Survival Narratives:
A Means of Protecting the Self from
the Threats of Psychosis

by
Linda Walley

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Abstract

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A grounded theory methodology is used to investigate people with psychotic experiences' constructions of their mental health problems. In-depth interviews were conducted on a sample of 9 people who had been given a diagnosis of schizophrenia. The focus of these interviews was on participants' understanding of the difficulties which had brought them into contact with psychiatric services, and their beliefs about mental illness and schizophrenia in general. The methodological approach taken in this research contrasts with the traditional research in this area (on insight) which assumed that deviations from the expert view of a psychosis were either deficiencies or distortions of knowledge and were in fact a symptom of an underlying pathology. Furthermore, this research challenges the notion that the discourse of people experiencing psychosis is meaningless and unintelligible, and that it should be ignored, discouraged or modified. This research suggests that people with psychosis may develop narratives to account for their subjective experiences of psychotic phenomena in the context of meanings which are available in their culture and in the context of relationships with important others both past and present. The survival narratives evident in this research embodied the struggle that people with psychosis have in maintaining a positive identity, when the core areas of that identity are challenged both by their actual mental health problems as well as the stereotypes and prejudices of mental illness and schizophrenia found in society and in the psychiatric system. Professionals working with people with psychosis must be alert to the negative impact that these social constructions potentially have on people’s self-concept and identities, and begin to address this secondary disability both in their individual work and on a systemic level.
DEDICATION

This research is dedicated to Nick Keelan, John Hall, Bill Hawkins and many others who ended their stories far too soon.
the sane have
nothing to say
alone

all they can do
is tell us we
are wrong

(Jon Swift)
Acknowledgements

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CHAPTER 1

INTRODUCTION
1.1 Introduction

Although there is a vast amount of literature pertaining to the topic of psychosis, only the dominant models of the aetiology of psychosis will be critically reviewed, as they have had the most direct impact on service users. Following this, literature pertaining directly to people's understanding of their psychosis will be reviewed from three perspectives: the psychiatric, the sociological and the psychological. Finally, research relating to the role of identity and cultural conceptions of psychosis will be discussed.

1.2 Theoretical Approaches to the Understanding of the Nature of Psychosis: The Illness Paradigm

1.2.1 The Diagnostic Classification of Psychotic Phenomena

A useful approach in developing an understanding of how people give meaning to their experience of psychotic phenomena, is to begin with an examination of the beliefs collectively known as the medical model. These beliefs are inherent in the context in which service users find themselves (i.e. the psychiatric system) and have dominated research and clinical practice for some 90 years. The medical model is embodied in the psychiatric diagnostic classification system of which there are two widely used versions, the DSM-IV (American Psychiatric Association, 1994) and the ICD-10 (World Health Organization, 1992). As psychosis is defined as a change in how people perceive and relate to the world, examination of the medical model not only provides insights into the theories and underlying assumptions about the nature of psychosis, but it also implies a position on the nature of the beliefs of people who experience psychotic phenomena.
1.2.1.1 Models of Schizophrenia

Although clusters of psychotic ‘symptoms’ have been divided into a number of different disorders, the diagnosis of ‘schizophrenia’ is the most prevalent diagnosis within the ‘psychotic disorders’ (0.5-1%) (Bentall, Jackson, & Pilgrim, 1988) and as such, has received the greatest attention from researchers. It is also the most contentious diagnosis and thus provides a good example of difficulties inherent in the medical perspective embodied in the psychiatric diagnostic classification system.

The Medical Model

For many years, schizophrenia was conceptualised as the manifestation of an underlying pathology (traditionally thought to be biological). A review of the literature typically suggests that biological explanations focus on neurochemical abnormalities (Birchwood, Hallett & Preston, 1988; Frith, 1992, and Kerwin, 1992). These generally suggest a genetic predisposition for the deficit or pathology (Murray & Reveley, 1986). Cognitive neuropsychology researchers also searched for a common underlying pathology in schizophrenia. For example, Frith (1987) suggests that schizophrenia is the result of deficits in the ability to distinguish between actions which derive from external stimuli and those that derive from internal intentions. Hemsley (1986; 1993), on the other hand proposes impairments in the rapid automatic assessment of the significance or lack of significance of sensory input. Both these theories suggest that these deficits are a direct result of biological abnormalities.

Although a strict disease model was adopted for some time, it was criticized for its highly reductionistic assumption that a wide variety of diverse experiences are determined almost solely by the influence of common biological deficits (e.g. Chadwick, Birchwood & Trower, 1996) Further criticism came from the characterization of schizophrenia as being discontinuous from the ‘normal’ experience (unlike most other clinical disorders) (e.g. Strauss, 1969). The
traditional medical model dismissed as irrelevant much of what from a psychological perspective is of central importance for studying human experience.

**The Biopsychosocial Model**

In light of the above criticisms regarding the biological model of 'schizophrenia', many researchers and clinicians began to adopt a biopsychosocial model (e.g. Fowler, Garety & Kuipers, 1995). This allows for the existence of a disorder in brain functioning, but emphasizes the role of social and psychological factors in shaping the person's symptoms. A common method of integrating these factors is through vulnerability-stress models, a number of which have been suggested (e.g. Zubin and Spring, 1977, Strauss and Carpenter, 1981, Neuchterlein, 1987; Ciompi, 1988, Perris, 1989). All share the core assumption that people who develop schizophrenia have a biological predisposition (e.g. through genetic endowment) which when combined with certain stresses (e.g. major life events) produces a psychotic episode. The chronic syndrome is believed to develop when the same stresses and/or new ones (e.g. the effects on self-worth of labelling and stigma) converge on the vulnerable person.

In their review of the research pertaining to vulnerability stress models, Fowler et al. (1995) found that while there is some evidence to support the models, the research fails to provide evidence for the mechanisms by which this vulnerability might interact with the environment. Instead the researchers turn to the various 'reductionistic' hypotheses concerning common deficits in psychosis. Furthermore, while adoption of these models gives some scope to research and interventions such as 'symptom management' or 'stress inoculation', they go only part of the way towards breaking down the dichotomy between psychological principles which are believed to govern ordinary behaviour, and 'schizophrenia', which supposedly obeys different laws. Even a psychotic person's beliefs are not considered to be subject to any of the psychological
principles of 'ordinary beliefs'. Thus delusions (although defined as 'false
beliefs') are argued to be empty speech acts, whose content is meaningless
(Berrios, 1991). Symptoms are seen only as pathological reflections of the
person's disease process to be managed or eradicated, with medication.

1.2.1.2 Deconstructing 'Schizophrenia'
Bentall, Jackson, & Pilgrim (1988) and Boyle (1990) examined the concept of
schizophrenia to determine whether the hypothesized disease was a valid object
for scientific inquiry. To this end they examined the reliability, construct validity,
predictive validity and aetiological specificity of the schizophrenia diagnosis, and
found that the scientific requirements which would warrant the grouping of the
'symptoms' into a syndrome (i.e. schizophrenia) are currently absent.

Based on this lack of empirical evidence to support schizophrenia as a valid
categorization of psychotic phenomena and its potential for stigmatization, they
called for the abandonment of the concept altogether (Bentall, et al., 1988;
Boyle, 1990). Despite this, the concept is alive and well in psychiatry possibly
because it embodies a disease model of 'mental illness' which legitimizes the
medical background of the professionals (psychiatrists) who hold the power
within the mental health services (Boyle, 1990; Pilgrim, 1990).

1.2.2 Symptom Based Approaches
Some authors suggest abandoning psychiatric diagnostic classification altogether,
by focusing on individual symptoms rather than syndromes (Bentall, et al., 1988).
They argue that this would be more likely to introduce homogeneity into the
subject matter to be studied and would help focus on phenomena that are usually
ignored, thus facilitating theoretical development. This approach reflects the
move away from seeing symptoms such as hallucinations and delusions as
discrete discontinuous entities, towards a model in which they are seen as extreme points on a continuum with normality (Strauss, 1969). Fowler, Garety & Kuipers (1995) found evidence for this from studies that demonstrate that symptoms are variable in course, may be preceded or followed by milder experiential abnormalities, are found in a substantial proportion of the normal population and may be induced in normal people when put under unusual conditions such as sensory deprivation.

Recent research on delusions (reviewed below) provides a good example of this conceptual shift and the assumptions which underpin it. Furthermore, as delusions are a form of belief, this research provides insights into some of the models of belief formation and maintenance in people with psychotic experiences.

1.2.2.1 The Formation and Maintenance of Delusions.

As Fowler et al. (1995) note, there are numerous theories about the aetiology of delusions some of which have a very long history. These can be roughly divided into perceptual theories, motivational theories, cognitive accounts and integrated theories.

Perceptual theories, in which the delusion is viewed as a logical deduction from an altered body sensation or perception have been proposed by Garety & Helmsley (1994) amongst others. Maher (1974, 1988) was one of the first researchers to argue that delusions are an entirely normal attempt to account for perceptual abnormalities. In support of this Maher and Ross (1984) note that delusions occur in many psychological and medical conditions and suggest that this indicates that they may serve some adaptive function, secondary to a primary perceptual disturbance.
While this provides a plausible explanation of delusional beliefs when anomalous experiences are clearly evident, it has been criticized for several reasons (Garety & Helmsley, 1994). The theory has difficulty accounting for delusions when these perceptual experiences are absent (e.g. Chapman & Chapman, 1988), and fails to give an explanation regarding the origin of the perceptual abnormalities. Further criticisms have centred around the fact that it does not take into account the increasing body of research which shows that reasoning may be different in people with ‘delusions’ (e.g. Garety & Helmsley, 1994), nor does the theory fit with recent evidence that the experience of anomalous percepts, such as hallucinations, is not a passive process as Maher suggests (Garety & Helmsley, 1994).

Slade and Bentall (1988) argue that delusions are but the second stage in a process of biased inference. They propose that hallucinations result from a failure of the skill of reality discrimination, so that the error lies not in the information that is available but in the inferences the person makes on the basis of that information. Other theories of delusion formation which involve cognitive abnormalities suggest that probabilistic reasoning biases such as jumping to conclusions may be involved (Huq, Garety & Hemsley, 1988; Garety, Hemsley & Wessely, 1991), while others such as Frith (1992) suggest abnormalities in metarepresentation, the cognitive mechanism that enables people to be aware of their goals, their intentions and the intentions of others. He would argue that for example, the inability to monitor one’s own ‘willed intentions’ can lead to delusions of alien control.

One difficulty with these cognitive theories is that they assume that the presence of reasoning biases is abnormal, when in fact, research has shown this not to be the case. For example, a review of the literature on studies which investigated causal attribution, illusions of control, expectancy and self-schema evaluations, suggest that distortions in self-awareness, as exhibited by overly positive
judgements and perceptions, are associated with positive mood states (Kiersky 1998). In contrast, more realistic or accurate views of the self, have been linked to depressive states and have been called depressive realism (Mischel, 1979).

Following this, some authors have argued for a motivational account of delusions. Drawing on attribution theory, Bentall, Kaney & Dewey (1991) and Kaney & Bentall (1992) found that people with persecutory delusions had an exaggerated self-serving bias, that is a tendency to attribute positive outcomes to the self and negative outcomes to external causes. As the self-serving bias is a mechanism for maintaining self-esteem for ‘normal individuals’, the finding that those with persecutory delusions had low self-esteem was interpreted as being evidence for a self-esteem preserving function for delusions of this type.

In a similar vein, Neale (1988) argues that unstable self-esteem is the psychological predisposition to bipolar disorder and to grandiose delusions in mania. Drawing from psychoanalytic thinking, he suggests that the predisposed person regularly makes use of pleasant fantasies as a means of coping with unfavourable comparisons between actuality and their ideal (which typically involves very high standards). Frequent use of these fantasies may make them more accessible and more real. In response to stress, Neale suggests that full delusions are formed as a means of keeping distressing cognitions out of consciousness.

Motivational theories of delusion are not new. Psychoanalytic theorists dating from Freud (1915/1956) have proposed that delusions are projections or externalizations of personal wishes, conflicts or fears. As such they are argued to be a reflection of a personal inner, unconscious state (for example unfulfilled need, unresolved conflict) which is expressed outwardly and attributed to an external source. There is strong scepticism about the theory underpinning these ideas, as some psychoanalytic accounts suggest that underpinning psychosis is an
ego shattered under the influence of strong conflicts (Laing, 1960; Fairburn, 1962).

Although there has not been a great deal of evidence to substantiate the motivational theory, it highlights a number of important themes in understanding delusions: that content may relate to pre-existing concerns, that delusions serve to reduce anxiety and that the personality of the patient may contribute to delusion formation. These themes, as well as the perceptual and cognitive difficulties discussed above have been incorporated into a model of delusion formation and maintenance (Garety & Helmsley, 1994) in which the various processes are thought to operate as interacting causal mechanisms with some pathways exerting stronger influences than others. They argue that the model may be most effectively used to provide hypotheses for understanding delusions in individual cases. Furthermore, Garety (1998) argues that the rigidity of delusions, being ‘firmly sustained in spite of what constitutes incontrovertible and obvious proof or evidence to the contrary’ (DSM-IV; American Psychiatric Association, 1987) may be the result of an extreme form of the normal mechanism of belief formation and maintenance, in which beliefs are generally maintained with little evidential support.

1.2.2.2 Critique: A Symptom by Any Other Name...

One of the purposes of rejecting the traditional psychiatric classification system and adopting a symptom model was to introduce homogeneity into the construct being researched. However, when one begins to examine the individual symptoms, homogeneity is not to be found. For instance, with delusions it is clear that all of the criteria previously thought to define them, that is their falsity, their reliance on incorrect inference, their incorrigibility, their modifiability and their ‘bizarreness’ in relation to a person’s culture (DSM-III; American Psychiatric Association, 1987), can be challenged (Chadwick, Birchwood & Trower, 1996).
In itself, this is a step forward, as it has generated much research. However one is left with a concept that essentially has no consistent criteria to define it.

A further difficulty with the concept of symptom, lies in its adherence to a traditional disease model in which psychotic phenomena are considered to derive from some underlying pathology. The implications of this approach remain problematic. For instance, anthropological studies of hallucinations have suggested that the conceptualization of psychotic phenomena as pathological may affect the frequency, content and emotional response to it, as well as influencing the development and termination of the hallucinatory experiences (Al-Issa, 1977). Indeed, this pathologising approach has implications for clinical practice as well, as will be explored in a further section.

A final criticism of these models comes from the assumption that people’s beliefs about their experiences are created in a social and cultural vacuum. The symptom model gives some value to the beliefs which arise out of the experience which a person has. However little thought is given to what these experiences might be, particularly in relation to the formation of beliefs about constructs such as ‘mental illness’, ‘psychosis’ etc. Furthermore, while delusions are considered to have some function in protecting self-esteem, there is no consideration of how beliefs about having a mental illness might affect someone’s self-esteem.

1.2.3 Summary

Research relating to psychotic phenomena has long been dominated by the psychiatric classification system which, in the case of schizophrenia, reduces diverse psychotic phenomena to a common underlying neurological abnormality. Research efforts have primarily been directed towards uncovering these underlying deficits, but have failed to find a common mechanism in psychosis. Recently, some researchers have begun to deconstruct the assumptions underlying
the psychiatric model, most notably by challenging the concept of schizophrenia. New models of psychotic phenomena are being proposed, primarily from a cognitive perspective, which reflect the move away from seeing people with psychosis as passive victims of a disease process whose behaviour and experiences are irrational and un-understandable. Instead, people who experience psychotic phenomena are being conceptualized as active agents making sense of their experiences, within complex systems of thinking, feeling and behaving.

Unfortunately, despite these advances, some of the assumptions of the disease model remain. Thus these new models ignore the effects that these assumptions might have on people’s experiences of psychosis and they fail to take into account the wider social and cultural influences on people’s beliefs about psychosis and mental illness in general.

1.3 Identity, Coping and the Meaning of ‘Mental illness’

It has been recognized for some time that a person’s responses to having a chronic mental health problem play a significant role in their subsequent adaption or disablement (Wing & Morris, 1981). In fact, these authors argue that adverse personal reactions to having a serious ‘mental illness’ constitute at least as important a factor in a person’s ensuing social disablement as the ‘symptoms’ of the illness itself and represent a substantial problem for that person’s ‘rehabilitation’.

Theories on identity and coping with long term mental health problems generally centre around a person’s reaction to their diagnosis. The medical or psychiatric perspective regards denial (construed as lack of insight) as a symptom of pathology and acceptance of diagnosis as a rational and healthy perspective to be
encouraged. This is in stark contrast to the labelling perspective which suggests that denial of the diagnosis is a rational attempt to avoid the stigma of mental illness, while acceptance may be the product of an uncontrollable social force (i.e. labelling). The psychological literature, on the other hand, regards people’s reactions to their ‘mental health problems’ as the result of an understandable search for meaning and control over their ‘mental health problem’ and their experiences. Recent research, discussed below, has begun to look at the significance of people’s self and identity in the context of wider social and cultural meanings.

1.3.1 The Psychiatric Model: Insight

1.3.1.1 Definition and conceptualization

Insight is a concept which typically refers to a client’s understanding of their mental health problems. Although widely used, in their review of the literature, Markova & Berrios (1992) found that the term has been conceptualized in a number of different ways, each signifying a particular aetiology for poor insight. Insight as commonly applied to psychosis is seen as the ability to recognize that one is suffering from a mental illness. Poor insight is thus seen as a cognitive deficit, often attributed to underlying biological dysfunctions.

Despite the early work of Lewis (1934) and Jaspers (1959) in attempting to define insight, scant attention was paid to the concept of insight in psychosis for many years. Dissatisfied with the conceptualization of insight, David (1990) argued for the elaboration and extension of the concept, suggesting that insight is not a unitary all-or nothing phenomenon, but falls into three overlapping dimensions: the recognition that one has a mental illness, the ability to relabel unusual mental events as pathological and compliance with treatment. David (1990) offers a standardized assessment using each of these facets of insight and suggests that
current models of cognitive psychology and neuropsychology be applied to ‘poor insight’ to elucidate the underlying mechanisms.

Amador (1991) reviewed the literature on insight and while acknowledging the possibility of lack of insight as a coping strategy or psychological defence, argues that these are tentative hypotheses which must be tested further through experimental paradigms. Drawing parallels between unawareness of illness in neurological disorders and lack of insight in ‘schizophrenia’, Amador argues that many of the self-awareness deficits observed in ‘schizophrenia’ are of diagnostic significance and have neuropsychological substrates. He further proposes that insight is a three stage process involving: 1) awareness of change 2) attribution of responsibility for change (e.g., alien forces, physical illness, or psychological disturbance or illness) 3) putting the experiences into words (which requires a high level of articulateness) (Amador, 1991).

Another approach to the cognitive deficits model of insight comes from Gillett (1995) who argues for the centrality of interpersonal interactions and socialization to normative cultural expectations for rational discourse and judgement in the development of an individual’s ways of thinking about and understanding the world. A lack of insight according to this model then, is a defect in the normative procedures of self-correction and adaptation of one’s dispositions to think or act. Gillett emphasizes the importance of real contexts of lived human activity around which social agreement is focused. He further emphasizes a qualitative difference in the thought processes of those with poor insight, the aetiology of which, he suggests is ‘biological derangement’.
13.1.2 Evaluation

Despite recent attempts to redefine and operationalise insight, there continues to be a great deal of ambiguity in the way the concept is used by mental health professionals. For example, insight is assessed as part of the standard mental state examination, where patients are said to have no insight, partial insight or good insight. However, no guidelines exist on how to qualify it or quantify it. This limited and ill-defined concept of insight is also reflected in the World Health Organization (WHO) International Pilot Study of Schizophrenia (Greenfeld, Strauss, Bowers & Mandelkern, 1989) which defined insight as present if there was awareness of an ‘emotional illness’ and absent if the illness was denied. This reflects the disease model of insight which assumes that lack of insight is merely a symptom of some underlying pathology.

Research on insight has also been affected by the difficulties in conceptualization and measurement of the concept. Insight was often considered to be a unitary entity such that it was either present or absent and the criteria for measurement were often unclear or inconsistent. Not surprisingly then, reviews of the literature in this area (Markova & Berrios, 1992; Dickerson, Boronow, Ringel & Parente, 1997) have found that the attempts that have been made to determine the relationship between insight and neuropsychological functioning, global functioning, total symptom scores, specific symptoms, prognosis, severity of psychotic episode, and compliance with medication/hospital admission have resulted in inconclusive or conflicting findings.

As well as the obvious difficulties in defining and operationalising insight, a basic flaw with the concept is that it essentially represents a client’s agreement with the doctor that they are mentally ill and must be treated for their illness according to the doctor’s advice. It therefore requires that the client reconstrue their
experiences in terms of the concepts of Western psychiatry, abandoning any social, cultural and idiosyncratic beliefs which do not concur.

These difficulties have lead some professionals to discard the concept as having limited value (Post, 1983) and others to suggest that it exemplifies a form of arrogance by relying on a single, narrow perspective (Perkins & Moodley, 1993). In a similar vein, Johnson and Orrel (1995) argue that the concept of insight is missing a social dimension in neglecting the way that people's understanding of their 'illness' may be shaped by the perceptions of mental illness and treatment which exist in their cultures and social groups. In support of this, there is considerable research on clients' and lay people's attitudes toward mental illness which has spanned over four decades and will be discussed below.

1.3.2 Labelling and Stigma

More than any other theoretical perspective, sociological theories of labelling (e.g. Scheff, 1975) and stigma (Goffman, 1961) have stimulated research and discussion about the psychiatric patient's self concept and the way it is altered by being labelled mentally ill. The processes involved in this change were proposed to be either engulfment in the patient role as a direct result of being labelled mentally ill or the disintegrative re-evaluation of self-concept as the result of institutionalization.

In support of these theories, Shephard (1984) identified two types of adverse personal reactions to having a long term mental health problem based on clinical observation. He suggested that some people cope by denying that they have a mental health problem and cling to fixed and unrealistic goals while other people adopt a 'sick role'. That is, they exaggerate their problems, as a defensive manoeuvre to preserve dignity. As a 'sick role' exempts people from some or all normal social responsibilities, the person is not blamed for any deficits.
Ultimately, these people find themselves in institutions where 'sick role' behaviour is generally expected and hence reinforced, resulting in a further exaggeration of the person's difficulties.

Reviews of the literature on labelling and stigma (Rabkin, 1972; Weinstein, 1983) suggest that much of the early research in this area primarily focused on patients' and lay people's attitudes towards mental illness or the 'mental patient'. They tended to concentrate on attitudes to the mentally ill and typically found a high level of intolerance. Such studies tell us little about the relationship between labels and the self-concept of those who are labelled, as they limited their examination to patients' beliefs about 'mental illness' in general, not about their own condition or status. These limitations are not surprising since labelling theory, as it was conceptualized at the time, depicted labelling as a process which was unilateral, and thus ignored individual interpretations and reactions.

A number of studies have challenged this limited view of labelling as it is applied to mental illness. For instance, Quadagno and Antonio (1975) argued against the traditional conceptualization of labelling which focused primarily on the social audience, successful labelling and the permanence of deviant roles. Using qualitative methodology, they found evidence that some psychiatric patients resisted labelling in order to maintain a normal identity in the face of stigmatization. They describe several forms of label resistance (symptom denial, physical ailment explanations, normalization and control maintenance) which they argued were a symbolic means of mediation through which patients cope with a stigmatized environment. They further suggested that the 'control maintenance' strategy in which patients took full responsibility for their problems, was a strategy to reject the passive mentally ill role and thus normalize difficulties. Unfortunately the conclusions that these authors made were not well supported by the data they presented as their only evidence that stigmatization
was involved came from the label rejection itself, which may have been related to other factors.

Research by Taylor and Perkins (1991) also found evidence contrary to labelling theory predictions that conforming to the stereotype of the mental patient goes hand in hand with entering the mental patient role. Instead they found that using coping strategies (by denying or adopting a sick role) was independent of people's identity as a patient or a community member and had different sets of correlates. Similarly, O'Mahoney (1982) argued that a sociological (or labelling) conception of people's reaction to their diagnosis, obscured the complex nature of patient attitudes as he found strong evidence that the self-perceptions of 'psychiatric patients' were significantly more favourable than the stereotyped views they held about mental illness. At the same time, participants also viewed themselves in hospital as being much more like the mentally ill than when they were well. He also rejected the medical conception of denial, in which denial is thoroughly unrealistic, irrational and counter-productive. He thus argued that patient denial is a normal process based on rational rejection of self-stereotyping and minor self-deception resulting from egocentric biases which play an important integrative role within the personality.

As the research has moved away from a strict labelling perspective, investigators have begun to look more generally at self-stigma and self-labelling by people with mental health problems and more specifically at the service user’s beliefs about the causes of their psychosis. Unfortunately, the latter research has been fairly limited. Two studies have looked at 'patients' causal explanations for their psychoses. In a study by Molvaer, Hantzi and Papadatos (1992) the participants' ratings of perceived causes were remarkably uninformative as they primarily rated most potential causes as neither extremely important nor unimportant. Angermeyer and Klusmann (1988), on the other hand, found that 'schizophrenic patients' were more likely to attribute the development of their illness to esoteric
influences and to their family environment than to biological factors. Unfortunately by asking people what caused their illness, both these studies were making explicit assumptions which were likely to affect their results. In fact, 22% of participants in the Angermeyer and Klusmann (1988) study refused to answer this question, which suggests that it may not have been meaningful to them.

With respect to self-stigma and self-blame, research suggests that 'insight' may reduce self-esteem and lower social status in the afflicted individuals (Link, 1987; Link, Cullen, Frank & Wozniak, 1987). Although the correlational nature of these studies makes the conclusions somewhat speculative, qualitative research looking at psychiatric patients in the community supports their findings and further shows that this self-perceived stigma and self-labelling may contribute to a sense of impaired efficacy, thus maintaining vicious cycles of emotional distress (Thoits, 1985; Corin & Lauzon, 1992). Certainly, work on attitudes to mental illness suggests that, despite the move towards community care, fear and hostility remain widespread (Bhugra, 1989). It therefore seems likely that this stigma towards mental illness impacts on people’s views of themselves and their difficulties, although the exact nature of this relationship is not well conceptualized.

As the research on people’s reaction to their diagnosis has moved away from focusing purely on external forces (i.e. labelling) acting on the person, and began to focus on internal psychological processes, two related approaches have emerged: defences and coping strategies. This research is discussed below.
1.3.3 Defences and Coping Strategies

1.3.3.1 Denial as a Psychological Defence

Deriving from psychoanalytic theory, many researchers have suggested that denial serves a defensive function. McGlashan and Carpenter (1976) provide evidence for this from the relationship between denial and postpsychotic depression (PPD). They argued that PPD arises from a lessening of defensive denial which results in the patients becoming aware of the 'tragic' circumstances of their illness.

Further evidence for this theory has been taken from the link between depression in people with psychosis and both the perceptions of an inability to control their 'illness' and the absorption of negative cultural stereotypes of mental illness (Birchwood, Mason, MacMillan, Healy, 1993). Unfortunately, the nature of the evidence is purely correlational.

Finally, the frequent finding that denial or 'lack of insight' is positively correlated with elated mood and grandiosity (see Amador, Strauss, Yale & Gorman, 1991), has also been interpreted as evidence for the defensive function of denial.

1.3.3.2 Coping Strategies

McGlashan, Levy, and Carpenter (1975) have proposed that there is a continuum of recovery styles in 'schizophrenia' which range from 'integration' at one end, and 'sealing over' at the other. They suggest that those who 'seal over' their experiences, have fixed, negative views of mental illness, and often rejected help and the illness label. They tend not to strive for any understanding of their problems nor to place their psychotic experiences in perspective with their lives. In contrast, those who use integration, cope with their 'illness' by searching for meaning of the event and attempting to place it in a coherent perspective. They
also elicit and accept help from others, are curious about their ‘symptoms’, and have a more flexible and variable attitude towards their illness.

Interestingly, these categories are very similar to two dichotomous dimensions found in the coping literature. These are repression/sensitization (Byrne, 1964) and monitoring/blunting (Miller, 1987). Both theories consider the individual’s use of and approach to information relevant to threat as part of the coping process. While sensitizers, or monitors continually scan for information about a threat, repressors or bluters would prefer not to have that information and may ignore it or forget it.

In contrast, McGlashan, Levy, and Carpenter (1975) suggest that different coping styles are more fluid and may both be used concurrently for different elements of a person’s experience.

The idea that someone can accept their illness and gain a sense of control over it has been generally viewed as the most appropriate model for psychotherapeutic intervention (e.g. Warner, Taylor, Powers & Hymen, 1989). This has been supported by research which shows that people attempt to self-manage their symptoms (Falloon & Talbot, 1981) or their signs of relapse (Birchwood, Macmillan & Smith, 1992). Furthermore, some studies have shown that an internal locus of control, rather than denial of illness seems to be associated with a better outcome in terms of the impact on the person’s disability (McGlashan & Carpenter, 1981; Warner et al., 1989). The study by Taylor and Perkins (1991) suggests a more complex picture. They found that higher levels of self-esteem and less subjective distress were correlated with denial of illness, and in comparison with hospital identity, community identity was related to better overall functioning but poorer compliance with medication. Equally, some studies have demonstrated that what is usually considered poor functioning (in terms of withdrawal), may represent active coping in the form of lifestyle
changes. These changes may come in the form of what Strauss (1989) called ‘plateauing’ at a low level of functioning followed by a resurgence of activity, or in the form of strategic social withdrawal dominated by an attitude of positive detachment (Corin & Lauzon, 1992).

1.3.4 Self and Identity

Concepts of the self and identity have long been central concerns in the study of psychoses. Traditionally, there have been two positions about the relationship of self to psychosis: loss or absence of self results in or constitutes the ‘illness’, and the ‘illness’ results in a loss of and change in self. Psychoanalytic researchers (e.g. Kohut & Wolf, 1978; Wolf, 1982) articulate the first position, suggesting that no formed or cohering self exists in someone with ‘schizophrenia’. A medical perspective would also fall within the first position, arguing that the psychological and biological pathology are located within the person, thus destroying or preventing the development of the self. On the other hand, social scientists, such as Erikson (1957), Goffman (1963) and Charmaz (1983) tend to emphasize the second perspective, describing the transformation of self and identity that results from serious mental illness. These authors suggest that it is external factors, such as responses to the individual by others and the individual’s experience with symptoms and treatment that erode, diminish and otherwise alter the self and social identity.

Since the advent of the ‘biopsychosocial’ model, research looking at self and identity in relation to psychosis has often adopted what appears to be a paradoxical stance incorporating both of the above positions. Implicit in this model is the suggestion that the self consists of biological or psychological deficits which are brought to light by the environment. At the same time, it points to ensuing social disablement (or the further disintegration of the self) as the result of external influences such as labelling.
Although in much of the research, implicit assumptions have been made about the unitary nature of the self in relation to psychosis, recent research has begun to suggest that the self consists of various domains formed within the context of the social world. Bentall, Kinderman, and Kaney (1994) offer a model of persecutory delusions which draws on Higgins' (1987) model of the self. In this model, the self consists of a number of different domains (e.g. actual-self as perceived by one's self; actual self as perceived by others, ideal-self, and ought-self). Distress is considered to result from a discrepancy between one or more of these domains. In a similar vein, Chadwick, Birchwood & Trower (1996) looking at self-concept, suggest that it can most usefully be assessed by measuring evaluative beliefs in three realms, self-self, self-other and other-self. This model focuses on the difference between inferences which are factual and evaluations which are value judgements.

This research suggests a model of the self which could be best described as humanistic or romantic (Potter & Wetherell, 1987). These authors argue that most research on self fits into three broad models of the self: the trait self, the self as roles and the humanistic self. Much like role theory, the humanistic theory of self suggests that there is the social self, but goes further in suggesting a true or real background self which chooses to act out roles and which monitors the success or failure of the performance.

A number of phenomenological studies have also looked at the self in relation to mental illness and propose what would be considered a humanistic model of the self. Thus, Davidson and Strauss (1992) found that the rediscovery and reconstruction of an enduring sense of self as an active and responsible agent proved to be an important aspect in the recovery from enduring mental health problems. Estroff (1989) suggests that many people with psychosis stress and reassert their similarities with others to retain a claim to their persisting but
unrecognized, 'not disordered selves'. She also asserts that a person’s protest or rejection of redefinition via diagnosis (or confinement) could be construed as a manifestation of this persisting, healthy, trying-to-survive self and personhood. Even in describing the process of engulfment into the patient role, Lally (1989) also highlights the importance of maintaining a positive self-image as a competent person while keeping some connections to the reality of the situation. Like Estroff (1989), Lally found that denial and minimization of people’s ‘psychiatric problems’ functioned to lessen the conflict between previously learned and culturally shaped stereotypes of mental illness and finding oneself in this category.

While this research has proposed that people with psychosis adopt what could be described as a humanistic position in relation to their conception of self, it is not clear whether this is the only position that people adopt. Drawing on Kohut’s object relations notion of a continuum between self, self-object, and object, Estroff (1989) suggests that the ‘illness’ may be experienced by some as an object and for others, a self-object while for others it may be inseparable from the self. In addition, Potter and Wetherell (1987) point out that one drawback to the use of the various models of self-as entity is that they claim to be the only valid self-portrait. These authors argue that what should be studied is how individuals construct themselves in different contexts for different purposes. In relation to psychosis this could be seen as an inquiry into how individuals locate or situate their experiences in relation to themselves or their selves given the various discourses which exist in society regarding such things as personhood, mental illness, madness etc.

Taking this further, Bakhtin’s notion of dialogicity (Bakhtin, 1975/1981) would have us look more closely at the relational nature of language. That is, Bakhtin was concerned with the way in which utterances and the speaking consciousnesses or identities that produce utterances (i.e. ‘voices’) come into
contact. Much like Vygotsky (1987), Bakhtin (1975/1981) makes a distinction between the external social speech and the internal inner speech. He proposed that inner speech is the internalisation of social intercourse, embodied in our outer speech. Furthermore, Bakhtin claims that the process of internalisation consists of two methods ‘reciting by heart’ and ‘retelling it in one’s own words’. Bakhtin suggests that ‘reciting by heart’ or repeating another’s words, involves taking them as an authoritative text, while ‘retelling it in one’s own words’ involves making the speech one’s own producing ‘internally persuasive discourse’ (Bakhtin, 1975/1981). In his view,

As a living, socio-ideological concrete thing, as heteroglot opinion, language, for the individual consciousness, lies on the borderline between oneself and the other. The word in language is half someone else’s. It becomes one’s own only when the speaker populates it with his own intention, his own accent, when he appropriates the word, adapting it to his own semantic and expressive intention. Prior to this moment of appropriation, the word does not exist in a neutral and impersonal language (it is not, after all, out of a dictionary that the speaker gets his words!), but rather exists in other people’s mouths, in other people’s concrete contexts, serving other people’s intentions: it is from there that one must take the word and make it one’s own.

(Bakhtin, 1975/1981: 293-294)

In sum, human communication was viewed by Bakhtin as being socially organised in certain ways that shape what individuals say. The utterances of someone with psychosis could therefore be seen as the ‘product of the reciprocal relationship between speaker and listener, addressee and addressee’ (Bakhtin 1984: 85) where both parties adopt positions or ‘voices’ within a wider social context with ‘languages’ concerning such concepts as mental illness,
One could further hypothesise that the person’s identity is negotiated within these relationships. As Bakhtin (1984:287) wrote ‘I am conscious of myself only while revealing myself for another, through another, and with the help of another.’

Kirmayer and Corin (1998) suggest that one way of looking at how the self is constructed in relation to psychosis is through the concept of narratives. Narratives embody collective knowledge in the form of semantic networks that confer meaning on experience, and include images, practices and links to external situations. They have been shown to be particularly important in the construction of a coherent sense of self against which events are evaluated through a process of self awareness (Bruner, 1990; Kerby, 1991). There is some evidence that the ability to organize discourse at the level of narrative is impaired in ‘schizophrenia’ (Hoffman, 1986) which may be linked to difficulties in self awareness. As the form of narratives differs cross-culturally, including narratives about the self, Kirmayer and Corin (1998) argue that insight in psychosis may be culturally dependent insofar as culture impacts at the level of what narratives of the self are available, socially coherent and credible.

1.3.5 Insight as a Sociocultural Process

As many social psychological studies show that self-knowledge is composed of context-dependent interpretations of one’s own behaviour and experience (Nisbett & Wilson, 1977; Neisser, 1988; Ross & Nisbett, 1991), then the implications of social and cultural beliefs and practices on people’s understanding of their psychosis cannot be underestimated. As has been discussed earlier, there is a sizeable amount of literature which confirms the existence of negative stereotypes of mental illness in general and schizophrenia in particular and suggests the deleterious impact that these stereotypes have on
people with psychosis. Indeed, clinicians have acknowledged this, and incorporated this thinking into their clinical work.

1.3.5.1 Promoting Illness Awareness: the Medical Model
In order to address the potential impact of negative stereotypes of mental illness on those who experience it, clinicians have promoted illness metaphors as empathic and clinically beneficial ways of understanding the adverse life predicaments of people in severe psychological distress (Sedgewick, 1982; Leff, 1993). The argument for promoting such a model is to avoid self-blame (attributing blame to illness rather than personal failure) and to assist the person in developing feelings of control and hope for the future. This model is also used as a rationale for advocating various forms of treatment, most commonly psychotropic medication.

For some clients, the illness metaphor is a useful one, and numerous studies suggest that agreement with the clinician’s diagnosis and awareness of symptoms often tend to be associated with better rather than worse outcome (Lin, Spiga & Forscht, 1979; McEvoy, Aland & Wilson, 1981; Heinrichs, Cohen & Carpenter, 1985; McEvoy, Apperson, Ortlip, Breckosky & Hammill, 1989; Warner, Taylor, Powers & Hymen, 1989). A sizeable proportion of people with psychosis, however, have not adopted this model and in fact maintain that they do not have a mental illness at all; in one study 35.3% of the men and 76.9% of women participants denied they had a mental illness (Taylor & Perkins, 1991). As ‘denial of illness’ can be related to medication non-compliance, and other forms of perceived behavioural deviance, the unwillingness to adopt an illness model has been seen by clinicians as a problem to be overcome for some time. Considerable effort has been made to overcome this problem which has resulted in the gradual realization by clinicians that promotion of the illness model is not straightforward; the model comes in different forms, and can be packaged in many ways. Thus, a biopsychosocial model was promoted in the hope that it
would have more face validity than a purely biological model. Similarly, didactic methods of promoting illness awareness (in the form of psychoeducation) have been replaced with more individual and empathic methods (in the form of cognitive behaviour therapy). Unfortunately, there is no research to suggest that these changes have made any difference and even if they have, many clients may not have access to a sympathetic clinician with time to discuss how a complex psychological model applies to them individually. Furthermore, insight continues to be thought of as the adoption of facts about mental illness, thus ignoring the growing literature which suggests that it is a social process negotiated among clients, families, friends and experts who may belong to the patient's culture of origin or may be situated outside of that culture.

A further issue which is overlooked in encouraging people to accept their diagnosis or adopt a 'biopsychosocial model' is the impact on that person of pathologising their experience. White (1995) refers to this process as the use of discourses of pathology, which he suggests consists of numerous ways of communicating and interacting with people that reproduce the subject/object dualism which is so pervasive in the structuring of relations in our culture. He argues that mental health professionals construct people as objects of psychiatric knowledge which claims to speak the truth, defining what is true and false, pathological and normal. This, then, may contribute to a sense of identity which has 'otherness' as its central feature.

From a clinical perspective, Blackman (1995) highlights the effect that traditional psychiatric discourse has on clients who hear voices ('auditory hallucinations'). She suggests that psychiatric discourse, in which an 'hallucination' is a symptom of a biological illness of the brain, denies the validity of voice-hearing experience for the individual involved and aims to 'bring the person back to reality'. Since attending to inner turmoil is considered a part of the illness process itself, a denial of voices is encouraged. She further reflects on the power of the psychiatric
discursive practice (through government and regulation) to translate subjects’ experiences into psychiatric abnormalities rendering the subject as a passive recipient devoid of responsibility and rationality.

A relatively recent therapeutic approach which challenges the pathologising nature of psychiatric discourse, is embodied in the Hearing Voices movement (Romme & Escher, 1993). A large part of this movement of users and former users of psychiatric services, has involved the development of self-help groups for people who hear voices (Hearing Voices Groups). These groups provide a forum on the margins of the psychiatric system, where people can talk about their experiences of hearing voices within a normalizing framework. The Hearing Voices Network thus seeks to change the meaning of voice hearing (both for the hearer and society) from an object of medical discourse, to a reasonable response within the interpersonal context of the voice-hearer’s life.

The rapid growth of these groups in the UK and elsewhere, suggests the value placed on this approach by some service users and professionals. Certainly, some users and ex-users are dissatisfied with their experiences of the psychiatric system, having struggled with the effects of the label of ‘schizophrenia’ or in some cases ‘section orders’. What is clear from listening to their narratives of their experience, is that the illness paradigm is embodied in a powerful political system which has far reaching implications for a person’s life. Thus, despite the fact that medication is not effective in all those who are treated and its short and long term side effects may be extremely aversive, failure to follow the advice of the psychiatrist regarding medication is likely to lead to a process which generally begins with persuasion and coercion, and could potentially end in involuntary confinement in a mental health facility.
13.5.2 The Implications of Cultural Concepts of Psychosis

From a cross-cultural perspective, Kirmayer and Corin (1998) argue that although psychotic behaviour is recognized as universally deviant, the systems of meaning surrounding the self and deviant behaviour (in terms of mental illness) may influence how a person with psychosis is able to integrate their experiences into their existing understanding of themselves and the world around them. He argues that the way in which many non-western cultures view deviant behaviour initially in terms of its interpersonal, social and moral significance, may provide more complete and satisfactory accounts of experiences for the individual than accounts that focus on illness. Religious interpretations may be particularly salient and credible for the sufferer and their social circle not only because they provide a proper ontology for supernatural experiences, but also because they have aesthetic, moral and rhetorical force. On the other hand, illness attributions, as embodied in Western societies may not give satisfactory accounts of the psychotic experiences, as the causes and mechanisms of disease remain shrouded from view and poorly worked out.

There is as yet little empirical research on insight in psychosis from a cross-cultural perspective. Drawing from existing cross-cultural phenomenological and anthropological studies of schizophrenia, Kirmayer and Corin (1998) suggest that culturally determined modes of insight and explanation may account in part for the better outcomes reported in less industrialized countries.

13.6 Summary

People’s understanding of their psychosis has been the topic of much research over the years. The traditional medical perspective conceptualizes this ‘insight’ as a transparent act of self-perception which is thought to be related to awareness deficits or cognitive errors which are biologically based and are directly connected to other symptoms of the person’s illness. This model assumes that
there is a correct attribution for symptoms and experiences that is in common
accord, or in line with medical authority. Research on labelling and stigma has
called into question the authoritative medical view of mental illness and has
drawn attention to the adverse and disabling effects on individuals with mental
health problems of the prevailing negative perceptions of mental illness. It is
clear, however, that attributing meaning to one's experience of psychosis is a
process which is far more complex than one which denies a supposed 'truth' or
'reality' (i.e. psychiatric thinking). Furthermore, it is far more than a mere
passive process of receiving a label. Instead recent literature suggests that
'insight' or self-awareness in psychosis is an active process of making sense of
experiences within a framework of social and cultural representations about self,
identity and mental illness. It is neither a defect nor a purely defensive
manoeuvre, but a genuine alternative construction of reality which makes sense
within the person's local world of meaning and hence confers meaning on an
unusual, chaotic or disturbing experience.

1.3.7 Rationale for the current study

Although much research has been devoted towards a better 'professional or
scientific understanding' of psychosis, and subjective accounts of psychosis are
becoming more popular in the mainstream research (i.e. Schizophrenia Bulletin,
1989), there has been a shortage of research which specifically looks at people
with psychosis' understanding of their mental health problem from a subjective
perspective. This 'understanding' clearly has an impact on a large part of their
lives (their actions/inactions, emotions, relationships etc.) as they live in a society
with a variety of views (and prejudices) and will likely have had contact with a
mental health system with a dominant view regarding their difficulties. As
clinicians work with people who experience psychosis to help them adapt to, cope
with or overcome their difficulties, insights into how people view their
difficulties are extremely important. Such views potentially have an impact on
people with psychosis' engagement with and experience of services, the rapport in the therapeutic relationship, the therapeutic framework which the professional adopts, the focus of any interventions and even the therapeutic techniques adopted. This research thus aims to capture the subjective meanings that people with psychosis ascribe to their difficulties and thereby begin to elucidate the processes by which they do so.

It was hoped that this research would address the following questions:

1) What are people's constructions of their so-called 'mental health problem' and the causes of the problems?

2) What meanings do people with psychosis ascribe to the professional constructs relating to psychosis (e.g. mental illness, psychosis, schizophrenia)? What is the relationship between people's meanings and where people with psychosis position themselves in relation to these constructs?

3) What factors or processes are involved in the creation of these personal meanings or constructions?

4) How do people see themselves in relation to their experiences?
CHAPTER 2

METHOD
2.1 Rationale for the Methodology Used: The Subjectivity of Psychosis

2.1.1 The Use of Quantitative and Qualitative Approaches

There is a long history of debate in the human sciences concerning the relative merits of quantitative or qualitative approaches. The debate covers many interrelated issues, which can be broadly categorized into two main strands: technical issues and epistemological issues (Bryman, 1988).

2.1.1.1 Technical Issues

The technical version of the debate assumes that quantity and quality are not separate and incommensurable paradigms at all, but are merely methods of research that are chosen because they are most suitable to the question which is under investigation. This approach is not a new one in psychology, where particular approaches are usually tailored to the particular problems.

A quantitative approach is generally deductive, and thus concerned with testing hypotheses and existing theory. The researcher decides in advance what constitutes the required data, and constructs questions in ways to elicit data which can be contained within these predetermined categories. Thus, quantitative research is appropriate when the phenomena being researched are well understood, defined, and easily quantifiable.

Many phenomena, however, are not well understood or are poorly conceptualized. In these cases, an inductive approach is ideally suited. That is, one which begins with raw unstructured data and moves towards hypotheses or theory. Qualitative research embodies such an approach providing the researcher with creative and flexible tools to analyse the data in order to generate concepts and theories. Good qualitative research would thus seem a prerequisite to quantitative research. In the initial stages of researching new phenomena,
qualitative approaches could be used to classify data into meaningful categories, thereby allowing it to be 'measured' subsequently using quantitative analysis.

Qualitative research can also be used in areas where the object of study is complex and difficult to operationalise numerically, as is the case for many phenomena in the social world. These phenomena may have been the subject of a considerable amount of research but some of the paradigms for studying such phenomena could be argued to have outlived their usefulness (e.g. attitude research; Potter & Wetherell, 1987). Qualitative research can therefore re-evaluate old problems by offering ways to step outside traditional assumptions and generating new perspectives.

2.1.1.2 Epistemological Issues.

This strand of the quantity-quality debate involves wider and more fundamental questions regarding the nature and practice of science and the generation and legitimization of knowledge. It is within this debate that the two approaches to research are potentially seen as distinct, and potentially conflicting research paradigms.

Quantitative research embodies the received view of science or positivism. Here, scientific knowledge is assumed to be a direct reflection of underlying objects in the empirical world. To gain access to this objective knowledge of the universal laws of cause and effect, hypotheses about the empirical world are tested. Quantitative research thus renders theoretical concepts observable, manipulable and testable.

In the social sciences, this presumed access to objective knowledge is problematic, hence some researchers adopt a second epistemological position (one embodied by the cognitive revolution of psychology). This position admits
that in principle it is possible to generate accurate scientific representations from objects in the world. However in practice a whole host of social and individual biases are likely to deflect the process of knowledge generation (e.g. demand characteristics: see Rosenthal, 1966). In order to maintain an empirical position, these biases are identified and attempts are made to control for them. One could question whether it really is possible to control for all biases, particularly when institutional biases (i.e. across the discipline as a whole) are given no recognition. Furthermore, one questions whether research on phenomena conducted in a hypothetically completely controlled environment actually reflects the phenomena in the real world.

A third epistemology, and one which is often adopted by qualitative researchers, is known as constructivism. It is more radical in its implications in that it suggests that the relationship between knowledge and objects is the opposite to that of the positivistic stance. Hence it proposes that it is knowledge (i.e. constructs) which defines how objects in the world are represented. That is, since we cannot have access to objects directly, objects are constructed through the act of coming to know about the world. This calls into question the very notion of objectivity and the possibility of eradicating subjective biases. This constructivism is embodied in qualitative research and states that multiple interpretations may be placed on human experience, thought and behaviour when viewed in context and in their full complexity. Qualitative approaches therefore encourage a sensitivity to people’s own understandings as seen from their local frames of reference, or from inside their own socially situated phenomenal worlds.
2.1.2 Using a Qualitative Approach to Understand Psychotic Experiences

2.1.2.1 Focus on Meaning

With some notable exceptions (e.g. the Hearing Voices Movement: Romme & Escher, 1989; 1993) the majority of research on the subject of how people make sense of their psychotic experiences has done little justice to subjective meanings, particularly with respect to an understanding of the function and context of those meanings. Primarily coming from an empirical perspective, it has narrowly defined both those it studied and the object of study. Potter and Wetherell (1987) suggest difficulties which arise in the context of this type of research. Firstly, there are problems in the translation between the participant’s terms and the analyst’s categories. These categories are often pre-determined and carry with them many assumptions (e.g. ‘insight’). Secondly, the object which is being described by the participant, whether ‘mental patient’ or ‘schizophrenia’; or the categories used for describing, whether semantic differentials or the researcher’s own categories, are generally assumed to have the same meanings for all people. This is clearly not the case, and in fact research in discourse analysis (Potter & Wetherell 1987) has shown that to attempt to separate the awareness of the object of thought from the attitudes, beliefs or attributions concerning that object, is an impossible task.

A qualitative approach aims to transcend these difficulties by emphasizing variability of meaning both between and within individuals. Thus it provides a tool to explore the individual’s subjective experiences of psychosis and provides a context in which a fuller understanding of detailed and delicate accounts can be achieved. Providing this context thus elucidates the potential function of those meanings for the individual.
2.1.2.2 Giving a Voice to an Oppressed Group

Although there is a sizeable amount of literature which looks both directly and indirectly at people’s understanding of their psychotic experiences, it is dominated by an illness paradigm which does not do justice to the complexity of the psychological and social mechanisms which operate in creating this understanding. While the medical model is beginning to be challenged, the dominant epistemological framework for researching this subject remains a positivistic one. Hence the research questions and the parameters of the data to be gathered are highly influenced by researchers’ constructions, which for the most part remain within the boundaries of an ‘illness model’. By selecting which information is to be collected, this positivistic framework thereby maintains a position of power for researchers and clinicians alike.

A qualitative framework, on the other hand, while not claiming to abandon the researcher’s assumptions (an impossible task), attempts to make them explicit, while encouraging an open approach to the data. While this is clearly helpful in generating new ideas, some of which may challenge the illness paradigm, it also facilitates the expression of a group of people who are clearly oppressed. Thus one could argue that using a qualitative research paradigm encourages people to reflect on the very system which has been party to that oppression and validates views which may conflict with that system. In essence, a qualitative approach to research could be seen as a means of empowerment.

Representing members of groups to which researchers do not belong (particularly groups which could be conceived of as oppressed in ways they are not) is not, however, a straightforward enterprise. Wilkinson & Kitzinger (1996) suggest that representations of ‘others’ by dominant groups can be a form of control over the processes of representation of that oppressed group. The ‘other’, thus becomes a construction or a set of discourses through which the dominant group defines
itself. Historically, this has resulted in the representations of others being 'de-authorized' or dismissed as neither credible nor coherent (mental illness is a prime example).

Wilkinson and Kitzinger (1996) point out that one way of avoiding this difficulty is to speak only for ourselves. They recognize, however, that difficulties in defining who 'we' are could mean that people could speak only for themselves as single individuals. Furthermore, this would result in an over representation of the dominant group's views, resulting in the continued silencing of others and the maintenance of the unequal power relations.

An alternative strategy to overcome the difficulties of representing others involves 'celebrating otherness', a strategy which involves celebrating the 'other's' survival skills, inherent strengths and positive cultures and traditions. Wilkinson and Kitzinger suggest, however, that this approach brings with it the danger of romanticizing the 'other' and projecting on to the oppressed others, the political and social ideals of the person representing them.

A final approach for dealing with the problems of othering has been termed 'Destabilising Otherness' (Wilkinson & Kitzinger, 1996). This recognises the categories that are created in the representations and acknowledges that they are never just descriptive, but serve a constitutive and regulatory function. These authors suggest a number of ways in which 'othering' has been interrupted in the research process. These include strategies such as: critical interrogation of the relevance of the autobiographies on what researchers say, openness to criticism and analysing the effects of speaking on the discursive material context (Alcoff, 1994).

Careful consideration of the conceptualization of 'otherness' and practices of representing others are vitally important when carrying out qualitative research.
Although there are no easy solutions to the questions that arise in this context, the choice of qualitative methodology used in this research was highly influenced by an awareness of these issues. The rationale for this choice will be elaborated below.

### 2.1.3 Rationale for Using Grounded Theory

A grounded theory approach was chosen for this study as it is a general methodology for developing theory that is grounded in data systematically gathered and analysed. It is often used to explore a research topic on which 'existing theory is incomplete, inappropriate or entirely absent' (Henwood & Pidgeon, 1992: 102), but it can be equally used to generate theory where existing paradigms are no longer adequate. In this case, the latter position is applicable. That is, that the current psychological models about people with psychosis' understanding of their mental health problems have only begun to incorporate subjective accounts of psychosis and do not, for the most part, capture the complexity of their subjective worlds.

It could, however, be argued that other paradigms might have been reasonably applied to this research topic. These include approaches such as discourse analysis (e.g. Burman & Parker, 1993), narrative analysis (e.g. Riessman, 1993) or a voice-relational approach (e.g. McLean Taylor, Gilligan, & Sullivan, 1996). These methods will therefore be discussed in relation to the aims of the current study, (taking into account the methodological issues which this topic raises) in order to demonstrate why grounded theory was believed to be the most appropriate approach.

#### 2.1.3.1 Discourse analytic approaches

Given that the objective of the research is to look at the impact that stigma and social representations of mental illness and madness have on people with
psychosis' constructions of their difficulties, one could have taken a social constructionist approach. Such an approach would examine how people use language to construct versions of their world and the function these constructions have for them. One would thus turn to discourse analysis as a research methodology, of which there are a number of frameworks (see Burr, 1995). As the current study aims to give voice to members of a group which is considered to be oppressed and it could be argued that there are a number of oppressive discourses relating to madness, mental illness etc., Burman and Parker's (1993) discourse analytic approach could have been applied. The aim of such an approach would be to increase the 'voice' of marginalised discourses by taking a critical, progressive and political stance to the truth claims made by dominant discourses which help maintain oppressive power relations. While these authors point out a number of difficulties with discourse analysis, one of the difficulties with using such an approach in this research concerns its focus. That is, a discourse analytic approach concerns itself primarily with macro-social phenomena of norms and laws. It might well concern itself with the experience of being a person, but only insofar as this is dependent upon the particular ways people account for themselves and the particular representations of selfhood that are available to people in their culture. What is not examined is who or what is doing the accounting and by what processes (Burr, 1995). These are clearly issues which should not be ignored, given the clinical focus of this research.

2.1.3.2 Narrative approaches

Like the discourse analytic framework, the narrative framework is also a collection of different approaches with a variety of analytic techniques (for example, see Gulich & Quasthoff, 1985; Cortazzi, 1993) These approaches derive from a number of disciplines and incorporate a number of epistemological frameworks. Common to these, is an emphasis on the way individuals make sense of their worlds through stories. As the interview questions in this research
were framed in a manner that was likely to elicit participants' stories (about the reasons they came into contact with the Mental Health Services), one could argue that a narrative approach would have been suitable. Like discourse analytic techniques, some narrative approaches take a social constructionist perspective and focus on the discourses which inform people's narratives. There are, however, other approaches within this framework (e.g. Riessman, 1992), which presuppose an individuality outside of and in tension with its social constructions.

The difficulty with using a narrative approach which would focus on what meaning people give to their experiences and would be flexible enough to incorporate the influence of wider discourses (e.g. Reissman, 1993), is that the processes by which interpretations about the data are made are often not made explicit. Thus (much like discourse analysis) narrative frameworks do not provide a sufficiently rigorous methodology which assures the reader that the analysis is not just a re-formulation of the researcher's a priori assumptions, nor has the analysis tempted the reader into trying to close the text to alternative readings. This aspect of reflexivity, or the impact of the researcher's assumptions on the analysis, is an area which needs to be developed further in these methods.

Another aspect of reflexivity in qualitative research using interviews involves the exploration of the interaction between the interviewer and the listener and the role taken by both in constructing the narrative account. Although such an approach was actually developed within a narrative framework, (Mishler, 1992) it is often not incorporated into many narrative analyses (e.g. Reissman, 1993). One methodological approach which does explicitly examine this area is the voice-centred-relational-approach developed by McLean Taylor, Gilligan & Sullivan (1996). This will be examined next.
2.1.3.3 **A Voice-centered relational approach**

An essential consideration of a voice-centred relational approach (McLean Taylor *et al.*, 1996) is a sensitivity to factors such as ethnicity, gender, class, age, sexual orientation etc. which the authors suggest effect both the hearing and the telling of a story. These authors see ‘voice’ as central to their analysis which focuses on exploration of difference in the data. While these authors describe procedures for analysing the data which include some techniques to chart where the analytical categories are originating, overall, the choice of which ‘relational voices’ to look for appeared to have arisen more from the researchers’ assumptions regarding the data, than the data itself. In fact, the authors themselves admit that an extremely important aspect of their data in one study was overlooked in the initial analysis, and that only when the data was examined by a fellow researcher with the same ethnic origin as the participant, was it discovered. While they suggest that people with similar ‘voices’ to the participants be included in an interpretive community, one wonders what criteria should be used to determine which of the many possible ‘voices’ should be represented.

2.1.3.4 **Grounded Theory**

In contrast to the above approaches whose procedures could be argued to lack rigor, Grounded Theory as developed by Glaser and Strauss (1967) is a set of logically consistent data collection and analytic procedures which are aimed at developing theory which is ‘grounded’ in experiences, accounts and local contexts. Grounded Theory thus has rigorous procedures for researchers to check, refine and develop their ideas and intuitions about the data, while encouraging them to be extremely wary of simply reproducing their pre-existing perceptions, ideas and concepts unchanged. A grounded theory analysis begins with the data and remains close to it, building levels of abstraction directly upon the data, and checking and refining concepts by gathering further data (Charmaz, 1995).
The Grounded Theory approach was chosen for this research in order to maintain a certain amount of rigor in this study. This researcher recognized that her experiences (both professional and personal) would sensitize her to certain issues in the data (see section 4.7.3.3) which might have excluded other issues from being discovered. A distinguishing feature of Grounded Theory is the emphasis on constant comparison; a process by which codes and categories are developed from the data, rather than from pre-conceived hypotheses. It was therefore envisioned that a Grounded Theory Method would help open up the researcher’s thinking to new possibilities thus leading the researcher in unanticipated directions (Charmaz, 1990). Furthermore, a Grounded Theory approach would explicitly examine the relationship between the emerging concepts and the researcher’s pre-existing assumptions thus preventing the analysis from becoming overly constrained by those assumptions.

Certainly, early versions of Grounded Theory, with their aims of transcending the boundaries between qualitative analysis as purely intuitive and impressionistic, and quantitative research as exclusively rigorous and systematic, appealed to this researcher, who at the start of the research, continued to operate within a framework which endorsed some positivist assumptions. This balance between ‘liberating and disciplining the theoretical imagination’ (Henwood & Pidgeon, 1995: 116) is a delicate one to achieve, and one which was somewhat obscured in the original theory by the omission of the precise role of the researcher’s interpretations in theory generation. Recent constructionist revisions of Grounded Theory (Charmaz, 1990; Pidgeon, 1996; Henwood, 1996) have developed the role of researcher interpretations and have further acknowledged the multiple dimensions of subjectivity which ground knowledge claims in science. Henwood and Pidgeon (1995) argue that well grounded research should meet the criteria of ‘strong objectivity’ in which the researcher makes public the full range of interpretive processes involved in knowledge production, thus seeking to reveal rather than obscure the hand of the researcher and social bases
for knowledge. Grounded Theory, thus taken from a constructionist perspective, begins to achieve this objective through the analytical techniques which emphasize reflexivity.

The constructionist revisions of Grounded Theory also suggest a move towards a more discursive form of analysis (see, for example, Potter & Wetherell, 1987). As such, some of the methods central to Grounded Theory (particularly the constant comparison method which emphasizes variety and variability of meaning) might well be used as a form of deconstructive analysis (Pidgeon, 1996).

In a similar vein, Grounded Theory is flexible enough to be used to focus on individual narratives (Charmaz, 1995) thus responding to the criticisms from researchers from the narrative tradition who are concerned with the way it fractures the data, and does not give sufficient attention to the individual’s stories (e.g. Conrad, 1990; Riessman, 1990). In fact researchers have used Grounded Theory to examine narratives (e.g. Mills, 1997).

2.2 Procedure

2.2.1 Selection of Participants

Initially, ethical approval was sought and received from the Leicestershire Health Authority (Appendix 1). The ethics committee insisted that the researcher should not approach clients directly, but contact them through mental health workers who worked with them. This caused some difficulties as mental health workers (especially nurses) were reluctant to approach their clients. This may well have reflected the perceived vulnerability and unpredictability of people with long term mental health problems, as one nurse was particularly concerned that talking to those with delusions would ‘entrench’ them.
People were eligible for inclusion in this research if they had a diagnosis of ‘a psychotic disorder’, were able to hold a ‘reasonably coherent’ conversation for at least 20 minutes, and would not be overly distressed by discussing the topics in question. Further problems were encountered recruiting participants because of the criterion of being able to hold a reasonably coherent conversation as this criterion was interpreted by mental health professionals in various ways. Thus, it was necessary to reassure several nurses that the ‘bizarre’ content of clients’ speech did not exclude them from participating in the research.

While the researcher’s original intention had been to interview people with a variety of views about their mental health problem and to include both those that agreed and disagreed with the professionals’ construction(s) of their mental health problem, it was necessary to restrict the criteria to only those who believed that they did not have a mental health problem. This was on the insistence of the Consultant Psychiatrist in the specialty, whose approval was required in order to satisfy the conditions of the local medical ethics committee (see discussion). It proved impossible to obtain a sufficient number of participants who strictly fit this category, primarily because mental health professionals found it difficult to determine whether their clients fit the criterion. This difficulty arose for two reasons. Firstly, not all mental health professionals were aware of their clients’ beliefs concerning these issues. Secondly, people’s beliefs concerning this issue were complex and did not necessarily fit into a simplistic criterion which required that they either believed or did not believe they had a mental health problem. As a result, the criteria were interpreted by some mental health professionals as being equivalent to ‘limited insight’. Other mental health professionals appeared to select clients they believed would be open and willing to talk in the interviews, irrespective of their beliefs. Ultimately, the difficulties encountered in recruiting participants worked in favour of the researcher’s original aims as the sample
included people with a wide selection of views concerning their 'mental health' problem.

Participants were selected from the Psychiatric Rehabilitation Services in Leicester. Potential participants were initially approached by the mental health professional who had the most contact with the person (i.e. keyworker, primary nurse, community mental health nurse, or psychologist). They were informed that the researcher was interested in their experiences of the difficulties which brought them into contact with mental health services, and that the interviews would be audiotaped and transcribed in order to fully understand what they had said (see Appendix 2 for a copy of the research information leaflet). If people were willing to participate, they were contacted either directly by the researcher or through a mental health professional known to them. Of the 37 people who were approached, 18 signed the consent form to be interviewed, 2 of whom subsequently refused to be interviewed. A further 2 people were not interviewed as they did not meet the criteria for inclusion in the study. Of the 14 people who were interviewed, 3 further people were found not to meet the inclusion criteria, thus their interviews were not included in the analysis. In the course of one interview, one person asked to withdraw from the study when he became convinced that the researcher was trying to make him 'ill'. His interview was terminated immediately. Another person withdrew from the study at the end of her interviews. In total, then, 9 people's interviews were included in the analysis, of which one was a client in psychotherapy with the researcher. The decision was made to include her as she had asked that her sessions focus on these issues. Every effort was made to ensure that this client did not feel obliged to participate.

The age range of the participants was 26-54, of whom 3 were female and 6 were male. The ethnic origin of participants was mixed: 2 of the participants were Afro-Caribbean, one was Asian, one was Irish and 6 were white British. All participants had been given a diagnosis of schizophrenia, while 2 participants
were also diagnosed as depressed at some point. The number of years of contact with psychiatric services ranged from 7-40 years. The participants lived in a variety of settings: 2 of the participants were living independently in the community, 2 others usually lived independently, but had been admitted to an acute residential unit for a 'relapse' and 5 of the participants lived in residential homes with varying degrees of support. Four of the participants were detained under sections of the Mental Health Act, while one was on a supervised discharge.

2.2.2 Developing an Interview Schedule

A semi-structured interview format was chosen to allow the interviewer the freedom to follow up interesting areas that arose, as well as follow the participant’s interests or concerns. This format is also helpful in establishing a rapport as it encourages a more ‘natural’ conversation than a structured interview. At the same time, the presence of pre-determined questions and prompts adds some structure to the interviews.

The interview schedule was designed to elicit people’s understanding of the experiences which have been labelled as their mental health problem and the causes of those experiences (see Appendix 3). Direct questions were included to explore the reasons people believed they were in contact with mental health services. Questions were also included which were designed to explore the meanings that people give to such terms as schizophrenia or mental illness, by encouraging discussion of these labels in general terms or by discussing them as they apply to other people. Questions also focused on the differences participants perceived between themselves and these ‘hypothetical others’. This interview approach was taken because clinical experience suggested that participants might not use these labels to describe themselves. Furthermore, it was anticipated that asking participants directly why they did not think they were suffering from
mental illness would have resulted in defensive and unelaborated responses (such as 'because I'm not'). In essence, by asking people to reflect on the labels which they did not feel applied to them, it was hoped that some of the reasons people chose to see themselves and their experiences in the manner that they had done would be elicited.

As a key feature of grounded theory is the simultaneous collection and analysis of data, the interview schedule was revised (see Appendix 4) in response to early data analysis. Thus, it became clear that more prompts were needed with regard to people's understanding of the professional constructs, and in response to one participant's comments, it seemed important to explore participants' experience of the interview itself.

In a similar vein, Grounded Theory advocates sampling during the initial stages of the data collection and analysis. In terms of research using interview data, this means that the interviews are adjusted while interviewing in order to follow up on emerging concepts. This was extremely difficult to achieve in this research, as the participants often spoke tangentially, making it very hard for the researcher to make decisions on which subjects should be focused on. Dividing the interviews into two sessions was helpful from this perspective as it gave the researcher time to reflect on the initial interview, and attempt to follow up areas of interest in subsequent ones.

Guidelines for carrying out semi-structured interviews were followed (Smith, 1995). Thus an attempt was made to avoid jargon, use neutral rather than value-laden or leading questions, and use open as opposed to closed questions.
2.2.4 Conducting Interviews

Interviews were conducted in residential homes, or at a community mental health team base by the researcher. For one person, the interviews were conducted in the presence of a Community Mental Health Nurse for personal safety reasons. A mental health professional known to each participant was available during the interviews, to support participants should they become distressed.

The nature of the interviews was fully described as well as confidentiality and the participant’s right to withdraw from the study (Appendix 5). This information was modified slightly for the participant who was seeing the researcher on a clinical basis, insofar as the interview was to be used to inform therapeutic work. Written consent was given for the interviews to be audiotaped and transcribed.

Interviews were conducted in either one or two sessions depending on the participant’s preference, the length of time participants were able to concentrate, and the quality of the participant’s discourse. Hence those participants who could only concentrate for short periods of time or alternatively those who spoke almost non-stop and/or whose speech was very tangential, were offered two interviews. Interviews lasted from 15 minutes to one hour.

In spite of the procedures designed to ensure that people would not be distressed by the interviews, 2 participants withdrew from the research, both becoming somewhat suspicious of the researcher’s intentions. This calls into question the suitability of interviewing some people and suggests that asking mental health professionals to make a judgement about whether their client would become distressed during the interview did not prove to be particularly effective.
This signals that researchers need to consider these issues more carefully, and perhaps consult several mental health professionals known to the client to obtain an opinion about their suitability to be interviewed.

The fact that these participants were able to withdraw from the study, however, is a good indicator of the sensitivity of the researcher to the potential distress of the participants. This was possible, in part, because of the clinical skills which the researcher had developed in working with this client group. The researcher was thus able to respond appropriately to both clients, withdrawing from the setting for the man who wanted no contact, and reassuring the woman who became suspicious of the researcher that she had no intentions of ‘putting thoughts in her head’. It was also likely that the researcher’s experience with this client group played a role in her success in negotiating the interview relationship in such a way that participants felt they had the choice on whether to participate or not. Given that this client group live in, or have contact with services in which they have traditionally been given little choice, the ability to make this decision is significant.

The researcher was also very careful to check out with participants that they were not upset at the end of their interviews. Those that may have been upset (but had opted to finish the interviews) were offered the opportunity to discuss any issues arising with a mental health professional known to them. While this may have been adequate, the nature of the interviews, prompted the researcher to offer the some participants an opportunity to discuss their issues with a psychologist, where it was felt appropriate. One participant took up this offer and was seen by a psychologist. King (1996) suggests post-interview debriefing sessions in order to clarify or refine aspects of the interview which might be confusing or concerning, and to clarify the process of the research. While this researcher did spend time after the interview, checking out any issues of concern, and built in a
question which looked at the process of the research, with hindsight, a formal de-
briefing might have been more appropriate.

It should be noted that, while this section has focused on the potential dangers of
distressing participants, the researcher received feedback from the mental health
professionals known to the clients that several of the participants had really
valued the experience of participating in the study.

2.3.3 Interview Transcription

It was initially anticipated that the interviews would be transcribed solely by the
interviewer. However time and physical limitations made it necessary to have
eight of the nine full interviews transcribed by an administrative assistant who
worked for psychologists and understood the importance of confidentiality. The
tapes were transcribed as soon as possible after the interviews. Tapes which were
not transcribed by the interviewer were later listened to in order to check the
accuracy of the transcription. Some parts of the tapes were listened to two or
three times in order to enhance the understanding of some of the emerging
concepts.

As the analysis of data using Grounded Theory is focused on the content and the
structure of the data rather than other features of discourse, transcription was
carried out at this basic level, and only long pauses and laughter included as non-
verbal material. The interviewer also kept note of any strong emotions which
arose in the interviews and used these as one of many guides to analysing the
data.

For reasons of confidentiality, only one part of one of the transcripts has been
bound in this volume. All transcripts have been bound in full as a separate
appendix (Appendix 6) which will be stored separately. Access to this Appendix
is limited to researchers and clinicians with no connection to the participants. Access can only be gained by written request to the researcher and will only be given to those who can sufficiently justify their requests.

2.2.2 The Process of Using Grounded Theory

Although a Grounded Theory approach was used in the current study, the researcher began with one approach to Grounded theory, and subsequently changed to another approach which better suited the emerging concepts in the data and the simultaneous changes in the researcher's outlook towards it. This shift of focus will be discussed in relation to the different versions of grounded theory, followed by a detailed explanation of the analytic techniques used.

2.2.2.1 Moving from an Empirical to a Constructionist Approach

Strauss & Corbin's (1990) version of Grounded Theory was used in the initial stages of the data collection and analysis as it provided very structured and clearly explained procedures aimed at assisting researchers with little experience in qualitative analysis. While the basic coding procedures and such techniques as negative case analysis and theoretical sampling (see page 56) were vital in the analysis, it soon became clear that the 'processual model' which is central to their analytic approach was no longer contributing to conceptual development, but was actually constraining the data. In fact, one of the original creators of Grounded Theory, Glaser (1978), took issue with Strauss and Corbin's coding paradigm, arguing that social phenomenon are not necessarily processual and that to insist that they are, may force the data. Glaser suggested that the coding paradigm is just one of many possible theoretical schemata, and thus should only be used if it fits the data.
The move away from Strauss and Corbin's model, also coincided with the emergence of concepts in the data which pointed to the need for an approach which acknowledged the joint construction of meaning between the researcher and the participants. Traditional Grounded Theory, as conceptualized by leading grounded theorists (Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin, 1990), does not offer such an approach. Instead they characterize their methods as compatible with conventional positivistic assumptions of an external reality that researchers can discover and record. It was therefore necessary to adopt a more social constructionist approach to Grounded Theory which takes an interpretive view of the research process as created through the researcher's disciplinary and theoretical interests, relationships with participants and the interactional construction and representation of the data (e.g. Charmaz, 1990, 1995). In line with this, Layder's (1993) suggestion to draw on the theory behind other approaches to research as well as other forms of general theory (Potter & Wetherell, 1987; Bakhtin, 1975/1981) was also followed.

2.2.2.2 Analytic Procedures

The analytic procedures which make up Grounded Theory are ideally suited to meeting the criteria for 'good' generative qualitative research (Henwood & Pidgeon, 1992). That is, Grounded Theory procedures should produce research in which the building blocks of emergent theory should fit the data well. Furthermore, it should create theory which is rich, complex, dense and contextually sensitive, and is therefore integrated at diverse levels of generality. Good grounded theory also demands that the researcher be sensitive to the negotiated reality of the interview, and therefore adopt a reflexive stance both in

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1 Although Grounded Theory aims to develop theory, many researchers using grounded theory find that rather than developing substantive or formal theory, they develop instead 'rich conceptual analyses of lived experience and social worlds' (Charmaz, 1995, p. 48).

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the interviews and in the analytic process. Finally, good Grounded Theory should have sufficient documentation to both facilitate the analytical process (to achieve the above aims) as well as demonstrate to the reader that the theory is grounded in the data (transparency).

The stages of the process of data analysis in Grounded Theory will be described separately, although in practice the analysis was a cyclical process not a linear one. That is, the analysis occurred at different levels concurrently or the initial stages were returned to in order to deepen the understanding of the data or elaborate on categories.

**Open Coding**

This is the initial stage of the analysis, and it involves opening up the data, examining it critically, comparing it to other phenomena and conceptualizing it. This process initially involved reading and re-reading the transcripts and labelling the phenomena using line-by-line coding. Similar concepts were grouped to develop the emerging categories with precision, specificity and increasing abstraction. An example of open coding is given in Appendix 3.

In the researcher’s attempts to give voice to participants, the researcher also attended to the meaning of participants’ accounts as a whole, as well as breaking them up to define their analytic properties. While this is not advocated in traditional versions of Grounded Theory (e.g. Glaser & Strauss, 1967), recent revisions of Grounded Theory suggest it is flexible enough to incorporate this approach from the narrative tradition (Charmaz, 1995).

**Techniques to Enhance Theoretical Sensitivity**

Strauss and Corbin (1990) suggest various strategies to stimulate thinking and develop the categories. Asking questions about the data is one such strategy. Questions asked included: “What is implied by this statement?”, “How does it...
relate to the person’s experience?” and “What process is occurring between the speaker and listener?” They also encourage using experience as an analytic device to stimulate reflection on the data at hand (Corbin, 1998). As a clinician, the researcher’s experience of interviewing people in a clinical setting involves attending to the thoughts and emotions which arise in the context of an interaction as a method of understanding the interview process. Since the researcher experienced extremely strong emotions in some of the interviews, it seemed reasonable to include them (in the form of memos) as a source of information about the data. While this is a rather unorthodox technique to use in mainstream research, Hollway and Jefferson (forthcoming) show that reflexivity can be used to acquire a new understanding of the dynamics which may arise between the interviewer and interviewee and their effects on the production of an account.

**Axial Coding**

This stage consists of a set of procedures whereby connections are made between categories thus identifying several main categories within which all others could be grouped. It is at this stage that Strauss and Corbin’s (1990) paradigm model is advocated. As previously discussed this was not found to be a helpful way of conceptualizing the data although the concept of axial coding did encourage the researcher to begin re-assembling the data in new ways, in which higher levels of abstraction were demonstrated. This was done through a series of diagrams which attempted to link the various categories together in different ways. The researcher then returned to the data to see if the relationships and new categories created were substantiated by the data.

**Selective Coding**

This process involves selecting the ‘core category’, or the central phenomenon around which all other categories can be integrated. It also involves systematically relating the core category to other categories, validating those
relationships and filling in categories that need further development. The data is thus integrated in new ways which involve a much higher level of abstraction.

**Theoretical Sampling**

This concept involves sampling on the basis of concepts that are relevant to the emerging theory in order to develop the theory further. This type of sampling can be done in a number of different ways, both from data yet to be gathered as well as from previously collected data. Theoretical sampling was limited in this research both by the tangential nature of the speech of the participants and by the time limitations necessary in carrying out a doctoral dissertation in conjunction with clinical training. Thus it was difficult to sample during the interviews and impossible to either select participants on the basis of emerging theoretical concepts or to follow up on concepts by arranging further interviews. Theoretical sampling thus took place primarily by returning to the data and recoding them in light of new insights. One example of this, involved sampling for other 'narrative voices' following the identification of the 'author voice' which contrasted with the 'victim voice'.

**Negative Case Analysis**

This procedure is a key component of theoretical sampling. It involves attending to the data to look for evidence, incidents and events which might challenge the emerging categories and/or their relationships. Rather than disconfirming the ideas already present, identifying negative cases helps develop variation in the emerging concepts and is thus an integral part of the constant comparative method. Negative cases are specifically labelled as such in the analysis section.

**Memos**

Memos are an integral part of grounded theory as they document the thoughts and ideas relating to the data, categories and emerging theory. They are generally written from the inception of the research project and continue through to the
final writing. They are an important element of analysis as they encourage thoughts about themes in the data and ensure these ideas are not lost. Steps were taken to maintain an awareness of the researcher's thoughts throughout the study in the form of a journal which recorded thoughts, feelings, interpretations and decision-making throughout the process.

Two examples of memos written in the reflexive diary are given below:

1) Date: January 9th '98
   Topic: Relationship between the interviewer and participant
   Cuthbert comments on the difficulties he had in communicating with me. He appears to be commenting on both the cognitive difficulties which he sees as affecting his thinking and the issue of trusting someone with very personal information. While it was virtually impossible to get him to clarify what he was trying to say any further (perhaps because of his 'unclear mind') it was clearly an important issue for him and one which should be followed up in subsequent interviews.
   What impact do I have on my participants' stories? What aspects of my biography influence what people say? How is my connection with the health service and all it stands for, perceived by participants?

2) Date: February 13th, 1998
   Following my interviews with Oliver, I felt extremely uncomfortable with his request that I return to talk to him. At the same time, I felt sympathy for the situation he was living in, being afforded little rights or dignity.
   When I approached the nurses to ask if he had any psychological input, one of them suggested that he only wanted someone to speak to as a ploy to have female company. In fact, she suggested he would be getting his
dirty magazines out for me next! I felt that there were no sexual overtones to the interview, and that this nurse was completely out of order to suggest that there was. I was livid with anger about this interaction as it only served to corroborate the things Oliver had been saying about the way he was treated. This incident makes me wonder about the functions of people’s accounts. Was his ‘story’ presented in such a way as to elicit my sympathy? What other functions might these accounts have? Oliver clearly pointed to my style of interaction as having influenced him. How did it impact on what he said and how he said it? Would someone who was less sensitive to the abuses which occur in institutional settings have received the same response?

Researcher Perspective

Charmaz (1990), argues that researchers should have a ‘perspective’ from which they seek to build their analysis on, without merely applying it to new areas. She suggests this ‘researcher perspective’ includes substantive interests which guide the questions asked, a philosophical stance which provides sensitizing concepts, and one’s personal experiences, priorities and values. These aspects of the researcher perspective were considered throughout the research and will be explicitly discussed in relation to the data in section 4.7.3.3 on reflexivity.
CHAPTER 3

ANALYSIS
3.1 Overview of the Analysis

As a result of the analysis, four main categories were identified, all which relate to the core category. This is summarized in Figure 3.1, which also illustrates the relationships between the categories and the core category.

A summary of the core category, the categories and their relationships will be described first. This is the general framework within which the results of the analysis are structured. It therefore provides an overview of the results.

Following on from this, the four main categories will be described in more detail. For three of these categories, this will involve a diagrammatic representation of the relationship between the categories and their sub-categories with directional arrows to indicate which categories had an impact on others. Where potential relationships between categories have not been grounded in the data, an arrow with a dotted line will be used.

The diagrams will be followed by a detailed account grounded in participants’ statements. As the ‘maintaining hope’ category emerged from the other four, it will be described only briefly as an individual category in section 3.2 but reference will be made to it in sections where it is applicable.

All verbatim material is written in italics followed by a pseudonym identifying the participant and line number(s) in brackets. Statements preceded by P were participant quotations and those preceded by I were the interviewer’s. Words which could not be deciphered from the tape are indicated with large X’s [e.g. XXXX] while words which were unclear from the tape are given in brackets followed by small x’s [e.g. (wishxxxx)]. Long pauses are indicated by (.) and stuttering is represented as hyphenated words.
In the interest of parsimony, text has been omitted from the verbatim material quoted, where it was felt to be either redundant (generally interviewer's statements\(^2\)) or where participants went off onto various tangents as in the following example:

P  Yeah. They give me injection after that.
I  And they gave you an injection after that?
P  Yeah. It's terrible. I feel hungry and thirsty and dizzy you know.

Whereas before I eat like greedy, then they they stop giving my full dinner.
I  Right, so you saw food and you used to eat, and you were greedy and you ate too much and then they stopped giving you food?
P  Yeah. 'cause I don't like meat, I don't eat meat and they put meat on my first meal.
I  Right. You don't like meat, but they cook meat here?
P  Yeah.
I  Do you eat the meat here or not? No?
P  I sometimes eat it if there's nothing else. I'm an Indian you know. XXXX goddess, you know.
I  And what?
P  Go to temple, prepare to go when somebody dies you know.
I  You go to the temple and you pray to God when somebody dies?
P  Yeah.
I  And what did you say about Goddess?
P  We are goddess if we're ladies you know.
I  Yes, you're a Goddess.
P  Get very bad things if you go with mens you know.

\(^2\) No text was omitted which would have changed the meaning of the sentence(s) in the form it was presented in the analysis.
Right, it's a bad thing if you go with men.

And it's upsetting when it's mens days (XXX). They steal mat, they steal my brother, steal my money and clothing and everything there.

(Mina; 296)

Empty straight brackets, [] are used in quotations in the analysis where text has been omitted. Text that is presented in straight brackets is intended to make explicit any references participants made to previous subjects. For example:

They're [the nursing staff] always laughing at me and pushing me about and acting big headed. (Oliver, 879)
Figure 3.1 The Core Category and its Relation to the Other Categories
3.2 Core Category: Survival Narratives

Participants developed survival narratives which accounted for their subjective experiences of psychotic phenomena by joining both minor and major life events related to the psychosis into meaningful and unified themes. These narratives were abstracted from the concrete categories relating to the aversive experiences that participants described, the stereotypes and stigma which participants endorsed or acknowledged as being associated with being labeled mentally ill, and the positions which participants adopted in relation to these threats. This research thus suggests that the survival narratives served a vital function in helping the individual survive the threats that psychosis posed to their sense of self.

Reflecting on what it was like to tell his story, one participant remarked:

*Well, it’s just a way I’ve always survived here. I know nothing’s done about it, or it seems like nothing’s done about it, whether it is or not, I don’t know.*

(Robert; 459)

One threat posed by psychosis involves the difficulties in making sense of often conflicting sensory experiences which are outside of what would be considered ‘normal experiences’. The challenge that faced participants was to develop a narrative which was both true to participants’ experiences and fitted with their understanding of themselves and the world around them. This was further complicated by interference of their thinking by unwanted thoughts, voices and other sensory experiences, which could impair their ability to make sense of their experiences.
My mind wasn't clear, that time. [ ] There was just like a cloud in my mind. [ ] Not being able to think straight. (Cuthbert; 480, 482, 485)

Other areas of the participants’ lives disrupted by psychosis also had a negative impact on how participants saw themselves (e.g. the loss of important roles or relationships). In addition, the dominant meaning systems (master narratives) available for making sense of these experiences proved to be intrinsically pathologising, thereby further denigrating the participant’s self concept. Survival narratives mediated against this denigration by developing meanings which maintained a positive identity. Intrinsic to this process was the maintenance of a sense of hope for the future.

So I expect sometime in the next two years, it’s going to come down and I should imagine shortly after that the voices will go. Umm, then I will be able to lead something of a normal life after that, hopefully. (Joseph; 850)

While Survival Narratives were created in the context of wider meaning systems, they were also created in the context of the participants’ present and past relationships with others who were real, or imaginary (i.e. they were represented in the form of voices or visions). Participants’ narratives evolved through the process of dialogue with these others, adopting positions in relation to the perceived stances of the other(s). For example, in the following quotation, Mark makes reference to dialogues with something similar to voices. These conversations made it difficult for him to decide whether to label his experiences as ‘real’ or ‘imagined’.

[I] can't make any decisions. When you try to question me, [about] these thoughts and imagination. [It’s] Like having a conversation with yourself but not actually talking to yourself, but talking to yourself inside your head, you know. You hear a voice saying this and that. I don’t hear voices...(Mark; 397, 399)
Mark suggests that it is the context of the interview questions which highlight the decision he feels he must make, but did not appear to see the interviewer's position as anything other than a curious researcher. Joseph's narrative on the other hand, incorporated a different perception of the interviewer's position regarding his difficulties. This perception of the interviewer's position was clearly based on dialogues he had had with other mental health professionals and reflected the wider medical discourse regarding his difficulties.

*Like, I mean like I could say to you two now you can both hear the voices I can hear and you'll both deny that and you'll both say the voices are inside me. []and that um, I'm not in an experiment that I'm schizophrenic.* (Joseph; 731)
3.3 Threats of Psychosis to the Self

A diagrammatic summary of this category and its relationships to the sub-categories is given in Figure 3.2. A brief overview of this category is provided below as an introduction to the following sections describing the sub-categories in more detail.

Participants' sense of self as embodied in their roles, relationships, material goods, life skills, moral worth, future goals and general competence was threatened by psychosis in a number of ways. Participants described aversive experiences (e.g. persecutory voices) which were embodied in the psychotic phenomena themselves. In addition, these phenomena disrupted the participants' abilities to function in everyday life and subsequently led to contact with the mental health system and the loss of significant aspects of the participants' lives.

Master narratives (Hyden, 1995) or cultural narratives which confer meaning to experiences added to this threat by imposing interpretations on those experiences which were devoid of hope, moral dignity, sense of agency and competence. These threats were incorporated in a form of narrative which this researcher termed a 'shadow narrative' to encompass both its threatening nature and to capture the fact that these narratives were not always explicitly elaborated but could be inferred from participants' descriptions of the challenges to their identities. These shadow narratives thus encompassed participants' fears or beliefs about what they had become (or always were) and as such embodied unacceptable versions of the self.

There was some evidence from participants' accounts that this shadow narrative reflected participants' individual vulnerabilities prior to their psychosis and may have been linked to traumatic life events. These life events also impacted directly on some of the participants, through the content of the psychotic phenomena.
Figure 3.2 Threats to Self of Psychosis
3.3.1 Aversive Experiences (Related to Psychosis)

A conceptual difficulty arises in describing the aversive experience as separate from their meanings, as some of the experiences might not have been aversive, were it not for the meanings taken from the master narratives.

The aversive experiences as described by participants can be roughly divided into unusual phenomena, distress, being out of character, trapped in the mental health system, life losses and lack of control. Many of these experiences were interrelated. For example, the various forms of distress were often seen as a consequence of the unusual phenomena. Participants, however, did not always see or indeed highlight these relationships. Thus the sub-categories will be considered individually, with descriptions of relationships which were explicitly described.

Unusual or ‘Psychotic’ Phenomena

A number of phenomena were described, including voices, visions, tactile sensations, involuntary memories, and thoughts. The content of these was often very personal and either obviously threatening or threatening because of their personal significance.

*I feel like lashing out quite a bit. [I] Umm, umm, becau...I’m under constant attack from the voices coming to me through-through these speakers all over the place.* (Joseph; 231, 233)

*Well basically I heard voices and some of them weren’t very nice. [I] they were telling me to jump out the windows and do silly things. At one time I opened the window to jump but me (CPNxxx) stopped me.* (John; 9, 16)
And they [the police] come out with things, just as you're thinking something, you know. They say something and it registers in your mind, at the same time, exactly the same time; something bad. (Robert; 113)

Distress

Participants described various negative affective states which they linked to their difficulties. These included anger, sadness, shock, emptiness, hopelessness, loneliness, fear, frustration, restlessness, worry and suicidal feelings. These were often described as the consequence of unusual phenomena and/or malice directed at the participant. The experience of distress was also described independently of any direct source but as a phenomenon in itself or a consequence of their experiences as a whole. Where the distress was not clearly labelled, often the tone of voice and language used communicated the person's distress.

I think of Hitler and the concentration camps. I don't like that. [...] the way they kill people, is like the way they kill animals in a slaughter house. [...] And that was shocking. (Oliver; 369, 378, 385)

...sometimes I, umm, I swing moods XXXX sometimes. You know, one minute I could be happy and or one minute I could be sad, or one minute I could be umm, umm, just (. ) sad or happy, more or less. [...] It all depends like, umm, your emotions of, umm, what's happening around me. (Cuthbert; 387, 395)

One participant described what it was like to be mad:

P Um, (sighs). Well, brain damage.
I Brain damage. And how does that affect you?
P Well it makes you feel any old how.
I And what's that like?
P It's like emptiness. An emptiness feeling.
I Right. And is that all the time or only sometimes?
P All the while. All the while.
I Yeah. And when you say emptiness is that like...
P Oblivion.
I Oblivion. Right.
P Nothing there, nothing there anymore.
I Right.
P That's what it feels like, brain damage.
I What did it used to be like?
P Well, there was never nothing there. But when me auntie was around, there was something there, and me uncle, but, my uncle is mad. His wife died. He's on his own now. I'm on me own.
I Right. So, are you saying that your oblivion is partly...
P Death. Death. (Oliver; 344)

Another participant describes seeking help for his extreme distress.

[I did] actually see a psychiatrist at the hospital for suicidal thoughts, feeling suicidal. (Mark; 198)

**Negative Case:** Unlike the other participants who described their experiences as causing distress, one participant, Diana, described her experiences as consisting of mostly positive phenomena and accompanying affect.

...they [the voices] kept saying things like 'isn't she lovely? isn't she fantastic?', you know, it wasn't negative, it was more positive things. (Diana; 54)

These experiences clearly influenced her narrative, and reflected both the function of her narrative in the interview and the relationship of her narrative in
maintaining a positive identity. See sections 3.2.4 for a discussion of these issues.

**Being Out Of Character**

Participants described various changes in their characters. For some, this included engaging in behaviour, which was a direct result of their ‘difficulties’ and was by implication unusual or abnormal for them.

...I’ve been in hospital twice for respite. The first time I told... I started punching the walls and stuff really hard, and then I told the manager here, R, my CPN, not CPN, my manager, and she phoned up the doctor and I was... the doctor came out and he took me straight into hospital and I was in for 2 weeks and the second time I’ve been in is where I never did nothing silly like punch walls... (Mark, 187)

You know, it’s like one time I remember I was that high, that high, and uncontrollably high and I was larry and cracking jokes and doing silly things in the middle of the street, and you know, trying to control it to a degree, but I couldn’t control it... (Diana; 691)

Participants also described impaired cognitive abilities and a general impairment in functioning. The cognitive impairments suggested that participants’ cognitive capacities were limited or overwhelmed by their experiences. The cognitive impairments described by participants included: restricted ability to think, confusion, indecisiveness, difficulties communicating with others, inability to put things into perspective, and a lack of clarity of thinking.

...you don’t focus properly and, You know, because you don’t focus properly, um, all the time, sometimes your mind goes kind of cloudy or blurry. So that’s a lot of, um, problems for me. (Cuthbert; 744)
Me mind isn't very good at the minute. Because I can't think, because the voices are that bad. And I can't concentrate on things, umm, [] I don't know what-what-what I register with an IQ test. Probably about zero. (Joseph; 865, 868)

Difficulties in day to day functioning were also described. Once again some people depicted these difficulties as the result of the unusual or distressing phenomena, while others described them as independent of other difficulties.

And I er, er, moved from flat to flat, I wasn't being able to look after meself properly. I wasn't cooking, cleaning, stuff like that; shopping, things like that. (Mark; 10)

Well, it got so I couldn't cope with everyday things, you know. (Gail; 10)

**Trapped in the Mental Health System**

Most of the participants described difficulties associated with having been in the mental health system and perceived the system as a trap which was difficult to escape from. For some participants this trap was very real insofar as they were involuntarily confined.

I'd like to be back in the community. I feel I'm quite ready to go back. I'm fed up with being in homes all the while. [But] I can't leave because I'm on supervised discharge. So that means if I leave, they'll bring me back. (John; 218, 221)

For others, the trap was more insidious as the participants recognized their need for or dependence on the services.
I always think it’s a vicious circle all the time innit? You can’t get out of the mental health system you know. It’s like a vicious circle, medication, support XXXX everything else. You can’t lead an independent life can you? [] But it is, it is good, I know, it is good, I think because if I don’t have that facility then people will be, I don’t know, people would just be really bad you know. But they’re... all the support is there you know. (Mark, 457, 461)

Another participant, while wanting to leave staffed accommodation to move to her own house was, at the same time, unable to access the resources to achieve this goal. Instead she feared she would be made homeless if she were to leave.

I want a flat or house or something but they won’t give me. [] I still wonder where to go, you know. If they send me out of here I’ll be in the street you know. I don’t know where to go. (Mina, 105, 196)

The effects of being trapped in the mental health system could be far reaching insofar as they restricted participants’ social contacts, their housing, their activities and the availability of employment or education.

...but I seem to be in a trap, a trap in the system. It’s all mental health issues isn’t it? When you meet mentally ill people with problems in places and activities. I mean the only place I get on with normal people is the XXXX at the adult education college. (Mark; 640)

...a lot of us would like to work or go back to the jobs we did before we became ill, or do a different type of job that is less stressful...[]..because the system, it doesn’t work that way, whereas they’re not allowing you to go to work and earn the money you wanna earn and survive. (Diana; 1064, 1066)
Another aspect of being trapped in the mental health system related to the ill-treatment of some participants when they were vulnerable. While this was described by participants as more serious in the days of the old psychiatric hospitals, participants also gave current examples which included denial of basic freedoms, cultural insensitivity, not being listened to and being bullied by staff.

You see when we want a drink, we can’t get one ‘cause the kitchen’s always locked. [\] And another thing, they won’t allow us to go for a walk even. [\] They let you out with staff, but not on your own. [\] and there’s never enough staff on to take you out. That’s what I’m so fed up with. [\] …and the way the staff were bullying me. [\] They’re always laughing at me and pushing me about and acting big-headed. (Oliver; 849, 852, 854, 859, 877, 879)

I don’t eat meat and they [the staff] put meat on my first meal. [\] I sometimes eat it if there’s nothing else. I’m an Indian you know. (Mina; 302, 307)

Participants also found that being in the mental health system meant associating at times with others who had mental health problems. This was seen as a difficulty by two participants who clearly saw themselves as being more ‘well’ than others.

I don’t like going into these hospitals, these psychiatric hospitals, I don’t like em. [Because of] the patients. Because they’re not well. (Mark; 204, 212)

Like I slip when I’ve been in here for a while, ‘cause there are that many people that were worse than me made me feel ill. If I’d have gone straight home I’d have been all right, if I hadn’t have come in here. (Robert; 307)

As having contact with the mental health services almost inevitably involves being treated with medication, the unpleasant effects of the medication were
described as another part of the aversive experience of being in the mental health system. Often people did not feel they had any benefit from the medication and some were angry at being over medicated and/or forced to take medication against their will.

*Medicine leaves scars, you see.* [I'm on medicine now. I'm on too much. I'm on 400 tablets a month. I take all them tablets a month. I don't want them.]

[They're doing me no good. (Oliver; 189, 192, 198)]

The impact this could have on a person is exemplified in the following.

...people trying to kill me. [Yeah, I've had that thought. Especially when you're taking drugs. You know, when you're taking drugs, the psychiatric drugs.]

[You know a lot of people would go to (I did this too) go to different chemists to get your drugs from because they're not going to be sure which chemist you're gonna go to, to get your drugs from. Because you don't know what you're taking in your body. ...because they never explain to you what's entailed in the drugs. Anything could be in there. (Diana; 835, 838, 842, 846)]

**Life Losses**

As a result of their difficulties, participants suffered significant losses in many areas of their lives. These included material goods, roles, relationships, and social and occupational opportunities.

*See when I was beaten up and caused to be mentally ill, I had a standard of living. I had a 4 bedroomed house; I had a pretty wife, two pretty children, three pretty children, all the money I needed in the world, motors. I had motors, I had more than one motor car. I had a big garden, I had a garage, I had planning permission for a builder's yard, I had the chance, the opportunity of becoming a director for a company. (Robert; 347)*
They took me in Psychiatric Hospital originally. Gave me a XXXX and I lost the keys of the house. [] I had to leave the house because he died in my arms. Two men died in my arms. My father died, a friend of mine died, my mother died. I had a terrible time after this you know. [] he, somebody(XXXX) took the keys out of my hand, you know, my bedsitter(XXXX). He stole my keys, he stole my money... Yeah. I lost many of my clothes, clothing getting lost. I lost many things as well you know. Lost the house and I got no house, I still..... (Mina, 11, 31, 41)

For some the losses of significant relationships were compounded by the lack of opportunity to form new relationships.

[I] still think of my auntie. She's been dead years. And (me uncle'sxxxxxxx) been dead 30 years and [] I've no-one else to talk to, have I? No-one else to talk to any more. (Oliver; 603, 606)

Lack of Control
A final and significant threat arising out of the experiences related to psychosis was the participants' perceived lack of control over their lives. This lack of control related to many of the aversive experiences of psychosis, from the unusual phenomena themselves and their effects on people's functioning to being trapped in the mental health system.

-the voices... I dunno, um kind of like overtaking my life, and because of the voices, I had no control over them. It meant that I was not eating, sleeping...(Diana; 10)

For some, the unusual phenomena were experienced as relentless persecution which was uncontrollable. This fostered feelings of frustration and powerlessness.
I sometimes get quite emotional, but like (.) It's -it's anger, agitation, they're
provoking me all the time. They're making me feel like lashing out, very, very
annoying to me because I'm under constant attack from things I can't fight back
against. (Joseph; 382)

So they [the police] keep saying those things to me until I collapse or go
screaming mad. They keep on and on and on regardless of what you do.
You can fall on the floor, twist and turn and do anything; punch yourself, bite
yourself, kill yourself. They're not bothered. Just so long as they get at you.
(Robert; 254)

As well as feeling powerless, these aversive experiences which participants
perceived as persecutory lead to participants feeling extremely angry.
Participant's narratives suggested that this anger could be externally directed as in
the 'lashing out' which Joseph describes above, or internally directed towards, as
Robert illustrates in the latter quotation.

3.3.2 Master Narratives

The master narratives (dominant meaning systems) which were available to
interpret participants' experiences fell into two categories: cultural narratives
relating to mental illness and sub-cultural narratives relating to super-natural
phenomena.
3.3.2.1 The Cultural Narratives of Mental Illness and Schizophrenia

Not surprisingly, standard social constructions of schizophrenia and mental illness which are often represented in the media were evident in most of the interviews. Participants described the threatening aspects of these master narratives by either endorsing the view embodied in the master narrative or arguing against the view using disclaimers. Most participants initially found it somewhat difficult to describe what schizophrenia was and had to be prompted to elaborate on their ideas. While this may have been due to the potentially threatening nature of the beliefs, some participants suggested that schizophrenia was the subject of expert knowledge and therefore believed they were not able to give a proper account of it. For most participants these expert narratives had reified the concept for them either as an external disease or as a description of the person.

*Well, you’re the expert about what schizophrenia is. I mean schizophrenics hear voices, um, I’ve seen lots of schizophrenics in my time, but I’m not sure how to define the illness.* (Joseph; 1031)

One theme taken from these narratives was the idea that people who suffer from mental illness or schizophrenia are in some way responsible for their predicament.

*People that are mad* just want to deliberately be mad, be insane (Oliver, 661)

In a similar vein, the master narratives implied a sense of moral inferiority often depicted through the mentally ill person’s behaviour. Thus the participants variously suggested that the mentally ill/schizophrenic was violent, out of control, lazy, greedy, and senseless.
I would say yeah, schizophrenia, um, I'll probably say to you... um, I don't really know that much about schizophrenia, but, as far as it goes, schizophrenia is more or less like, You know like, somebody who like, umm, can't control theirself... [] People can't help... I don't really understand it myself, but, schizophrenia... Because they got schizophrenia, they say it's an illness or whatever, but I mean, they can't help what they're doing. (Cuthbert; 643, 664)

Well, [mental illness means] doing irrational things, doing first things that comes into their head. [] Oh, smash the tele' up, break some furniture, or just throw a cup of tea at the wall, or spat on the floor, like that. (Robert; 292, 294)

[people that have schizophrenia] They're mental, they beat each other up, they kill each other. (Mina; 787)

I've heard stories, true stories about people with mental health problems get mad and throw something and I don't know, someone told me they was in this hospital and then this bloke who's got this knife and he slashed his leg, cut open like a piece of meat, you know. [] And, but, er, but we're [schizophrenics] not dangerous. (Mark; 552, 557)

[mad people] act strange, you know. [] Perhaps it's just the way they're made. (John; 131, 133)

For some participants, schizophrenia meant changes or abnormalities of the personality.

I remember when I first took ill [] asking doctors and nurses, ' have I got a split personality?' (Diana; 909)
No, I don’t know much about schizophrenia, no. It’s a personality change isn’t it? (Gail; 229)

Many participants believed that there was a potential for mental illness/schizophrenia to be permanent.

I think schizophrenics can get over the illness, but I think the majority of the time, once you’re schizophrenic, that’s it, you’ve got it for the rest of your life. (Joseph; 1055)

For some of the participants mental illness/schizophrenia was visibly stigmatizing.

You can tell those people who have got mental health problems and you can tell those people who are normal. [] They look, you know over years and years and years of being in the psychiatric, you can have a look about you which makes you look like they know of the fact you’ve got a problem. (Diana; 574, 589)

Participants had various beliefs about society’s attitudes towards the mentally ill, some of which clearly came from narratives represented in the media. The general theme was one of being treated as outcasts. Thus, even if participants did not label themselves, the implication of having a mental health problem was that they would be labelled by society.

...I can’t believe I’ve got schizophrenia because (sighs) I just think it’s a big word for the doctor, you know. I’m a schizophrenic and that’s it, you know. I’m treated like one, you know. In the society, in the community, I’m treated like one. (Mark; 421)
And I remember, um, the village was in outrage about the fact that these people like myself, or them, or whatever, who were gonna move into this house, into their area, and they said that they know they're mentally ill and they're not, you know, they're worried about their children and, you know, they're elderly and all that kind of stuff, you know. That kind of bombardment was put on to the media. (Diana; 946)

3.3.2.2 Sub-cultural Narratives: the Supernatural

These narratives embody beliefs which are not so widespread but are held by subcultures (such as religious groups). Due to the mass media, however, they are reasonably familiar to most people. These narratives provided alternative explanations for some of the participants’ unusual or distressing experiences which were supernatural and included such things as psychic phenomena, religious beliefs, and extra-terrestrial influences.

But I've often thought it being, you know, something to do with aliens or something, you know, making me see things XXXXX. (Mark; 372)

At least one participant’s account suggests that her openness to supernatural beliefs may have had an influence on the narratives she created to account for her experiences.

...it's like saying I seen a ghost, someone might see a ghost, or a UFO or something like that. It's hard to believe, but people do believe in these things, there's quite a lot of people that do believe in these things. [...] So they show things like sci-fi on TV about, um, like poltergeists and all that kind of stuff, you know what I mean? People must believe in these sort of things, otherwise they wouldn't depict them on TV. [...] I always had feelings about... I see things on TV and I
think, that's gonna happen to me, or I do believe in that, if it happened to me, (Diana; 1194, 1196 1200).

Unfortunately, these narratives could also provide threatening interpretations of phenomena as in the following quotation, where the participant's religious narrative suggested the mark of the 'beast' would appear on her forehead thus signalling the end of the world.

...and I can remember hearing like, erm, like a coffin being nailed down, around me, there was a nail catching on to my side of my forehead, and the name Jesus was written. It scared the hell out of me because I thought 666 was going to appear, you know. (Diana; 76)

3.3.2.3 Competing Master Narratives

For some participants, subcultural narratives also appeared to compete against cultural ones as interpretive frameworks within which participants could make sense of their experiences. This is exemplified in the following quotations in which Diana talks about the contrast between interpreting her experiences of having had contact with Jesus as real or viewing them as a symptom of schizophrenia.

Because it was pushed into my head, it was an illness and this is schizophrenia, paranoid schizophrenia [...] some said, when I told them what I experienced 'well, I really do believe in God, so I don't dismiss what you're saying to me.' And then others will say things like, erm, 'well, you know it's not true, don't you? You know you're not special. Why should Jesus choose you?' And I was not taking it because I was not well, not totally aware of faculties at the time. [...] because I was weak. (Diana; 255, 262, 282)
It was clear that the cultural narratives were very powerful, given the context within which participants found themselves and (as Diana suggests above) their position of relative powerlessness. The power of the cultural master narratives also lay in their capacity to describe what was normal and what was not.

They think it's because the fact is I went into a psychiatric hospital, it was seen as if to say, you know, it was abnormal, it was not natural what you experienced, seeing a vision of Jesus and hearing his voice and hearing the voices in your head, you know what I mean. It isn't normal. Nobody hears things like that, you know what I mean. So, I totally dismissed it, I pushed it under the carpet.

(Diana; 241)

Although this resulted in a dismissal of her experiences, she went on to describe how she could not sustain a belief that her experiences were the result of an illness as they did not fit what she was going through.

But there were times when I did experience the same things again, do you know what I mean? So it was kind of like, you know, one minute I was trying to subside it, submerge the feeling, but it was bubbling up all the time. (Diana; 246)

In a similar vein, another participant demonstrated in the interview the conflict he experienced when he attempted to choose between a cultural master narrative pertaining to schizophrenia and a subcultural master narrative relating to extraterrestrials as a frame of reference to make sense of his experiences.

I think they could be real, yeah. [I] Er, probably because I just, er, can't believe it, you know. [I] Can't believe it's true, you know that I see these things. If I think they're real...I believe they are real, you know. [I] They might be, I don't know. I can't see it myself though. But I've often thought it being you know, something to do with aliens or something, you know, making me see things XXXX.
"Cause I've got a friend who lives upstairs, his name's T, he experiences a lot of trouble with aliens from what he's told me. But I don't know whether to believe him or not, you know, what he talks about it. 'Cause I don't know, it could be true, I don't know, you don't know these things do you? Could easily be. If it's all imaginary, it's different. I just accept it. ...and sometimes I can't believe I've got schizophrenia because (sighs) I think it's a big word for a doctor, you know, I'm schizophrenic, and that's it, you know, I'm treated like one, you know. In society, in the community, I'm treated like one,... (Mark; 363, 365, 367, 372, 377, 385, 393, 421)

The choice for this participant was between adopting a belief system which fits with his feelings regarding his unusual experiences, but which was not widely culturally endorsed, or adopting a belief system widely held in society which suggests that his experiences are a product of a disease which renders a person a misfit in society. While this participant appears to be aware of this dilemma which directly affected how he saw himself, for others the threats to participants' identities appear to be outside of awareness to a much greater extent. The researcher therefore created the hypothetical category of the shadow narrative to account for what appeared to be identity conflicts which for the most part appeared to be outside of the participants' awareness.

3.3.3 Challenges to Participants' Identities: The Shadow Narratives

One of the major challenges to participants' identities came from the master narratives, as the implications of adopting these narratives were unacceptable to participants. For example, the above quotation from Mark illustrates how the master narrative relating to schizophrenia was unbelievable as it meant that he would be labelled a 'schizophrenic' and would suffer the stigma associated with such a label. In another part of his interview, Mark demonstrated the negative impact that believing he had schizophrenia had on how he viewed himself.

85
But I often think of myself as not being normal, you know, because I got it [schizophrenia]. (Mark; 463)

Other participants’ identities were challenged directly by voices or other psychotic phenomena which often embodied a sub-cultural narrative. In the example below, the sub-cultural narratives which are evident are both religious and political ones.

I mean for most of their (the people behind the voices) lives or half of their lives whatever, um, they probably thought that I’m the wild beast from the book of revelations. It’s the Marxists drawing the threads together and that’s perhaps all they’ve really known. (Joseph; 286)

The voices and other psychotic phenomena could also be set within a framework which endorsed cultural narratives. This was the case for Joseph whose identity was challenged by the voices suggesting that he was mentally ill. Like Mark, the implications of being mentally ill were unacceptable.

I mean they (the voices) keep going on about me having a nervous breakdown, and to be honest really it’s really just infuriating really. (Joseph; 638)

One participant’s identity was challenged by the behaviour of others towards him. These challenges came from people in his life both in the past (see section 3.3.4) and in the present.

Well people think I am different, they think I’m ugly, horrible ugly and dirty and despicable. That’s the impression I get from people, ‘cause they want to bite their tongues, don’t want to know me as well as help me and won’t do anything for me.
I Right, because they won’t help you and they won’t bother talking to you, so you feel like they think you’re ugly and despicable.

P I’m being ignored.

I Yeah.

P Being ignored. (Oliver; 715)

These unacceptable narratives of the self, or shadow narratives were a threat to participants because the participants believed or feared them to be accurate descriptions of who they were. Even those participants who rejected their shadow narratives, gave subtle indications that they feared or believed they were true. This occurred with two participants who denied they were mentally ill, while at the same time suggesting that they did indeed see themselves this way. This is exemplified in the following quotation in which Joseph clearly places himself in the category of a schizophrenic by referring to ‘other schizophrenics’, while at the same time maintaining that he was not mentally ill, but the victim of an experiment, the aim of which was to make him mentally ill (when he states ‘I’m the experiment’).

Well, to be quite honest, I’d rather f.... I think to be honest, some of feelings I have, some of the sensations I have, um, the way I feel sometimes I think other schizophrenics have those same feelings. I think it’s brought about by me voices working on the mind. I-I-I don’t know. I mean, I’m the experiment. (Joseph; 1063)

This challenge to participants’ identities via the shadow narrative appeared to be the result of the participant’s endorsement of the assumptions inherent in the master narratives (see previous section on master narratives). This is also illustrated in the following example where Diana endorses the narrative that mental illness alters an individual’s personality and is permanently disabling. She also discounts her shadow narrative which suggests that she has a mental health
problem in order to maintain hope in the possibility of achieving her life-long goal of having children.

...someone said to me, you know, wait 10, 15 years, 20 years or 30 years, then have no children until you're right, or until you're right in your head, or you've got your personality back, how your personality should be. I think there's nothing wrong with my personality to be fair. This is somebody who's abnormal themselves, you know. They're definitely...there's something wrong with them. They need seeing to. [] But basically, this person said, you know, wait until you're totally well before you have any more relationships and then you can offer more and give more to the person. But I think that no matter whether or not if, um, you had a breakdown, [] whether it's schizophrenia and depression or, erm, manic depression or anxiety, whatever, you're always going to have it. (Diana; 1004, 1011, 1015)

The potential for the master narratives to predict a dismal future for participants was a major threatening component of the shadow narrative. This was especially evident where the shadow narratives pertained to mental illness. This is exemplified in the following quotations.

Because what I firmly believe is that they're [the voices are] not going to persecute me, harass me, bully me, all me life until I'm a little old man going around to the off-licence, with me walking stick in one hand, doddering along with a pension which in today's money is going to be worth £40 a week or something. (Joseph; 332)

This participant actively resists the implications of his shadow narrative (which suggests he is schizophrenic and will be disabled by his voices for the rest of his life). Others, however did not reject the shadow narrative, as in the following quotation.
but I get depressed you see because I live on me own now. What woman would ever want me now, do you think? [] What woman could live with me? []

Well, 'Cause I'm mentally ill... (Robert; 159, 162, 164)

Robert's shadow narrative implies that he is unlikely to ever have an intimate relationship with a woman. He clearly links this to feeling depressed. In a similar vein, Mina also adopted a shadow narrative which predicted a hopeless future (in terms of her potential role as a mother). It is likely that this was particularly significant for her because of the cultural expectations of her as an Asian woman.

My sisters got married they've both got 2 daughters. My brother got married and he's got 2 boys. I'm lucky I don't have children, I hope I don't have children you know. [] I'm lucky I don't have children you know. [] I don't like children 'cause I can't have them. I'm blind and I can't look after them. (Mina; 211, 215, 219)

While Mina adopted a strategy of dealing with this perceived loss of potential (by suggesting that she does not even like children), she later gives an indication of the depth of her hopelessness regarding her situation.

I just want to sleep and sleep and sleep you know. That's what I want do, like. [] 'Cause I'm getting old, I'm getting ill now. I need a rest now you know. I need a lot of rest you know. 'cause I want to die one day you know. My mum died, I'm going to die as well, you know. (Mina; 326, 329)

Mark also adopts his shadow narrative which predicts he will never have the life he had expected.
[I should be in a house] Yeah, I should have been. In my own house probably with a car, a girlfriend probably with two children. That'll never be possible for me. That'll never be possible for me or anything like that. 'Cause I'm ill.

(Mark, 618, 620, 621)

Although he does not describe becoming depressed he certainly saw his problems in that light. Asked about what it was like to talk about these things, he replied:

My experience, I found it a bit depressing. 'Cause I mean it's not exactly the highlight of the conversation is it, to talk about my problems. (Mark; 673)

Given the above examples, one could hypothesize that the adoption of one's shadow narrative could lead to hopelessness and feeling depressed.

3.3.4 Significant Life Experiences

Although it was not within the remit of this research to explore people's past experiences and their impact on their understanding of their difficulties, it is likely that these would have impacted on the way participants viewed themselves and the world. Where these experiences were traumatic, they may have created certain vulnerabilities which might have dictated which experiences were the most threatening to the participant and thus influenced the content of the shadow narrative, which may only have surfaced in further traumatic circumstances.

Most of the participants mentioned either traumatic life experiences, or strong beliefs, which they held, prior to the onset of their difficulties, although only two participants made explicit links between this and what they saw to be their mental health problems.

Well, it was from my childhood really. It was 'cause, me dad died when I was about 2 or 3 years old and I was in a children's home up to the age of about 8
years old, and, er, I ran away from that, I ran all the way to my sister's. She fostered me, and... [] Yeah, and then one sister fostered me. Her husband gave me a hard time, you know. I mean, he was black, he was an Afro-Caribbean, but he was making me fight with his sons, he was making me do things to my brother, and he was, you know, he wasn't a very nice person. [] ...and they wouldn't feed us or anything, you know. They'd look after their own children, but me and my brother had to suffer, you know. [] I got sexually abused when I was 9 years old as well. (Mark; 49, 54, 64, 125)

P Just had me and dragged me in the rapist, the rapist, x̂̂̂̂̂̂̂̂ idiotic looking.
I He was idiotic looking?
P No, he said me idiotic looking. Idiotic looking.
I Idiotic looking? He thought you were?
P Yeah, I were. But before I were raped I was better looking, you know, but now I've been raped I'm worse than ever now. (Oliver; 760)

This trauma appeared to reinforce the participant's shadow narrative which he had partially adopted as his narrative in the interview. The participant's negative shadow narrative is further reinforced in subsequent relationships.

Well people think I am different, they think I'm ugly, horrible ugly and dirty and despicable. That's the impression I get from people, 'cause they want to bite their tongues, don't want to know me as well as help me and won't do anything for me. (Oliver; 715)
3.4 Narrative Construction in Relationships

A diagrammatic summary of this category is given in Figure 3.3 and a brief outline of the category is described below. This is intended to give an introduction to the following section in which the details of each sub-category and their relationships are provided.

Participants gave meaning to their experiences in the context of relationships. As such, participants’ survival narratives were constructed in dialogue with significant others in their lives, both past and present. As some participants clearly had some form of dialogue with their voices, visions and others they perceived as being connected to their experiences, these relationships clearly had a strong impact on their narratives.

The process of narrative construction in relationships involved a number of factors: the perceived position of the listener(s) (i.e. the other person(s) in the dialogue), the ability and willingness to communicate the narrative, the narrative voice, the emotional effect on the listener(s), the subsequent response from the listener(s) and finally the interpersonal function that the narrative came to play. While these have been depicted as stages in the overall process, many of these factors were clearly interdependent. These connections will be discussed below.
Making Sense of Experiences

Ability to Communicate Narrative

Willingness to Communicate Narrative

Narrative Voice

Emotional Effects on Other

Other's Responses

Validate

Ignore

Change Story

Discount

Interpersonal Functions

Perceived Position of Other

Figure 3.3 Narrative Construction in Relationships
3.4.1 Making Sense of Experiences

Although the data pointed towards the master narratives available to participants for interpreting their psychotic experiences (see section 3.3.2), it was clearly the case that there were many meaning systems which impacted on participants’ narratives on a number of levels. For example, it was clear that participants endorsed various narratives about what it meant to live a normal life (see life losses). While these narratives appeared to stand on their own as beliefs or values, participants had obviously been exposed to them at some point in their lives through their social interactions, whether directly with significant others, or indirectly through education and media (see section 3.3.2). The process of making sense of experiences was therefore a social one which the data indicated was an ongoing process which occurred in the interviews themselves.

3.4.2 Perceived Position of the Other

Central to the process of constructing narratives in relationships was the perceived position of others (real or imagined) with whom the participant was in dialogue with. This perceived position represented participants’ beliefs about the other’s frame of reference which in turn embodied that person’s (or entity’s) aims and beliefs in relation to the participant’s narrative.

One participant comments on what he believes the position of the interviewer was:

*Well, you’re the expert [about] what schizophrenia is.* (Joseph; 1031)

The perceived position of the other also incorporated what the participant believed to be the listener’s power relative to the participant. This power came in the form of both expert knowledge, as in the above example, but also in terms of
the power over the participant’s freedom, or the resources which the participant relies on.

I think it’s me, that’s myself, my body is beginning to function right again, back to normal. Not necessarily the drugs. [But] for the focus of the doctors and psychiatrists, yes [possibly it’s the drugs]. [] Because the policy with the people I live with [housing association], they’ve said, you know, if you live here, you have to take drugs. (Diana; 864, 868, 871)

Clearly, this participant acknowledged that her narrative changed for the doctors and psychiatrists whose frame of reference regarding her problems was a medical one and who potentially had power over her through her housing.

Participants’ narratives were not only constructed in relation to the interviewer, but were clearly constructed in relation to others with whom they had some present or past relationship with, whether it be their voices, society, or their family for example. This dialogical nature of participants’ narratives is exemplified in the description Mark gave of the difficulties he had explaining to the interviewer whether his experiences were real or imagined. He described the decision making process as having a conversation with himself.

...sometimes it does seem as if (.) somebody’s tried to... (.) like control me life you know, make decisions for me, can’t make any decisions. [Like]When you try to question me, these thoughts and imagination. Like having a conversation with yourself but not actually talking to yourself, but talking to yourself inside your head, you know. You hear a voice saying this and that... (Mark; 393, 397)

It was not clear from the interview who these others were nor what their position was. In the following quotation, however, the position of the ‘other’ was much
clearer even though the identity of the other was not. In fact, the identity of the ‘other’ changed over the course of Diana’s quotations from a hypothetical other, to someone she suggested she had actually had a conversation with.

*If someone said to me, you know, in 10, 15 years, 20 years or 30 years, then have no children until you’re right, or until you’re right in your head or you’ve got your personality back, how your personality should be. I think there’s nothing wrong with my personality to be fair. This is somebody who’s abnormal themselves, you know. They’re definitely, there’s something wrong with them, they need seeing to. I mean...* [Yeah. But basically this person said, you know, wait until you’re totally well before you have any more relationships and then you can offer more and give more to the person. But I think no matter whether or not if, um, you had a breakdown, whether you’re being young or old, you know, whatever, you know, it doesn’t matter when it’s happened, whether it’s schizophrenia and depression or, erm, manic depression or anxiety, whatever, you’re always going to have it. (Diana; 1004, 1011)]

### 3.4.3 Ability to Communicate Narrative

Not surprisingly, the participants’ ability to communicate their narratives had an impact on their construction in conversation with the listener. Some of participants’ experiences were overwhelming (see discussions on ‘being out of character’ and ‘lack of control’ in section 3.3.1). They disrupted participants’ abilities to make sense of their experience by disrupting their cognitive processes. This disruption took the form of direct influence on their abilities, generating experiences of being unclear or unfocussed, or by occupying their thoughts and feelings, leaving little room for the participant to think independently. In its extreme form, the latter manifested itself as a ‘being in experience’ in which the participant was living in the experience.
One participant began by reflecting on what his ‘madness’ made him feel like:

*I think of Hitler and I think of Hitler and concentration camps. I don’t like that [They’re] horrible, horrible thoughts. [] I’m having them now. I get them regular.* (Oliver; 369, 374, 387)

The thoughts soon became a ‘being in experience’ thus precluding his self-reflection and resulting in an ‘overwhelming narrative’.

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**P** Oh, uh, *I have nightmares.*

**I** Right. *What happens in your nightmares?*

**P** Well, obviously should never happened. The voicesxxxx never happened. The voicesxxxx never have happened the xxx xxx were saying well the voices never have happened

**I** The voices?

**P** You see Hitler, what he should have done is....What the German people do...He...he xxx xxx the German people and it was bloody rubbish. Hitler wasn’t a man, Hitler was a Goon. [] The way he spoke to the German people. He made a fool of all the German race. [] Knowing that anyone in power could make a fool of these people, you know? [] Anyone in power could make a fool of these people. His xxx xxxxxx.

**I** So, would you say that these thoughts are like a nightmare?

**P** Yeah it is. I wouldn’t like it to happen again. But it’s xxxxx xxxxx xxxxx xxxx xxxx. [] 4,000 people got killed. [] They did, yeah. It’s a lot of people, you know.

**I** It is, it is. *Does it bother you a lot?*

**P** *Women and children and men, they’ve all been buried in the xxxx grave. I think that uh....I don’t like things like that.*

**I** No. *So it must be horrible to think about it all the time.*

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Oh it is, yeah. You see, it's molten lava and molten rock an it's an earthquake and the earth explodes from underneath. Molten lava comes from the middle of the earth to the top of the earth and and xxx xxxx people and kills people. It happens.

So, do you get those kind of thoughts as well?

I do, yeah. It might happen, xxxxx. You never know what could happen in this country. Anything could happen in this country.

( Oliver; 447, 457, 462, 465, 469, 473)

In this example, the participant clearly lost sight of the interviewer's questions, which ask him to self reflect, and talks about the experience as if he were living it at the time. When he is later asked to link his thoughts with previous aspects of his narrative, he interprets this as a suggestion that his experiences are not real.

Right. And the reason that you get these thoughts is because you have brain damage?

No, no, no. These things are true! Earthquakes are true. They're on the Richter scale.

Yeah.

They're powerful. They're like an atomic bomb. An earthquake is xxxxx as an atomic bomb.

Yeah. I know they are true, but, what I meant was, that you had said you get these thoughts about Hitler because you get a bit mad because you have brain damage. No?

No. It's not like that. It might be, it could be. It could be. It could be.

It could be but you're not sure. So why else might you get these thoughts, then about Hitler....

Well, he invaded Russia. He invaded Russia in the war time. He's xxx and torturing people.

Right. I know it's true. I'm not saying that it isn't. I was just
I can't believe it happened. I can't believe it happened. I can't believe it happened. I don't like to believe it happened. I try not to believe it happened, but it did happen because Hitler did start the war. I read all about the second world war and what happened in the wartime.

( Oliver; 481 )

Clearly, then, for some participant’s ‘being in experiences’ are temporary, but by their nature, might be difficult to integrate into the narrative. As such, participants had aspects of their narratives which were overwhelming. For example, in the following quotation by Joseph, he clearly loses sight of the interviewer's perspective and constructs his explanation almost as if he were reciting it in a lyrical form from some authoritative text. There were also non-verbal indications that he was hearing voices at the time (e.g. he moved his lips as if he were muttering something), which would explain why he made references to statements that the interviewer did not make.

I think, I think, oh yeah I mean didn't mention that obviously, you know, Styler succumbs and it's cramping his style, Styler succumbs accent or design and they say design, Styler has succumbed and the whole of the lefties kind of demoralized and things. The whole of the left politically is demoralized and becomes Stalinists because its so how Styler succumbed. And really it's a lie put forward by the political right and the ruling class isn't it? [ ] And I think like, I think now it's like everyone ( xxxx ) Styler succumbed he has got to succumb, he has got to say your in xxx xx. I-I-I don't really know. I-I-I can't I can't like, but like you were saying it's cramping your style, Styler succumbs and uh the militant agree with that. Like I say, Peter Taff could have operated ( Joseph; 198, 206 )
Some participants were aware of their difficulties in communicating their narrative, although this awareness was not necessarily present throughout their account.

*I can't think about all-all the feelings I get, but like, I mean...[I] because the voices drowning out me thoughts. [] I mean me head's a kind of blank, like just listen to voices, like.* (Joseph; 443, 453, 455)

Others seemed completely unaware of their difficulties communicating. One woman spoke so rapidly at times that it was virtually impossible to decipher what she said. This suggests she became unaware of my basic position as a listener who required a certain rate of speech for comprehension.

*’Cause I kept running away from home to go to work. My father XXXX, but I couldn't get it XXXX children go get you XXXX. People here go to work.* (Mina; 115)

Although participants did not make any references to this, it is also possible that what the participants believed the other’s position to be may have impacted on their ability to communicate. That is, if they perceived the other’s position as threatening, it may have caused anger or anxiety which could clearly have temporarily impaired the participant’s communication abilities.

### 3.4.4 Willingness to Communicate Narrative

Whether a narrative was to be communicated, and how much was communicated or withheld, depended on how much the participant believed they could trust the potential listener. This trust incorporated the anticipated outcome of sharing the narrative, based on how the participant had made sense of their experiences from their own frame of reference and the perceived frame of reference of the listener.
In this research, none of the participants elaborated on how the content of their narrative directly affected their willingness to reveal certain information, possibly because this elaboration would in itself have revealed too much. One participant did however spontaneously reflect on his experience of sharing his narrative with me:

*Communication is like a way of in deepness to, um, you know, um, to open yourself to somebody, um, let them know about you. [] I feel a bit, um, I feel a bit shy or whatever, but that's just me, I mean, I do feel a bit shy to communicate, to tell you everything, you know, like, everything that my senses tell me, but...[] But, i-it's not very easy though. It's hard. [] Even if it might seem, like...I'm not finding it easy, but I am, because my mind is more or less, like, um, not altogether, um focused properly.* (Cuthbert; 818, 838, 842, 844)

In this example, the participant reflected on two factors which led to a sense of incompleteness in his communication with me: feeling shy, and impaired cognitive abilities. With respect to the latter, he clearly made an internal attribution regarding his shyness which suggests that he saw himself as generally shy when communicating about his unusual experiences, and/or he was protecting me from the suggestion, that I had somehow been responsible for what was in essence his inability to trust me with certain aspects of his narrative.

While this participant was willing to share his narrative in spite of his awareness of his communication difficulties, others may not have been. For instance, the two participants who withdrew from the research had such great difficulty communicating that it was almost impossible for me to make sense of their narratives. While one can only speculate on their reasons for withdrawing from the study, it seems reasonable to suggest that for some, the refusal to communicate their narrative may stem from their communication difficulties.
Alternatively, they may not have been able to make sense of their experiences for themselves, which the interview would have highlighted.

### 3.4.5 Narrative Voice in Action

Participants also adopted certain ‘voices’ or positions in their survival narratives which embodied their sense of self or identity in relation to their experiences. These ‘narrative voices’ included the representation of others’ ‘voices’ in the participant’s consciousness. That is to say these narrative voices included an implicit or explicit stance towards the opinions of others, particularly where those opinions referred to explanations about the participants’ unusual experiences or their role and identity. There was evidence that the perceived power of the ‘others’ opinions also influenced the adoption of the voice in the narrative. That is, those relationships which had the most perceived influence over the participant’s experiences, appeared to be the ones which were instrumental in determining the nature of the voice.

...where people say he is a reincarnation of Trotsky and the Marxists are pulling the threads together therefore he has got to be Trotsky and it’s got to be a Marxist (holdingxxxxx) the threads together. [] And I uh, I think it’s highly/wholly incorrect, you know, [] ‘cause all I can see in my life is what I have learned in this lifetime [] and the fact that I’ve been the one that has been made an experiment and the one -the one that’s been bullied or whatever all my life. (Joseph; 161, 166, 168, 170)

For this participant, the ‘people’ (or those responsible for his problem) have complete control over his life. In contrast, mental health professionals were powerless to help him.
and he sent me to see Dr. O at the General Hospital and the first thing uh first thing I said when I saw him was, he said what can I do to help you? or something like that. and I said well, I think I'm in xx this experiment that's ruined me life. I've been in an experiment all my life. It's ruined me life and really I am absolutely fuming about it. I want something done about it...t'a end the experiment to end the harassment, the persecution, the oppression. and I wanted I wanted him to do something about it. And obviously all he could do was give me tablets. I was so angry and annoyed at finding out that my life had been ruined. And being an experiment, being a psychological experiment has ruined me life. and I wanted help but there was nothing anyone could do to help me. (Joseph; 20, 25, 31, 36, 39, 41, 44)

As a result of his experiences, the participant in the example above adopted a 'victim' voice in which he saw all his difficulties as arising from persecution by an omniscient and omnipotent group of people. This 'victim' voice was one of six categories of voices which related to participants' speaking identities (the others being: special, a victim, untouched, author, ill and new role) This will be discussed in greater detail in section 3.5.

In adopting voices in their narratives, participants further took into account what they believed to be the other's position and the anticipated impact that their own position would have on this other person. This is reflected in the above quotation. However, contrary to the position one would expect Joseph to adopt towards the researcher (i.e. one of hostility) given that she is a psychologist and he believes his life has been ruined by being a psychological experiment, his account suggests that he accepts the researcher's enquiring stance and adopts a position which explains and justifies his position to her as an impartial third party.
3.4.6 Emotional Impact on Others

Participants’ narratives produced a number of different emotional responses in the others which arose from the interaction between the voice of the narrative and the position of the listener. This was mainly demonstrated in the interview relationship where as a researcher, I experienced emotions such as fear, sadness, shock, surprise, amusement, embarrassment, sympathy, protectiveness, admiration, confusion and frustration. I experienced these emotions in varying combinations and strengths with each participant and was often able to make links between them and my own frame of reference (as a psychologist, researcher, and a person with my own life history). Thus, where participants narratives were very tangential, with the relationships between events, largely unexplained (e.g. Joseph and Mina), I often felt very confused and somewhat frustrated at not being able to make sense of the narrative in the interview. Where participants described a series of losses or injustices inflicted upon them (e.g. Oliver, Robert, & Mina), I felt sadness, sympathy and sometimes protectiveness. Where a participant’s narrative was ‘fantastic’, and sexually explicit (Joseph), I was shocked, embarrassed and shamefully amused. Finally, where I was threatened in an interview (not subsequently used in the analysis), I felt very frightened.

Most participants did not comment on the emotions that their narratives generated in the dialogue with the researcher or others, although this does not mean they were unaware of them. This does, however, mean that it is impossible to know to what extent participants’ perceptions of their impact on others was accurate.

Two participants did comment on the impact of their narratives. One participant had realized that his story had had an emotional impact on me, although he was somewhat vague about what he thought the emotion was. In fact, I had felt sad because of his many losses.
And I'm sorry if I upset you. (Robert; 202)

Another participant described the reaction of a friend to the behaviour which resulted from her narrative at the time.

And it hurt him to see me like that. [I] It was hurting him a lot, and I can remember him walking out of the room and someone said 'is that your woman?' and he said 'no'. He denied it, [I] I don't know. Probably felt embarrassed. [I] He didn't understand. (Diana; 299, 301, 305, 307)

In some cases, these emotional effects were intended, although not necessarily consciously so (see section 3.5.4 & 3.5.7). However, there were instances when certain emotional reactions would clearly have been unwanted.

One participant made reference to the possibility that her narrative may have been humorous and could have led to her being teased.

Oh yeah, I mean at one stage I thought I could read people's minds. I thought I could read...there was a certain girl he liked, M did, and he felt...And I said, 'oh she does like you, I can hear her voice'...He never laughed, he never took the mickey. If they [friends] did, they didn't do it in my vicinity anyway. (Diana; 138)

**Negative Cases:** Two participants' narratives (Gail's and John's) elicited very little emotion in me at all. This mirrored their lack of emotion in their presentation which accompanied their 'untouched voice' (see section 3.5.2).
3.4.7 Other's Responses to the Narrative

The responses of others played a key role in participants' construction of their narratives, both through the function that the narrative came to play in the relationship and through the effect it had on participants' perception of the listener's position. Listeners responded by validating, ignoring, discounting, or changing the narrative.

Validating Response

In this response, participants were given the message that their narrative were heard and confirmed as a reasonable explanation for their experiences. This was clearly a positive experience for participants. In the following example Diana discusses how some people had seen her account of having had contact with Jesus as plausible.

...after discussing it with like [] the student nurses, doctors, psychologists and psychiatric doctors and nurses, you know, talking to all the different wide range of people, carers who look after you...Then some said, some said when I told them what I experience, ‘well I really do believe in God, so I don’t dismiss what you’re saying to me’. [it was] uplifting me. (Diana; 258, 260, 266)

One participant remarked that he had found my response to his narrative validating.

You see, you talk to me. If people talk to me like you talk to me, I’d be all right. (Oliver; 950)

Ignoring

For some participants their stories went unheard and unnoticed. This led to feelings of anger, frustration and a sense of powerlessness.
For one participant, being ignored led him to believe that he was disliked.

Well, people think I am different, they think I'm ugly, horrible ugly and dirty and despicable. That's the impression I get from people, 'cause they want to bite their tongues, don't want to know me as well as help me and won't do anything for me. [I] I'm being ignored. (Oliver; 715, 721)

Even where participants were heard, they felt ignored insofar as no action was taken to redress the perceived injustice of their experiences.

It's ruined me life and really I am absolutely fuming about it. I want something done about it to end the experiment, to end the harassment, the persecution, the oppression. [I] And I wanted help. [I] but there was nothing anyone could do to help me. (Joseph; 27, 41, 43)

**Discounting**

Much like ignoring, discounting involved dismissing the participant’s narrative. Unlike ignoring however, discounting involved an active challenge to and summary rejection of the participant’s perspective.

And (.) if I speak to people and say 'you can hear these voices I'm listening to, um, they'd obviously deny it to me face. Like when I've been examined by doctors down there, like. I mean th-they haven't really acknowledged that I've got a lump there. Um, and obviously they deny that I'm in an experiment and that I have got a lump down there. (Joseph; 744)

For some participants, having their narrative discounted implied that the other person was adopting an antagonistic position. For one participant, this led to the breaking of a long-standing trusting relationship.
'Cause I've touched, I mean, I may have touched on certain subjects with other people, about the fact that the name Jesus was written across my forehead, and a third eye. I was laughed in the face about that by one of my CPNs. An old CPN, laughed in my face and said "Where? well I can't see no third eye". I said "Can't you see it there?", you know, like the shape of an eye in my forehead, you know. She said "I can't see anything", I thought, you know, I thought 'f' you then, you know. That's her... that's her problem. I'm come across a lot of that. At the time it hurt 'cause I thought, you know, we had an affinity with each other, she'd been my CPN for nearly 4 or 5 years, you know what I mean. She knew me well enough. Why would I lie for? (Diana; 1205)

One participant, while experiencing a 'being in' experience, clearly believed that the researcher was discounting his experience by making reference to previous statements he had made about his madness. In discussing the thoughts he had he said:

P You see, it's molten lava and molten rock and it's an earthquake and the earth explodes from underneath. Molten lava comes from the middle of the earth to the top of the earth and XXXX XXXX people and kills people. It happens.

I So, do you get those kind of thoughts as well?

P I do, yeah. It might happen, XXXX. You never know what could happen in this country. Anything could happen in this country.

I Right. And the reason that you get these thoughts is because you have brain damage?

P No, no, no. These things are true! Earthquakes are true. (Oliver; 474)

He therefore initially reasserts his position that his experiences are real, as they pertain to actual events occurring in the world. In response to reassurance from
the researcher, he later shifts his position and considers a new version of his story (see below).

Changing the Story
In this response, the participants’ stories are re-written or challenged in a way which is acceptable to them. For example, following the above exchange, Oliver began to consider a new version of his narrative in response to links the researcher had made between various elements in his narrative, in spite of previously responding as if she had discounted his narrative. This was likely because he had clearly valued the fact that he had been listened to.

I Yeah I know they are true, but what I meant was that you had said you get these thoughts about Hitler because you get a bit mad, because you have brain damage. No?

P No. It’s not like that. It might be. It could be. It could be. It could be. (Oliver; 490)

Another participant described how his voices had led him to see a group of people in a different light

I know what the Marxists are like now because the voices have told me; and they were sick perverts, I mean, I realize now, that there were about 10 of them and they were sick perverts who were very very aggressive and very, very nasty people. (Joseph; 272)

What effect challenges had on the construction of participants’ narratives were possibly a function of the degree of threat the other’s position is believed to pose, the amount of power in that position and to what extent the participant felt they had been understood.
3.4.8 Interpersonal Function

Participants' narratives were constructed in order to have an effect on others in such a way as to meet their interpersonal needs. These interpersonal functions included: avoiding blame, eliciting help or sympathy, feeling understood, increasing contact with others and increasing their power. Ultimately, participants' narratives were developed to maintain a positive identity, within and through relationships (see section 3.2.4).

The avoidance of blame was a central interpersonal function of many of the participants' narratives. Through the voice of victim, participants deflected blame away from themselves.

Yeah, it's the police. Well it's the police that's caused me illness, so I think everybody's a police officer when I go out. (Robert; 119)

Adopting the voices of an ill victim, participants' narratives elicited sympathy in the researcher and a desire to help them (which one might suggest is not an uncommon response to an illness or victim voice). These feelings were particularly strong in response to two participants as these participants explicitly requested that I visit them again.

It's important to come to see me, you know. I like somebody kind, you know, who look after me and come to see me. They're chucking me out, I've got nowhere to go yet, you know. (Mina; 630, 632, 637)

I'd like to see you again sometime. You see, you talk to me. If people talk to me like you talk to me, I'd be all right. You see nobody takes me out much, nobody. I've got no case manager you know who takes me out. Nobody bothers
with me. [] You see you've bothered with me. You've got an interest, but the majority of people don't have the interest with me. (Oliver; 948, 950, 959, 962)

As well as sympathy and help, it is likely that another function of these participants' narratives was to increase their social contact with those whom they felt understood them. Indeed, feeling understood in itself was one of the core interpersonal functions of the survival narratives as it validated a basic sense of identity in spite of the threats imposed upon it.

Efforts to increase the participants' power in their relationships was another core interpersonal function of participants' narratives. One method of doing this was to make themselves special as an alternative to being mentally ill, which was perceived as having reduced their power and control.

So you go to school and you say 'I'm a child of God, you know, I'm special'. You're gonna alienate a lot of people aren't you? [] People can either make their mind up now at this age, at my age now because before I had... A lot of people are jealous of me, you know what I mean, they still are jealous of me. [] I'm not saying it's like I'm amazing, you've got a gorgeous figure, this, this, this, this, this, just things I do in life itself. The kindness I show to people. Generosity. You know what I mean? Understanding. Tolerance. (Diana; 451, 455, 461)

Where the participants saw that others had usurped their power, the survival narratives reflected participants' constant struggle to regain control over their lives.

...because my problem is, is (...) voices can be very annoying to me, they can get me quite angry at times and I've just got to keep meself controlled. (Joseph; 357)
Often this struggle was with the people behind the voices and unusual experiences, but for some this struggle was with mental health professionals.

*I smashed a couple of chairs a couple of weeks ago and I've got to pay 500 quid for it. [Why?] through the (fagxxx) situation and the way the staff were bullying me. [It's] a protest.* (Oliver; 872, 877)

In the above example, the participant chooses a physical means of protest with the staff as he does not believe that they will listen in any other way. With the interviewer, however, he takes the opportunity to increase his power through the voicing of what he saw as injustices. In a similar vein, another participant creates his narrative to protest his continuing confinement in a staffed residential home.

*Well, basically I feel that the treatment's too long and it's not, it's not...They have a review about every 6 months, but basically [ ] It's the same sort of review as what it always is. [ ] They don't, they don't give you a chance to go in the community and see how you get on. [ ] Well, I don't know [what the reviews are for]. Basically mine's, basically they talk about tablets, and that's all they talk about. [they should be talking about] getting me back in the community. [I get a chance to talk in the meetings], but no-one listens to you.* (John; 192, 196, 198, 204, 207, 209)

This position was clearly very important to this participant, as it contrasted with the voice of the rest of the interview which was extremely restricted and vague.

Unfortunately, the short-term function of the narratives may not necessarily meet the needs of the participants in the long term. In fact, as can be seen from people’s responses to narratives, the impact of someone’s narrative can be just the opposite of what was intended, thus creating a vicious circle which ultimately
might damage the individual's relationships. For example, if a participant uses a 'special' voice in their narrative, but is instead seen as someone whom the participant might construe as not special (i.e. mentally ill), the consequences of the mismatch could be anything from a feeling of hopelessness, to anger towards the person.
3.5 Maintaining a Positive Identity

A summary of this category is given in Figure 3.4 and a brief outline of it is described below. This provides an introduction to the following section in which the details of each sub-category and their relationships are elaborated.

Participants' survival narratives were constructed in order to maintain a positive identity in the face of threats to their sense of self. Thus, in the process of making sense of their experiences, the narratives were developed in such a way as to give the greatest possibility for definition and elaboration of the self in relation to both their experiences and the meanings of those experiences imposed by their culture. These narratives were active in maintaining some sense of hope for the future.

As the experience of psychosis as a life event elicits questions about the locus of responsibility and power, the choice of narrative was influenced by these two factors. That is, central to all of the narratives were answers to the questions of who or what was responsible for participants' experiences, and who or what had power to influence them. In addition, participants' narratives also reflected a stance in relation to the question of whether they were mentally ill or schizophrenic. This usually involved a distancing from the negative stereotypes associated with these labels.

In answering these questions in their narratives, each participant positioned themselves in relation to the perceived causes of their experiences and thus created the six categories of speaking personalities or narrative voices.
Figure 3.4 Maintaining a Positive Identity
3.5.1 Locus of Responsibility and Power

Psychosis threatened participants with lack of control over their lives (see lack of control in section 3.3.1) and further threatened them by locating that control in the hands of others (whether real or imagined). At the same time, the participants’ shadow narratives (which were often situated within a framework which endorsed the dominant master narratives about mental illness) suggested that they may have been to blame for their predicaments and even may have wanted to be mentally ill. Other shadow narratives suggested that participants might be sick, abnormal, handicapped or out of control, thus challenging their identities. Faced with the threats which the psychosis posed, it was necessary for participants to explain their position in such a way as to retain some sense of agency and moral dignity. In doing so, they adopted certain speaking identities or ‘narrative voices’ which reflected their perceived responsibility for and power over the experiences and relationships related to those experiences (e.g. with voices). These issues of responsibility and power were highlighted in the section on the function of participants’ narratives. A further example of this is provided in the following quotations, where Joseph protests his innocence in the face of experiences he saw as largely uncontrollable.

*Because it's like (.) everyone's always hated me like, I've always been bullied. [/ but, I mean, well, I've done nothing wrong! I've done nothing wrong.*

(Joseph; 405, 417)

By presenting himself as a victim, he blamed his predicament on a group of people to whom he ascribed great power.
3.5.3 **Narrative Voice**

Six categories of 'narrative voices' were identified in participants' narratives. Some participants adopted one dominant voice throughout their narrative, incorporating other voices to a very limited degree. This was the case for Joseph and Oliver who primarily adopted 'victim voices' but also adopted other voices (i.e. 'ill voice') at various points in their interview. Other participants' narratives also reflected more than one 'voice'.

*The ‘Victim Voice’*

This 'narrative voice' embodies both external control of and responsibility for participants' distressing experiences. Inherent in the victim voice was also a great deal of frustration and anger towards those believed (rightly or wrongly) to be responsible for the person's difficulties as these others were perceived by some participants as having malevolent intentions. For some participants the presence of the external locus of the misfortune allowed the 'normal' or 'healthy' self to be preserved. In such cases, any disabilities were thought to be the direct result of ongoing persecution. Joseph, for instance, spoke of his difficulties arising from a grand experiment being conducted on him. He believed that when the experiment was over, he would return to a normal life.

*And the voices started in 1990 about 7 years ago. [J And that was like a continuation of the experiment where the object is just really to break me down and destroy me. [J So, I expect that sometime in the next two years, it's going to come down and I should imagine shortly after that the voices will go. Um, then I will be able to lead something of a normal life after that, hopefully.*

(Joseph; 63, 65, 850)

At some points in the interview, Robert saw the police as responsible for both initiating and maintaining his mental health problem.
Yeah. You see they’re [the police are] running the country.

So, when you said that sometimes you think that people are getting at you, who do you think is getting at you?

The police. Yeah. I don’t go out at night. They sit there doing this on the table all night long. (drums fingers on the table) It would drive anybody mad. (Robert; 102)

For other participants, the once ‘normal’ and ‘healthy’ self had been radically altered by malevolent others, thus implying that they had neither asked for their fate nor been born into it. Often participants suggested that the others had made them ill, sometimes intentionally.

[I first came into contact with mental health services] Uh, because a guy tried to kill me on my motorbike. A gang tried to kill me on my motorbike. [...] I were only a kid when they hit me. [...] They were tough, really tough. They sorted me out. One of them punched me in the stomach when I was a child. Yeah, he bloody nearly killed me! [...] I climbed over the fence, the fella punched me and uh, I’ve not been well since. (Oliver; 6, 18, 50, 64)

In this extract of Robert’s interview, he suggests that the police had been responsible for his mental illness which he saw as permanently disabling.

Yeah. You see I think that the police interrogated me. They tried to make me ill. But if I take them to court and tell the truth, I don’t know whether they’ll lie again and make believe I was blind drunk or something, and I caused the affray at the club, because they tried to charge me with the damages. But they squashed that because there was a detective at the club, and I wasn’t there when the damage was caused. But they tried to charge me with it. [...] It sent me mentally ill. [...] I was unconscious. They damaged me brain. (Robert; 61, 70, 77)
Mina also suggests that she had been made ill by others.

So I’ve got nowhere to go at all. Nowhere. I need a house now you know. I can’t stay in this place like this. They keep on troubling me. [] Um. Made me very ill. (Mina; 182, 184)

One participant described being the victim of abuse and neglect from an early age.

Because (.) I wasn’t living a normal life in the community. [] And, er, er, I moved from flat to flat, I wasn’t being able to look after meself properly. I wasn’t cooking, cleaning, stuff like that. Shopping things like that. [] Well, I needed help in other words, I needed help. [] Well, it was from my childhood really. It was ‘cause, me dad died when I was about 2 or 3 years old and I was in a children’s home up to the age of about 8 years old, and, er, I ran away from that... [] Yeah, and then one sister fostered me. Her husband gave me a hard time, you know. I mean, he was black, he was an Afro-Caribbean, but he was making me fight with his sons, he was making me do things to me brother, and he was, you know, he wasn’t a very nice person. [] ...and they wouldn’t feed us or anything, you know. They’d look after their own children, but me and my brother had to suffer, you know. [] I got sexually abused when I was 9 years old as well. (Mark; 4, 10, 16, 49, 54, 64, 125)

Two participants saw themselves as victims of abuse and/or neglect by the mental health services.

Yeah but that’s why I’m mad. ‘Cause of all them injuries. [But] the doctors couldn’t care less. Couldn’t care less. [] Couldn’t care less. But they got...I’m on tablets now. I’m getting tablets, now, for me heart disease. [] That’s right,
yeah. They—they’re doing me no good. [] No. I’m still the same. I’m like I am now. [I don’t like taking the medicine] (Not all the while xxxxxxxxx), no. Not to be overdosed. You see when I was in the Towers, they gave me three thousand gallons of Largactil to drink. In ten years. Ten years. Three thousand gallons of Largactil. [] I was on a pint of Largactil a day in the Towers. [] I am angry! It does make me angry. Treating me like that! They had me in my pyjamas for six years without going for a walk off the ward! [] For six years. Yeah! [] I couldn’t go nowhere. And somebody tried to murder me on the Ward! That’s why I’m angry with the whole thing. I mean, you fancy drinking a pint of Largactil a day for eight years! (Oliver; 175, 178, 198, 200, 202, 207, 209 212, 214)

Mina talked about feeling confined in the mental health services. She also links her illness to being troubled by fellow residents and being put on psychiatric medication.

I want to live on my own but they won’t let me. [] But I’ve hurted my eyes you know. They keep on upsetting me when I go out and my eyes goes up [] XXXX hours and hours, you know. I need to sleep at that time you know. [that didn’t happen before] No. XXXX my school I like to read and write and everything. Until that time that the doctor give me tablet. I feel lousy and dizzy. [] Yeah. They give me injection after that. [] Yeah. It’s terrible. I feel hungry and thirsty and dizzy you know. (Mina; 279, 288, 292, 294, 296, 298)

The ‘voice’ of victim could be argued to be a socially acceptable position as well as an active one, as it suggested that there were injustices to be redressed. Some participants reacted with anger.

I’ve been in an experiment all me life. It’s ruined me life and really I am absolutely fuming about it. I want something done about it... (Joseph; 27)
Even those participants who had begun to despair, were active in their recounting of the injustices to the researcher. This seemed to suggest that there was still hope that something could change or that those they held responsible should be held accountable.

_I'm sure everybody in the hospital must know what happened to me by now, because I've been open about it and I've told everybody. [] I know nothing's done about it, or it seems like nothing's done about it, whether it is or not, I don't know._ (Robert; 451, 458)

[At the] Psychiatric hospital, yeah. They pinched all me property as well. [] About 20 thousand quid's worth of property and I haven't got it back yet. Nobody's done anything about it. Nobody sort of cares about it. If they wanted me to have me property back, they come and say here's your property, now that's it, paid you back, you know, but they won't do it. They won't pay me back. (Oliver; 616, 618)

**Negative Case:** Like many of the other participants adopting a victim voice, Cuthbert clearly identified a traumatic event (in which he was a victim of violence) which he believed was a trigger for his mental health problems. However unlike the others, he did not present himself as a victim. Rather he saw it as a stage in his life which had transformed him in both positive and negative ways (see author voice).

_Uh, what I'm saying now about like getting depressed, like quite a few things happened, 'cause like, at one stage I got into a fight, and I got, I mean I got beat up one time. And then because of that, ever since, um, ever since I haven't been the same person, more or less. [] But, that was at one stage, You know what I mean? So like because of that I'm more or less, um, more wiser in everything I
do. My approaching things is more wiser, than how it was, since then.
(Cuthbert; 33, 39)

The 'Ill Voice'
Participants who adopted this voice, presented themselves as disabled by their 'illness' for which they believed they were entitled to some form of help. Rather than conceiving illness as a failing on their part, it was presented as an unfortunate occurrence much like a physical illness. In fact, physical complaints were both included in the narratives alongside mental health problems as well as being perceived to be the cause of them, perhaps because they increased the social acceptability of their position.

One participant discussed the consequences of others troubling her:

Um. Made me very ill. [] Feels dizzy in my brain. [] Pains everywhere. Eyes go up you know. Coughing, and cold and flu and snowing. [] Frostbites. [] Maybe frostbites of my hand. The doctor gave me a sicknote after that, you know. (Mina; 186, 188, 190, 193, 195)

In a similar vein, she talked about how she felt after getting a strange thought.

I just want to sleep and sleep and sleep you know. That's what I want do, like. [] 'Cause I'm getting old, I'm getting ill now. I need a rest now you know. I need a lot of rest you know. (Mina; 326, 329)

Another participant linked physical illnesses with his mental health problem.

I am a bit mad. [] I am not quite sane. [] Well, uh, I've got false teeth, a broken back, a broken toe, I've got heart disease, I've got bit of a fractured skull, and, umm, me eyesight is bad. That's all is wrong. (Oliver; 166, 178, 170)
When asked how this related to his belief that he was a bit mad, he states:

Yeah but that's why I'm mad. [']Cause of all them injuries. (Oliver; 174, 176)

Oliver later goes on to elaborate what he means by mad.

Umm, (sighs). Well, brain damage. [']Well it makes you feel any old how. [']
It's like emptiness. An emptiness feeling. [']All the while. All the while.
(Oliver; 344, 346, 348, 350)

One participant describes her 'illness' by referring to a social construction about mental health problems which used to be very common:

P Well, I have trouble with my nerves. My nerves go.
I And what sort of things do you do when your nerves go?
P Well, I'm just not very well, you know.
(Gail; 39)

Some participants saw their illness as temporarily affecting their functioning, as in the above example, while others saw themselves as permanently disabled by it.

Nobody can cure me. Since I died, I'm dying, you know. (Mina; 414).

Mina also emphasized her need for help with her difficulties.

I need some more medicine, taking, especially taking for my eyes. [']Yeah. I need a lot of help you know. I need a lot of help. [']'Cause my eyes goes up, like this you know. I need to sleep for a long time you know. 'Cause I get upset you know. (Mina; 396, 398, 400)
The 'New Role Voice'

The focus of this voice was on how participants had adapted to their situation in such a way as to discover a new role for themselves. This voice contrasted with the loss of roles participants described as having resulted from their experience of psychosis.

One participant described helping other users in the respite facility.

I've helped no end of people through that. Just telling them, saying don't do that yet, you wait, wait until your tablets, have a rest and see how you feel. Then do that if you've got to. Perhaps going to smash something or something like that you see, or steal a cigarette, see what I mean? You're that close to these people I can help them a lot. I'd love a job in this area or whatever. (Robert; 382)

For another participant, the new role involved working in a voluntary mental health organisation set up to challenge prejudices against ethnic minorities and people with mental health problems.

That's [stigmatizing labels of mental illness] something I'm trying to get rid of at the moment through the mental health system, through the mental health shop. [] It's hard to explain, people use the terminologies: crazy, loony, mad, er, freak, whatever, and, er, their daily life, do you know what I mean. [] But I'm trying to sort of find, lobby the word, trying to be politically correct again, like you've got to be political about, you know, don't call it black coffee, but call it black coffee, call it, erm, erm, coffee, you know. (Diana; 973, 983, 991)

The 'new role voice' was separate from the other voices in their narratives and seemed a more progressive and less defensive voice.
The ‘Special Voice’
This voice portrayed the participant as someone special who was different to and often better than other people. At the same time, this specialness was believed to be acknowledged by others. Because of this specialness, others were perceived to admire and adore or even be jealous of the participant.

But, I don’t think I’m a normal person. I think I’m genetically different. And obviously my background being an experiment is different to everybody else’s. I think I’m genetically-I-I think I’m genetically unique and a special person genetically and the fact that this experiment has made me special as well, like. (Joseph; 1124, 1128)

I knew the president [of America]. I told him to use a garden (rollerxxxxx). Garden roller. A steam roller. I know Richard Attenborough, even. Yeah, Princess Anne’s boyfriend. I told him buy her an American lorry, but he wouldn’t. (Oliver; 418, 420, 426, 435, 436)

One participant believed she was special from an early age.

Erm, like if you was try to tell a child at the age of 7 or when they were able to comprehend or understand, you’re special child you, or a child of God or, you know, whatever, a child like that is not going to keep it to itself, it’s going to tell all her friends at school. So you go to school and you say I’m a child of God, you know, I’m special. (Diana; 448)

The ‘Untouched Voice’
This voice contrasted greatly with the other narrative voices as it dominated most of the narratives of two participants and involved very brief and unclear explanations about their experiences. In contrast to the other participants’
interviews which lasted from 40 minutes to 1 1/2 hours, these two interviews lasted from 20 minutes to 1/2 an hour and involved much prompting on the part of the interviewer to get any picture at all about their difficulties. It is particularly difficult to represent this voice purely by including the verbatim material from the transcripts (in the limited form they had been transcribed) as the whole interviews took on a feeling which was very different from the other interviews. In fact, the impression given by these narratives was that discussing the participants' experiences of the difficulties which brought them into contact with the mental health services would have elicited the same reaction as discussing the weather.

On being asked why she first came into contact with the mental health services one of the participants stated

*It's after I had children, but this time it wasn't.*  (Gail; 5)

Further prompts revealed:

*Well, it was really, you know, um, depression and um, you know, my nerves aren't very good. * [] *Well, it got so I couldn't cope with everyday things, you know. So I had to come into hospital. * [] *I couldn't look after me children properly and, um, I had to come into hospital and they had to be cared for.*  (Gail; 7, 10, 13)

Similarly, another participant gives a very short description of why he first had contact with the mental health services:

*Well, I had voices.*  (Mark; 7)

After further questions he elaborated slightly:
Well, basically, I heard voices and some of them weren't very nice. [...] ...they were telling me to jump out the windows and do silly things. At one time I opened the window to jump, but me (CPNXXX) stopped me. (Mark; 9, 16)

Unlike other participants' narratives, these narratives contained explanations for their experiences which were vague.

I Right, OK. And what do you think caused your nerves and your depression?
P Well I don't really know. I don't really know, hormones. That's what the doctor said anyway.
I Right, and is that what you think?
P Yes, I do really, yeah. Yes. But this time I've been here since January here. I was having trouble at home with me neighbours.
I Right. What was happening with the neighbours?
P Well, it wasn't really them in a way, it was because, it was after Christmas, it was very noisy. Noisier than usual. So the doctor suggested I come in here for a bit. (Gail; 24)

I Right. At the time, do you remember why you thought you were having the voices?
P No.
I No, you didn't have any idea?
P No.
I Right. So, do you remember when you were going to jump out the window?
P Do I remember about it?
I Yeah
P I don't remember about it. (Mark; 18)
There was evidence that this voice was not just restricted to their discussion of the events which brought them into contact with the mental health services, but permeated their discussion of other topics as well (e.g. the reasons others were in contact with the mental health services).

I OK, fair enough. And have you got any ideas about why other people come into contact with Mental Health Services?
P No idea.
I You've no idea. What about the other people that are here – any ideas why they're here?
P Well, some of them are mad.
I Some are mad, right, OK. And when you say mad, what do you mean by that?
P Well, they're nuts.
I They're nuts. What does it mean to be nuts?
P Well, they act strange, you know. (Mark; 121)

A similar style of explanation is given by Gail:

I Right, so you haven't any ideas about why people are here and what their problems are?
P No, I don't know why they are over here, no. Some of the women have marriage problems, but I'm divorced anyway, I'm divorced. My ex-husband's still alive, you know. I think the other people they have got marriage problems.
I Marriage problems, right.
P But I haven't, no.
I And how does that affect them, the marriage problems?
Well, I think they have difficulty going home. I think they have rows with their husbands. Going home from here it's a bit difficult I think for them.

Right, OK, and what do you think causes their marriage difficulties, do you have any ideas?

No, no. (Gail; 198)

This voice suggested that the participants' unusual experiences had very little impact on them (apart from forced contact with the mental health services). In fact they did not see that they had been changed at all by their experiences.

OK, fair enough. And would you describe yourself now as being any different than before you had the voices?

No.

No, you haven't changed at all?

No. Got older. (John; 112)

Would you describe yourself now as being any different than you were before you got the depression

What, years ago you mean, or

Yeah

January?

No, well either really, but do you feel that you've changed at all, or do you feel that you're the same person, or...

I feel the same person, yeah. I really feel the same person, yeah.

Right, and that's all the way through, even before you became ill the first time. Would you say ill, or just not coping?

Just not coping.

Just not coping, right. OK. So you feel that you haven't changed in yourself.

129
No, no. (Gail; 177)

The Author ‘Voice’

The author ‘voice’ involved a position which suggested that participants had begun to take control of their own lives. The meanings given to participants’ experiences of their mental health problems when adopting an author voice were ones which did not seek to blame themselves or others for their difficulties, but were part of a normalising frame of reference which incorporated their own strengths and limitations.

One participant, Cuthbert, suggested that his ‘depression’ was a stage in his life like many other stages.

It's just one of them things. I went through a stage in-in um, I just went through a stage in life of just like, um, everything getting depressed, everything getting, um harder, um like, you know what I mean, everything getting hard, everything getting more depressed. So, it's just one of them stages... (Cuthbert; 5)

Cuthbert then goes on to normalise his difficulties.

Things were going wrong now, but.... You know what I mean? ‘Cause all the things I used to do then, that was just one that was like a stage. Like everyone goes through a stage, but that was like my stage. (Cuthbert; 118)

He also incorporates an understanding of the differences between himself and others, which normalizes the changes he has noticed in his thinking.

Umm, Going back to being, like, thinking clearly, I mean, No one's got a perfect mind, but for me, umm, my mind is more expand. (Cuthbert; 172)
Another participant also normalizes mental health problems by putting them on a continuum. In discussing her understanding of schizophrenia, she discussed her theory about the relationship between stress and mental illness.

Well, I think so. I think it's something in the brain that no-one knows about which chemical, which just gets over-loaded sometimes. You just have to...it's like some people's stress level is more tolerant than others, you know like some people their stress level could be a factor 5, and that factor 5 could be they blow their top after a certain time, and that's when they let the steam out. Some people's factors are factor 10, you know what I mean? They can, then can sort of sit back and say that person can be bombarding them with abuse or whatever and they're as cool as cucumbers, you know what I mean? But, yeah, they're the ones who, are ones who blow their top more than anything else. Because they're not letting out the anger, you know, to the person itself, letting it out to somebody else, who's close to them and sometimes that can be seen as, er, mental health or, um, you know, where the person is not altogether in control of their behaviour, you know what I mean? So, it can be seen in different sorts of ways. (Diana; 929)

Another aspect of striving to normalize their lives involved work and other activities.

I just want to do normal things, like you know, which I am doing, I'm starting back in college on Monday 11th May, doing pre-GCSE English and maths and I think I might go into sports and social groups. I might want to do some work as well. My case worker's coming at 2.15 and he's taking me to this place sheltered employment workshop do you know it? (Mark; 468)
One participant valued activities and work as a means of structure and contact with others, but more importantly as a means of being a productive member of society.

_They think I swan around and, you know, just follow the leader, but I've been doing writing, I write actually for a magazine, I've been doing that for 2 years. I've been doing other things I've been doing working in charity shops without telling the DHS about it for the last 4 or 5 years, you know what I mean? That's the only kind of job I can do. It gets me out the house and makes me meet people. You know I meet the public, you know, that kind of stuff, know what I mean._ (Diana; 1101)

Another characteristic of the author voice involves an awareness of personal limitations and strategies to manage them. In essence participants had found various ways to look after themselves.

_Oh yeah that's right, I've done that, I've done silly things in my time when I've been on a high. But now I can control it to a degree. You know, I try to calm myself down a bit more. I know when I'm getting high. _[I] _Well I can control it to the degree anyone I know, I know what to do when I'm high. It's either OK for...admittedly, like take time out, literally take time out, you know. I might feel like, well I'm so high, I wanna sort of like, um, be out and about, it's a lovely day. Even if it's raining or snowing, I want to be out and about. I could be dancing in the snow, I could be walking in the snow, that kind of stuff, or in the rain, do you know what I mean, but, um, now I'll say take time out and go to sleep. Sleep for a bit. That's what I do._ (Diana; 664, 755)

These strategies also included ways of combatting the negative effects of psychiatric medication.
...but, the medication, now, at times you feel tired and whatever, but...[.] with me now, I, like, ‘cause I am how I am, I like, I like to train now, you know what I mean? [] You know I’m really into training. I think to myself, I can’t let the medication get the better of me...[.] Are there things that help me? (.) Boxing. It makes me feel better. I like boxing. (Cuthbert; 206, 209, 212, 221)

An acceptance of participants’ difficulties was prominent in the author voice and usually included participants’ perceptions of having an element of control over their lives. One participant, Joseph, talks about coming to terms with his voices. He struggled with managing his difficulty while still seeing himself as a victim.

I’ve just-I’ve just got to keep meself controlled, because my problem is, is (.) voices can be very annoying to me, they can get me quite angry at times and I’ve just got to keep meself controlled. [] I go home each weekend and see me mum and uh, I’ve sort-of come to terms with me voices, I think,. It’s very difficult for me to keep meself controlled some of the time...[.] And I find the best way of t’a...the best drug, I can take to help keep meself controlled is alcohol (Joseph; 356, 576, 358)

In a similar vein, two participants presented themselves as people who were able to control their tempers and avoid physical violence towards others, even when provoked.

I’m a person who, like, instead of lashing out at people, I really XXXX lash out on myself... (Cuthbert; 261)

I’m not a dangerous person and I wouldn’t do anything, you know. [] I’ve got no intention, got no reason to like actually punch somebody or start beating somebody up, slashing my wrist or taking an overdose or whatever. It’s just...
I've got control that side of things, it's just that in the past things just wound me up, you know... (Mark; 558, 418)

One strategy for managing participants' difficulties involved detaching themselves from others. For one participant, this meant that he physically distanced herself from others as a way of looking after herself.

I've learnt this from the age of 20, 21. I've had to sort of like slow down when I first took ill, when I was 20. I knew then there was times I had to sort of like back out of things. And I've stood, lived by that rule now, do you know what I mean? I take time off for myself, like when my sister had a baby it devastated me. I wanted to be there for her, but I took time out. I went away for the weekend, get my head around things. Come back refreshed, renewed, revived about it, you know what I mean, and no-one knew the difference. (Diana; 1049)

Another participant described how he gets on with his own life and avoids getting involved with other people's problems as a way of looking after himself.

'Cause there's just so many problems, you know what I mean, and like, if you're around people loads of things revolve, you know what I mean, so like, you know how it goes, [ ] With me, now, I don't want to watch what the next man's doing or what a girl's doing or whatever, you know what I mean, I don't watch, I don't really like watching what people are doing. I just like to do what I have to do. (Cuthbert; 159)

A final characteristic of the author voice involved participants describing positive changes in themselves.
I don't really, I mean I don't relate to any of them things I used to do now. Umm, I don't really, I don't relate to any of them things I used to do now, so I'm more, I'm more how I wanna be now. You know what I mean? (Cuthbert; 107)

Yeah, I'm not afraid, put it this way, I'm afraid to explore things like I was before. [ ] That I think, that's what I really wanted to be like that, like I am now, when I was younger. That is not frightened to explain, talk about things. But I was frightened, I was a frightened child, didn't was too scared to open her mouth, and say how she really felt. [ ] And now I'm not a frightened little child any more. No, I will say how I feel. I might bite my tongue at times to make... because I'm sure if I say how I really feel. (Diana; 496, 499, 504)

In both cases participants had come closer to their ideal self. Thus the author voice could be seen to involve a mature voice which suggests participants are responsible and independent.

Uh, what I'm saying now about like getting depressed, like quite a few things happened, 'cause like, at one stage I got into a fight, and I got, I mean I got beat up one time. And then because of that, ever since, umm, ever since I haven't been the same person, more or less. [ ] But, that was at one stage, You know what I mean? So like because of that I'm more or less, umm, more wiser in everything I do. My approaching things is more wiser, than how it was, since then. [ ] 'Cause that was, uh, like my youth days, You know what I mean? I'm still a youth...[ ] But, like in my younger days, You know what I mean, that was like in my younger days, I mean 'cause I still was- I was like a big baby them days. I was like a baby them days, but...[ ] but now, uh, I-I'm my own man now, You know what I mean, I'm my own, I'm my own self. You know what I mean? [ ] So, like, You know, if I got things to do now, I mean, what I have to do now is like run my flat and everything, things like that. (Cuthbert; 33, 39, 43, 46, 50, 53)
3.5.4 Distancing from the Stereotypes of Mental Illness and Schizophrenia

Given that participants' identities were challenged by the negative stereotypes embodied in the concepts of mental illness and schizophrenia, and taking into account the context of the interview which specifically addressed these issues, it is not surprising that participants' narratives served to position themselves in relation to these stereotypes. That is, at various points in their narratives, participants distanced themselves from these labels and the group of people they saw as representing those labels. Thus when asked why people were in contact with the mental health services, or what participants understood by the labels of madness or schizophrenia, the participants did not often include themselves in these categories, but described how they saw others who did. John for instance, when asked why other people lived in the mental health facility he was living in, said:

*Well, some of them are mad.* (John; 126)

Not only did John not include himself in this category, but clearly he left open the possibility that some of the other people in the ‘home’ might also not be mad.

Robert also presented himself at one point as ‘not mentally ill’.

*I'm not mentally ill right now, I know I'm not. So I'm telling you, it's the honest truth. I'm quite rational I am, I'm allowed out. I can go just where I want, go home if I want.* (Robert; 273)

He then described how he saw those who were mentally ill.
Well, [Mental illness is] doing irrational things, doing first things that comes into their head. [Like] Oh, smash the tele up, break some furniture, or just throw a cup of tea at the wall, or spat on the floor, like that. (Robert; 292, 294)

Robert subsequently distanced himself by describing others in the respite unit by suggesting they were worse than him. He also suggested that being with them actually made him feel unwell.

Like I slip when I’ve been in here for a while, ‘Cause there are that many people that were worse than me made me feel ill. (Robert; 307)

Diana also separated herself from others she characterized as mentally ill.

I don’t see myself as being mentally ill, so when I see other people that have been in hospital with, who might shout my name in the middle of town, I might stop and say hello to them, but I’m not like them. (Diana; 522)

She was, however, very aware that she adopted this position and was uncomfortable with it.

I see it as a negative thing because, ummm, it’s hard to say (.) I just feel different from them. I don’t feel the same as them in that it’s hard to put into words, but, erm, it’s like them and... I said this last time, it’s like them and me, do you know what I mean? They’re on one side and I’m on another side. [] That’s a negative thing for me because I shouldn’t feel that way, do you know what I mean, I should be feeling that, you know, I should be united in their cause because I’ve been through the system myself. But I’m not. If anything I do see it as being them and me. (Diana; 599, 604)

While this attests to the difficulties faced by an individual in challenging the prejudices and stereotypes inherent in our culture, it also demonstrates the
conflicting and often shifting positions which participants adopted in their narratives in response to the multitude of meanings which made up their subjective worlds.
CHAPTER 4

DISCUSSION
4.1 Overview

A summary of the outcome of the data analysis will be presented. This summary will focus on the function that survival narratives serve in maintaining a positive identity in the face of the overwhelming threat imposed by the experiences of psychosis and the meanings attributed to those experiences. These findings will then be discussed in relation to the literature, and the implications for clinical practice will be explored. Finally, a critique of this study will be offered.

4.2 Summary of the Analysis

The analysis identifies the struggle that people with psychosis have in maintaining a positive identity, when the core areas of that identity are challenged both by their actual mental health problems as well as the personal and social constructions of their difficulties. This struggle results in the creation of survival narratives which maintain a positive identity through the development of narrative voices, or alternative speaking identities.

Most participants were painfully aware of the devastating impact on their lives of the experiences which had brought them into contact with the mental health services. These experiences included unusual and disturbing phenomena, and negative affect which disrupted their ability to function in many areas of their lives (e.g. daily living skills and cognitive, social and occupational functioning). The ensuing social environment within which they found themselves (i.e. the mental health system) also contributed towards their disablement as it could be stigmatizing, and for certain participants took away some of their basic freedoms. The long term impact that these experiences had on participants involved a multitude of losses. These included both actual loss of roles, relationships and
material goods and the loss of the potential to fulfil the basic expectations that most people have for their lives.

A large part of the participants’ struggle to maintain their identity revolved around the meanings (i.e. the master narratives) available to participants to make sense of the experiences they encountered. As the dominant or cultural narratives revolved around mental illness, participants were faced with interpretations of their experiences which incorporated stigmatizing labels and negative stereotypes. As master narratives, these meanings were very powerful in their ability to suggest that the person is transformed into the illness, to blame the person for their predicament and to predict a dismal future. This is in accord with Goffman (1961) who suggests that the symptoms of mental illness can lead to ‘disintegrative re-evaluations’ of patients’ self concepts through the process of labelling. However, he focused primarily on the effects of institutions in this process and ignored self-labelling. By contrast, this research suggests that the power of the master narratives came from the endorsement of various aspects of these narratives by participants. Thus, having adopted the beliefs and values inherent in these narratives, participants’ understanding of who they were and what their future held was threatened.

This threat to participants’ identity took the form of a shadow narrative which was a potential but unacceptable self-narrative based on the master narratives. Due to their threatening nature, some participants were only aware of them to varying degrees. In this research, the shadow narratives most prevalent were the ones relating to madness or mental illness. Other shadow narratives were evident, however, and one was based on accusations by the person’s voices.

In response to the shadow narratives concerning mental illness, many of the participants rejected the medical label or construct in favour of alternative narratives (survival narratives) which both explained their difficulties more
readily and protected their sense of self. These narratives included various 'narrative voices' or speaking identities which could be categorized in terms of the identity(s) which was most central to the person’s strategy of coping with the threats of psychosis. Most of these narratives functioned to distance the person from the shadow narrative(s) by creating an explanation which was either more socially acceptable (i.e. ‘victim and illness voices’), or exceptional (i.e. ‘special voice’). The ‘new role voice’, functioned to establish a new role given the context participants found themselves in, while the ‘author voice’ involved rejecting the shadow narrative(s) and developing meanings which were accepting of participants’ limitations while capitalizing on their strengths. It was not possible to determine the functions of the ‘untouched voice’ although it may have functioned to restrict participants’ awareness of their difficulties.

The survival narratives were also created and functioned in relation to others in the participant’s environment (whether internal or external). Thus some participants’ ‘narrative voices’ were adopted in relation to others whom participants believed to be responsible for the voices they heard. In all cases, the narratives were negotiated according to the participants’ perception of the others’ perspectives or frames of reference. This meant that the ‘narrative voices’ were not fixed within the interviews and participants moved among them (usually two or three). This reflected the dialogical nature of the conversation which clearly rendered the narratives in a relatively constant state of change.

4.3 Survival Narratives: Making Sense of the Serious Disruption to Life

4.3.1 Making Sense

A large body of the research on psychosis adopts a disease model which typically invalidates the core experience of people suffering from psychosis by reducing the content of their experiences to diagnostic categories or marginalising their
understanding of their experiences as the rantings of mad people. A recent quote on delusions illustrates this: “Delusions are likely to be empty speech acts, whose informational ‘content’ refers to neither the world nor self. They are not the symbolic expression of anything. Its content is but a random fragment of information ‘trapped’ in the very moment the delusion becomes crystallized” (Berrios, 1991: 12). In a similar vein, any disagreement that those with psychosis have with the ‘medical perspective’ is pathologised. That is, this ‘lack of insight’ is assumed to be the direct result of an underlying cognitive deficit.

This study challenged this notion by daring to give a voice to those thought of by some as senseless. It derived from the growing body of research which suggests that there was meaning to what people said, even when those utterances seemed very bizarre. Thus this study began with the assumption that people with psychosis seek to make sense of their experiences, and proceeded to explore how they did so.

This exploration was no easy task in the space of two interviews per participant. What very quickly became clear at the beginning of the interviews was that some people’s communication of their understanding of their mental health problem had, like their lives, been disrupted by the psychosis. Thus, while the dominant themes of the narratives were immediately evident, details of the complexities were not clear in the interview, sometimes even after further exploration. Participants often went off on tangents, found it difficult to focus or think and there was some evidence that they may have had interference from voices. Furthermore, some participants had difficulties themselves in making sense of some of the experiences or had made an internal sense of them which was difficult to communicate. Perhaps what was most difficult for me as an interviewer was some participants’ periodic lack of awareness of their difficulties in communicating (e.g. in the ‘being in experience’), which made our conversation confusing and frustrating.
These discourses however, were far from the ravings of mad people. In fact, as the transcripts were examined, it soon became clear that (with the exception of the two participants with restricted discourses) it was the plethora of meaning rather than a paucity of it which led to the interviewer’s confusion. Thus in the attempt to give the participants a voice, some interviews involved a form of mental gymnastics on the interviewer’s part in order to gain as much meaning as possible.

In spite of all of this, it was clear that, contrary to Berrios (1991), these meanings both reflected an understanding of participants’ selves and the world around them. Participants repeatedly demonstrated that they were aware of and could reflect on their experiences while bearing in mind my own position as listener. Thus participants described the painful experiences which had dominated their lives, from the unusual experiences themselves to their emotions, confusion, losses and the reactions and beliefs of others.

4.3.2 Narrative Reconstruction in Response to the Upheaval of Participants’ Lives

The social, emotional and cognitive upheaval of participants’ lives as a result of the experiences related to psychosis can be seen as a disruption of the person’s biography or life narrative and thus a challenge to the self. As Kerby (1991) suggests, the self can be seen as something which is lived and may or may not have been explicitly narrated. Thus people do not continually concern themselves about their identity much of the time, as it is unthematically supported by their day to day experience: their body, work, friends, home and general style of living. He points out, however, that the identity and a person’s views of their life can persist only through the continued integration of ongoing experience, that is only if he or she can implicitly or explicitly show how particular events are actually
part of, or aspects of a continuous self and whole life. Thus when a situation arises in which day to day experience does not support the person’s identity, explicit narration of who the person is, is called for. Psychosis is such a situation as it entails the inability to control one’s self and life in ways that had been hoped for, anticipated or assumed.

A similar situation has been described of chronic illness. Thus, Bury (1982) pointed out that disease, particularly chronic disorders, can be regarded as disrupting an individual’s biography. As such, previous patterns of behaviour and lifestyle are no longer feasible and individuals are faced with diminished control over their lives and their futures. Charmaz (1983) suggests that this results in a ‘loss of self’ which she suggests arises because the processes which normally sustain the self are absent and the images of self reflected to the ill persons by others are inconsistent with their core self-concepts. While the latter appears to be true for the participants in this research, the findings of this research differ significantly in that the data in the current research suggest the person has not lost their self but has in fact maintained it (to a greater or lesser degree) in spite of the experiences which would serve to erode it. That is, the participants reconstructed their life narratives, thus creating survival narratives.

Narrative re-construction has in fact been suggested as a response to chronic illness (Williams, 1984). Thus the person’s account of the origin of the illness is an ‘attempt to establish points of reference between body, self and society and to reconstruct a sense of order from the fragmentation produced by chronic illness’ (Williams, 1984: 177). The illness as a disruptive life event, therefore, tends to force individuals to face not only the question of what has happened, but also why it has happened and what constitutes the unity of life. This was also evident in participants’ survival narratives particularly with reference to the question of moral responsibility for their predicament. Hyden (1995) found a similar theme in his examination of psychiatric and former psychiatric patients’ discussion of
the history of their illness. In fact, it seems this theme is fundamental to most conceptions of illness (Young, 1980). Charmaz (1983) suggests that the theme of self-blame as well as self-discreditation may be drawn from culturally available meanings. In this research this was clearly the case and therefore this will be explored further in the following section.

4.4 The Impact of Master Narratives of Madness on the Self

4.4.1 The Master Narratives

Participants’ narrativization of the phenomena related to psychosis connected the individual’s experiences with cultural and sub-cultural narratives collectively known as master narratives (Hyden, 1995). They provided frameworks within which participants could interpret their experiences in terms of causes and sometimes the course and outcome of the phenomena as they related to participants’ lives. Hyden (1995) came to a similar conclusion in his research on the narrative re-construction of mental illness, but focused primarily on the interplay between cultural narratives relating to illness and the personal illness narratives. As such, he suggested that the moral evaluation undertaken in these narratives (incorporating the goals and basic values of the person) is related to the link in the industrial world between the actions of the individual and illness or disease. While one could make a similar argument in this research, it is clear that additional master narratives were influential. Thus master narratives relating to religion, social control, politics, extra terrestrial life, and madness were clearly drawn upon in participants’ survival narratives. Hyden (1995) suggests only a tentative influence from narratives like these which he called ‘folk narratives’. This difference in emphasis may be a result of sampling differences. In Hyden’s (1995) research, his participants adopted ‘illness narratives’ whereas in the present study a variety of explanations were adopted, many of which rejected the notion of an illness. In fact, the relationship between the master narratives and
participants' 'survival narratives' suggests a far more complex process than the one suggested by Hyden. That is, this research suggests that the process is one which relates to labelling, stigma and stereotypes.

As the negative stereotypes of mental illness, madness and schizophrenia clearly impacted on participants’ narratives and their lives, an examination of this impact naturally begins with evidence for the sources of these constructs. Research looking at lay beliefs about schizophrenia (Furnham & Rees, 1988) suggests that people variously viewed people with schizophrenia as dangerous, amoral, egocentric and vagrant. Similarly, De Rosa (1987) examined the social representations of mental illness and presented research on their development. De Rosa discovered that children and adults’ social representations of mental illness in our modern society were actually polymorphic in nature such that they included various archaic representations (e.g. madman as a criminal, as handicapped and emotionally disturbed). A review of the literature on mass media representations of mental illness found similar themes arising in a majority of the research (Wahl, 1992). Furthermore, there was evidence that the presentation of negative stereotypes in the media contributed to negative and rejecting attitudes toward mental illness amongst the general public.

4.3.2 Stigma and Labelling

Given that these master narratives exist in society, it is not surprising that the participants would not wish to associate themselves with the labels of mental illness or schizophrenia. It would seem to be a result of the conflict that Goffman (1963) suggests is created when one has learned the prejudices directed towards a stigmatised class, only to later find oneself to be a member of that class. A strict labelling perspective does not however explain the results of this study. That is, a labelling perspective suggests that although most hospitalised mental patients resist institutional definitions early in their patient careers, they are eventually forced to take the psychiatric staff’s view of their personal history (Goffman
1961). Recent research on the process of engulfment into the patient role similarly suggests that minimising psychiatric problems; distancing oneself from other patients; and presenting alternative, non-psychiatric reasons for hospitalisation is just a brief stage in a developmental process which ends in the adoption of the psychiatric labels (Lally, 1989). However, this study found that, prior to adopting the labels, these patients’ beliefs and definitions of mental illness shifted in order to maintain a positive view of the self. In contrast to Lally, the participants’ unwillingness to see their difficulties as a mental illness in the current research did not appear to be a brief developmental stage which would necessarily end in the acceptance of labels. Some of the participants had maintained for many years that they were not mentally ill.

Since most participants held negative, stereotyping views of mental illness or schizophrenia while simultaneously rejecting the labels as reasonable explanations for their difficulties, one can reasonably suppose that not only did their constructions of these labels not fit their experiences (as supported by the data), but the stereotypes proposed a threat to the self. Thus participants either wished to distance themselves from the stigma and the potential consequences of that stigma, and/or they were protecting themselves from the implications that adopting these stereotypes would mean to who they were and what the future would hold. In fact, in a study looking at label resistance techniques in psychiatric patients, Quadagno & Antonio (1975) conclude that these techniques were used to maintain a normal identity in the face of stigmatisation. Unfortunately, their conclusions are mere speculation as they are not supported by their data. In the current study, however, it seems that both explanations (the threat to self of the implications of being mentally ill and the fear that one would be treated that way) are valid, particularly if one sees one’s self as privately known and one’s self as known by others as being related. Clearly a labelling perspective would argue that to be treated like someone who was mentally ill could lead to the transformation of the person into this label (e.g. Becker, 1963;
Erikson, 1962). In fact, one participant suggested such a link. A more complex formulation of the impact of cultural meanings on the self is called for however, as one is still left to explain the process by which the participant can both endorse cultural stereotypes about mental illness, and yet deny the applicability of the very labels they endorse.

4.4.3 The Self and its Voices

Bakhtin’s notion of dialogicity provides a useful framework in which to understand how the master narratives impact on the participants’ survival narratives. Bakhtin saw a person’s speech as not belonging wholly to that person, but populated by different intentions, opinions and positions of others (i.e. different ‘voices’). From a Bakhtinian perspective, then, the speaking identities (or ‘voices’) embodied in the master narratives (often relating to mental illness) were internalised by participants, only to have been made their own in the context of their experiences. In the situation which participants found themselves in this research, it seems likely that they both accepted many of these ‘voices’ as authoritative, and appropriated them into the internal conversations which Gagnon (1992) suggests compose the self. These conversations, then, clearly seemed to incorporate the tension between the unacceptability of applying the derogatory meanings from the master narratives to what participants saw as their selves, and the recognition of the similarities between their experiences and situations and the pictures painted by the master narratives. One could therefore argue that the shadow narratives were a collection of internal ‘voices’ that incorporated master narratives (e.g. of mental illness) and maintained their authority because they continued to be reinforced by voices in the external world (e.g. through the psychiatric system) or indeed in the person’s mind. The survival narratives thus incorporated a position in opposition to the shadow narratives, incorporating new voices adapted to explain the participant’s situation and
negotiated in the context of the interview relationship with the researcher and all the ‘voices’ she was perceived to embody or enact.

In support of the multi-voiced nature of the narratives in this research, Doubt (in press) demonstrates the double-voiced language used in schizophrenia. He challenges the traditional linguistic perspective on ‘psychotic discourse’ which suggests that it is dysfunctional and illogical and proposes a metalinguistic perspective which ‘preserves the social membership and human significance of people with schizophrenia’ (Doubt, in press). Georgaca & Lopez (1995) suggest a similar approach to understanding psychotic discourse.

4.4.4 The Survival Narrative as a Defence

When one begins to examine the relationship between participants’ survival narratives, their master narratives and the shadow narratives, one cannot help but invoke psychological metaphors relating to defence mechanisms. That is, one could argue that a survival narrative serves as a defence against the painful awareness of an unacceptable version of the self. In this research, this defence could be construed as primarily (though not exclusively) against the perceived implications of being mentally ill. This certainly fits with a considerable body of research which suggests that delusions and delusional thinking are defences erected in order to protect the self from overwhelming emotions such as shame, personal inferiority and loss of control (e.g. Sullivan, 1965; Colby, 1975; Melges & Freeman, 1975). In this literature, however, these defences are seen as underlying causes of the psychosis, rather than a reaction to it, as the data in the current research would suggest.

Further support for this ‘defence’ model comes from literature (reviewed by Amador, Strauss, Yale & Gorman, 1991) which suggests that self-awareness deficits in psychosis stem from psychological coping mechanisms or defences. A
traditional (i.e. psychoanalytic) formulation of denial in psychosis was proposed by McGlashan & Carpenter (1976) who, in reviewing the literature, suggested that denial is a stage of recovery from psychosis that follows from postpsychotic depression. They further concluded that ‘Patients who try to integrate information from their psychosis (rather than use extensive denial) may be more prone to react depressively to insight.’ (McGlashan & Carpenter, 1976: 235) In concordance with this research, the data from the current study might be used to make the prediction that those participants who adopted their shadow narrative as an accurate version of self (which for some meant adopting a label of mental illness) were more depressed and hopeless. Unfortunately, it is not possible to draw any firm conclusions regarding this. What does seem clear however, is that denial of a mental illness and the presentation of an alternative construction of one’s difficulties (often categorised as delusions) are adaptive insofar as they present a version of the person’s life and their future in terms which are more acceptable than the perceived alternative. This is supported both by research on delusions (e.g. Roberts, 1991; Bentall, Kinderman & Kaney, 1994) and on denial of illness (O’Mahony, 1982). In fact the latter researcher found that (much like the participants in this study) psychiatric patients viewed themselves as being like the mentally ill in some ways but did not characterise themselves in these terms as they endorsed the negative stereotypes of mental illness. He concluded from this that denial of a psychiatric illness is a normal process of rejecting self-stereotype identities.

Another defensive position taken in the present research could be argued to be embodied in the untouched narratives. There are some similarities between those participants whose narratives were categorised as untouched and what McGlashan, Levy & Carpenter (1975) proposed was a ‘sealing over’ recovery style (i.e. one which involved fixed negative views of their illness and one which was characterised by lack of interest in thinking about their difficulties or placing them in the context of their lives). In the current research however, those with
untouched narratives seemed to adopt even more extreme positions than those described by McGlashan et al. (1975). That is, not only did the two participants in the present research seem to have no interest in thinking about their experiences, they seemed to have restricted their whole capacity to understand it. While one might reasonably argue that this restricted narrative was a function of their unwillingness to discuss their difficulties with the researcher, there was evidence that in fact they adopted this style throughout their lives. This is supported by nurses’ comments of one of the participants that ‘you won’t get much out of him’ and their concern over another participant’s memory difficulties which (after psychometric testing) proved to be selective forgetting of information related to her mental health problem. One could argue that this was merely a side effect of medication, or to take a medical approach one might argue that their presentation was due to underlying cognitive deficits (negative symptoms). However, literature on coping styles suggests that denial, repression or blunting may be a general coping style used by people when faced with threat (Byrne, 1964; Miller, 1987). Support for this also comes from the bereavement literature (e.g. Parkes, 1972). Clearly further research is needed to elucidate the nature of this narrative voice.

In sum, traditional research looking at delusions and denial of psychotic illness has conceptualised these as defences to protect the fragile self. As this research arose from traditional psychoanalytic theory, this process was often seen to be pathological. More recent conceptualisations of these phenomena, while positing a similar protective mechanism, suggest that these defensive strategies are actually adaptive strategies which are secondary to the primary difficulties faced by people suffering from psychosis. The current research would be in accord with the latter approach, not only because the research suggests that denial and self-deception are commonplace in our society (e.g. Shean, 1993) and may be normal mechanisms to promote positive mood states (Kiersky, 1998), but because of the very essence of the continuing struggle evident in the survival narratives.
4.4.5 The Survival Narrative and the Shadow Narrative as Constructions of the Self

Constructivist models of psychology provide particularly useful ways of looking at the current data as they suggest that people actively construct their world in ways that are meaningful to them (Bannister & Fransella, 1986). Kelly’s (1955) Personal Construct Theory was one of the first of these theories, suggesting that people act in response to the way they make sense of and anticipate the world. Kelly’s basic philosophical assumption, constructive alternativism, can be summarised in the following:

Like other theories, the psychology of personal constructs is the implementation of a philosophical assumption. In this case the assumption is that whatever nature may be, or howsoever the quest for truth will turn out in the end, the events we face today are subject to as great a variety of constructions as our wits will enable us to contrive. This is not to say that one construction is as good as any other, nor is it to deny that at some infinite point in time human vision will behold reality out to the utmost reaches of existence. But it does remind us that all our present perceptions are open to question and reconsideration and it does broadly suggest that even the most obvious occurrences of everyday life might appear utterly transformed if we were inventive enough to construe them differently.

(Kelly, 1970: 1)

Kelly further went on to suggest that a person anticipates events by construing their replication and that this construing is in essence people’s capacity to recognise replicated themes. He labelled these themes ‘constructs’ and suggested that irrespective of whether they have verbal labels attached to them, the
constructs are the discriminations people make, not the labels attached to them. As these constructs are discriminations, he argued that they were usefully thought of as dichotomous, or having two poles. That is, in order to make discriminations among things, people are making the decision about what something is, only in relation to what it is not. Thus, he asserts people never affirm without implicitly denying, within a given context.

Kelly suggests that each person has a system of constructs which are hierarchically ordered such that some constructs (i.e. ones relating to basic values and the self) are superordinate to others, and thus have far more implications and applicability. This theory would suggest that the disruption to their lives that participants in this research described could be thought of as events which overwhelm the person’s construct system as they invalidate the person’s core constructs (i.e. those that are most superordinate) about themselves, their roles and the world around them. Using Kellian terminology, the participants suffered ‘threat’ insofar as they were aware (at some level) of an imminent comprehensive change in their core structures. Bannister and Fransella (1986) suggest that a person suffering threat can either become ‘hostile’ (i.e. extorting validational evidence in favour of a type of social prediction which has already been recognised, at some level, as a failure) and resist all change or may plunge into the kind of chaos that earns them the title of psychotic. In fact, while some participants clearly described points in their life that could be considered chaotic, many of the participants were in fact presenting as ‘hostile’.

The participants could also be said to be experiencing what Kelly termed ‘guilt’ or awareness of dislodgement of the self from one’s core role structure (that system of constructs which deals specifically with the self). That is, participants were faced with redefining themselves in terms of their constructs relating to madness, mental illness, and schizophrenia with their attendant implications. These could be clearly seen to be contrasting poles of constructs about the self.
One could therefore argue that participants' constructs might look something like: 'normal-abnormal', 'sane-mad', 'depressed-schizophrenic' or 'us-them'. The shadow narrative, in construct terms, could then be conceived of as the non-preferred pole of a core construct with all its unacceptable implications.

In response to 'guilt' as a process which incorporates the shadow narrative, hostility might arise. 'Guilt' may also have led to constriction, a process in which the individual narrows their perceptual field in order to minimise the incompatibilities within their construct system. The latter appears to capture those with the untouched narratives, although one can only speculate that these were caused by incongruencies in their construct systems as opposed to side-effects of medication.

Applied to this research, Kelly's choice corollary suggests that participants chose hostility or constriction as it was the option which to them made the most sense. This suggests that the participants tried to move away from confusion towards understanding even if that understanding was at odds with the understandings of those around them (i.e. in the victim, ill and special narrative voices). While these may have been adaptive strategies within themselves, they could potentially suggest severe limitations for the person's life. That is, if a person constricts their world to such an extent that they cannot make predictions about the future, that person becomes a victim of those who would make those decisions for them. If a person continues to extort validational evidence for a personal construction that has already discredited itself, that person will gradually alienate themselves from those around them, particularly if those constructions are not based on shared meaning systems. Where the evidence being extorted threatens to compromise their personal safety or the safety of others, the person will lose their freedom to continue testing their constructs as they would wish to and may conclude that in fact those who claim to help the person are threatening them.
In contrast to this, the ‘author voice’ suggests that, even given the ‘threat’ and ‘guilt’ which participants experienced, there was still the possibility of elaborating their construct systems in such a way as to transcend the contradictions in their construct systems, that is, to create constructs which adequately explain their experiences, without invalidating their core constructs. The new role voice also provided a way for participants to elaborate their core-role construing, almost irrespective of their personal constructs relating to their difficulties.

In sum, participants’ experiences threatened to invalidate their most fundamental understanding of themselves and the world through the adoption of a shadow narrative which embodied unacceptable constructions of themselves. As a result they creatively adapted their construct systems (through survival narratives) to make sense of their worlds in ways which validated their sense of self.

4.4.6 Summary

The meanings that people with psychosis give to their difficulties can be understood as the struggle to survive the threats to the self that are imposed by psychosis in today’s society. This threat arises not only from experiences central to psychosis which drastically alter the person’s life, but from the social constructions of mental illness and schizophrenia which continue to embody stigmatised, prejudicial and inaccurate images of those given these labels. Thus mental illness and schizophrenia are seen as far more than the illnesses which afflict someone, but represent a moral judgement of the individual where society represents the judge, jury, prosecutor and the supposed defence (i.e. the experts). These master narratives obtain their power, both because they are internalised and adapted into personal constructions (via the shadow narrative) prior to the occurrence of the psychotic experiences, and because they continue to be enacted by others in everyday life.
The consequences of this internal and external struggle are embodied in survival narratives which place the psychotic experiences in the context of people’s life narratives in order to invest them with meaning. Furthermore, in adopting dominant voices within the survival narratives, the identity of the individual is intended to be preserved (in spite of the threat) both for the listener and the narrator. This attests to people’s resilience and creativity, even though certain survival narratives are based on psychological strategies which can themselves be extremely limiting for the individual.

4.6 Clinical Implications

4.6.1 Direct Interventions

Many of the participants in this research indicated that they valued the opportunity to discuss their understanding of their mental health problem with someone who was open and non-judgmental. Some participants found this a liberating experience as they felt that, when they had made attempts to talk about such issues previously, they had not been taken seriously. Thus, one could conclude that clients should be given the opportunity to discuss their understanding of their mental health problem in the context of therapeutic work, both because it provides information which could enrich the therapeutic work and ground it in clients’ frameworks, but also because it allows people the opportunity to discuss something which may have been hidden for many years. Three issues however, are important to highlight.

Firstly, it seems that not all people with psychosis will benefit from such conversations and in some cases it may upset or disturb people. In spite of all the precautions that were taken to ensure people were not upset by the interviews, two participants dropped out of the study, both becoming extremely suspicious of the interviewer’s motives and one suggesting that the interview was making him
ill. While it was clear that these participants had similar experiences in a wide range of interpersonal contexts, one cannot rule out that the interview was in fact too threatening for them. Furthermore, it was difficult to judge the impact that the interview had on two participants who had restricted narrative voices both in and out of the interview. This signals that clinicians should proceed with caution.

A second issue concerns trust. That is, it may very well have been that the two people who refused to continue the research were disturbed by the fact that I was a stranger to them and thus they did not have a trusting relationship with me. Certainly, one participant commented on his inability to disclose certain things because he did not know me. This would imply that a trusting relationship would be best established prior to this type of discussion. Perkins and Repper (1996) however, suggest that developing a relationship with someone who has a serious ongoing mental health problem, can take a long time as the person has often seen numerous relationships with family, friends and mental health workers break down and disappear. They can also be suspicious of new people and understandably reluctant to invest their trust. Given that this is the case, discussions which centre around clients' understanding of their difficulties might best form a part of ongoing work rather than, for instance, being included as part of an initial interview.

A third issue, related to the issue of trust, concerns the position that is taken by the clinician in the conversations. Narratives which emerge from interviews are generally regarded as the joint construction of interviewer and interviewee (Mishler, 1986), and it was clear from the interviews that both the perceived and actual stance that I took had an impact on the narrative. Certainly, some participants saw me as an open minded, and curious researcher, while others saw me as an expert who endorsed a medical model. It seems reasonable to argue that adopting a curious approach rather than one which endorses a particular perspective (whether a biopsychosocial or cognitive-behavioural), would be more
likely to allow clients to explore their own views, thus establishing a mutually respectful relationship. Unfortunately, it is likely that many clients will have preconceptions about clinicians, which could clearly influence the narrative. It would therefore be wise for clinicians to be vigilant for signs that the client is construing them in a particular way and try to address the preconceptions (or conceptions in some cases) where it seems appropriate.

Adopting a curious, open approach, within the context of therapy is far more difficult than many psychological therapies would acknowledge, primarily because much of psychology is based on the assumption that, as a science, it is objective and value free. Many therapies endorse this assumption (CBT for instance) which results in clinicians failing to recognise the impact that the therapeutic perspective might have on the client who comes to the therapeutic relationship with their own set of meanings and values. Even the ‘Socratic questioning’ used in CBT (e.g. Turkington & Kingdon, 1996), which purports to be impartial, implicitly defines what is and what is not acceptable to talk about. The current research clearly points to the dangers of imposing one’s perspective without an awareness of the consequences of that perspective for the person’s own system of construing. For instance, if a clinician imposes a biopsychosocial model, which is interpreted by the client as the clinician suggesting the client is mad, the clinician may well be inadvertently encouraging the client to adopt one of their shadow narratives. While one can only speculate as to the outcome of such a folly, at the very least, the therapeutic relationship will be damaged. In addition, the client may well either retreat into a further defensive or closed position or may become depressed and hopeless as their sense of self (as seen through their life-narrative) is essentially invalidated.

One could further argue that adopting an open approach is more of an ideal than a reality. As humans, clinicians cannot be completely objective, for the very act of being involves making sense of the world in the context of our culture and past
experiences. To be in conversation with another is to communicate our understandings, our values and so on, both by what is said and what is not, how it is said, and the context within which it is said. Those psychological therapies which acknowledge this (e.g. psychoanalysis) should be applauded for their recognition of the impact of the therapist’s construing in the therapeutic relationship and for their requirement that therapists have their own therapy, so that at the very least, they can begin to decipher whether the information arising from therapy sessions is related to the therapist’s own construing or the client’s.

In order to adopt an open approach with clients, one must also look at the assumptions which underpin the psychological therapies which might inform that approach. For instance, some theorists suggest that most psychological therapies have an inherent potential to pathologise the individual. That is, Parker, Georgaca, Harper, McLaughlin and Stowell-Smith (1995) argue that psychologists, like other mental health professionals, impose their own stereotypical distinctions onto others and thereby locate the responsibility for an individual’s distress in the person, rather than in the social structure from which it came. This forms what has been referred to as the ‘psy-complex’ or a dense network of ‘expert’ theories and practices (including psychiatric diagnosis) which works throughout culture and defines who is normal and who is not.

As there are clearly parallels between the master narratives evident in this research and elements of the ‘psy-complex’ (i.e. issues of responsibility and blame) one could argue the use of certain psychological therapies might inadvertently endorse an individual’s shadow narrative. Furthermore, by locating the responsibility for psychological distress in the individual (i.e. in their dysfunctional beliefs), no attempt would be made to look at the systems that inform those beliefs, nor would any attempt be made to discover how such distress might be maintained by the oppression inherent in the psychiatric system and society as a whole.
In contrast to traditional psychological therapies, narrative therapies (e.g. White & Epston, 1990) locate a person’s experience of a problem as both a conflict between the narratives storied by the person, or storied by others about the person, and the lived experience. Furthermore, White suggests that these narratives are significantly informed by the ‘truth’ discourses (or master narratives), thus subjecting themselves and others to the specifications for personhood and relationships that are carried in these discourses. He further suggests that the presenting problem must be externalised in such a way as to help people identify and separate from these ‘truth’ discourses that are subjugating them. Once this has been achieved, then other discourses can be identified and the person encouraged to create meaning around them.

This would be a particularly valuable approach in light of the present study, as it suggests that if people diagnosed as ‘schizophrenic’ could either be encouraged to challenge the master narratives which may be informing their shadow narratives, and/or develop new meanings outside of their shadow narrative, this would give them greater control over their lives. In essence, they might be helped to move from adopting a dominant ‘victim or ill voice’, to an ‘author or new role voice’.

This approach necessarily involves a great deal of flexibility, as people’s psychotic experiences may be overwhelming, leaving little room for reflection, or their shadow narratives may be so threatening that even highlighting their existence may not be helpful for the person. It might therefore be necessary to attempt limited elaboration of people’s constructs within the tight system of meanings that already exist. For example, helping someone to verbally challenge the aliens which the person believes control him. Alternatively, therapy might focus on helping the person develop new roles in spite of the psychotic phenomena, thus helping them achieve control over at least one area of their lives and validating one aspect of their self-narrative.
4.6.2 Indirect Interventions

Given that the current research points to both the deleterious impact of the master narratives of mental illness and the oppression suffered by participants as a result of both the psychiatric system and society, one cannot look only to individual therapy as the sole means of alleviating these difficulties. Orford (1992) suggests various alternatives to traditional therapeutic practice which have as their aim the empowerment of individuals and communities. These include educating communities to help raise the status of people with psychosis, acting as an advocate or ‘professional ally’ for individuals or facilitating self-help groups and user groups. Psychologists share similar values to many user organisations, and like these organisations, offer non-medical treatment alternatives. The Hearing Voices Movement (Romme & Escher, 1993) for instance, has been highly successful in the establishment of user groups which challenge the dominant psychiatric notion of voice-hearing as a symptom of a disease and offer alternative paradigms within which ‘users’ can explore their experiences. Generally, these groups are set up and facilitated by professionals, although the emphasis is on the eventual transformation of the group into one which is purely user led. The Hearing Voices Movement is also a political movement which challenges psychiatric practices which would serve to pathologise those individuals it seeks to classify and thus increase people’s distress at the moment it defines it.

Certainly the master narratives of mental illness and schizophrenia need to be challenged in society as a whole, which necessarily involves campaigning to raise awareness and challenge the stereotypes. While psychologists have not traditionally seen political involvement as being within the boundaries of their role, this may be changing as evidenced by the existence of PPR (Psychology, Politics, Resistance) an organisation which brings together psychologists, self
help groups and campaigning organisations to fight oppression in psychology and related fields.

Whether or not psychologists see their role as a political one, they do not have to look very far to see where changes need to be made in the interest of the psychological well-being of their clients. That is, the current research suggests that, in spite of community care, whose aims included the promotion of patient choice, control and independence (Caring for People, DoH, 1989), institutional practices which deny the clients all of the above, continue to exist in health care facilities (e.g. residential units) in the community. That people who already suffer from a wide range of distressing experiences (not least the prejudicial and stigmatising attitudes of society) should be further subject to practices by mental health professionals which erode their dignity, rob them of their independence and leave them powerless, is a disgraceful situation in today’s society and one which should be addressed as a matter of priority by psychologists and other mental health professionals alike. Sadly, ‘institutional practices’ still exist in the community (Perkins & Repper, 1996) and despite the fact that psychologists are well aware of these situations, limited energy is directed towards resolving them.

Goffman (1961) highlighted the damaging institutional practices that were characteristic of large psychiatric institutions and described the key features of such institutions. A number of these features are directly relevant to the findings of this research and will be discussed here, along with recommendations to combat the institutionalisation. Perkins & Repper (1996) make similar recommendations.

1. The totality of institutions is perpetuated when residents work, sleep, and spend their leisure time in the same place. At least one participant highlighted this difficulty in the residential setting in which he lived. In part, this problem arose because of restrictions placed on his freedom by the mental health act. It
was also clear, however, that insufficient staff numbers contributed to this problem. This clearly has implications for other clients, whose mobility is restricted either by being under sections of the mental health act or through their mental health problems. Clients should therefore be helped and supported to engage in different activities in different places to avoid spending all their time in the same place. Staffing should take account of these needs.

2. **Total institutions are segregated from the wider community and everyday social life.** Participants highlighted similar difficulties in the context of being trapped in the mental health system. While it is important that groups of people with mental health problems should not be segregated from the wider community, participants in the present study highlighted the continued rejection of people with mental health problems by the community. For integration to occur it is essential that the existing stigma and discrimination should be challenged by rendering communities accessible to and accepting of people with mental health problems.

3. **Institutions are depersonalising and have rigid routines which guide even the smallest detail of people’s lives.** This point was highlighted by the fact that one participant could not even choose when to have a cup of tea, while another was forced to eat meat against her cultural practices. While the implications of this type of treatment have already been discussed, it should be emphasised that clients cannot feel valued unless flexible routines and treatment are encouraged and individual choice is promoted. Furthermore, cultural and ethnic diversity should be respected.

4. **In institutions there is a large social distance between staff and residents.** While this applied to one participant’s living situation (insofar as he felt that staff looked down on him) some participants suggested that there was just as much social distance between mental health professionals in general and their clients.
Given that the participants in this research were aware of others’ perspectives, and positioned their narratives in relation to these, the social distance between clients and mental health professionals should be decreased to avoid the degradation implied by practices which leave the clients with little dignity or power.

5. **In total institutions, residents have little control or say over what happens.** This also appeared to be the case for participants in this research, whether or not they lived in residential units. Furthermore, it compounded the lack of control they felt they had over their mental health problems. Clients should have control or say over what happens to them (within the limits of legality and safety afforded all citizens). Such practices may involve a certain amount of risk as people are given the right to make ‘wrong’ or ‘bad’ choices. However, the concept of choice is meaningless unless people are allowed to make mistakes as all adults do.

6. **Clients should be helped and supported to engage in ordinary everyday activities and to develop normal social roles.** This may be a very difficult task, as people may have lost their ability and or confidence to perform these roles or may require considerable support to find new ones. This is particularly important in light of the importance of the ‘new roles voice’ in some of participants’ narratives.

Clearly, these recommendations are based on individual instances which have been identified, thus further research is warranted to validate the current findings. Such research would perhaps also highlight the extent of the problem and might move managers and clinicians alike into a position where they would be forced to address these issues. Where such institutionalizing practices are found to exist, one might wish to turn to the field of learning difficulties for guidance in combating these difficulties.
In this field, the principles of ‘normalisation’ (Wolfensberger, 1972) have had a large impact on professional thinking. One particularly important innovation arising from these principles has been through the development of a tool to evaluate settings in which people with learning disabilities find themselves, particularly service settings, in terms of the goals of normalisation. This Programme Analysis of Service Systems’ Implementation of Normalisation Goals (PASSING) (Wolfensburger & Thomas, 1983) evaluates settings in terms of the degree to which they enhance the social image and personal competencies of an otherwise devalued group of people. One is tempted to recommend that such tools as PASSING be routinely used in psychiatric services, as perhaps quantifying the situation would lead to greater action, both at an institutional and an organisational level.

4.7 Evaluation of the Study

This section will include a discussion of the difficulties encountered during the process of the research and the impact of these difficulties on the research. Issues relating to reliability and validity will then be discussed as they apply to the qualitative methodology used in this research.

4.7.1 The Research Process

The process of conducting this research was not a smooth one as barriers arose at every stage. While these barriers impacted on the participant selection procedure, they also raised a number of issues regarding mental health professionals’ relationships to this client group, and wider issues related to psychological research, which will be discussed below.
The first obstacle encountered, and one that was overcome, came from clinical psychologists, who were required to make a judgement about the feasibility of the research. These psychologists questioned the value of getting the views of people who might be ‘deluded’. While this did not come as a complete surprise, it served as a reminder that the discourse of people with psychosis continues to be viewed by some as meaningless, even by clinical psychologists.

The next set of difficulties arose when the health authority ethics application had initially not been approved because it had not been endorsed by a psychiatrist with considerable influence in the area. Given the obvious differences in backgrounds between psychology and psychiatry, this raises the issue of whether, as psychologists, we should be content with a situation in which psychiatry has power to dictate the boundaries of psychological research. What was even more surprising was that, rather than being very strict on ethical guidelines, the psychiatrist suggested that, if it could be proven that the research was valuable enough (i.e. it meets his criteria of advancing our understanding of psychosis), then there were ways to persuade people to participate in the research even if it meant that it might be distressing to them. His approval was eventually obtained; however future contact with him was avoided.

4.7.2 Participant Selection

Due to the methodological constraints (discussed in the methods section), which included difficulties in recruiting participants, time constraints and limitations imposed on my methodology, biases clearly existed in this research. For example, participants may have been chosen because they had particularly strong views about their treatment, or because they craved social contact. Health care professionals may also have chosen clients because they were ‘well enough’ to participate. In fact, my conversations with staff suggested that both of these factors did influence the selection procedure. What’s more, it was clear that some mental health workers had ignored the inclusion criteria altogether, even to the
point that a man who had never experienced any psychosis was accidentally put forward as a potential participant.

Despite these biases, a quite diverse sample of people was successfully interviewed, which in some ways may have balanced out the difficulties encountered in theoretical sampling for participants. One group of clients which was omitted (because of my original focus on those who rejected the idea that they had a mental health problem) were those who blame themselves for their difficulties. Both clinical experience and evidence from research (Chadwick, Birchwood & Trower, 1996) suggest that a proportion of people believe that they deserve their predicament, because they are inherently bad. As these are also concepts to be found in master narratives of mental illness, an examination of these narratives might have extended the results of this research even further and could be a focus for further research.

4.7.3 Reliability and Validity

The criteria for judging psychological research has traditionally been limited to questions of reliability and validity, and characteristics of theory which include parsimony, empirical content, internal consistency and generality (Henwood & Pidgeon, 1992). These criteria have been based on quantitative experimental research methods in which the need for objectivity is seen to be paramount. As qualitative research challenges the notion that any research can be completely objective and free of bias, qualitative researchers would argue that there are no methodological criteria capable of guaranteeing the absolute accuracy of research. However, a number of criteria which embody good practices, have been suggested which demonstrate the rigour of the research (Henwood & Pidgeon, 1992).
4.7.3.1 Goodness of fit

Rather than reliability, qualitative research is judged in terms of its comprehensiveness and the ‘fit’ of the data with the final account (Clegg, Standen & Jones, 1996). Grounded Theory Methodology aims to ensure that the theory is grounded in the data through the use of a number of techniques which help develop, then challenge initial assumptions and categories. This researcher believes that the ‘theory’ does in fact fit the data, and has demonstrated this through the use of verbatim material, and an explanation of the analysis as an interplay between the researcher’s ideas and the emerging concepts.

4.7.3.2 Theory Integrated at diverse levels of abstraction

Grounded Theory techniques are intended to create a conceptually dense theory which is integrated at diverse levels of generality. While the theory in this study does contain readily apparent connections between data and lower and higher level conceptual abstractions of categories and properties, problems encountered in the research (because of the nature of participants’ difficulties) meant that some categories and concepts were not fully saturated. That is, because the participants often went off onto tangents, making interviewing difficult, the commonalities between the categories generated in the initial stages, were few. The researcher was thus forced to move to higher levels of abstraction in order to integrate the diverse data, thus leaving theoretical sampling largely to the latter stages of the analysis. Although Charmaz (1995) advocates such an approach in order to ensure that the relevant issues in the research were defined, and to allow significant data to emerge, it was not possible to then return to the participants to gather more data on the emerging categories. This necessarily meant that some categories were not fully saturated.

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3 Henwood & Pidgeon (1995) recognize that for newcomers to qualitative research, it may not be possible to build a comprehensive theory, and instead suggest more realistic objectives such as
The ‘narrative voices’ are a good example of this approach, as it was only when I tried to integrate the loose collection of categories (e.g. coping, being a victim of malevolent others) with the categories emerging around the relational aspects of participants’ accounts and the prejudices and negative stereotypes relating to mental illness, that the concept of ‘narrative voices’ emerged.

4.7.3.2 Internal Reliability

This refers to the extent to which phenomena are consistently assigned to the same category by different observers or by the same observer on different occasions and is an important issue in qualitative research (Silverman, 1993). In the present study, both forms of internal reliability were used. Hence open coding was performed by the researcher twice on each transcript and selected portions of transcripts were open-coded by a fellow trainee. Not surprisingly, there was not a perfect concordance in either case. However discussion of the differences between the other trainee and myself provided additional useful data (most notably around the contradictions in participants’ accounts) and forced the researcher to be continually aware of the assumptions behind the process of categorisation. Furthermore, to assume that one could achieve perfect internal reliability, would be to adopt a positivistic stance which ignores the complexities of the social world and the subjectivity of the individual.

As only selections of transcripts were coded by another person, some of the differences which arose, did so because she did not have access to the full transcript, which would have made some of the categories more meaningful.
4.7.3.3 Reflexivity

Qualitative research, in contrast to quantitative, acknowledges the ways in which the research activity inevitably shapes and constitutes the object of inquiry. The research participant and the researcher are interdependent in the social process of research. This reflexivity acknowledges that the position or stance taken by the researcher will affect the way the research is undertaken and understood (Henwood & Pidgeon, 1992). In the present study, the constructivist stance of the researcher, which was largely derived from her interest in Personal Construct Psychology (PCP) (Kelly, 1955), clearly influenced the design of the interview schedule. An integral part of this theory involves attempts to understand the meaning of the contrasting pole of a construct (in this case mental illness/madness etc.) in order to understand why someone might choose the opposite pole (i.e. whatever not-being-mentally-ill meant). The endorsement of this theory may also explain the way in which I anticipated a straightforward dichotomy between beliefs that a person was ill versus beliefs that they were not, which were translated into the participant selection criteria and ultimately contributed to the difficulties in obtaining participants.

It was interesting to note that PCP had notably less influence on the researcher's expectations concerning the stories the participants might tell. That is, I expected that participants would have relatively coherent and stable stories that could reasonably be elicited in the context of two interviews. These expectations did not hold up. Given that I have a great deal of experience of working with this client group and had heard many of these stories in the past, one can only suppose that my familiarity with the client group lead me to underestimate the time and trust that was necessary to hear those full stories.

Certainly, I was aware, prior to the start of the research, that there was literature which specifically focused on narratives. However, I chose to follow the
grounded theory approach of delaying the literature review as much as possible in order to stay open to the data. It was only when the data began to move me towards a more social constructionist account of participants’ experiences (through one participant’s comments) that I began to look at that literature (e.g. Bakhtin, 1975/1981; Potter & Wetherell, 1987) which altered my perspective and the course of the research. Indeed, Strauss & Corbin (1998) suggest that intensive research is likely to result in some reciprocal shaping, which helps the researcher become more theoretically sensitized. They argue that one aspect of this might involve ‘scrutinizing the literature for received theories that might possibly be relevant to the emerging theory largely developed through the continuing conversation with the data’ (Strauss & Corbin, 1998: 280). Constructionist revisions of Grounded Theory further alert the researcher to the fact that the data should guide but certainly not limit the theorizing (Layder, 1993).

One further effect of my assumptions on the data analysis, relates to my passion to address injustices against vulnerable individuals. While this passion clearly has roots in my personal history, it also arises from years of working in modified Therapeutic Communities where I learned the disabling effects of institutionalization and the dramatic influence of an environment filled with choices and positive expectations. I therefore expected that some participants would describe various abuses and neglect in the mental health system. While I tried to give voice to these views in my research, I neglected to focus on this particular aspect of participants’ concerns, as I believed at the time that it would detract from the original aims of the research. With hindsight, I believe that the decision not to follow that particular issue also arose from the risk that is inherent when one begins to challenge such practices in large institutions such as the mental health system.

Taking a reflexive position, the researcher might also influence responses given in the data. This was obviously the case in the current study and in fact was a
feature which was highlighted in the analysis and was integrated into the overall ‘theory’. For example, the two participants who appealed for me to see them again, may well have been adopting this position in response to my empathy and my status as a mental health professional. In addition, some participants commented on the effects on their discourse of both the newness of the relationship and the ‘expert, medical position’ which the researcher was perceived to endorse. Others however, appeared to accept the open-minded impartial position which the researcher sought to adopt, as they both felt able to criticise the mental health services and disclosed a great deal of personal information. It is interesting to note that, although I sought to be open-minded, in fact, my position had an impact on the narratives. It seems likely that in spite of my attempts to dispense with the traditional models of psychosis (which I once endorsed), I approached the data from a pathologising stance. This was particularly evident with Cuthbert, about whom I’d been inadvertently given information regarding his numerous compulsory hospital admissions. Although I did not record these thoughts at the time, I clearly recollect being surprised and suspicious at how ‘together’ he presented. One could argue then, that my position, though subtly conveyed, had encouraged an authoring voice. In fact, the whole focus of the interviews suggests a problem centred approach, which may well have influenced the ‘narrative voices’. One wonders what ‘voices’ might have been present, if the interview merely asked participants to talk about their lives, or if they had been interviewed by service users.

Reflecting on the impact of the researcher on the participants also raises ethical issues. That is, one wonders whether, as a researcher asking people to talk about very sensitive and potentially emotional issues, I was just not recreating the dynamics often found in institutional settings in which clients are expected to disclose very personal information to numerous professionals. This is a very difficult issue as, by its nature, qualitative research relies on people’s willingness to divulge personal information. One might counteract this, by only choosing
clients who are already in therapy with the researcher. However, this clearly places huge constraints on the type of research undertaken and causes ethical dilemmas in the therapeutic relationship. On a more practical level, psychologists might work with other health care professionals to ensure that people do not feel obliged to reveal very personal aspects of their lives, and to ensure that the number of professionals who might encourage them to do so is much more limited.

4.7.3.4 **Transferability**

The question of the extent to which findings can be generalised is an important principle in quantitative research. In qualitative research the term transferability has been used (Henwood & Pidgeon, 1992). This refers to the ability to apply findings of a study in contexts similar to the ones from which they first originated. Henwood and Pidgeon (1992) argue that ‘rich and dense grounded theory which is contextually sensitive at diverse levels of abstraction, will in itself suggest its own sphere of relevance and application’ (p. 108). The diversity of the participants’ experiences and the depth of the analysis suggests that this research might be applied to other people who are struggling with psychosis. However the limited theoretical sampling clearly limits its transferability, which suggests further research is necessary.

4.8 **Future Directions for Research**

4.8.1 **Qualitative Research: a Paradigm of Choice**

While one might be tempted to use the present research to inform future quantitative studies, to do so would be an extremely difficult task in order not to discount some of the fundamental results of this research. For example, if one were to devise a system of basic typologies to measure survival narratives, one would ignore the very essence of survival narratives as complex social
phenomena created in the context of relationships. This would ultimately render such typologies relatively meaningless.

For too long, researchers have attempted to categorise the experience of people with psychosis, by imposing their values and beliefs at the expense of people's dignity and humanity. What is needed is a new era of research which dispenses with the old assumptions of the medical model and takes as its starting point the lived experience of people with psychosis (Borgna, 1981). At the same time, research needs to acknowledge the existence of the medical model as a powerful contextual force in the lives of people with psychosis, and further examine its impact on their experiences.

The current research suggests that a qualitative paradigm is ideally suited to exploring the experiences of people with psychosis as it embraces the complexity of their worlds and values their perspectives, no matter how deviant these may be deemed by society. Some researchers have already begun to use this methodology in their studies, thus highlighting strengths and adaptations as well as the suffering and vulnerabilities described by those with psychosis (e.g. Estroff, 1981; Sass, 1988; Corin & Lauzon, 1992; Quigley, 1997). By adopting such a paradigm, qualitative research has begun to challenge the notions of psychosis as a pathology and an abnormality, instead valuing the contribution that people with psychosis can make towards our understanding of the human condition.

A final point concerns the implications of research for clinical practice. A qualitative paradigm lends itself particularly well to clinically relevant research (see Clinical Psychology Forum, 1998). That is, not only is it more sensitive to the complex social phenomena which clinical psychologists are in the business of working with, but it also bridges the ever increasing gap between research and clinical practice. Increasingly, clinical psychologists are becoming interested in
qualitative research as clinical practice moves away from the strict model of science, which saw clinical psychologists as expert psychometricians or strict behaviour therapists, towards models based on social interaction.

4.8.2 Narratives and Discourse

Given that some authors argue that narrative is the basic form of human social cognition, and the results of the present research suggest that the explanations people with psychosis have for their experiences are in narrative form, the further exploration of these narratives using qualitative methodology seems justified.

Many questions relating to the present research are yet to be answered. For instance, although there is some evidence to suggest that narratives are constructed in the context of conversations, there also appeared to be evidence that, for some, certain parts of the survival narratives remained relatively unchanged over time. One might reasonably wish to explore, then, how survival narratives change over time and what factors might be related to any changes. For instance, one might wish to examine the ‘being in experiences’ and their relationships to emotions, and the type of narrative created. One could hypothesise that those experiences are overwhelming precisely because of their emotional tone, or that the greater the frequency and duration of ‘being in experiences’ the more likely that a victim, or special narrative might be adopted.

In a similar vein, people’s shadow narratives could be explored further, examining both their structure and their process in people with psychosis as well as people with other mental health problems. By their very nature, shadow narratives are difficult to access; therefore one might employ personal construct techniques to access them and explore them further.

As the survival narratives clearly have an impact on people’s lives, one could equally ask what relationships exist between survival narratives and both subjective and more objective measures of functioning. Furthermore, since there
was some evidence that adoption of a shadow narrative as a descriptor of the self could foster helplessness, hopelessness and possibly depression, one might wish to examine the narratives of those who are seen as depressed and psychotic, or those who blame themselves for their illness. Finally, one might wish to examine narratives in the context of therapy, to determine what effect, if any, different therapeutic techniques had on them.

A related area of research concerns the discourse which people with psychosis use. Two issues are pertinent here. The first concerns the language which was used. The interviews with these participants were highly challenging for the researcher precisely because of the way the participants took part in the conversations. Language production in people with psychosis has been widely studied from a medical perspective and a traditional linguistic perspective. Both of these approaches employ a reductive view, that speech is a transparent and neutral means of transmitting information and can be used to draw conclusions about the cognitive, emotional and neurophysiological state of the speaker (Georgaca & Lopez, 1995). The current research provides evidence which suggests the contrary. That is, although Grounded Theory methodology was used, some of the principles of discourse analysis (e.g. what are the functions of these statements, both in the conversation and for the individual, and what are the positions of the speaker and the listener?) informed the thinking behind the analysis. This suggested that the discourse of people with psychosis does not occur in a cultural and contextual vacuum. It was beyond the scope of this research, however, to perform any in-depth analyses on the discourse used. One area of further research in psychosis then, could be to further develop and apply what Georgaca & Lopez (1995) termed a ‘discursive analytic approach’, that respects the complex relations between the speaker, the system of language and the communicative situation (Potter & Wetherell, 1987; Potter, 1996).
The second issue concerning the accounts of people with psychosis, relates to the methods used to obtain people’s accounts and make sense of them. That is, this research highlights the difficulties of using a Grounded Theory approach within the space of one or two interviews. Not only does this limited contact with people with psychosis mean that theoretical sampling is made difficult, but trust also becomes an issue (although clearly this is an issue for any interview approach). Conducting one of the sets of interviews with a client in ‘therapy’, allowed me to take the time to later elaborate and discuss my interpretations of her interview. This highlighted the benefits of such a dialogue, which would not have been possible in one or two interviews. Such an approach also addresses some of the ethical dilemmas which arise when interviewing vulnerable people about very emotive or personal subjects.

A further related issue concerns the method of transcribing participants’ accounts. Using a Grounded Theory approach meant that very basic, content-oriented transcribing conventions were used. As a result of participants’ tangential nature of speech, the written transcripts made far less sense than the actual interviews. This is because there are a number of aspects of speech (e.g. inflections, emphases, etc.) which signal to the listener what to attend to and how, and these seemed particularly important for people with psychosis who are juggling with many ideas and voices in their conversations. Future research with this client group should carefully consider what aspects of language are to be transcribed. This is, however, no easy decision as different transcription conventions lead to and support different interpretations and ideological positions.

4.9 Summary and Conclusion

The present study suggests that people’s constructions of their experiences of psychosis may be organised into survival narratives which position their
experiences in relation to their self and the meanings of psychosis available in society. Furthermore, the analysis of survival narratives suggests that they are joint constructions of reality, negotiated between narrator and listener. As such, they provide evidence that people with psychosis are in fact aware of the impact that their difficulties have on their lives and are aware of the position that others take regarding their difficulties. Those who work therapeutically with people with psychosis, should therefore acknowledge the important role that survival narratives may play in constructing people's self-concept and their identity in relationships. In order to do this, mental health professionals should allow people with psychosis the opportunity to discuss their survival narrative in the context of a trusting and non-judgemental relationship. This is in stark contrast to the medical perspective which currently pathologises people whose construction of their difficulties is at odds with the dominant medical view of psychosis, and either discounts their perspective and the person who holds the perspective, or encourages it to be suppressed.

The present study further highlights the powerful role that social constructions (or master narratives) of mental illness and schizophrenia play in the oppression of individuals with psychosis. That is, the dominant master narratives in society suggest that the psychosis is an internal attribute of the individual and, as such, it transforms them into morally reprehensible, senseless, or dangerous people who may never lead a normal life. As it is likely that people with psychosis adopt these values and beliefs long before they have their first experiences of psychosis, they are threatened with an unacceptable construction of the self, from the moment that they either recognise that they may have a mental health problem or they are aware that others would see them that way. This construction of the self, embodied in the shadow narrative, threatens to invalidate the very core of people with psychosis' understanding of who they are. In response to this, people with psychosis construct their survival narratives to protect their sense of self from this
threat and assert an alternative identity through the narrative voice(s), an identity which gives them back their dignity and some hope for the future.

In working with the survival narratives of people with psychosis, it would seem to be important that mental health professionals do not inadvertently endorse the stereotyped views inherent in the master narratives and thus encourage participants to adopt their shadow narrative. That is, it is important to question the assumptions inherent in one’s personal perspective and one’s therapeutic orientation (e.g. models of the self) to ensure that the techniques and goals of the therapy do not ultimately invalidate the person. Narrative therapies endorse techniques which do not pathologise the individual, by externalising the problem and locating it in the culture as a whole (e.g. White & Epston, 1990). Other interventions which may be helpful, include user groups (such as hearing voices groups) which challenge the social construction of mental illness and encourage members to find new meanings for their experiences.

This study suggests that the master narratives of mental illness also have a disabling effect on people’s lives through the enactment of these beliefs on a daily basis. People with psychosis live in a society which acts as if the stereotypes and prejudices relating to mental illness and schizophrenia were true. Thus, even if people have been able to challenge the master narratives, they will be constantly faced with them through the practices and discourses in the community and, more significantly, in the psychiatric system. This suggests that what psychologists and other mental health workers need to address is a secondary disability which may well be more disabling than the primary one. In order to do this, stereotypes of madness must be challenged in the community and more urgently in the psychiatric system itself, which has traditionally endorsed a pathologising dehumanising view of people with psychosis. Psychologists working with people with psychosis must be aware of systemic issues and avoid restricting their role to individual psychotherapy. Individual work with a person for one hour a week
(e.g. in developing their self-esteem) is unlikely to be very effective if, for the remainder of the time, that person lives in a community where individuals and institutions adopt beliefs and practices which devalue, degrade and oppress people who are extremely vulnerable. This implies that psychologists move away from individual problem-focused models of work and look toward models which legitimise the individual’s experience, emphasise the person’s strengths and attempt to combat the social problems that people with psychosis are constantly facing.
References


DoH (1989). Caring for People: Community Care in the Next Decade and Beyond (Cm.849). London: HMSO


Appendix 1: Leicestershire Health Authority Ethics Committee Approval

Melanie Sursham
Direct Dial 0116 258 8610

11 November, 1997

Ms L Walley
233 Clarendon Park Road
Leicester LE2 3AN

Dear Ms Walley

Service User’s Understanding of their Mental Health Problems - our ref. no. 4848

Further to your application dated 22 October, you will be pleased to know that the Leicestershire Ethics Committee at its meeting held on the 7 November, 1997 approved your request to undertake the above-mentioned research. The Ethics Committee assumed that indemnity for this study would be provided by the Leicestershire Mental Health Service NHS Trust.

Your attention is drawn to the attached paper which reminds the researcher of information that needs to be observed when ethics committee approval is given.

Yours sincerely

R F Bing
Chairman
Leicestershire Ethics Committee

(NB All communications relating to Leicestershire Ethics Committee must be sent to the Committee Secretariat at Leicestershire Health)
Appendix 2: Research Information Leaflet and Consent Form.

Research Information Leaflet

Dear _____________

I am a trainee clinical psychologist studying at Leicester University. I am currently running a research project which looks at people's experience of their contact with mental health services and any difficulties which may have brought them into contact with these services. In order to do this, I would like to talk to a number of people who are currently in contact with the mental health services to get their views.

I would therefore like to ask if you would be interested in participating in this study. If you agree, we would meet at a convenient location. The discussion would last up to one hour and would focus on your views about the difficulties which brought you in contact with mental health services. I would also be interested in discussing what you think may have caused or contributed to these difficulties as well as what you think may have helped with them. The discussion will be taped, but the tapes will only be used by me to write out a word for word transcript which will not have your name on it. The tape will then be destroyed. The written copy of the interview will be included as an appendix in the study, however, this will be used for research purposes only and will be kept strictly confidential.

Participation in this study is purely voluntary and will not affect any treatment you may be receiving. You are under no obligation to participate if you do not wish to, however, if you feel you would have something to contribute to this
study, your participation may help improve mental health services by making them more sensitive to views of the people who use them

If you are interested, please fill out the consent form, return it in the envelope provided and I will contact you to arrange a convenient time. If you would like any further information about the study, or would prefer to phone me instead, please feel free to contact me on (0116) 225 5600 Extension 5617.

Thank you for your consideration.

Yours sincerely,

Linda Walley
(Trainee Clinical Psychologist)
Appendix 2 continued

**Consent Form**

I would like to participate in this study about people's experience of mental health services and the difficulties which may have brought them into contact with these services. I understand that my participation is completely voluntary and that I have the right to withdraw from the study at any point. I also understand that this study will not have any effect on any treatment I may be receiving and that the information I give will be kept strictly confidential.

Name: .......................................................
(block capitals)

Date: .......................................................  

Telephone number .......................................................
(or address if not on the phone)

Signature: .........................................................
Appendix 3: Initial Interview Schedule

Questions to Guide Discussion

1) How long have you been in contact with mental health services?

2) Why do you think you first came into contact with mental health services?
   Prompts: What difficulty(s) were you having which brought you in contact with the services?
   Have these difficulties changed since you first experienced them?
   How?
   Are there any additional reasons that you are still in contact with mental health services?

2) What do you believe is the cause or causes of your difficulty(s)
   Prompts: If difficulties changed, what are the causes of original difs, later difs etc. What caused them to change?
   Is there anything else that you think contributed to your difficulties.
   If so, what was it?

3) What lead you to believe that your difficulty(s) was caused by

4) What sorts of things have made your difficulty(s) worse/better?
   Prompts: How do you believe it has made them worse/better?
   Are there any things which you can do yourself which make your difficulty(s) worse or better?

5) Given that your difficulty is caused by __________, are there any types of help or treatment which you feel would be beneficial to your difficulties?
   Prompts: If so, can you tell me about them?
   How would they be beneficial
   (explore how this is related to perceived causes or contributing factors)

6) Are there any types of help or treatment which have been beneficial in the past?
   Prompt: If so, can you tell me about them?

7) Given that your difficulty is caused by __________, are there any types of help or treatment which you feel would be not be beneficial or might even make your difficulties worse?
   Prompts: If so, can you tell me about them?
Why wouldn't they be helpful/ why would they make matters worse? (explore how this is related to perceived causes or contributing factors)

8) Would you describe yourself now as being any different than before...
   a) you came into contact with mental health services?
   b) __________ happened?
   prompt: If so, how are you different?

9) Has anyone ever given you a different explanation about the causes of your difficulty/or why you are in contact with MH services?
   Prompt: If so, can you tell me about it?

10) Have you got any ideas as to the reasons other people come into contact with mental health services?
    Prompt: If so, can you tell me about them?

11) What do you think about people who are mentally ill?
    Prompt: What are the person's beliefs and attitudes about the term?

12) How do you see yourself as different from those people?

13) Is there anything that I have not asked you about which you think is important relating to the topics we have talked about today?

End Interview
Thank Interviewee
Reiterate about confidentiality and right to withdraw form the study

14) If I had any further questions regarding the subjects we talked about today would you mind if I contacted you again and arranged to discuss them further?

15) When the study is finished, would you like a written summary?

16) Would you be interested in commenting on the findings of the study?
Appendix 4: Revised Interview Schedule

Questions to Guide Discussion

1) How long have you been in contact with mental health services?

2) Why do you think you first came into contact with mental health services?
   Prompts: What difficulty(s) were you having which brought you in contact with the services?
   Have these difficulties changed since you first experienced them?
   How?
   Are there any additional reasons that you are still in contact with mental health services?

3) What do you believe is the cause or causes of your difficulty(s)
   Prompts: If difficulties changed, what are the causes of original difs, later difs etc. What caused them to change.
   Is there anything else that you think contributed to your difficulties.
   If so, what was it?

4) What lead you to believe that your difficulty(s) was caused by

5) What sorts of things have made your difficulty(s) worse/better?
   Prompts: How do you believe it has made them worse/better?
   Are there any things which you can do yourself which make your difficulty(s) worse or better?

6) Would you describe yourself now as being any different than before.
   a) you came into contact with mental health services?
   b) (difficulty) happenened?
   Prompt: If so, how are you different?

7) Has anyone ever given you a different explanation about the causes of your difficulty/or why you are in contact with MH services?
   Prompt: If so, can you tell me about it?
8) Have you got any ideas as to the reasons other people come into contact with mental health services?

*Prompt:*  If so, can you tell me about them?

9) What do you think about people who are mentally ill/schizophrenic?

*Prompt:* What are the person's beliefs and attitudes about the term? What happens to people who are mentally ill? How do you feel about people who are mentally ill? Have you got any thoughts about why people are mentally ill? Do you have any ideas about what causes it? How long do you think people are mentally ill for?

10) How do you see yourself as different from those people?

11) Is there anything that I have not asked you about which you think is important relating to the topics we have talked about today?

12) What was it like being asked to talk about these things.

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**End Interview**

Thank Interviewee

Reiterate about confidentiality and right to withdraw from the study

14) If I had any further questions regarding the subjects we talked about today would you mind if I contacted you again and arranged to discuss them further?

15) When the study is finished, would you like a written summary?

16) Would you be interested in commenting on the findings of the study?
Appendix 5: Interview Information and Consent

Information and Consent

This interview is not part of any treatment you may be receiving at the moment, rather it is concerned with your experience the difficulties which have brought you in contact with mental health services and what you believe to be the cause or causes of these difficulties.

I am going to ask a few questions which will allow you to talk about these issues. There are no wrong or right answers to any of these questions, I am simply interested in your experience of your difficulties. Please take your time answering the questions and tell me if there is anything you do not understand, so I can explain it more clearly.

As I explained in the information sheet, I will be tape recording our discussions so that I can later write them out word for word to help me remember exactly what we talked about. The tape will only be listened to by me and will be destroyed within 14 days. Are you still happy for me to tape our conversation? (give consent form)

I will also be making a few notes from time to time to remind me of any important thoughts I had at the time about the interview. These notes will also be kept strictly confidential and will not have your name on them. Are you happy for me to make these notes?

I would like to emphasise again that our discussions will be completely confidential. None of what we discuss today will be communicated in any form to the nurses, psychiatrists or other mental health professionals that you have contact with. Also, if you feel uncomfortable with any part of our discussion today, this can be erased and will not be included in the written form.
The interview should take up to one hour, however, we can break it into two sessions if you would prefer to. Finally, I would like to remind you that if at any point you wish to withdraw from the study, you are free to do so. That is, if at any time during the interview you decide that you don’t want to continue we can stop the interview.
Appendix 7: Example of Open Coding in a Transcript

173 P: My XXXX my money and everything. XXXX Then he put a bolt on my
door so they wouldn’t get in the house. XXXX
174 I: They put wood on your door so they couldn’t get in your house? Right.
175 P: I lived in Highfield. neighborhood
176 I: In Highfield. Right.
177 P: So I’ve got nowhere to go at all. Nowhere. I need a house now you know. I
can’t stay in this place like this. They keep on troubling me.
178 I: They keep on troubling you, right. And so it was the fact that they were
troubling you that’s what made you sick?
179 P: Um. Made me very ill. — caused externally ill
180 I: Made you ill. And when you were ill, what was that like?
181 P: Feels dizzy in my brain.
182 I: Dizzy in your brain.
183 P: Pains everywhere. Eyes go up you know. Coughing, and cold and flu and
snowing. pain
184 I: Coughing and cold and flu and snowing
185 P: Frostbites. Poor circulation?
186 I: Frostbites?
187 P: Maybe frostbites of my hand. The doctor gave me a sicknote after that, you
know. I still wonder where to go, you know. If they send me out of here I’ll
be in the street you know. I don’t know where to go.
188 I: So you’re worried that they’re going to throw you out of here and you’ll be on
the street?
189 P: Yeah. I’ve got no house and I need a house. I had a fancy flat and I lost the
key ‘cause somebody took the key out of my hand, you know.
190 I: So it sounds like you’re quite upset about the loss of your flat.
191 P: I am, yeah. I lived there for 7 years in my own flat and they took it away.
192 I: You lived for how many years - 7 years?
193 P: 7 years, yeah. I’m from Kenya you know.
You're from Kenya?

I'm from Kenya, yeah. I'm in England now. My father died you know.

My father died, yeah, you said. England

My sisters got married they've both got 2 daughters. My brother got married and he's got 2 boys. I'm lucky I don't have children, I hope I don't have children you know.

Sorry, you don't ...

I'm lucky I don't have children you know.

You're lucky you don't have children?

Why do you feel lucky that you don't have 2 children?

I don't like children 'cause I can't have them. I'm blind and I can't look after them.

You can't look after them, right.

You're lucky you don't have children?

Why do you think that is?

I'm getting older. I'm getting weak now you know. I don't get much food, nice drinks to drink. And I'm upset about losing my flat, I'm really upset you know. Grieving over loss of flat.

Right, yeah, I can tell. It's obviously quite important for you. That flat was very important for you.

It was you know. Broke my door, they broke my door. Smashed my door. I've got nowhere to go. now, after this place, I don't know where to go. If they send me out of here I don't know where I'm going. XXXX