not eliminate the negatives, but may lessen them. Birchwood and Chadwick (1994) suggested that people who viewed their voices as benevolent were less distressed by them than those who experienced them as malevolent. Miller et al., (1993) found that those with a more positive attitude to the voices were less likely to respond to treatment. Whilst levels of distress were not the focus of this study, it is clear that people found benefits from the positive aspects of their experiences of psychosis.

An implication is that the degree of comfort or distress can be mediated through psychological formulation focussing upon the understanding a person has of his/her experience so that the person's subjective well-being can be enhanced.

External consequential factors

Participants identified some personal and situational factors resulting from the experience and suggested that these had been 'a bonus' to them. Some spoke of reaping the benefits of the educational and professional opportunities afforded by the experience, and one spoke of 'feeling special' because as a result of her experience she felt she belonged to an exclusive group of high-profile, leading professionals. In their conceptual model of recovery Jacobson & Greenley (2001) suggest that recovery occurs when two conditions (internal and external) reciprocate each other. Internal conditions are defined as attitudes, experiences, and processes of change and include conditions such as hope (primarily the individuals self-belief that their recovery is possible), healing (not being 'cured' but defining a self apart from illness and control), empowerment (the ability to act independently, the courage to speak ones voice, and the responsibly to stand for others who need a voice), and connection (ability to forge connections with others based on hope, empowerment and healing).

External conditions are defined circumstances, events, policies and practice that facilitate recovery including human rights (a system that reduces stigma and discrimination, provides equal opportunities, employment, housing and other necessary resources), a positive culture of healing (an environment that provides safety, respect, tolerance, empathy etc) and recovery-oriented services (services that address the needs of those with a mental illness).

Finding solace in being absolved from responsibility

Participants talked about finding solace in being absolved from the responsibility of everyday life, but suggested however, that it was only when they felt strong enough to take back that responsibility that they could begin the process of recovery. Only one theme was identified exclusively by participants in the NHS Group which was a subscription to a belief that they were 'perfectly normal/extremely well'. This seems to be associated with being at an earlier stage on the continuum of recovery. It is possible that this belief will develop as people progress through their recovery into a feeling of being absolved from responsibility and then into a feeling of emancipation when in a position to reclaim that personal responsibility and the sense of agency and autonomy which is commensurate with it.

Szasz (1961; 1991) suggested that important ethical considerations, such as personal responsibility for behaviour, are obscured when different behaviours are conceptualised as a 'mental illness' within a medical framework. Davidson (2003) argues in his overview of the recovery movement, that a key component of making the transition into the recovery stage is assuming a sense of agency and responsibility for dealing with difficulties. The recovery model aims to deconstruct notions of 'mental illness' and encourage agency within the individual to interpret his/her own experience (Walker, 2006). Davidson (2003) identifies key components of this perspective, which include assuming a sense of agency and responsibility for dealing with one's difficulties, and of hope regarding a positive outcome.

The implication is that there are some aspects of adopting an illness identity which are enjoyed by the individual and may diminish the desire to reassume their personal identity. This gives insight into ambivalence towards treatment interventions designed by professionals determined to progress recovery. Participants suggested that, clarity of understanding brings its own challenge as 'recoverers' begin to conceptualise what has happened to them from a potentially traumatic, objective perspective, and are thus vulnerable whilst emerging from the experience. Increased

support in the form of psychological treatment informed by the Recovery Model, should be made available for people as they try to make sense of the experience. Jacobson & Greenley (2001) referred to recovery-orientated services as an external condition which is key to recovery.

Psychological formulation and treatment could benefit from building a narrative of the clients' experiences from their perspective since this process may help to facilitate a shared understanding of the value placed by the client upon personal agency and responsibility.

Finding hope in belonging to a group who understand when you talk about the experience

Some participants found sharing the experience of psychosis with others to be positive. This sharing sometimes involved speaking with an empathic friend or hearing about the stories of other service users. The common thread was coming to see psychosis, through comradeship, as being a shared human experience, which seemed to help normalise events and so make the individual feel less troubled by them. May (2006), who occupies the rare, though not unique, position of being a clinician with a personal experience of psychosis, argues that exposure to other people's accounts of the experience of and recovery from psychosis can have important therapeutic value through engendering hope in those who may be struggling with their own experience of psychosis, "Meaningful accounts of psychosis that allow us to connect with others and make choices about our lives are essential to any recovery process". Jacobson & Greenley (2001) referred to self-belief that recovery is possible and empowerment, as internal conditions which can facilitate recovery. Some of the participants were convinced that believing that you can recover is empowering but there seemed to be some difficulty for others in daring to hope for fear of disappointment.

Symbolic Interaction Theory (Blummer, 1938, 1969) suggests that people respond to an object, experience or situation depending on the meaning it has for them; that this meaning arises from social interaction, and is modified through an interpretative process. If thoughts and behaviour are linked to past experience but can be modified through social interaction and through the individual's ongoing interpretation, it is possible that in sharing their experiences with others who could empathise, people with psychosis have an important opportunity to make meaning out of what has, or continues to happen to them and to find hope for the future.

Historically, the terms schizophrenia and psychosis have had attached to them a somewhat pessimistic outlook regarding the possibility of recovery. The Recovery Movement, in contrast to historical pessimism, demonstrated that recovery from 'severe mental illness' is possible even for the most chronic cases (Harding, Brooks, Ashikaga, Strauss & Brier, 1987). Since the prospect of recovery from psychosis is a relatively new notion, one which has not yet permeated a significant number of clinical services, it is understandable that the participants reported feelings of uncertainty in daring to hope for recovery.

Reflections on positive aspects of the experience

Most of the participants felt that a discussion of the positive aspects should be an integral part of the mainstream discourse on how people experience psychosis. They explained that the value of positive aspects lay in an increased feeling of well-being and self-esteem which were factors associated with recovery. If a positive aspect of the shared experience is the strengthening and developing of hope and if hope promotes recovery (Jacobson & Greenley, 2001), then an understanding of the positive aspects could be incorporated in the approach to treatment. Part of the positive psychology approach is hope theory which posits the belief that one can find pathways to desired goals and become motivated to use those pathways, in order to drive their emotions and psychological well-being (Snyder et al., 2002).

May (2002) speaks about the importance of challenging the prevailing notion that mental health problems are to be seen only as disabilities. He suggests that this can be challenged through seeing positives in the experience, and recommends celebrating the uniqueness and resilience of those who have been through the mental health services. Participants were able to speak of a range of positive aspects of their experience of psychosis, which would suggest that challenging the deficit-focussed models of psychosis is a worthwhile endeavour. Since internal and external resources are a larger factor in outcome than therapist factors (Lambert, 1992), it is likely that those with fewer resources will find change more difficult. Being part of a system which emphasises negative aspects of their experience may restrict access to internal resources already held and opportunities to gain further, external resources. The whole group identified a variety of positive experiential, sensory or societal aspects or consequences of the experience.

Research question 2: How do these accounts of positive experiences fit into the experience of their psychosis as a whole?

This question was designed to allow the accounts of positive experience to emerge in context: the temptation in investigating one aspect of an experience is to focus on one narrative and overlook other experiences. Examining participants' accounts of the experience as a whole will give a sense of the balance between positive and negative accounts. It will enable examination of differences in the positive aspects at different points on the continuum of recovery, and allow me to make comparisons with the participants in order that I can make an informed judgement about the representativeness of my sample. Participants suggested that psychosis in its most fully expressed form can be one of the most horrifying experiences to afflict an individual. This question is an attempt to guard against embellishing participants' descriptions of psychosis, or elaborating the experience with glamour that, for some, it does not possess. This section is about finding balance in order to avoid downplaying the suffering that participants spoke of, but at the same time recognising the significance of it. These findings will give insight into the value that participants place on different aspects of their experience and thus provide direction for the relative importance and appropriateness of introducing positive aspects into psychological interventions.

Sometimes feeling you can't cope

Lally (1989; p254) comments:

In general there has been a neglect of the patients' perspective, and there is very little information about how people with mental disorders cope with the challenges their hospitalization and symptoms present.

Participants spoke of times when they have felt they could not cope. One participant in the Non-NHS Group used the past tense when talking about these times; the remaining participants, regardless of group, spoke in the present tense of their continuing struggle, at times, to cope.

Coping strategies will be discussed further in response to research question 4, but this feeling of inability to cope reflects the personal nature of the relationship and interaction with the phenomenological aspects of experience. The common presupposition of psychological approaches is that 'not coping' is associated with dysfunctional outcomes and professionals endeavour to equip individuals with a plethora of strategies for coping. It may be important to reconcile the ongoing

feelings of doubt reported by participants by validating their experience in therapeutic interventions.

Identifying factors which impede or promote recovery

Some participants were clear in articulating the positive transitions which enabled them to further their journey towards recovery, and factors which would impede their recovery. This was meaningful for them since it defined a very personal discovery whereby they had begun to foster a sense of optimism and hope about their futures.

Participants spoke of becoming more insightful through accepting what had happened to them. Two participants in the Non-NHS Group said that they had gained in strength, and had rediscovered their identities by breaking-through the worst of the experience. They said that accepting the voice as part of their personal identity was a transition which allowed them to make meaning out of the experience, a pivotal point in their recovery. Romme and Escher (1989) spoke of three phases involved in adapting to hearing voices, the first being the onset about which participants described feeling shocked and panicked; the second involved struggling to find ways of coping; the third involved finding a way of regarding the voices as a positive facet of themselves. The feeling of inability to cope which my participants described, may be part of the second of these phases, and the process of finding aspects of the experience that collectively allowed them to flourish would seem to be in keeping with the third phase. Consideration of Romme and Escher's three phases allows me to begin to estimate the potential chronological occurrence of the experiences described by the participants.

Factors which impeded recovery were not identified as aspects of the phenomenology of the experience itself, but rather outside influences, mainly concerned with treatment. The participants identified unhelpful aspects of treatment, e.g. loss of control, personal identity and dignity, aggressive treatment interventions, lack of meaningful activities to occupy their time, medication. Knight and Bradfield (2003) noted the difficulties that participants associated with feeling that personal identity is subsumed by an illness identity and Cohen's (2005) participants linked the experiences of aggressive treatment interventions with trauma and internalised oppression. My participants expressed resentment of aggressive intervention, and a suggestion that alternative treatment should be explored, since it would be less disempowering or disabling than the hospital experience. This corroborates Cohen's

(2005) findings that participants found forced medication, electro-convulsive therapy, restraints, seclusion and verbal abuse during their treatment to be traumatic and oppressive. This would suggest that the psychological impact of mental health treatment needs to be given careful consideration. Cullberg (2006) suggests that trauma following psychosis “stems from the experience of what it means to be psychotic as much as from the frightening and sometimes integrity destroying experiences around the admission to hospital”, (p.186). It may be that external attribution of negative experiences may correspond with one of the three phases referred to by Romme and Escher, an implication being that psychological treatment could be tailored and targetted at different stages of the experience.

Participants in both groups talked about the tedium of long days punctuated by meaningless tasks in hospital. Mahoney (2002), reflects on the experience of psychosis from a constructivist stance and suggests that, “During periods of intense destabilization, clients may need highly structured experiences to help them deal with phenomenological chaos” (p.57). The participants implied that having to adhere to a hospital regime had made them institutionalised and more likely to have their personal identity subsumed by an illness identity. Charmaz (1991) found that over the course of illness, people go from initially accepting illness labels, to later fighting against these as they become interpreted as threatening personal identity. The participants in this study suggested that their personal identity had been subsumed during hospitalization, but that rediscovering and reclaiming it was part of the recovery process. The combined challenges of managing the intensity of the experience of psychosis and being hospitalised were described as being a threat to the maintenance of a positive self concept. The implication is that aspects of the experience of being hospitalised are a hindrance to independence, self-awareness, and inevitably the recovery process. This is a vast and potentially controversial area of research which might give rise to another study where it can be explored further.

Being made to feel worthless as a result of being stigmatised, excluded, verbally abused and harassed

Participants identified societal influences which shaped the context of the experience and recovery. Stigma made them want to be reclusive, and caused them to worry about their future place in society because the diagnosis would mitigate against them. They felt rebuked, and experienced a sense of worthlessness with regard to the way they were viewed by others and felt that their opinions were not considered to be

worthwhile. People with psychosis live in an environment where others often have low expectations of them (Jorm, et al, 1997). Research suggests that the ‘chronic patient’ is characterised in psychiatric literature as poor, dishevelled, unproductive, unkempt, dependent, and is an unemployable drain on taxable finances (Harding, Zubin & Strauss, 1992). Problems associated with psychosis are largely manifest in the social domain and include difficulties in relating to other people, problems pursuing employment or education, and problems functioning meaningfully in mainstream society. Deveson (1992) talks of people with mental illness being ‘silent and silenced’ by a culture which invalidates their contribution and regards them with contempt.

Reflections on positive experiences in relation to the experience of psychosis as a whole

Although this study was designed to elicit positive elements of the experience of psychosis, it was found that these ran concurrently with negative aspects of the experience. The data describe the range of participants’ experiences of psychosis and the discussion has now set the positive aspects discussed in research question 1, in the context of the experience as a whole. The danger of over-romanticising needs to be considered since negative factors cannot be ignored any more than positive ones. It is possible that professionals could be concerned about over-romanticising or dismissing the emotional distress of psychosis by introducing positive aspects into therapeutic discourse. An implication is that sensitivity in timing is required in introducing these complex conversations. McGorry and Jackson, (1999) suggested that “A balance needs to be struck between respecting the patient’s interpretation of their psychotic experiences while conveying to the patient one’s own clinical judgement and advice regarding treatment” (p.159). Clinicians have a responsibility to keep the client and the community safe, and the challenge comes in maintaining the balance between engaging in discussions about the client’s understanding of his/her experiences, and offering one’s clinical opinion.

Research question 3: What frameworks do they use to find meaning in their experience?

This question was designed to identify frameworks which give insight into how the participants understand their experiences, so that the meaning of changes, differences, contradictions and similarities can be explored. Consideration is given to the functionality of influential factors through which people are drawn to particular

explanations at different times e.g. exposure, social construction and chance, family and friends. Frameworks help participants communicate their experience by locating the phenomenological aspects within a cognitive framework which makes sense to them, and this communication empowers the person. Acknowledging the importance and validity of the range of belief systems and frameworks allows people to maintain authorship of their lives in the way that works most fruitfully for them (May, 2006). The participants identified three frameworks within which they made sense of their experiences, namely illness, spirituality and society.

The Illness Framework

The first framework identified was an 'illness' model. Jones (2003) notes, "Being sick is not a fact, it is a social definition" (p.2). Participants took dichotomous positions when viewing their experience within an illness model. Some said they believed they were, or had been, ill, and others believed that their experiences should not be conceptualised as an illness. Two participants in the NHS Group spoke of their experiences as being wrongly defined as an illness. One participant suggested that it was unhelpful for people to be described in terms of an illness identity. Ridgway (2001) suggests that an essential component of recovery is reducing the sense of internal stigma and rediscovering the self as separate from the illness identity. Three participants used an illness narrative to explain their experience of psychosis. An illness model allows for a causal explanation which is external to participants and to which responsibility can be attributed and therefore personal responsibility delegated (Locker, 1981). The medical framework of understanding psychosis has long been the dominant model and consequently specific linguistic codes are in place and are accepted by professionals in services designed to operate with this model. These codes however, had negative undertones for the participants, since they were forced to face the consequences of the stigma attached to them, felt limited in their freedom to make sense of their experiences in personally meaningful ways and were sometimes forced to comply with treatments concordant with an illness approach to their experiences.

Social Representation Theory (Moscovici, 1973) posits that there needs to be a shared language within which to locate concepts and ideas which are beyond the experience of some. It is important that language is not stigma-laden and an implication is that participants could be given an opportunity to develop a shared language with their therapist which is acceptable to both.

The Spiritual Framework

The second framework within which participants located their experiences, was a spiritual one offering a range of interpretations. For some, subscribing to this framework was problematic, painful and frightening because it had a demonic aspect to it, within which death and punishment were recurrent themes. For others it was inspiring and validating since gifts and privilege were integral themes.

Romme and Escher (1989) found that people who viewed their voices as guides giving useful advice would be much less likely to experience distress than those who viewed their voices as manifestations of a powerful evil force. They also found that people who understood their voices in a compassionate framework (e.g. a guiding spirit) were less likely to be distressed than those who experienced the voices as being from a powerful demonic source. These findings are similar to those from my study in that those who saw the voices as powerful in a demonic manner found them frightening and distressing, whereas those who located them within a benevolent framework were more accepting and felt less persecuted. Whilst research investigating a spiritual theme in the psychotic experience is scarce (Geekie & Read, 2008), this study has demonstrated that spiritual issues are taken seriously by those who experience psychosis.

Averill, (2002) suggested that one way of looking at spirituality is “as an attribute of other emotional states to the extent that they have features in common with mystical experiences” (p.179) and Wagner and King (2005) found that the search for meaning and spirituality were the primary needs of people who experience psychosis. An implication is that opportunities for exploring meaning and spirituality should routinely be offered to clients as an integral part of their therapy so that it can be explored in a safe and validating environment.

The Societal Framework

In describing the influence of society upon their experiences of psychosis, the participants talked exclusively in negative terms about suffering as a result of societal stigma. This framework considered the self in relation to others and included those directly influencing him/her, namely family, friends and colleagues. Participants were unanimous in their reference to needing the support of family, and some spoke of the trauma of having had their experience dismissed by family. Those in the Non-NHS Group lived with the guilt of having made huge demands on close family members

and of having seen the results. Family were the ones by which they judged their own actions; they served as a moral barometer.

The need for support is a recurrent theme in the work of Davidson and Strauss, (1992), Ridgeway, (2001) and Young and Ensing, (1999), who studied recovery accounts and found that there is always one person who has remained a constant source of support, treated them with dignity and valued them. Having people around who gave space, but also believed in and valued participants' abilities and potential was appreciated by those who took part in my study.

Some participants talked about having suffered as a result of not having had support from friends and of suffering as a result of taunts of colleagues. Public stigma is one of the key barriers to the process of recovery from psychosis (Knight, et al., 2003). The inability to connect with others and form meaningful and trusting relationships to aid recovery is compounded by the sense of exclusion. Through accessing the personal accounts of life experiences (be it in a group setting or on an individual basis), the varied and multiple ramifications of psychosis can begin to be uncovered. Lapsley, Nicora & Black, (2002) report that those who have recovered from mental health problems identify rebuilding of relationships, (social integration) as being central to the recovery process. Participants across both groups emphasised the importance of this process in the early stages of their recovery.

Having a network of supportive people available may give individuals an opportunity to engage in a range of relationships within which they can enhance and rebuild their confidence and social skills (May, 2006). This study adds to these findings by emphasising the importance of key relationships both in terms of destroying hope and self-belief and in terms of rebuilding a sense of self-worth and motivation to recover. An implication is that people may particularly benefit from psychological treatment offered in a group setting, such as the Hearing Voices Network which provides a forum for people to come together with a shared vision in a safe and accepting environment.

Reflections on the three frameworks

The three frameworks discussed above were discernable from the narratives and were held in combination by most participants. There are however, inherent disadvantages in conceptualising peoples' experiences within a specific framework since overly- cognising may detract from the complexity, thus giving it a simplicity which it does not possess.

Research question 4: What are the similarities and differences between the descriptions of the NHS Group and the Non-NHS Group?

This question was designed to investigate attributes of the Non-NHS Group and the NHS Group and to explore differences that might exist in descriptions of the experience. The intention was also to elicit factors which promote recovery and can be used to identify implications for those continuing with treatment. The value of including the two samples in terms of the richness of the findings will be discussed next. In terms of process, having interviewed the Non-NHS Group participants first, proved a valuable decision since it sensitised me and enabled me to enter into focussed discussions about positive aspects with those with continuing treatment needs and I was able to notice aspects which I may otherwise have overlooked or missed.

Describing the experience

Participants suggested that finding language to describe experiences which were difficult to understand was challenging. The whole group referred to the lack of adequate vocabulary for communicating the intensity of the experience to those who had never had it. They believed it would be impossible for others to comprehend it fully, an implication being that adequate linguistic codes have yet to be developed. Moscovici (1973) referred to this in terms of social representation which he described as: “systems of values, ideas and practices with a two-fold function ... [the second of which is] to enable communication to take place amongst members of a community by providing them with a code for social exchange and a code for naming and classifying unambiguously the various aspects of their world and their individual and group history”.

The participants said it was less frightening being in the midst of the experience of psychosis than it was looking back on it. When living through the experience, it was impossible to see it from an objective perspective, since their efforts were concentrated on surviving day-to-day. This was echoed in the language they used to describe their experiences, with the Non-NHS Group using stronger vocabulary to describe the trauma of the psychosis. When participants talked about being shocked and startled by the experience, it is possible that looking back on the event and describing it whilst not experiencing the feeling, is different from being in the NHS Group, still coping with the experience. One of the participants gave insight into this by saying that it was less frightening being in the illness state. An

implication is that, clarity of understanding brings its own challenge as ‘recoverers’ begin to conceptualise what has happened to them from a potentially traumatic, objective perspective, and are thus vulnerable whilst emerging from the experience. It is at this stage that the person needs intensive support in accepting the experience and redefining his/her identity in relation to it (Lapsley, et al., 2002).

McGlashan, Levy and Carpenter (1975), consider that there are two ways in which people relate to their experiences of psychosis. They suggest that attitude determines whether people respond by integrating or sealing over. Those who seal-over have negative views of the experience, detach themselves and their prior life experiences from the psychosis, are dismissive of the experience and do not seek to understand it in relation to themselves. One participant in the Non-NHS Group coped on a daily basis by sealing-over the negative aspects of his experience and detaching himself from them. All other participants appeared to be integrators. Those who integrate, find personal meaning in the experience, and see it as an opportunity for personal growth. Despite the suggestion that integrators fair better in their recovery from psychosis (McGlashan, 1987), it would seem from my study that even the integrators face challenges when emerging from the experience and it is significant that the person who coped by sealing-over was in fact in the Non-NHS Group. An implication from the findings of this study is that it is beneficial for clinicians to show patience in allowing their clients to find personal meaning when they initially experience the shock and panic of onset, rather than striving for them to begin the process of integration. A further implication is that at this time the approach of the clinicians supporting them needs to be integrative also, in order to maximise the potential for recovery (Whitehorn & Betz, 1960).

A sense of preparing

All members of the Non-NHS Group made reference to having sensed a need for preparation and they felt an urge to act on it in a variety of ways. Their descriptions conveyed a sense of urgency and purposefulness, indicative of a high stress-response. They talked of having been in a state of high alertness, anticipating that something would happen but not knowing what that would be. Maybe they were pre-empting the onset of any further shocking and terrifying experiences, and felt that because the first experience of psychosis was so unexpected, surprising and unwelcome, it would be unwise, and too painful to leave oneself unprepared and vulnerable to further, similar experiences. Participants may have been describing an

early warning sign, whereby the stress response alerted them to the imminence of a profound experience, a sense so strong that they were unable to ignore or dismiss it. This sense of preparing is not referred to in existing research literature but was a prominent aspect of the participants' experience. An implication for research is that further exploration of the purpose, meaning and frequency of this aspect of the experience could be valuable, particularly in terms of informing psychological interventions targeted at young people identified as being at high-risk of developing psychosis.

In different ways, all of the participants in the Non-NHS Group also spoke of feeling stronger by having got through a test or a 'dark place'. They were able to look back on their survival with pride, and reflect on their having come through it as an indication of their personal strength. This could be because of the historical pessimism associated with the possibility of recovery in services, where the medical model has traditionally predicted a poor prognosis for those with experiences of psychosis. Roberts and Woolfson (2004) reported that an internal transition, such as finding personal meaning in the experience of psychosis, is key to beginning the recovery process. An implication is that interventions informed by positive psychology could nurture the 'survivor' within the person who is recovering from the experience and build upon this strength by acknowledging it.

Another difference between the two groups became clear when discussing living with the experience. Whilst considering the accounts I was asking myself, how do coping strategies develop, and what is it that participants are or are not assimilating? Two of the participants did not speak about ways of coping since they felt that they did not have anything to cope with and were limited by the frameworks used by mainstream society to conceptualise their experiences. Exploration of the differences between the continuing treatment needs and Non-NHS Groups suggested that those who were more advanced in their recovery had access to a greater range of strategies for living with their experiences of psychosis. The implication is that if they cannot recognise the factors that promote recovery, then they cannot fully access it. By increasing accessibility to coping strategies and by offering forums for mutual exploration of the meaning of their experiences, recovery could be accelerated.

Coping strategies to aid recovery

Participants from both groups spoke of doubting or having doubted the possibility of recovery. The Non-NHS Group spoke of benefiting from helping others

with similar experiences to their own, either directly or indirectly. This was not identified by any participants in the NHS Group. Positive psychology suggests that people can gain therapeutically from applying their existing skills and attributes to meaningful occupations.

The Non-NHS Group showed greater awareness of the factors involved in recovery and demonstrated a greater range of coping strategies than the NHS Group. The NHS Group did not identify a significant number of factors involved in recovery or recognise such factors within themselves. An implication is that recognised coping strategies could be made available to those with continuing treatment needs so that they can assimilate and employ those which are most suitable at times they feel ready to use them. Positive psychology suggests that determination and responsibility are factors which can be addressed in therapy and may enhance a person's ability to recover.

The only coping strategies identified by the NHS Group were, listening to music, watching TV and painting, talking to others for reassurance and making friends with the voice. The Non-NHS Group made use of these, but supplemented them with a range of proactive and sophisticated strategies, such as adhering to their treatment regime, rationalising situations, putting restraints on lifestyle, blocking it out at times, keeping active and busy, using the past as a benchmark. 24 distinct mechanisms for managing the experience were identified by the three participants in the Non-NHS Group whereas only five mechanisms were cited by the seven participants in the NHS Group.

The Experience of Recovery

Evidence suggests that service users with an optimistic attitude about their rehabilitation are usually the same individuals who can avoid experiences which can compromise their recovery, such as depression and hopelessness (Seligman & Csikszentmihalyi, 2000). Professionals who identify, enhance and encourage reliance on individuals' strengths may be able to maximise recovery (Wright & Fletcher, 1982; Gillham & Seligman, 1999). The findings suggested that participants were more likely to engage positively with professionals when they felt as though they were actively involved in finding ways to understand their experiences, and responded negatively when they felt that they held a passive position and were being 'done to'.

Participants in the Non-NHS Group suggested that many of the positive factors they identified assisted their move towards recovery and identified converse

factors as impeding that transition. They explained that doubting the possibility of full recovery and living with the fear of relapse had contributed to a sense of hopelessness. Reporting on a qualitative analysis of recovery narratives for those who have had mental health difficulties, Ridgway (2001) found that a common theme in these narratives is reducing the sense of internal stigma and seeing that the condition does not define the self. This would suggest that when people are able to separate the self from the psychosis, they are more likely to be able to have increased hope for their future. The participants in this study said that they were more able to be self-accepting after they had found a way of making meaning out of what had seemingly been benign, incomprehensible, malevolent experiences. One participant in the Non-NHS Group, who was unable to understand why he had been hearing voices spoke in a self-critical manner and remained secretive of his experiences for fear of the reactions of his family and colleagues. Roe and Ben-Yishai (1999) found integration of self and illness to be helpful in recovery. An implication of the findings is that it would be beneficial for psychological treatment to focus on helping people find ways of integrating their experience at their own pace, since this could serve as a protective factor in preparing them for a resurgence of the negative aspects of psychosis in their future.

Participants in the Non-NHS Group suggested that recognising that personal strengths helped in getting through the experience of psychosis allowed them to have an increased sense of agency in taking control over their future. Through analysing the narratives of women who had recovered from serious mental illness Ridgway (2001) was able to identify common themes, including finding hope, understanding and accepting one's condition, becoming actively engaged in life, and moving from having a sense of alienation to having meaning and purpose in life.

May (2006) outlines factors influencing recovery based on Anthony's (1993) eight principles:

1. Each person's recovery is different.
2. Recovery requires other people to believe in and stand by the person. Other people / opportunities play an important part in enabling the person to make this recovery journey.
3. Recovery does not mean cure. It does not mean the complete disappearance of difficulties.

4. Recovery can occur without professional help. Service users hold the key to recovery.
5. Recovery is an ongoing process. During the recovery journey there will be growth and setbacks, times of change and times where little changes.
6. Recovery from the consequences of mental distress (stigma, unemployment, poor housing, loss of rights etc.) can sometimes be more difficult than recovery from the distress and confusion itself.
7. People who have or are recovering from confusion and distress have valuable knowledge about recovery and can help others who are recovering.
8. A Recovery vision does not require a particular view of mental health problems.'

Recovery is a multi-dimensional concept: social and psychological recovery processes are increasingly (although not predominantly) seen as being as important as clinical recovery (Coleman, 1999). Psychological recovery describes the process of developing ways to understand and manage psychotic experiences and regain some sense of structure in one's life. May (2006) stresses the importance of these distinctions since services and research currently focus too heavily on clinical recovery.

Summary

People continuing with treatment and recovery have a wide range of experiences, and literature indicates that we have no current overall rubric within which to conceptualise some of the experiences especially if they are positive. The aim of this study was to investigate this imbalance and identify factors which could be used to redress it. It is clear from the discussion of the findings that exploring potential positive aspects of the experience of psychosis is a worthwhile endeavour, and one which most participants had no previous experience of. To look at psychosis as a collection of experiences with positive consequences, as well as negative, has considerable implications for recovery which have been discussed in this chapter. A further implication is that if the construction of psychosis is more balanced in terms of ability/disability the potential consequences of experiencing psychosis may be improved by providing people with psychological interventions that do not overlook aspects of their experience (Friedsen, 1970; Scheff, 1968).

The findings supported the notion that there are many ways people with psychosis understand their experience. The participants identified three of

frameworks, (spiritual, illness and societal), which they used to make sense of their experiences. By examining the underlying processes which inform how a person has come to locate his/her experience within a particular framework, clinicians can identify the different underlying psychosocial processes which determine how best to work with him/her, and by doing so, can mediate the degree of comfort or distress he/she may feel. As clinical psychologists, we are trained in particular ways of understanding this experience. If clinicians can be open to the fact that we bring one way of understanding psychosis, (which is one of many valid ways), this will encourage people to be more open in sharing their experiences. This way of working may pose a threat to professionals who have traditionally exercised control in this area, and should be incorporated sensitively into multi-disciplinary work.

CRITICAL REFLECTIONS

The aim of IPA is to offer observations which are generated directly from the context of a phenomenon as it is described (Willig, 2001). The strengths and limitations specific to this study will be considered next in relation to sampling, data collection, analysis, making use of the results and generalisability.

Strengths and Limitations

Sampling and recruitment

However valuable, it would be near impossible, and unethical to elicit the subjective experience of psychosis from those who are too acutely affected by, distressed by, or unwilling to discuss, their experiences at that particular time. People who were actively psychotic were excluded from this study in theory, although in practice, during the interview some participants described ongoing experiences of psychosis. Such interviews, although difficult to conduct, provided a wealth of experiential information which enriched the data. This strengthened the results, since a range of distress and varying degrees of symptomatology were included. It is possible that people who were more acutely affected by their experiences were less likely to persevere with the recruitment and interview process and therefore the research may not be representative of the full range of experiences of psychosis. There remains a possibility, however, that people who do not chose to engage in research studies have a markedly different way of relating to their experiences and so caution would be recommended in generalising the findings to others who are continuing with their recovery and treatment. A strength of this study is that participants with a range of experiences of psychosis were recruited.

The focus of IPA is on depth of information rather than large, representative samples, and using this methodology meant that the number of participants would necessarily be limited. Both male and female participants from a broad range of ages and educational attainment were recruited. The results could be tentatively applied to adults across a range of ability who have experienced psychosis. Since all participants were White British, it is difficult to ascertain the extent to which the findings apply to people of non-Caucasian heritage.

Viability of the Group Comparison

Participants were recruited and allocated to a specific group based upon their contact with the NHS. In analysing the data it was clear that the participants could have been grouped differently based upon similarities and differences in the themes they alluded to in the interviews.

Data collection

In designing this study I was concerned that participants may not have been able to identify any positive aspects of their experience of psychosis. In approaching the participants, with an expressed interest in understanding the potential positive aspects, I was also mindful that this could limit their account with regard to their willingness to be open in discussing negative aspects. The interview schedule was designed to allow participants to discuss their experience as a whole. The analysis of the data suggested that participants felt comfortable in discussing both positive and negative aspects of their experience.

A limitation of using an interview is that the answers offered by the participants may be affected by the type of questions asked and the style in which they are asked. Consultation with the relevant research community (members of a qualitative research support group, my academic supervisor and a colleague also conducting an IPA study) enabled me to refine the interview schedule and develop strategies for positive style, tone and clarity of the questions. Though the interview schedule was lengthy in its written format, it was used flexibly and alternative ways of asking the same question were omitted in the interviews.

Future research could benefit from increased service-user involvement in conducting the interviews and analysis of the data. Since this research was for my doctoral thesis it was not possible to adopt a role of secondary researcher in order to produce a service-user led project.

Data analysis

In interpreting the findings the reader should be cognisant of the perspective and subjectivity of both participant and interviewer. The potential influence of the researcher's subjectivity inevitably affects qualitative research. When a researcher is involved in gaining and analysing data, his/her own interpretations are a key factor in influencing the results. Adopting a reflexive approach to the study, which involved keeping a reflective diary and being transparent in the personal and research processes involved in producing the results maximises the reader's ability to assess the influence of myself as interviewer. By detailing the processes involved in analysing the data and by making my own position transparent, potential bias was minimised. I have endeavoured to make my role in the research as clear as possible in order to allow readers to make a fair evaluation of how my role may have influenced the findings. I have described my knowledge of psychosis and experience of working with those affected by it, and have endeavoured to provide a description of the analytical process. In my experience, I have found that individuals' descriptions of their experiences have been overlooked. I was determined to give those with first hand experience of psychosis, a voice. An improvement to the study would have been to use the diary more systematically in the overall evaluation of the results.

Flexibility was important and the personal nature of the accounts given, implied engagement with the process and good relationships within the interview. Since the findings are, to some degree, a reflection of my own interpretation, the data remain open to re-examination and re-interpretation.

Data presentation

All of the participants had been in contact with mental health services and had been exposed to clinical conceptualisations of their experience. While this is unavoidable when conducting research within this setting, it may have influenced the participants' frameworks for conceptualising psychosis and the language used to explain their experiences. The most common discourse was around illness, which is unsurprisingly the most popular and socially accepted conceptualisation of the experiences described by the participants. An area worthy of further exploration would be investigating those who describe experiences which may fit with the diagnostic criteria for psychosis, but have remained invisible to formal mental health services.

The focus of this study was on capturing the essence of the participants' experience rather than producing universal factors which apply to all of those who took part. The themes established from analysis of the data should be viewed in light of the fact that they cannot have captured the experience of the participants in its entirety. The themes discussed also do not apply to all of the participants who contributed, but are considered to be representative of the essence of the group's contributions as a whole.

In Chapter 3, numbers were a useful indicator of how strong each theme was and the reader is, therefore able to judge how strongly each theme was represented across the sample.

Future research

The findings of this study are inevitably tentative and there are a number of avenues for future research that could be explored in relation to the current findings. The following suggestions could, however, risk diluting the interview as a unique experience, in favour of attempting to make the findings more reliable or replicable.

Increasing the sample size or pool of potential participants, or using a different method, or changing researchers, may increase the generalisability of the findings. There is potential for developing the schedule into a questionnaire. Including material of a written nature e.g. diaries, letters or of an audio/visual nature e.g. digital recording, video, may enhance the data because it would be current and not retrospective. Focus groups could be considered as an option for collecting additional data, or targeting a wider range of participants who may feel safer in a group environment whereas they might not be comfortable in participating in a 1:1 interview.

This study considered the views of people who had experienced psychosis, and did not include those of staff, carers, family members or proxy informants. Similar interviews with other people would allow a comparison for establishing the positive aspects of the experience of psychosis, or for seeing whether conversations are exclusively about negative aspects thus reinforcing society's discourse that psychosis is a negative experience.

Interviews with people who have experienced different types of psychosis such as bipolar disorder would enhance knowledge and understanding of a variety of experiences of psychosis. My experience of conducting one interview with a person who had been diagnosed with bipolar disorder gave me an opportunity to hear about positive and negative aspects of his phenomenologically different experiences.

Making the study longitudinal by conducting multiple interviews over time, e.g. when inpatients are first discharged, and later through a stable recovery, would enrich and give more depth to the accounts. It would also provide information about aspects of experiencing psychosis, and the processes described over a period of time; changes could be observed and patterns identified.

Extending the analytic procedure, so that several interviewers review the analysis on all transcripts might produce themes which could possibly have been overlooked.

CONCLUSION

This study has confirmed that people who experience psychosis can provide coherent and valuable accounts of the positive aspects, and are in a prime position to inform psychological assessment, formulation and intervention, as well as service planning, design and delivery, and research focus. The findings suggest that the positive and negative aspects of the experience of psychosis are not diametrically opposed, but rather that they are the same entities experienced differently depending on the influence of a complex network of factors (including social networks, treatment opportunities and frameworks for interpretation). Acknowledging the whole experience is key. People who were further along the continuum of recovery identified factors which promoted their ability to cope with the experience, and offered a rich, unique and insightful perspective when reflecting. Findings suggest that people strive to uncover sophisticated, personally-meaningful frameworks through which to interpret their experiences. Three frameworks were identified which could be refined and developed into constructs for informing clinicians in their endeavours to deconstruct psychopathology and approach the phenomenon of psychosis in a meaningful and psychologically healing way. I have attempted to increase the understanding of the experience of psychosis and bring prominence to the often neglected positive perspective.

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APPENDICES

National Research Ethics Service**Leeds (East) Research Ethics Committee**

Room 5.2, Clinical Sciences Building

St James's University Hospital

Beckett Street

Leeds

LS9 7TF

Leeds Research Ethics Committee Letter

& Research and Development Letter

Telephone: 0113 2065652

Facsimile: 0113 2066772

9 August 2007

Miss Sarah Louise Richards
 Psychologist in Clinical Training
 University of Leeds
 Academic Unit of Psychiatry and Behavioural Sciences
 15 Hyde Terrace
 Leeds
 LS2 9LT

Dear Miss Richards

Full title of study: An investigation of service users' positive experiences of psychosis using Interpretative Phenomenological Analysis (IPA)

REC reference number: 07/H1306/83

Thank you for your letter of 12 July 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

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

Confirmation of ethical opinion

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

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA). There is no requirement for other Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

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

Approved documents

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

Document	Version	Date
Application		12 June 2007
Investigator CV		10 June 2007

Protocol	v.1	05 March 2007
Covering Letter		14 June 2007
Interview Schedules/Topic Guides	Draft v.1	10 June 2007
Participant Information Sheet: Phase 2	2	10 July 2007
Participant Information Sheet: Phase 1	2	10 July 2007
Participant Consent Form: Phase 2	2	10 July 2007
Participant Consent Form: Phase 1	2	10 July 2007
Response to Request for Further Information		12 July 2007
University of Leeds liability insurance		13 June 2007
Posters	v.1	05 March 2007
Staff information sheet	1	10 June 2007
Draft interview schedule	v.1	10 June 2007
CV for supervisor, Dr Anjula Gupta		
CV for supervisor, Dr Carol Martin		07 June 2007

R&D approval

All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

Guidance on applying for R&D approval is available from <http://www.rdforum.nhs.uk/rdform.htm>.

Statement of compliance

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

Feedback on the application process

Now that you have completed the application process you are invited to give your view of the service you received from the National Research Ethics Service. If you wish to make your views known please use the feedback form available on the NRES website at:

<https://www.nresform.org.uk/AppForm/Modules/Feedback/EthicalReview.aspx>

We value your views and comments and will use them to inform the operational process and further improve our service.

07/H1306/83	Please quote this number on all correspondence
--------------------	---

With the Committee's best wishes for the success of this project

Yours sincerely


 Dr John Holmes
 Chair



Our Ref: 2007 / 50 / L

West Yorkshire Mental Health R&D Consortium
Research & Development Department
North Wing, St Mary's House,
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E-mail: john.hiley@leedsmh.nhs.uk
Direct Line: 0113 295 2387
FAX: 0113 2952412

Sarah Louise Richards
Academic Unit of Psychiatry
15 Hyde Terrace
Leeds
LS2 9LT

02 October 2007

Dear Sarah,

RE: Service users' positive experiences of psychosis

I am pleased to inform you that the above project has been approved by the relevant Consortium panel and we now have all the relevant documentation relating to the above project. As such your project may now begin within the Trust.

This approval is granted subject to the following conditions:

- You must comply with the terms of your ethical approval. Failure to do this will lead to permission to carry out this project being withdrawn. If you make any substantive changes to your protocol you must inform the relevant ethics committee and us immediately.
- You must comply with the Consortium's policy on project monitoring and audit.
- You must comply with the guidelines laid out in the Research Governance Framework for Health and Social Care¹. Failure to do this could lead to permission to carry out this research being withdrawn.
- You must comply with any other relevant guidelines including the Data Protection Act, The Health and Safety Act and local Trust Policies and Guidelines.

¹ Details from:

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4108962&chk=WdeITv

The Consortium members are:

- Bradford District Care Trust
- Leeds Mental Health Teaching NHS Trust
- South West Yorkshire Mental Health NHS Trust
- Leeds Metropolitan University
- University of Bradford
- University of Huddersfield
- University of Leeds

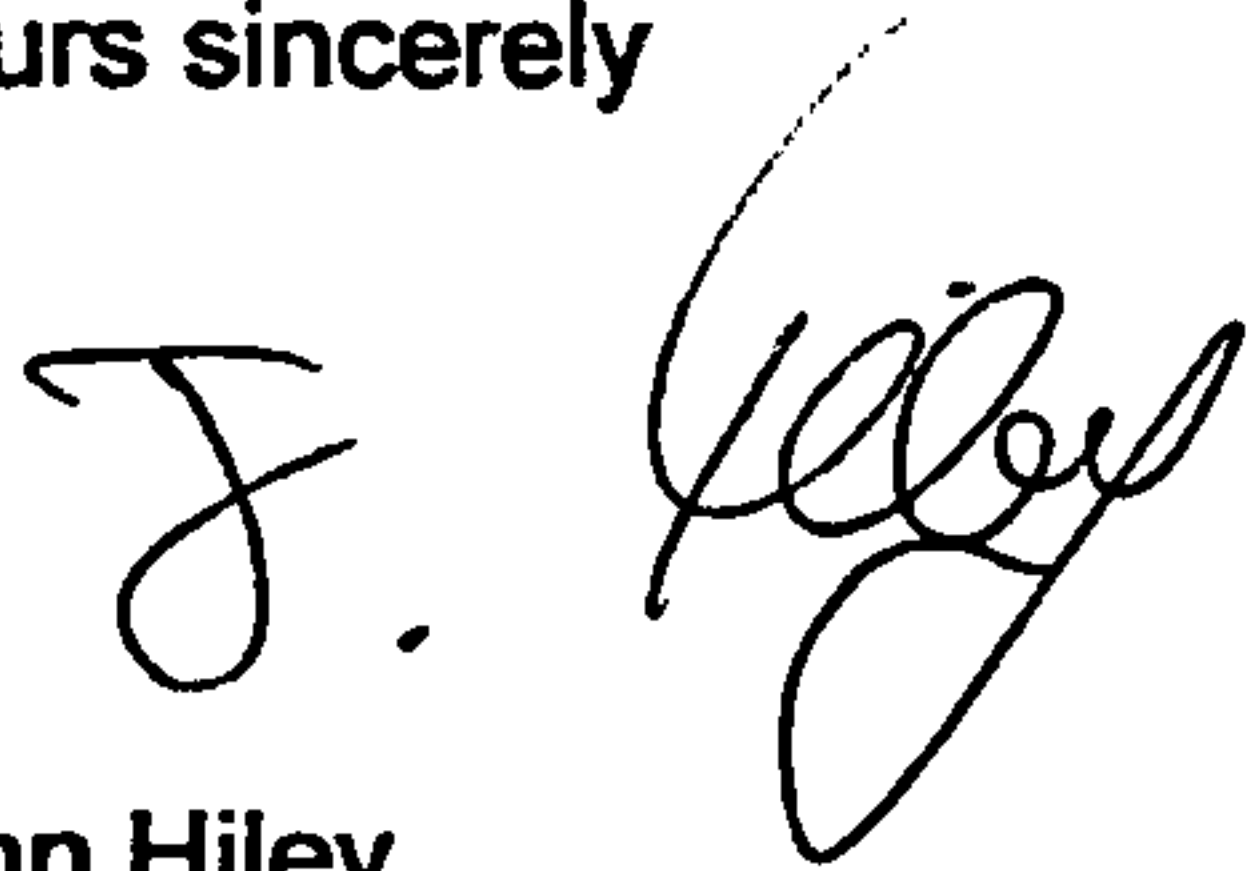
- You must adhere to the Trust's Counter Fraud policies. If you suspect that research misconduct or fraud is taking place you must report this immediately following the instructions provided in the enclosed Counter Fraud leaflet.
- If you encounter any problems during your research you must inform your supervisor and us immediately for advice/assistance.
- Research projects will be added to the National Research Register.

Once you have finished your research you will be required to complete a Project Outcome form. This will be sent to you nearer the end date of your project (Please inform us if the expected end date of your project changes for any reason).

We will require a copy of your final report/peer reviewed papers or any other publications relating to this research. Finally we may also request that you provide us with written information relating to your work for dissemination to a variety of audiences including service users and carers, members of staff and members of the general public. You must provide this information on request

If you have any queries during your research please contact us at any time

Yours sincerely



John Hiley
Research Governance & Programme Manager

The Consortium members are:

- Bradford District Care Trust
- Leeds Mental Health Teaching NHS Trust
- South West Yorkshire Mental Health NHS Trust
- Leeds Metropolitan University
- University of Bradford
- University of Huddersfield
- University of Leeds

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APPENDIX B

Participant Information Sheet: Non-NHS Group



UNIVERSITY OF LEEDS

Participant Information Sheet

**What is it like to have psychosis? -
We'd like to know how you have found it**

***A research project to look at positive experiences of
psychosis***

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the information carefully. You may also like to discuss it with other people before you make your decision.

You can ask if there is anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

***If you decide to take part, please leave a message for me on
0113 343 2732***

Many thanks for taking the time to read this information.

Sarah

Sarah Richards

Psychologist in Clinical Training

Participant Information

1. Who is conducting the study?

My name is Sarah Richards and I am the main researcher on this project, which is part of my training course in Clinical Psychology at the University of Leeds.

The research is sponsored by the University of Leeds, and has been accepted by the Leeds East Research Ethics committee.

2. What is the reason for this study?

Studies have looked into the problems of psychosis, but none have looked at good points or benefits of psychosis. Studies tell us that it is helpful to talk to people about their experiences but those with psychosis have not often been asked. This study aims to find out any benefits of psychosis from the point of view of those who experience it.

3. Why have I been chosen?

You have been invited to be a part of this study because you are a person who has experienced psychosis who may be feeling that your life is now (in the main) productive and satisfying for you. I am hoping to talk to around ten people, three of whom feel that their life is now productive and satisfying for them, and who may be able to offer a clearer picture in retrospect of their experience of psychosis.

4. What would taking part involve?

Taking part would mean meeting with me for about one to one and a half hours, to talk about your experiences. It is possible that, if we decide it would be useful to continue, we might arrange to meet a second time. You can choose where to do the interview - this could be at the University, at your own workplace, or another NHS base. Any travel expenses would be reimbursed.

5. Do I have to take part?

You do not have to take part. If you do choose to take part, you will be asked to sign a consent form; but you can pull out of the study at any time if you change your mind without giving a reason. If you do choose to pull out of the study, this will not affect your care in any way. If you withdraw from the study you can decide whether any information you have already given is used or not.

6. Will my taking part in the study be kept confidential?

When I write my thesis, I would like to use quotations from interviews to show people the different ideas or themes which have been discovered. No one will be able to find out who has talked about particular things because the information will be anonymised. If you don't want me to write some of the things you say in my thesis, just let me know.

The researcher will not inform the employer or care team of any person who participates in the research. However if something mentioned in the interview leads me to be concerned about you or someone else I will discuss the need to share that information with someone else.

When I have finished the study and written my thesis, the recorded interviews will be kept securely for up to 24 months and then destroyed.

7. What are the possible benefits of taking part?

This study will give you a chance to tell your story. Some people say that talking with someone about their experiences can be enjoyable and even helpful. This is an opportunity to talk about the good things about having psychosis and this might help people think differently. The findings of this research might help people to understand what is important to people with psychosis, especially in their recovery. The results of this study may help people to understand psychosis and change ideas about it.

8. What are the possible risks of taking part?

Sometimes talking about experiences of psychosis can be uncomfortable or upsetting. If you find any aspect of taking part upsetting, arrangements can be made for you to have a one off session with a Clinical Psychologist from the Trust within one week of the interview.

9. What will happen to the results of the research study?

The results of the project will be written up and handed in to the University of Leeds.

When the study is finished, the results will be on display at the Continuing Treatment and Recovery Units but no one will be able to identify who said what. If you like I will send you a summary of the results. I may publish the study in a scientific journal.

10. What will I need to do to take part?

If you want to find out further information about the study, you can contact Dr Anjula Gupta, (Clinical Psychologist) by phone on

Tel: 0113 343 1962

If you decide to take part, please leave a message for me on

Tel: 0113 343 2732

Many thanks for taking the time to read this information.

Charles Thackrah Building
University of Leeds
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Leeds LS2 9LJ

W www.leeds.ac.uk/hsp/hr



UNIVERSITY OF LEEDS

Participant Information Sheet

What is it like to have psychosis? - We'd like to know how you have found it

***A research project to look at positive experiences of
psychosis***

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the information carefully. You may also like to discuss it with other people before you make your decision.

You can ask about anything that is not clear or if you would like more information. Please take time to decide whether or not you wish to take part.

If you decide to take part, please let a staff member know or contact me.

Many thanks for taking the time to read this information.

Sarah

Sarah Richards

Psychologist in Clinical Training

Participant Information

1. Who is conducting the study?

My name is Sarah Richards and I am the main researcher on this project, which is part of my training course in Clinical Psychology at the University of Leeds.

The research is sponsored by the University of Leeds, and has been accepted by the Leeds East Research Ethics committee.

2. What is the reason for this study?

Studies have looked into the problems of psychosis, but none have looked at good points or benefits of psychosis. Studies tell us that it is helpful to talk to people about their experiences but those with psychosis have not often been asked. This study aims to find out any benefits of psychosis from the point of view of those who experience it.

3. Why have I been chosen?

You have been invited to be a part of this study because you are a resident, over the age of 16, living in one of the Continuing Treatment and Recovery Units in Leeds. If possible I am hoping to talk to about ten people altogether.

4. What would taking part involve?

Taking part would mean meeting with me for about one to one and a half hours, to talk about your positive experiences of psychosis. I plan to talk with you where you live, but if you are uncomfortable with that, please let me know.

Sometimes I may ask to meet people twice, when there is more to hear or so that I can make sure I have understood what has been said in the first interview.

5. Do I have to take part?

You do not have to take part. If you do choose to take part, you will be asked to sign a consent form; but you can pull out of the study at any time if you change your mind without giving a reason. If you do choose to pull out of the study, this will not affect your care in any way. If you withdraw from the study you can decide whether any information you have already given is used or not.

6. Will my taking part in the study be kept confidential?

Interviews will be recorded and then typed out so that I can make sense of what people have talked about.

When I write my thesis, I would like to use quotations from interviews to show people the different ideas or themes which have been discovered. No one will be able to find out who has talked about particular things because the

information will be anonymised. If you don't want me to write some of the things you say in my thesis, just let me know.

The staff where you live will know about my study, but I won't talk to anyone about the things you say in the interview. If you tell me something which makes me feel concerned about you or someone else I will talk to you about sharing that information with staff. When I have finished the study and written my thesis, the recorded interviews will be kept securely for up to 24 months and then destroyed.

7. What are the possible benefits of taking part?

This study will give you a chance to tell your story. Some people say that talking with someone about their experiences can be enjoyable and even helpful. This is an opportunity to talk about the good things about having psychosis and this might help people think differently. The findings of this research might help people to understand what is important to people with psychosis, especially in their recovery. The results of this study may help people to understand psychosis and change ideas about it.

8. What are the possible risks of taking part?

Sometimes talking about experiences of psychosis can be uncomfortable or upsetting. Your key worker will know the time and date of the interviews and he/she can talk to you about the interview if you found it upsetting in any way. If you remain upset after that, arrangements can be made for you to have a one off session with a Clinical Psychologist from the Trust within one week of the interview.

8. What will happen to the results of the research study?

The results of the project will be written up and handed in to the University of Leeds.

When the study is finished, the results will be on display where you live so that you can see what came out of the interviews, but no one will be able to identify who said what. I may publish the study in a scientific journal.

What will I need to do to take part?

If you want to take part

- 1 – Please tell a member of staff or tell me (Sarah Richards)
- 2 – Then I will arrange to meet you.

Many thanks for taking the time to read this information.

If you want to know more about taking part please talk to a member of staff.

Charles Thackrah Building
University of Leeds
101 Clarendon Road
Leeds LS2 9LJ

APPENDIX C
Staff Information Sheet



W www.leeds.ac.uk/hsphr

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Staff Information Sheet

**What is it like to have psychosis? -
We'd like to know what service users think
about their experiences**

***A research project to look at service users' positive
experiences of psychosis***

Service users at the Continuing Treatment and Recovery Units across Leeds are being invited to participate in a study. The study will involve interviewing people about any experiences of psychosis which may have been enriching, beneficial or positive to them in some way. Before they decide to participate, it is important for them to understand why the research is being done and what it will involve. Please take time to read this information about the study.

If service users decide to take part, they will be asked to sign both copies of the consent form and give them to a member of staff.

Many thanks for taking the time to read this information.

Sarah

Sarah Richards

Information for Staff

1. Who is conducting the study?

My name is Sarah Richards and I am the main researcher on this project, which is part of my training course in Clinical Psychology at the University of Leeds.

The research is sponsored by the University of Leeds, and has been approved by the Leeds East Research Ethics committee.

2. What is the reason for this study?

Research studies rarely focus on asking what life is like for service users with psychosis. I would like to understand more about how life is for people living with psychosis. I want to include service users in letting people know what is like to live with psychosis.

Most studies about people's experiences of psychosis only look at the negative aspects, yet service user authored accounts point to aspects which have been beneficial, enriching or positive in some way. Service users are rarely involved in research about psychosis and by learning more about this, professionals can be clearer about how best to work with them.

The findings of this research are intended to help shape the engagement of service users within recovery services. Knowing more about positive aspects of psychosis will

- help professionals using the recovery model enhance engagement of service users
- help professionals to encourage hope and feelings of self-worth in service users with psychosis
- help professionals connect with service users' hopes for recovery

3. How will the study be conducted?

We are hoping to recruit around 10 participants. Each service user will be interviewed for around one hour. In some cases, a second interview will be arranged. Then common themes will be drawn from what service users say.

4. Who can take part?

Any service user over the age of 16, living in the Continuing Treatment and Recovery Units in Leeds can take part.

Inclusion Criteria

- Adults above the age 16 years
 - Have at some time in their lives, been given a diagnosis of schizophrenia
 - Are fluent in English
-

Exclusion Criteria

- People under the age of 16 years
 - Have never received a diagnosis of schizophrenia
 - May find an interview too distressing regardless of the flexibility of interviewing times and places
 - Are unable to be interviewed (including people who are too acutely affected by their symptoms, and people who are unable to understand or reply to the interview questions)
 - Are, at no time, able to give informed consent to participate in the study
 - Are not fluent in English
-

5. What are the possible benefits of the study?

- Learning about what service users' experience, could help us to maximise aspects of recovery and reduce risk of relapse.
- Looking at positive consequences of psychosis may enhance recovery and adjustment.
- Staff and professionals can get insight into the real nature of having psychosis, leading to improved recovery services.
- The way people care for and communicate with service users could be improved if service users talk about what is helpful or unhelpful.
- By listening in depth to service users' stories, staff and professionals can learn more about unusual experiences.
- Listening to service users' experiences can make them feel valued and accepted.

A summary of the findings will be available in the Continuing Treatment and Recovery Units giving you an opportunity to see, overall, what service users think about their experiences of psychosis.

Who should I contact for further information about the research?

If anything is not clear, or if you would like more information about the study please contact: Dr Anjula Gupta, Clinical Psychologist, (Tel: 0113 2009170, email: anjula.gupta@leedsmh.nhs.uk)

**Many thanks for taking the time to read this information.
I would be grateful for your support.**

APPENDIX D

Posters

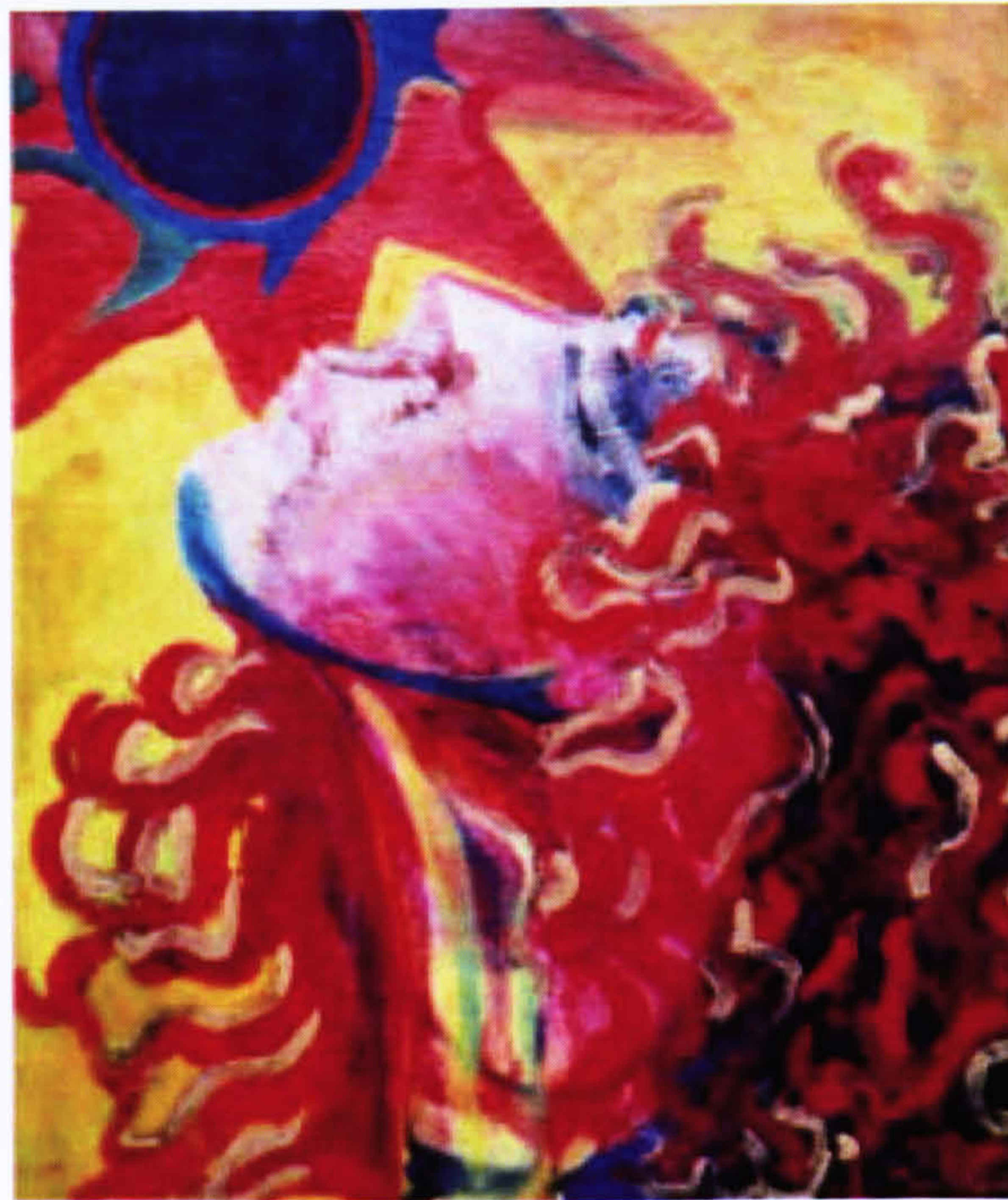
Feel like no one's listening?

Have your say!

Tell your story

And

Be heard



**We are gathering stories of people's
experiences of psychosis**

**We want to give you a say by getting involved in a
research study**

Would you be willing to share your story?

**If you're interested, speak to a member of staff.
Feel like no one's listening?**

Have your say!

Tell your story

And

Be heard



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Charles Thackrah Building
University of Leeds
101 Clarendon Road
Leeds LS2 9LJ

APPENDIX E
Consent Forms



UNIVERSITY OF LEEDS

W www.leeds.ac.uk/hsphr

CONSENT FORM

Study title: An investigation of positive experiences of psychosis using Interpretative Phenomenological Analysis (IPA)

Thank you for agreeing to take part in this study. Please answer all of the following questions. **Many thanks.**

1) I confirm that I have read the information sheet (dated x, version no. x) about the above study. Yes / No

2) I have had the opportunity to consider the information on the sheet and ask any questions. Yes / No

3) I understand that participation is voluntary. Yes / No

4) I understand that the interview with the researcher will be audio-taped. Yes / No

5) I agree to parts of my interview being quoted in reports of the research on the basis that any identifying details are removed. Yes / No

6) I understand that I can withdraw from the study at any time and withdraw consent for any information collected to be used. Yes / No

7) I agree to take part in this study. Yes / No

Signed (Participant):

Date:

Print name:

Signed (Researcher):

Date:

Print name:

Charles Thackrah Building
University of Leeds
101 Clarendon Road
Leeds LS2 9LJ

W www.leeds.ac.uk/hsphr



UNIVERSITY OF LEEDS

CONSENT FORM

Study title: An investigation of positive experiences of psychosis using Interpretative Phenomenological Analysis (IPA)

Thank you for agreeing to take part in this study. Please answer all of the following questions. Many thanks.

- | | |
|--|----------|
| 1) I confirm that I have read the information sheet (dated x, version no. x) about the above study. | Yes / No |
| 2) I have had the opportunity to consider the information on the sheet and ask any questions. | Yes / No |
| 3) I understand that participation is voluntary. | Yes / No |
| 4) I understand that the interview with the researcher will be audio-taped. | Yes / No |
| 5) I agree to parts of my interview being quoted in reports of the research on the basis that any identifying details are removed. | Yes / No |
| 6) I understand that I can withdraw from the study at any time and withdraw consent for any information collected to be used. | Yes / No |
| 7) I agree to take part in this study. | Yes / No |

Signed (Participant):
.....

Date:

Print name:

Signed (Researcher):
.....

Date:

Print name:

APPENDIX F

Interview Schedule
Exploring Positive Experiences of Psychosis

I am interested in your personal story and the ways that you have made sense of your experiences. I am interested in finding out what it is like to have psychosis. I would like you to help me to find out whether there are any good things about experiencing psychosis.

**THANKS FOR TAKING PART
 CONSENT**

What words do you use to name the experiences/problems that you're having?

How are you feeling about the interview today?

Have you got any final concerns/questions/feelings about taking part in the research?

Looking back – how would you say you're doing now?

EXPERIENCES THAT LED YOU TO REALIZE THAT YOU HAD PSYCHOSIS

- *What is your experience of having psychosis?/ What's your understanding of psychosis?*
- Can you tell me about the time when you first began to notice that things were different for you? First time you started having problems with (eg.voices)
- What were your experiences like?
- How were these experiences different to usual?
(PROMPT: *What did you make of that?*)
- What did other people tell you about what you were experiencing?
(PROMPT: *Can you tell me about what other people around you said about your experiences?*)
- Did the things that other people said about your experiences make sense to you?

MAKING SENSE OF PSYCHOSIS

- What are some of the reasons you think you have these experiences?
(PROMPT: *if you had to explain to someone else why you had these experiences, what might you say?*)

LIVING WITH PSYCHOSIS – THE IMPORTANCE AND EFFECTS OF EXPERIENCES OF PSYCHOSIS IN DAILY LIFE

- What things have helped you to make sense of your experiences?
(PROMPT: *Are there things you have found which make managing your experiences easier?*)
- Can you think of any things which might have helped you more?

(PROMPT: Can you think of anything that other people could have done to make things better/easier for you?)

PROMPT: Who has been the most helpful person/people in making things better for you?)

- Can you think of an example where you, and another person had different thoughts/views about your experiences?

(PROMPT: Is there anything that that person/group of people could have done differently?)

- Can you think of any things that have made you a better person because of your experiences?

POSITIVE ASPECTS OF PSYCHOSIS

Some people say that experiencing psychosis can cause them a lot of problems, but that there are also some positive aspects of it. Some people find experiencing psychosis scary or frightening, other people say there are benefits to their experiences.

- What feelings do you have about your experiences of psychosis?

(PROMPT: How has it been for you?)

Some people find it easy to think of some positive things about experiencing psychosis

- Have there been things which you have found positive about experiencing psychosis? Can you tell me about these?

(PROMPT: Are there any other aspects of your experiences which have been positive in some way?)

- Have there been any times when you have been happy about having experiences of psychosis?
- What made you realise that there *could* be positive aspects of experiencing psychosis alongside the negative?
- How often do you remind yourself of the positive aspects of your experiences?
- Can you tell me if you've ever come across anyone (else) who has said that their experiences have been positive for them in some way?

(PROMPT: Can you think of any reasons why some other people might be pleased they have had their experiences of psychosis?)

PROMPT: Can you think of any reasons why people might be grateful to have experienced psychosis?

PROMPT: What did you make of that?

PROMPT: What do you think other people might have thought about that?)

- Is there anything you can do now which you would not have been able to do if you hadn't experienced psychosis?

(PROMPT: Are there any skills or talents that you've developed since you have experienced/been experiencing psychosis?)

- *Sometimes it is difficult for people to think of any positives in their experiences* – do you have any ideas for why it is sometimes difficult to see the positives?

PERSONAL SKILLS – RECOGNISING PERSONAL STRENGTHS

- Can you think of any aspects of yourself which have been particularly helpful in getting you through some of the more difficult times?
-

-
- (PROMPT: What are the things that got you through the more difficult times? What things have other people identified which have got them through?)
 - Do you think that the way you make sense of your experiences has helped you with your recovery in any way?
 - What might other people say are your strengths?

CHANGES IN SELF

- Do you ever feel that you have seen an improvement in yourself or your circumstances after the experience of psychosis?
(PROMPT: Do you think differently about your experiences now than you did when you first noticed that things were different to usual? How are things different for you now than they were then?)
- Have there been any consequences of having psychosis that you didn't expect?
(PROMPT: Have you experienced things you didn't expect to experience?
PROMPT: Have you seen things that you didn't expect?)
- Have you talked to anyone else about the things you have noticed?
(PROMPT: If yes how did they react?)
- Have there ever been times when you have considered yourself to be better off than before your psychotic experiences?
- Have your feelings about your experiences of psychosis changed since you first noticed something was different/since you were diagnosed?

THINKING BACK

- When you think back over your experiences, how do they make you feel?
(PROMPT: People have a variety of emotions – how have you felt?)
 - How do you make sense of these memories of past experiences?
-

FINAL REFLECTIONS

- At the start I mentioned that if you were experiencing any difficulties after the interview that there were different options for helping with that – I am just wondering how you are now?
 - Is there anything that you expected me to ask that we have not talked about today?
 - Is there anything else about your experiences which we haven't talked about today?
 - Is there anything that you wanted to say but haven't been asked?
 - How have you found taking part in this interview?
(PROMPT:-How has it been talking about your experiences with me today?)
 - We have now finished the interview. Is there anything that you specifically don't want me to include?
 - (If yes) It may be helpful for me to meet with you again for a second interview – do you think that would be OK? Thank you for taking part in this interview.
 - (If no) Thank you for spending the time to talk to me today
-

**TEXT BOUND INTO
THE SPINE**

APPENDIX G

DW_BU Worked Example of a Subset of the Analysis

professionally 400 probably a bit more unique in this actually, is that
 401 professionally it's been a fantastic opportunity which seems
 402 quite strange but I know as a psychology undergraduate there
 403 is absolutely no question that I would be able to do the kind of
 laborating 404 work that I do and collaborate with the people I have had this
 her opps. 405 not happened to me, so conversely what was a devastating
 stating 406 experience did yield an immensely positive outcome just in
 tive outcome 407 terms of professional status which does seem quite strange
 professionally 408 and I know that's not something many people would
 409 experience. You know people like me and Rufus aren't that
 410 common because obviously people recover but they don't
 experience 411 necessarily use their experiences to then you know, so that
 412 really isn't that generalisable a point but so temporarily it did
 413 have this positive impact in that it put me in this position of
 sounds 414 .. this sounds terrible self-loving but almost having this quite
 ribly self loving 415 high profile kind of which again, I wouldn't have had you know
 n profile 416 if I'd done psychology at 18 and even if I had decided to do
 417 clinical psychology I would be in a very different position now
 was v. tive. 418 than I would be, had it not happened you know that was very
 419 positive but in terms of the experiences themselves yeah there
 person narrative 420 were some positive things about it. In the first instance I gave
 re assuring 421 you, you know about the third person narrative was actually
 422 quite reassuring. I think another thing about it that was quite
 incidental 423 positive is that it gave me, again this is an almost incidental,
 424 rather than direct impact rather, that the actual experience itself
 se of own 425 it kind of...erm I'm trying to think of the best way to put it... I
 strength. 426 think it gave me a sense of my own strength in a way because
 horrendous 427 I remember going through some really horrendous, it was at
 MPLE EXPER. 428 night particularly, and there would be things coming through
 429 the walls, there terrible maniacal laughter and this sense of
 430 insects crawling over me, really terrible stuff and yet almost
 431 feeling that it was a kind of, and this did come later, you know
 432 it wasn't like this to begin with eventually I got to the point of
 test. 433 seeing it like a test almost and I thought if I can get through
 lean get 434 this, if I can get through these experiences that most people
 rough thro... 435 can't even imagine and I can cope with it and I can get through
 436 it and I can come out the other side then it's a way of showing
 wing strength 437 how tough I actually am. If I survive this then I can go out into
 438 the world and I can look at those people who spat at me when
 439 I came out of hospital, you know those people who defaced
 440 my door and those people who goaded me to put a cigarette
 441 out on myself in front of them, which all happened when I was
 442 a student. Then when I had the breakdown at university, you
 443 know I can go out there and look at those people and walk
 444 straight past because this has shown I have reserves of
 445 strength and courage that I never really gave myself credit for
 446 and I think in a way I still feel like that now and this sounds
 447 vaguely morbid but I have quite bad scaring on both my arms
 448 from self inflicted injuries and they were something that I did
 449 do 9 times out of 10 under the influence of voices and I had

Q

WANTS TO
 MAKE SURE
 I'VE GOT A
 THOROUGH
 UNDERSTAND
 CONSIDERATE

Honest +
 not feeling sh
 has to excuse
 herself by thi
 stage of the
 interview.