

***Making Sense of First Episode Psychosis***

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## **OVERVIEW**

This thesis is presented in three parts. Part One is a literature review, in which literature related to first episode psychosis and early intervention is discussed. The concept of illness perceptions is then presented, and subsequently the question of whether this framework could be usefully applied to first episode psychosis is considered. Part Two presents the empirical paper, describing the main qualitative study completed for this thesis. This paper explores the experiences and beliefs of twenty participants who had recently experienced a first episode of psychosis. In Part Three, the process of conducting the main empirical study is reflected upon in a critical review.

## **ACKNOWLEDGEMENTS**

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## **PART 1**

# **LITERATURE REVIEW**

**Making Sense of First Episode Psychosis:  
Can the concept of illness perceptions help us to  
understand and work with people with  
first episode psychosis?**

**ABSTRACT**

This paper addresses whether the concept of illness perceptions, which has been developed in the arena of chronic physical illness, can be applied to an acute mental illness such as first episode psychosis. Literature related to first episode psychosis and illness perceptions is reviewed and the potential benefits and problems of using the illness perceptions framework when trying to understand how people make sense of a first episode of psychosis are discussed. Finally, areas warranting exploration in further research are highlighted.

**Key terms: First episode psychosis, illness perceptions, illness representations, engagement, treatment adherence and early intervention in psychosis.**

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## INTRODUCTION

Research into first episode psychosis is a rapidly growing area, fuelled nationally by the UK Government's intention to set up specialist early intervention in psychosis services across the country (DoH, 2001), and internationally by increased service development across much of the developed world. Whilst there is some contention about the role of specialist early intervention teams (Pelosi & Birchwood, 2003), there is a growing consensus that intervening early in someone's psychotic illness can lead to better experiences, treatment adherence and ultimately outcomes (Holloway & Aitchison, 2003).

Vital to being able to intervene early is being able to engage people with appropriate mental health services. However, there is much research showing limited engagement with existing mental health services by people with psychosis, especially first episode, with people commonly being lost to follow up (Birchwood, 2004).

Research exploring issues related to engagement and treatment adherence has tended to focus on the concept of insight, usually measured by the degree to which an individual's beliefs about their experiences concur with those of the medical professionals treating them. However, only a limited relationship has been established between insight and engagement, treatment adherence and outcomes (David, 1998). To date our understanding of how people make sense of the experience of a first episode of psychosis, and hence how they choose to act, remains very limited.

Similar dilemmas have faced those working in physical illness. Despite mass information provision and public health campaigns, people often remain consistently non-compliant with the advice given to them in their best interests by health care specialists. For example, why do some people who have had heart attacks still resist changing their diets and lifestyles?

Developments in health psychology have made some significant steps forward in resolving such questions. By exploring people's own subjective perceptions and sense-making when faced with a health threat, health psychologists have developed the concept of illness perceptions, and shown these to be related to engagement, treatment adherence and outcomes in many areas including cancer, diabetes and heart disease (Petrie & Weinman, 1997).

Despite the utility of illness perceptions becoming increasingly established in the domain of physical illness, the application of illness perceptions to mental illness has only recently been considered. Some preliminary research has begun to explore whether what is known about illness perceptions in physical health can be translated to mental health problems such as psychosis. Little is known, however, about the content and construction of these representations at the first onset of illness and the implications this may have for working with people with first episode psychosis.

Moreover, in a mental illness such as psychosis, which is by its nature defined as a departure from reality, and frequently not labelled as an "illness" by those experiencing it, can the concept of illness perceptions still offer a useful framework?

It is the aim of this paper to expand on the above issues by reviewing current literature relevant to first episode psychosis and illness perceptions. The potential benefits and problems of using the illness perceptions framework when trying to understand how people make sense of a first episode of psychosis will be explored, and the implications for professionals trying to engage and work with people who have experienced a first episode of psychosis discussed.

## **FIRST EPISODE PSYCHOSIS AND EARLY INTERVENTION**

### **The Development of Specialist Early Intervention in Psychosis Services**

The Department of Health's (2001) "Mental Health Policy Implementation Guide" detailed plans to establish "Early Intervention" teams for people experiencing a first episode of psychosis. This multi-million pound investment is largely based on the experiences of pioneer services in Canada, Scandinavia and Australia, and some experience in Birmingham in the UK, and these teams are intended to become an integral part of standard mental health services throughout the UK.

There has been some resistance to the development of these specialist services. Arguments against specialist early intervention teams centre on the division of resources and the recruitment of experienced staff and "interesting" clients to specialist services at the cost of existing generic services and their remaining staff (see Pelosi & Birchwood, 2003; Pelosi, 2004). Whilst there are limitations and criticisms of the specialist early intervention team model, there does nevertheless seem to be a growing body of evidence supporting at least the idea of the importance

of intervening as early as possible in the course of someone's psychosis. One preliminary outcome trial has also shown some, albeit moderately, positive outcomes for a specialist early intervention service in south London (Craig, Garety, Power, Rahaman, Colbert, Fornells-Ambrojo & Dunn, 2004), although further evidence supporting specialist early intervention in psychosis services still awaits conclusive confirmation in randomised controlled trials (Lewis, 2002).

### **The Importance of Early Intervention**

Evidence supporting the value of intervening early in psychosis is largely predicated on two concepts. Firstly, the concept of a longer duration of untreated psychosis "DUP" has been associated with poorer long-term outcomes and secondly, evidence of a "critical period" in the first 1-3 years after the onset of psychotic symptoms in which engaging people with appropriate mental health services and getting them to adhere to treatment is also seen as key to later prognosis.

#### *Duration of Untreated Psychosis (DUP)*

There are frequently long delays before people with a first episode of psychosis receive potentially effective treatment (Johnstone, Crow & Johnson, 1986; Loebel, Liberman & Alvir, 1992), with an average delay of 12 months between the onset of positive symptoms and first treatment (Norman & Malla, 2001). This delay between the initial onset of psychotic symptoms and treatment from mental health services is referred to as the "duration of untreated psychosis" (DUP).

Whilst the precise conceptualisation and consequences of DUP remain somewhat equivocal (for a detailed review see Norman & Malla, 2001), several correlations have been established between longer DUP and adverse long-term prognosis (Drake, Haley, Akhtar & Lewis, 2000; Loebel et al., 1992; McGlashan, 2000). For example, longer DUP has been shown to be associated with higher hospital readmission rates (Malla & Norman, 2002), medication non-compliance (Novak-Grubic & Tavcar, 1999), increased chance of being sectioned under the Mental Health Act 1983 (McGovern, Hemmings, Cope & Lowerson, 1994), increased risk of suicide (Nordentoft, Jeppesen, & Abel, 2002), deterioration in cognitive functioning (Ho, Alicata & Ward, 2003), and greater symptom severity and social damage (Birchwood, McGorry & Jackson, 1997; Bottlender, Sato & Jager, 2003; de Haan, Van der Gaag & Wolthaus, 2000; McGlashan, 2000; McGorry, Krstev & Harrigan, 2000; Norman, Townsend & Malla, 2001; Verdoux, Liraud & Bergy, 2001).

Some controversy surrounds this concept of “duration of untreated psychosis” and whether it is causally linked to adverse outcomes, or whether there are confounding factors such as severity of illness, which better explain the link (Norman & Malla, 2001). Nevertheless, being psychotic for a long time without treatment has clear implications for human suffering and risk, whether or not the duration of untreated psychosis has a directly toxic effect. There is certainly justifiable clinical and ethical support for recognising psychosis earlier and getting help to people sooner. (Holloway & Aitchison, 2003).

### *A Critical Period for Intervention*

In addition to duration of untreated psychosis impacting upon prognosis, it is also likely that people's initial understanding and experience of both a first episode of psychosis and the treatment they receive for it, will have a substantial influence on their later behaviour and relationship to help.

Varying levels of satisfaction with existing mental health services have been well documented amongst those with chronic mental health problems, and particularly negative views recorded about in-patient care (Quirk & Lelliott, 2001). More recently similar findings have been shown amongst people who have just experienced a first episode of psychosis (Gould, Johnson, Billings, Pilling, Bebbington et al., 2005, unpublished). In a qualitative survey of 20 first episode psychosis clients Gould et al. (2005, unpublished) found that people presented with a lot of ambivalence regarding the treatment they had received and were particularly negative about the emphasis on medication and containment in hospital, at the cost of the more psychosocial help they felt they needed and expected.

Rethink, the UK mental health charity (previously the National Schizophrenia Fellowship), also recently surveyed young service users who had experienced a first episode of psychosis. Respondents reported finding existing services stigmatising, therapeutically pessimistic and youth insensitive (Pelosi & Birchwood, 2003). This has consequently led Rethink to launch a campaign, "Reaching People Early" (<http://www.rethink.org/reachingpeopleearly>), to bring attention to the poor state of mental health services for young people with severe mental illness.

The idea that what happens once people have come into contact with mental health services is as important as how long they were ill for before, is supported by research that has shown that DUP only explains between 8%-15% of the variance in outcome at 1 year follow-up (Malla, Norman, Manchanda, Ahmed, Schotlern et al., 2001; McGorry, Edwards, Mihalopoulos & Harrigan, 1996). Indeed, there is evidence that most of the deterioration in disorders such as schizophrenia occurs in the first 2-3 years following onset of psychosis (Birchwood, Todd & Jackson, 1998; Birchwood, 2004), and furthermore, research has shown that outcomes at 2-3 years strongly predict outcome 20 years later (Harrison, Hopper, Craig, Laska, & Siegel, et al., 2001). Rates of depression and suicide have also been shown to be particularly high during this early period (Power, 2004) and levels of social exclusion and lost contact with support systems increased at this key time (Levinson, 1986; cited in Linzen & Birchwood, 2002).

It can therefore also be argued that this initial period of time when people are first in contact with mental health services can be seen as critical for later outcomes, with the concomitant challenge to mental health services to engage people early, and then retain them during these key first few years.

Evidence of both the correlation between DUP and poorer long-term outcome, and the levels of dissatisfaction and disengagement with existing mental health services, underpins much of the philosophy and planning of early intervention services. By intervening early, specialist teams aim to both reduce DUP and improve people's initial experiences of services, and hence improve engagement, adherence and ultimately, longer-term outcomes.

## **Engagement, Treatment Adherence and Insight**

The potential value of early intervention in improving outcomes for people who have had a first episode of psychosis has been highlighted. Key to successful early intervention is being able to get people to adhere to appropriate treatment, which in turn is predicated on being able to engage people with appropriate mental health services. Engagement, however, has been shown to be a particular problem in early psychosis (Birchwood, 2004).

Evidence shows that even after people have received help from specialist mental health services following a first episode of psychosis, disengagement is very high, with over 50% of people having been lost to contact with standard psychiatric services within 12 months (McGovern et al., 1994). Similarly, whilst the effectiveness of anti-psychotic medication has been established as central to the treatment of psychotic illness (NICE, 2002), estimates have suggested that over half of patients presenting with psychotic illnesses have significant difficulties in continuing to adhere to prescribed medication (Fenton, Blyer & Heinsses, 1997). Inner city services are especially notable for the presence of many service users who are difficult to engage and negative about the services they have been offered (Sainsbury Centre, 1998).

Traditionally, the concepts of engagement and treatment adherence have been linked with the notion of “insight”. A client is deemed to be more or less engaged with a service, and consequently more or less likely to adhere to prescribed treatment, depending on the level of “insight” that they have into their mental health problems.

Insight is the conventional way of conceptualising how people with mental illness appraise their experience of it. Insight by definition inherently implies a degree of acceptance of the medical idea of illness. It follows that if a person recognises the nature and severity of their mental health problems then they are more likely to be willing to accept the help of mental health services, comply with subsequent treatment and therefore have better outcomes (McEvoy, Howe, & Hogarty, 1984; McEvoy, Apperson, Appelbaum, Ortlip, Breckosky, & Hammill, 1989).

Whilst there is face validity in this conclusion, there is one major caveat. Many studies have explored the relationship between insight and clinical outcomes, usually mediated through engagement with treatment; however, consistent findings have shown only a modest correlation between traditional measures of insight, engagement in treatment and outcome (David, 1992, 1998). For example whilst overall there is a positive association between measures of insight and adherence to medication (Bartko, Herczeg, & Zador, 1988), there are many individuals who do not believe that they have a mental illness yet also adhere to medical treatment (Lobban, Barrowclough & Jones, 2003).

Moreover, the assumption that understanding psychotic symptoms within a strict medical model is beneficial to the patient has been challenged. White, Bebbington, Pearson, Johnson and Ellis (2000) found a strong positive association between insight into psychosis, as measured by adherence to a medical model, and depression. Similarly, Jackson, McGorry, Edwards, Hulbert and Henry et al. (1998) found that people who “integrated” their experiences more fully, accepting that they had experienced a psychotic episode, actually showed higher levels of depression, than

those who adopted a more “sealing over” approach. This led them to argue that integration may actually reflect the individual becoming engulfed by the demoralization and stigma that they associate with mental illness.

More recently, there has been some recognition of a more complex relationship between insight, adherence and outcomes, with the work of Anthony David and colleagues representing a move towards a more multi-dimensional understanding of how people might experience psychosis. Rather than postulating a simple and linear relationship between insight and outcomes, David and colleagues have argued that insight can be conceptualised as a complex, multidimensional and fluid concept (Amador & David, 1998), with three different but overlapping dimensions: a recognition by the individual that they are suffering from a mental illness, a willingness to comply with treatment and an ability to re-label unusual mental events (e.g. delusions and hallucinations) as pathological (David, 1990). These dimensions are seen as correlated but also able to vary independently, so that it is possible for an individual to have insight along some dimensionS whilst still not accepting the label of “illness” (David, 1990; Amador & Strauss, 1993).

David (1998) has also suggested that outcomes in psychosis may in fact be more related to individuals appreciating the personal and social consequences associated with having a mental illness rather than acknowledging an illness label *per se* (Watson, Garety, Kuipers, Weinman, Dunn et al., 2004, unpublished). Hence rather than measuring the degree to which patients’ views of their illnesses concur with the dominant medical model, it is increasingly being recognised that it may be more

important to explore how patients themselves actually explain and understand their experiences.

To date, however, there has been little published research into how people with psychosis (and none relating to people with first episode psychosis) actually do make sense of and perceive their “illness”. A better understanding of this would clearly be useful to inform the development of sensitive early intervention services, that would be acceptable to their clients, able to engage them, and get them to adhere to treatment.

Before considering literature which has made some steps toward exploring these issues in relation to psychosis, this paper will turn to explore developments that have been made in understanding how people perceive and make sense of their “illness” and the relationship this has to engagement, adherence and outcomes, in the related area of physical health.

### **ILLNESS PERCEPTIONS IN PHYSICAL HEALTH**

Similar dilemmas in terms of engagement and treatment adherence as those raised above have long perplexed clinicians and researchers alike in the domain of physical health. Questions such as “Why don’t people take prescribed medication as advised to them by their doctors?” “Why don’t people go to their doctor straight away when they notice a lump?” “Why don’t people who have had a heart attack stop smoking and change their diets and their lifestyles?” continue to be frequently asked by physicians and health care promoters. This section will review developments in

answering questions such as these, and in so doing introduce the framework of illness perceptions.

### **The Development of Interest in Illness Perceptions**

Interest in illness perceptions in physical health was first generated about 40 years ago, at a time when health promotion programmes, such as those used for vaccinations and screening, were becoming more common. At this time there was a great deal of enthusiasm for prevention rather than cure and an increased motivation to prevent poor health through early intervention (not dissimilar to current drives in psychosis and early intervention). The public were given a lot of information about their illnesses and potentially unhealthy behaviours, whilst professionals sat back and waited. However, nothing happened. It seemed provision of information alone had very minimal effects on behaviour change (Leventhal, Benjamini, Brownlee, Diefenback, Leventhal et al., 1997).

Initially, health care promoters put this lack of success down to the presentation of information being too neutral, and not inducing enough fear, and concomitantly motivation, in people to seek help. In an early study by Leventhal and Niles (1965), this premise was explored in relation to tetanus vaccination promotion. Four conditions were compared with combinations of high or low fear message, and high or low information (in the format of exactly how and where to get the vaccination). Response was measured by uptake of the inoculation. The group that received both the highest fear message and the highest information levels did have the highest rate of uptake. However, uptake was still only 30%.

Research such as this was making it increasingly clear that something other than access to information and fear was mediating people's response to health threats, and hence arose the interest in the cognitive mechanisms by which individuals appraise their illness experiences.

### **Social Cognition Models of Illness Perceptions**

The last few decades have seen the development of several social cognition models related to physical health and illness, paralleling the wider "cognitive revolution" (Mahoney, 1974) in psychology, as interest has grown in exploring how individuals develop beliefs that mediate between their interpretation of experiences and how they act.

Theories such as the "Health Belief Model" (Rosenstock, 1974), "Theory of Reasoned Action" (Ajzen & Fishbein, 1980), "Theory of Planned Behaviour" (Ajzen & Fishbein, 1991), "Health Locus of Control Model" (Rotter, 1966; Wallston, Wallston & DeVellis, 1978) and "Common Sense Model" (Leventhal, Nerenz & Steele, 1984) all have in common the assumption that individuals develop beliefs that influence their interpretation of information and experiences and which in turn guide their behaviour. These theories then draw varyingly on combinations of personal and social beliefs to predict attitudes, intentions and actual behaviour. (For a detailed overview of these social cognition models see Conner & Norman, 1996; or de Wit & Stroebe, 2004.)

Of these theories, Leventhal et al.'s (1984) Common Sense Model has been developed and applied most extensively in the area of physical illness and perhaps provides the most clear foundations for work on illness perceptions.

### **The Common Sense Model of Illness Perceptions**

Based on such dilemmas as those observed above, Leventhal and colleagues (1984) developed the Common Sense Model of illness cognitions (varyingly termed the Self-Regulatory Model), which is based on the premise that individuals are active problem solvers who try to make coherent sense of symptoms or illnesses by developing their own cognitive representation of the threat, which in turn determines how they respond (Leventhal & Diefenbach, 1992). Just as people construct representations of the external world to explain and predict all sorts of events, patients develop similar cognitive models of the changes that reflect illness (Weinman & Petrie, 1997a).

Specific illness experiences (such as experiencing symptoms or being given health information) are seen to activate specific illness representations which will be based on previous personal, social and cultural sources, and which have been stored in memory. Such sources may include direct personal experiences of illness, witnessing experiences of family members and friends and portrayals of illness in books, TV, films and other media. A representation of the individual's present condition is then formed by matching and integrating current symptoms and contextual information with these pre-existing beliefs (Cameron & Moss-Morris, 2004).

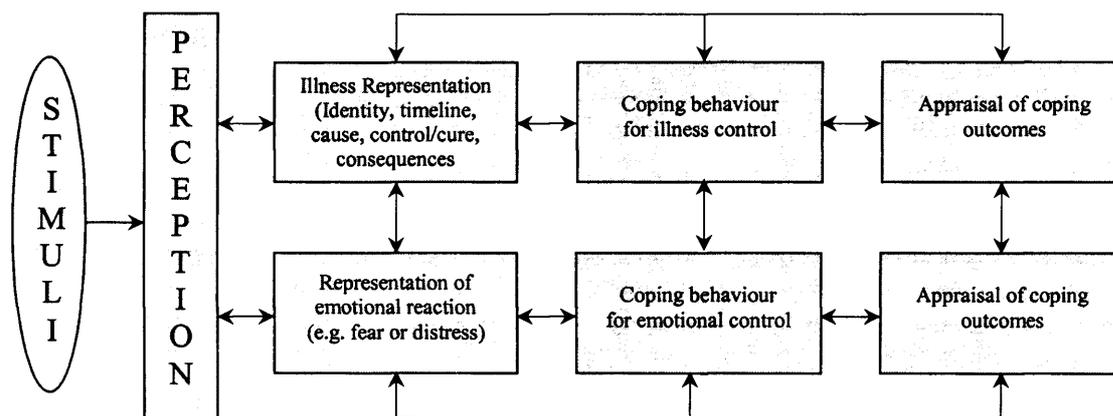
The representation an individual constructs of their illness then guides the selection of coping actions. In addition to a cognitive representation of an illness, Leventhal et al. (1984) also hypothesise an emotional processing component, or emotional representation, in their model. Coping strategies will also be employed to respond to this emotional component. For example, if an individual has a representation of an illness as mild, transient, and related to immune deficiency and tiredness, such as thinking he has a cold, then he might choose coping strategies such as taking vitamin C and a day off of work, but otherwise carrying on as normal, and feeling mildly frustrated. However, if an individual has a representation of similar symptoms as potentially serious, chronic and debilitating, then he may feel very anxious, stop work and other activities immediately, confine himself to bed and present repeatedly to his GP or other health professionals. The representation may, or may not, closely represent medically established knowledge about the nature of the symptoms/illness.

In turn, these coping strategies, or other actions, are appraised in terms of their success in controlling or eliminating the illness symptoms and the emotional reactions and/or their consequences. For example, in the case of the individual above who thought he might have a cold, if the taking of Vitamin C and a day off of work did not lead to his symptoms abating, then he may decide he needs to take the rest of the week off work, rest at home, and make an appointment with his GP.

These behavioural outcome appraisals in turn lead to refinements of the original representation, the selection of new coping strategies, and also link back to emotional responses. In the example above, the individual may come to think that the same

experiential symptoms are actually indicative of a more serious underlying virus or infection, retreat to bed and start to feel more depressed and anxious.

As such the Common Sense Model is more dynamic than other social cognition models, as it does not just allow for the unidirectional influence of beliefs on behaviour, but considers how behaviours and outcomes also influence beliefs and representations (Lobban et al., 2003). Leventhal’s (1984) model is represented diagrammatically in figure 1.



**Figure 1.** Leventhal’s Common Sense Model of illness cognition and behaviour; from Leventhal, Nerenz & Steele, 1984.

Leventhal and colleagues (Leventhal, Nerenz & Steele, 1984; Lau and Hartman, 1983) have identified five key components in the cognitive representation, or illness perception. These are *identity* (comprising both the label given to the illness and the symptoms the patient views as being part of the disease), *causes* (the ideas a person holds about the aetiology of the illness), *timeline* (how long the patient believes the

illness will last), *consequences* (the expected effects and outcomes of the illness) and *cure/control* (how the illness can potentially be controlled and treated by the individual and/or medical treatment). More recently, a sixth component, *coherence*, referring to a sense of having a comprehensive understanding of the illness, has also been added to the model, and the control/cure component has been qualified to include personal control and control through treatments (Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002).

These components are logically interrelated. For example, beliefs that an illness will last a long time and have a number of undesirable symptoms are likely to be associated with beliefs that the illness has more severe consequences and is less likely to be controlled or cured.

Whilst the content of illness representations may vary widely both between and within different illnesses, research so far has pointed to the relevance of these dimensions in the structure of a range of illness perceptions. To date several studies have explicitly tested and confirmed the reliability and validity of these cognitive illness constructs in relation to specific chronic illnesses, and a recent meta-analytic review of 53 studies concluded that the key components and predictions of the model were supported. (Hagger & Orbell, 2003).

### **Measuring Illness Perceptions**

A number of methodologies have been used to explore illness perceptions (see Kaptein, Scharloo & Weinman, 2001). Originally several studies relied on

qualitative methodologies, principally conducting semi-structured interviews with patients. This qualitative approach enabled exploration of the content and nature of perceptions in a variety of illnesses. Developments in the quantitative measurement of illness perceptions have further facilitated research into the pervasiveness of particular perceptions (Horne, 1997).

The Illness Perception Questionnaire (IPQ; Weinman Petrie, Moss-Morris, & Horne, 1996), and latterly the Illness Perception Questionnaire-Revised version (IPQ-R; Moss-Morris, Weinman, Petrie, Horne, Cameron, & Buick, 2002), provide a quantitative operationalisation of Leventhal's model of illness perceptions and contain questions assessing specific beliefs along each of the dimensions listed above. The development of the IPQ and IPQ-R has been particularly useful in facilitating research into illness perceptions in a range of illnesses as well as in a variety of different cultures (Landrine & Klonoff, 2001). The interested reader should refer to the IPQ website (<http://www.uib.no/ipq/>) which lists all known published studies using the IPQ and IPQ-R to explore illness perceptions.

Several of the studies discussed later use the IPQ as a starting point for exploring illness perceptions, although several other quantitative assessment methodologies have been developed for use with specific illnesses, for example, the "Personal Models of Diabetes Interview" (Hampson, 1997), and the "Beliefs about Medicines Questionnaire" (Horne, 1998). (For more illness-specific assessment tools refer to Petrie & Weinman, 1997.)

## **THE POTENTIAL CONTRIBUTION AND LIMITATIONS OF THE ILLNESS PERCEPTIONS FRAMEWORK**

Research has established that idiosyncratic illness perceptions can be elicited from individuals in relation to particular illness symptoms or experiences. The structure of these perceptions along the six key dimensions has also been observed in both qualitative and quantitative studies in relation to many different chronic illnesses. But what use are illness perceptions when it actually comes to working with people with physical illnesses, especially when our goal is usually to improve people's engagement and adherence with treatment, and ultimately improve health outcomes? Furthermore, what advantages and disadvantages might consideration of the illness perceptions framework have for our work with people with mental health problems such as early psychosis? In attempting to answer these questions, I present below my arguments (synthesised from existing literature pertaining to illness perceptions), for what I believe may be the possible benefits and limitations of using the illness perceptions framework, and in particular, what issues may need to be considered if trying to apply it to first episode psychosis.

### **The Potential Contribution of the Illness Perceptions Framework**

The following five areas discuss some of the potential contributions that considering the illness perceptions framework could make when working with people with physical (and potentially mental) health problems.

#### **1. Illness Perceptions link to Coping, Adherence, and Outcomes**

Much research has focused on coping as a way of explaining illness adjustment and outcomes in a variety of physical illnesses. Weinman and Petrie (1997b) have argued that illness perceptions may underpin explanations of the wide variety of coping responses to the same illness, but may also be more directly related to such outcomes as treatment adherence, emotional distress and clinical outcomes.

Several studies have indeed demonstrated that illness perceptions are related to engagement, treatment adherence and outcome in several chronic illnesses, such as myocardial infarction (Petrie, Weinman, Sharpe & Buckley, 1996; Petrie, Cameron, Ellis, Buick & Weinman, 2002; Weinman, Petrie, Sharpe & Walker, 2001), diabetes, (Hampson, 1997), chronic fatigue syndrome (Moss-Morris, 1997) and breast cancer (Buick, 1997). Hagger & Orbel's (2003) meta-analytic review also reported consistent links between illness perceptions, coping, adherence and outcomes.

## **2. Theoretical Foundations Guide Clinical Work**

Many conventional interventions currently used in physical health such as cardiac rehabilitation and pain management programmes have been developed empirically, are standardised, fixed and information driven, and are not based on a sound theoretical understanding of underlying psychological processes (Petrie et al., 2002). The illness perceptions approach provides a theoretical framework for both designing and evaluating specific and targeted psychological interventions.

In addition, consideration of illness perceptions also provides a conceptual framework for understanding how people make sense of information and advice from health care professionals (Petrie et al., 2002).

### **3. Understanding Illness Perceptions Facilitates Patient Centred Care and Engagement**

Typically medicine has seen illness as an objective endpoint and has focused only on psychological factors in terms of aetiology or in the psychopathological consequences of illness (Petrie et al., 2002). By contrast, the illness perceptions approach begins with the patient's experiences of their illness and the main emphasis is on the patient's own model of their condition.

Patients' models of their illness are however by their nature, individual and private. Research on medical consultations has shown that patients are often reluctant to disclose their beliefs about their illness because they fear they may conflict with their doctor, or that they risk being thought of as stupid or misinformed (Weinman & Petrie, 1997). Recently however, general practice policy has advocated a more patient-centred approach, and current GP training recommends that the doctor try to encourage the patient to share their own views about the nature and aetiology of their illness early in the consultation (Campion, Foulkes, Neighbour & Tate, 2002). The illness perceptions approach encourages the elicitation of patients' own views of their symptoms at the start of a medical encounter, as well as fitting with a model of the patient as an active consumer, rather than passive recipient, of health care services.

As well as supporting a patient-centred approach to medical consultations, starting from the point of the patient's own illness perceptions should have an obvious impact on engagement, with the patient feeling listened to, and that their ideas and concerns are taken seriously. Further, by having elicited and being aware of the patient's own model of their illness, doctors should be better prepared for potential barriers in adherence to their recommended treatment regime, and these can be addressed directly and collaboratively with the patient.

#### **4. The Role of Emotion**

The Common Sense Model of illness perceptions also emphasises the role of emotion in illness cognitions, by including a more "subjective" emotional processing system alongside the more "objective" cognitive processing system (Leventhal & Diefenbach, 1992). This emotional processing system may be particularly important in mental illnesses such as psychosis, which are often a particularly distressing and frightening experience for the individual and the people around them (Linszen & Birchwood, 2002). Stigma is also particularly pronounced in relation to public attitudes to psychosis (Crisp, Gelder, Rix, Meltzer & Rowlands, 2000), and is therefore particularly likely to impact on the emotional processing and coping part of the illness representation.

#### **5. Illness Perceptions are Amenable to Change**

Illness perceptions are also potentially important because, unlike other static risk factors for poor illness outcomes, such as socio-demographic and personality variables, illness perceptions are dynamic, and therefore amenable to change. If unhelpful thinking about an illness can be identified early, then there is the potential for developing cognitively based interventions to foster more adaptive models and expectations, much as would be done with problematic thinking in other areas of cognitive psychology (Petrie, Cameron, Ellis, Buick & Weinman., 2002).

This paves the way for the development of targeted cognitive interventions to modify or take account of specific patient cognitions such as beliefs about the cause or potential for control of an illness, and thereby promote more adaptive coping strategies and enhance clinical outcomes. For example, Petrie, Cameron, Ellis, Buick and Weinman (2002) demonstrated that patient's beliefs and perceptions about their illness were key determinants in recovery from myocardial infarction (MI), and that outcomes could be improved through a brief, targeted cognitive illness perceptions intervention.

In their study Petrie et al. (2002) included 65 first time MI patients in a randomised controlled trial. Patients in the treatment as usual control group received standard MI educational information whilst the intervention group received three 30-40 minute individual sessions with a psychologist, tailored to their existing illness perceptions (as established by the IPQ), in addition to being given standard information. Sessions focused around exploring patients' beliefs about the causes of their MI, addressing in particular the common misperception that stress was singularly responsible for the illness, with the aim of widening the patients' causal models, as

well as working on negative beliefs about the consequences, timeline, course and control of the illness. Petrie et al. (2002) demonstrated promising results even with this brief hospital based intervention, showing that the intervention group patients held significantly altered beliefs about their illness (relative to controls), including lower levels of belief that their heart condition would have serious long-term consequences, stronger belief in the controllability of their condition and less distress about symptoms. In addition, the illness perceptions intervention group rated themselves as having a higher level of understanding of their illness, reported feeling better prepared to leave hospital, and rated themselves as more likely to attend rehabilitation.

This study also has several points of relevance for considering how illness perceptions could usefully be employed in psychosis, particularly first episode. People often after an MI attribute the heart attack to stress, believing that they only need to remove excess stress from their lives. People who sign up to this “stress” model of MI are more reluctant to accept an “underlying heart disease” view of MI or see longer-term cardiac rehabilitation as relevant to them (Petrie et al., 2002). Similar issues have also arisen in relation to first episode psychosis. Gould et al. (2005, unpublished) in interviews with 20 first episode psychosis patients found that many people tended to adopt a stress model of their psychosis, seeing the episode being triggered solely by psycho-social stresses such as work stress or housing problems. Even amongst people who had one or more first-degree relatives with a psychotic illness, there was very little recognition of any underlying bio-psycho-social vulnerability. If an illness perceptions intervention can be used to widen causal models with MI patients as described above, then there is the potential for

illness perceptions to be a point of intervention in early psychosis, similarly to widen causal models and to extend perceptions of valid risk factors.

As Petrie et al., (2002) also pointed out in their study, fresh beliefs close to the time of onset of a health problem are more amenable to change, so this highlights that intervening early in an illness like psychosis could be particularly important. If beliefs about psychosis could be elicited, explored and broadened early on in the illness then perhaps better results could be seen for first episode psychosis patients, much as for the MI patients in this study.

Research into interventions with illness perceptions is a relatively new area, and the challenge still very much remains to establish and evaluate specific interventions that will impact upon and modify illness perceptions, and potentially impact positively on outcomes. For further examples see cognitive intervention packages designed for chronic pain (Williams, Nicholas, Richardson, Pither & Jostin et al., 1993), chronic fatigue syndrome (Sharpe, Hawton, Simkin, Surawy & Hackman et al., 1996) and arthritis (O'Leary, Shoor, Lorig & Holman, 1997).

### **Critique of and Problems with the Illness Perceptions Framework**

Despite the above acknowledged benefits and potential value of using an illness perceptions framework, I would argue that the following critiques and problems need also to be borne in mind, especially when considering adapting the concept of illness perceptions for use in early psychosis.

## 1. Different Dimensions?

The dimensions of the Common Sense Model of illness perceptions (*identity, cause, timeline, consequences, cure/control and coherence*) have been shown to be reliable and valid constructs in relation to a variety of chronic physical illnesses. Each also has some face validity, as concepts that are likely to be a relevant part of a perception of an illness. However, there may well be other aspects of perceptions that are particularly important, within or across particular physical illnesses. For example, in an in-depth qualitative interview study of illness representations in people with non-epileptic seizures, Green, Payne and Barnitt (2004) found that people did spontaneously mention elements of the Common Sense Model of illness perceptions, but that two other themes were also generated which did not fit within the model: one relating to the participant's own acceptance of, or feelings about, their situation, and the other relating to the acceptance and understanding of others (Green et al., 2004).

With regard to mental illnesses, and specifically psychosis, certain dimensions of the Common Sense Model may prove to be more or less relevant, and other factors again not included in this model, may be found to be potentially more relevant. This warrants attention in more exploratory, open-ended research.

## 2. Chronic Illness vs First Episode

Most of the illness perceptions literature has been related to chronic illnesses, with very little focus on the construction and content of illness perceptions at the onset of an illness for the first time. With chronic illness, individuals are likely to have lived

with their illness experience for a considerable time and had more exposure to medical services. It is not known at this stage how much illness perceptions change over time, nor what, if any, stages of an illness are particularly key in the formation of certain perceptions. More research into first episodes of illness, in physical illness as well as first episode psychosis, is needed.

### **3. Social and Cultural Aspects**

Related to the above point about the construction of perceptions in the early stages of illness, are also questions about where perceptions come from. The social origins of illness perceptions is a point emphasised by Leventhal and Diefenbach (1992) and is a strength of the model, but does seem to have been an aspect that has been more neglected in most of the research literature. More research into the social and cultural origins of certain illness perceptions could usefully inform our understanding, as well as highlight areas of social (for example through the use of public education campaigns), as well as individual, intervention.

### **4. Methodological Problems**

The Common Sense Model of illness perceptions posits that its components are dynamic, with all variables impacting on one another, and with beliefs that influence responses in turn being modified in light of the appraisal of the outcome (Lobban et al., 2003). Whilst making this a realistic model, the interrelationship of all the variables can make the identification of dependent and independent variables in research very difficult, with the models needing to be reassessed over time as they

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are constantly evolving (Lobban et al., 2003). This may be an unavoidable limitation of such a model, but does need to be borne in mind when testing hypotheses in quantitative research.

## **5. Acceptance of Illness?**

The model of illness perceptions seems to rely intrinsically on someone recognising symptoms and perceiving that they do have some form of “illness”. The model then assumes that attempts are made to identify and label the illness or health threat, and corresponding attempts made to cope with it. However, in psychosis, individuals often do not, either at the time, or subsequently, identify or label their experiences as an “illness” (Fowler, Garety & Kuipers, 1995).

This limitation may not only apply to psychosis. In the Green et al. (2004) study of non-epileptic seizures, the authors noted that individuals who did not have a clear label or diagnosis for the problems they were experiencing also did not have clear ideas relating to other areas of the Common Sense Model, such as timeline, control or consequences.

A clear label of “illness” may not however need to be a prerequisite for using the illness perceptions framework. In the Gould et al. (2005, unpublished) study of people with first episode psychosis, the authors found that even though most participants did not label their experiences as psychotic, they were in many cases able to identify and label some subjective psychological deterioration, such as stress, worry or paranoia. This may offer at least a starting point for further research into

illness perceptions with this group. Arguably, instances where coherent models of illness have not been constructed, as well as where they have, are still potentially very useful information for clinicians.

## **6. Coherence?**

The Common Sense Model of illness perceptions, and indeed nearly all cognitive models, are grounded in the assumption that individuals are driven to make coherent sense of the world and events around us. As Cameron and Leventhal (2003) argue in their book on the self-regulation of health and illness, human beings possess two inherent, overarching goals; survival and coherence (Carver & Scheier, 1996; quoted in Cameron & Leventhal, 2003). Whilst humans may not be consciously aware of these goals whilst going about their daily activities, they are nevertheless fundamental goals from which all other goals are generated. Illness experiences can threaten both survival and a sense of coherence in a person's sense of self and life goals, and hence underscore the critical importance of illness-related events and why adaptation to illness can present critical challenges to self-regulation (Cameron & Leventhal, 2003).

In an "illness" like psychosis, however, which is by its very nature defined by symptoms that represent a departure from reality and normal experience, is it possible to assume that individuals are able to, or even desire to, form coherent and comprehensive models of their experience? Moreover, even if they do, can these be accessed with people in the early stages of psychosis in research?

Clinical experience does however suggest that individuals with psychosis do attempt to make some sense of their experiences and in so doing do form cognitive representations, even if these representations may often be at odds with the representations held by mental health professionals (Lobban et al., 2003). Methodological issues in terms of accessing these models in people with psychosis may be more difficult to resolve. However, to preclude people with mental health problems from research implies a distinction between physical and mental illnesses, implying that subjective psychological processes are not inherent in physical illnesses nor people with mental health problems able to reflect on their experiences. This is a distinction not borne out by evidence (Lobban et al., 2003). Further, limitations in self-report methodologies to access people's meanings apply across all areas of social research.

These limitations when trying to access representations from people in the early stages of psychosis need to be borne in mind, but are not sufficient to preclude conducting research with people in the early stages of a severe mental illness. Ultimately, questions about whether people faced with psychosis do form representations of their experiences and whether these can be accessed, can only be answered by conducting research to explore these issues with this client group.

## **Summary**

Research in this area has established that illness perceptions are important determinants of engagement, adherence and outcomes in a range of physical illnesses, and can also be used to guide clinical work, facilitate engagement and

provide a source of intervention to improve coping and outcomes. Some of the limitations and potential problems with the illness perceptions framework have also been highlighted, particularly with relation to adapting it for use in psychosis. With this issue in mind, this paper will now turn to consider relevant literature related to perceptions of illness in psychosis itself.

## **ILLNESS PERCEPTIONS AND PSYCHOSIS**

Despite the developments discussed above in the physical health field, the application of illness perceptions to mental health in general, and psychosis specifically, has only recently been considered. To date, only four published papers have directly explored illness perceptions in relation to psychosis, although two unpublished research dissertations and three other as yet unpublished papers will also be discussed below.

### **Psychosis and Cognition**

The cognitive revolution in psychology has had a particular influence on work with people with psychosis. Previously, beliefs and behaviours that by their very nature departed so far from reality were not considered amenable to psychological intervention, but rather were left largely to treatment by anti-psychotic medication alone (Chadwick, Birchwood & Trower, 1996).

With the development of cognitive theory and therapy in psychosis, the study of appraisals and beliefs has certainly not been neglected. However, as Lobban et al.

(2003) point out, to date the focus of research in clinical work has been on attributions in relation to the maintenance of specific symptoms, rather than on exploring models of “illness” as a whole. For example, research has explored how beliefs about thoughts may predispose an individual to hear them as auditory hallucinations rather than internal thoughts (Morrison, 1998). Similarly, Garety, Kuipers, Fowler, Freeman and Bebbington’s (2001) influential model of the positive symptoms of psychosis regards cognitive appraisals as key in determining whether anomalous experiences will be translated into positive symptoms, and draws on reasoning and attributional biases and dysfunctional schemas as key influences on appraisals.

With a few exceptions, there has been little exploration of other potentially important beliefs, highlighted in the physical health literature, such as the possible causes of the experience, beliefs about control and treatment, perceived consequences, and how long the experience is likely to last for (Lobban et al., 2003). Yet understanding and inclusion of these factors could enhance our understanding of the experience of psychosis and could help to tailor individual interventions, particularly at the early stages of an illness, when these appraisals are being constructed, and engagement is so important.

### **Research on Illness Perceptions in Psychosis**

Haley, Drake, Bentall & Lewis (2003) have looked at illness perceptions in relation to first episode psychosis, drawing on the health belief (Rosenstock, 1974) and health locus of control models ” (Rotter, 1966; Wallston, Wallston & DeVellis, 1978). In

their quantitative study however, Haley et al. (2003) only addressed beliefs related to one aspect of perceptions about illness, “locus of control”. The authors did find links between participants with higher internal locus of control scores tending to have shorter DUP, but also those with higher external locus of control scores tending to have more positive attitudes to pharmacological treatment. This study supports the argument that considering beliefs about illness could usefully inform our understanding and treatment of people with first episode psychosis. However, this study is limited in that it only looked at a single aspect of people’s perceptions, and therefore gives a limited indication as to the potential value of considering illness perceptions in first episode psychosis.

In a recent review article, Lobban et al. (2003) looked specifically at Leventhal et al.’s (1984) Common Sense Model (termed Self-Regulatory Model in this paper) and argued that it could be applied to mental illnesses such as psychosis, and in so doing provide a useful framework for integrating several currently disparate areas of research. (The reader is referred to Lobban et al.’s thorough summary of this model in the original source. It is not the aim of the current paper to repeat the conclusions of this review, but rather to update it, and further question whether the concept of illness perceptions can be usefully applied to psychosis, and first episode psychosis in particular.)

Lobban et al. (2003) also cite two prior studies that have attempted to apply illness perceptions to people with psychosis, both of which are unpublished dissertations. In the first of these, Clifford (1998) administered the IPQ to a sample of 38 patients with a diagnosis of schizophrenia. The study concluded that the subscales of the IPQ

showed acceptable levels of internal reliability, and also that non-adherence to medication was positively associated with perceptions of fewer and less severe symptoms, short duration of illness, external attribution of cause and beliefs about more severe negative consequences (Clifford, 1998; cited in Lobban et al., 2003). In a second study, Talley (1999) also used the IPQ with people with a diagnosis of schizophrenia, but found that only the subscales measuring consequences and symptoms were internally reliable (Talley, 1999; cited in Lobban et al., 2003).

In two further empirical papers, Lobban and colleagues have explicitly explored illness perceptions directly in relation to psychosis. In the first of these studies, Barrowclough, Lobban, Hatton and Quinn (2001) investigated models of illness in 47 carers of people with schizophrenia, using a modified version of the Illness Perception Questionnaire. The authors found that the modified IPQ used did provide a reliable measure of carers' perceptions, and that these were related to the carer's functioning (in terms of carer distress and burden), the relationship between the carer and the patient (in terms of expressed emotion), and patient illness characteristics. This led Barrowclough et al. (2001) to conclude that the cognitive representations of illness held by carers could have important implications for both carer and patient outcomes.

More recently, Lobban, Barrowclough and Jones (2004) again used a modified version of the IPQ with 124 people with a diagnosis of schizophrenia, as well as measuring symptom severity, coping and appraisal of outcomes, at two time points six months apart. The authors found that once severity of symptoms was controlled for, beliefs about mental health were found to be significant predictors of outcome.

In particular, beliefs about greater negative consequences were found to be the strongest and more consistent predictors of a poorer outcome in both cross-sectional and longitudinal analyses.

Lobban and colleagues have also completed some further, as yet unpublished, research (F. Lobban, personal communication, 05/08/04) into adapting the IPQ-R for use in schizophrenia, leading to the draft of a specific Illness Perceptions Questionnaire for Schizophrenia (IPQ-S; Lobban, Barrowclough & Jones, 2004, unpublished; Lobban & Barrowclough, 2004, unpublished). In the first part of this research, Lobban and Barrowclough (2004, unpublished) aimed to qualitatively explore illness perceptions amongst 22 people with a diagnosis of schizophrenia and 18 of their relatives, in order to provide information for adapting the IPQ. Participants were asked to write down their answers to an open-ended question regarding their understanding of the term “schizophrenia”. These response statements were then recorded individually on cards and used in a card sort exercise. The authors found that they were able to sort the cards largely according to the dimensions of the Common Sense Model, although the category of ‘symptoms’ was used most commonly, and other dimensions, such as timeline, control and coherence, not spontaneously mentioned by any participants. Thirty naïve sorters, comprising clinical psychologists who were familiar with working with schizophrenia but unfamiliar with the illness perceptions literature, were also asked to sort the cards according to any categories that made sense to them and then label these categories. The naïve sorters also grouped the comments with some overlap with the dimensions of the Common Sense Model, although again, the most frequently used categories related to identity and symptoms. Lobban and Barrowclough (2004, unpublished)

concluded that there was a statistically significant overlap between both their own and the naive sorters' categorising of the cards, and that the study provided some construct validity for the dimensions of the IPQ-R in the understanding that people with a diagnosis of schizophrenia and their relatives have of the illness.

Based on the results of this study, Lobban, Barrowclough and Jones (2004, unpublished) piloted a version of the IPQ-R for schizophrenia (the IPQ-S) on 124 people with a diagnosis of schizophrenia. They argued that the IPQ-S subscales were shown to be both internally reliable and reliable over time, and by examining correlations with symptom severity, emotional state and attitudes to and adherence to medication, that the subscales were also validly measuring the constructs that they were designed to measure. Lobban et al. (2004, unpublished) hence concluded that their IPQ-S is a reliable and valid measure of the cognitive representations of mental health problems held by people with a diagnosis of schizophrenia.

In another, as yet unpublished, study Watson and colleagues at the Institute of Psychiatry (Watson, Garety, Kuipers, Weinman, Dunn et al., 2004, unpublished) have also attempted to adapt the IPQ-R for use with people with schizophrenia (P. Watson, personal communication, 17/08/04). Their modifications were not based on any preliminary qualitative research, but included changes in wording and emphasis that the authors felt to be relevant, based upon their clinical and research experience of working with people with schizophrenia. Using this modified version of the IPQ-R, Watson et al. (2004, unpublished) explored the relationship between illness perceptions and emotional dysfunction in people with chronic schizophrenia, and found that illness perceptions explained approximately 40% of the variation in

emotional dysfunction, such as levels of depression, anxiety and self-esteem. They found that it was subjectively perceived symptom severity rather than objectively rated symptom severity that correlated with emotional distress, suggesting that it is the *appraisal* of symptoms rather than their occurrence that is distressing.

These preliminary studies show some interesting results and highlight the potential value of using specifically modified versions of the IPQ-R for people with schizophrenia, particularly in relation to predicting outcomes. However, as Leventhal and Nerenz (1985) argue, it is important to avoid a methodology that suggests attributes that fit the model to be tested, but that may not reflect those actually of concern to the patient themselves. Hence at this point it would seem that more in-depth qualitative work is needed in order to further elicit the components that are most relevant to people experiencing psychosis themselves. This qualitative work may also need to focus on the experience of psychosis in order to elicit a more multi-dimensional illness representation, rather than just focusing on what the term “schizophrenia” means to clients. More exploratory work may be particularly needed before applying the IPQ to first episode psychosis to explore the relevance of these dimensions at the crucial point of the onset of illness.

## **CONCLUSIONS & DIRECTIONS FOR FURTHER RESEARCH**

This paper has questioned whether the concept of “illness perceptions” which has been developed in chronic physical health could be usefully applied to an acute mental illness such as first episode psychosis. Several benefits of the illness perceptions approach have been presented, but also some potential problems and

issues in transferring the model to mental health, especially first episode psychosis, have been discussed.

A few recent, and mostly as yet unpublished, studies have shown some promising results in using measures of illness perceptions with people with chronic schizophrenia. However, these studies have relied on adapting a measure validated with people with chronic physical health problems, and at this stage, more in-depth, qualitative work seems warranted in order to establish whether the key constructs used in models of chronic physical illness are indeed similar or not to those people use to make sense of a first episode of psychosis. Perhaps more fundamental questions also still remain, such as whether someone can actually have a perception of illness if they do not perceive themselves to be ill? Again, questions such as these can only really be answered by conducting preliminary research in order to explore these issues with this client group.

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## **PART 2**

### **EMPIRICAL PAPER**

# **Making Sense of First Episode Psychosis: Experiences and Beliefs about “Illness”**

## **ABSTRACT**

Research into first episode psychosis is a rapidly growing area, fuelled nationally by the UK Government’s intention to set up specialist early intervention services across the country, and internationally by increased service development across much of the western world. To date, however, there has been little published research on people’s own experiences of first episode psychosis or on their beliefs about psychotic “illness”. Yet a better understanding of factors such as these would clearly be useful to inform the development of sensitive and effective early intervention services. This study aimed to redress this gap by exploring the experiences and beliefs of twenty people recently diagnosed with first episode psychosis. Semi-structured interviews were conducted with the participants and analysed using interpretative phenomenological analysis (IPA). The participants described a range of experiences, explanations and beliefs about first episode psychosis. There were also several processes and dilemmas that repeatedly appeared in the participants’ narratives, with most accounts marked by uncertainty, confusion and contradiction as the participants sought to make sense of what had happened to them. The findings of the study are discussed in relation to the clinical implications of setting up appropriate and acceptable early intervention services.

**Key words: first episode psychosis, experiences, illness beliefs, early intervention services, qualitative, interpretative phenomenological analysis (IPA).**

## INTRODUCTION

The Department of Health's (2001) "Mental Health Policy Implementation Guide" outlined plans to establish "Early Intervention" teams for people experiencing a first episode of psychosis. This multi-million pound investment is based largely on the experiences of pioneer services in Canada, Scandinavia and Australia, and these teams are intended to become an integral part of standard mental health services throughout the UK. Whilst there is some contention about the role of specialist teams (see Pelosi & Birchwood, 2003) a growing body of evidence suggests that early intervention in someone's psychotic illness can lead to better experiences, treatment adherence and ultimately outcomes.

There is frequently a long delay before people with a first-episode of psychosis receive appropriate treatment, with an average of 12 months between the onset of positive symptoms and first treatment (Norman & Malla, 2001). This delay in receiving potentially effective treatment has been associated with adverse long-term prognosis in many areas of social, emotional and cognitive functioning. (Birchwood, McGorry & Jackson, 1997; Ho, Alicata & Ward, 2003; Loebel, Liberman & Alvir, 1992; McGlashan, 1999). Some controversy surrounds this concept of "duration of untreated psychosis" and whether it is causally linked to adverse outcomes, or whether there are confounding factors such as severity of illness, which better explain the link (Norman & Malla, 2001). Nevertheless, being psychotic for a long time without treatment has clear implications for human suffering and risk, whether or not the duration of untreated psychosis has a directly toxic effect. There is certainly justifiable clinical and ethical support for recognising psychosis earlier and getting help to people sooner.

A further rationale for early intervention is that the first few years after a first episode of psychosis can be seen to constitute a “critical period” for later outcomes (Birchwood, 2002). Evidence has shown that much of the deterioration in disorders such as schizophrenia occur in the first two to three years following onset of psychosis (Birchwood, 2002), and moreover, that outcomes at two to three years strongly predict outcomes 20 years later (Harrison, Hopper, Craig, Laska & Siegel, et al., 2001). The first year or so following a first episode of psychosis has also been highlighted as a time of increased risk for co-morbid mental health disorders such as anxiety, depression or post-traumatic stress disorder (McGorry, 2004) and as a time of increased suicide risk (Power, 2004). Hence the Mental Health Policy Implementation Guide (DoH, 2001) advocates that services endeavour to assertively follow up their clients for the first three years following referral.

Vital to both being able to intervene early and retain people on the caseloads of specialist services throughout this critical period is being able to engage people with appropriate mental health services. However, there is much research showing only limited engagement with mental health services by people with psychosis (especially first episode), with estimates of more than 50% of people being lost to follow up within twelve months when under the care of existing psychiatric services (McGovern, Hemmings, Cope & Lowerson, 1994). A recent survey by UK mental health charity Rethink also indicated that young service users found traditional services stigmatising, youth insensitive and therapeutically pessimistic ([www.rethink.org/reachingpeopleearly](http://www.rethink.org/reachingpeopleearly), no date). Specialist early intervention services hence face the challenge of not only trying to identify psychosis soon after onset, but also to provide a more acceptable service for their clients that will

maximise their engagement and increase their adherence to evidence-based interventions.

Research exploring issues related to engagement and treatment adherence in psychosis has tended to focus on the concept of insight, usually measured by the degree to which an individual's beliefs about their experiences concur with those of the medical professionals treating them. However, only a limited relationship has been established between insight into "illness" and engagement, treatment adherence and outcomes (David, 1998). To date, there has been little published research into what beliefs people with psychosis actually do have about their experiences, and hence how they chose to act. Yet a better understanding of this would clearly be useful to inform the development of sensitive early intervention services, that are acceptable to their clients, able to engage them and able to increase their adherence to treatment.

In the arena of physical illness, health psychologists have made some significant steps forward in resolving such issues. By investigating people's own subjective beliefs and sense making when faced with a health threat, health psychologists have developed the concept of "illness perceptions" and explored how these influence illness related behaviour. Using this illness perceptions framework, links have been found between illness beliefs, engagement, treatment adherence and outcomes in many areas including cancer, diabetes and heart disease (Petrie & Weinman, 1997).

Several different social cognition models related to health and illness are contained within the illness perceptions framework, including the "Health Belief Model" (Rosenstock, 1974), "Health Locus of Control Model" (Wallston, Wallston &

DeVellis, 1978) and “Common Sense Model” (Leventhal, Nerenz & Steele, 1984). All of these theories have in common the assumption that individuals develop beliefs that influence their interpretation of information and experiences and which in turn guide their behaviour.

In psychosis, beliefs have certainly not been ignored, however most research has concentrated on exploring psychotic beliefs, and there has been little focus on more “normal” beliefs that people might have about their illness experience. More recently, some preliminary research has begun to consider whether any of the social cognition models used in physical illness could be applied to mental illnesses such as psychosis. Barrowclough, Lobban, Hatton and Quinn (2001) used Leventhal et al.’s Common Sense Model to investigate models of illness in 47 carers of people with schizophrenia, and found that these carer models were related to their own functioning (in terms of carer distress and burden), the relationship between the carer and the patient (in terms of expressed emotion), and patient illness characteristics. Lobban, Barrowclough and Jones (2004) also explored illness perceptions with 124 people with a diagnosis of schizophrenia, and found that once severity of symptoms was controlled for, beliefs about mental health were found to be significant predictors of outcome. Haley, Drake, Bentall and Lewis (2003) explored health beliefs specifically in relation to first episode psychosis, drawing on the health belief and health locus of control models. The authors, however, only addressed beliefs related to “locus of control”, finding that those participants with higher internal locus of control scores tended to have shorter duration of untreated psychosis but that those with higher external locus of control scores tended to have more positive attitudes to pharmacological treatment.

These preliminary studies highlight the potential value of considering patients' own beliefs in helping us understand their engagement with, and adherence to treatment. However, all these quantitative studies have adapted measures used in physical illnesses and none have asked people themselves what their beliefs are about their experiences. Furthermore, in a mental illness such as psychosis, which is by its nature defined as a departure from reality, and frequently not labelled as an "illness" by those experiencing it, we do not as yet know whether exploring illness beliefs with this client group is even possible or valid.

This study aimed to redress some of the gaps identified above by exploring the experiences and understanding of people who have recently had a first episode of psychosis. A qualitative, phenomenological methodology was employed in order to explore people's own meaning making when faced with the experience of psychosis for the first time. This approach was also adopted in order to access peoples' own spontaneously generated views and beliefs, which would seem to be a vital preliminary stage before any further research adapting the illness perceptions framework can be conducted in this area. Finally, this study also aimed to consider the implications of the findings for setting up and running specialist early intervention in psychosis services.

Specifically, this study addressed the following research questions:

1. What are people's experiences of the onset of psychotic symptoms and coming into contact with mental health services for the first time?
2. How do people make sense of these experiences?
3. What beliefs do people form about this "illness" experience?

## **METHOD**

### **Setting**

The research took place within a newly established Early Intervention Service (EIS) in an inner London borough. The EIS is a specialist mental health service designed specifically for the assessment and treatment of young people, aged 14-34, experiencing a first episode of psychosis.

Clients referred to the EIS are initially screened to make sure they meet immediate eligibility criteria for the service (i.e. age and no previous history of psychosis) and then accepted for an eight-week multidisciplinary team assessment. Clients that meet diagnostic criteria for a first episode of psychosis (either affective or non-affective) are then accepted onto the team's permanent caseload, and followed up for three years, in line with Early Intervention Guidelines (DoH, 2001).

### **Ethical Approval**

The study was approved by the Local Research Ethics Committee (see appendix A). All participants were given an information sheet regarding the research (see appendix B) and gave written informed consent to take part in the study (see appendix C).

### **Participants**

The research participants were recruited from a continuous sample of referrals made to the EIS during 2004, which were accepted onto the team's caseload by the end of

February 2005. All research interviews were conducted over a six-month period between October 2004 and March 2005.

The inclusion criteria were that participants were aged 18-34 years, had recently experienced a first episode of non-organic psychosis and were well enough to give written informed consent to take part in the interview. Clients were excluded if they had not received the majority of their care from the EIS, were discharged from the EIS team's caseload during the study period, were not available for interview in the UK or could not be interviewed in English without an interpreter.

Within the twelve months from 1<sup>st</sup> January 2004 to 31<sup>st</sup> December 2004 the EIS received 96 referrals, of which 47 were subsequently taken onto the team's caseload by March 1<sup>st</sup> 2005. Of those, 14 people were excluded as not meeting the inclusion criteria, and a further three excluded as they remained too unwell to take part in the interview as judged by the medical professionals treating them, throughout the six-month data collection period.

Of the 30 people eligible, 25 were invited to take part in the study. The remaining five people were not approached as most of those initially approached agreed to take part, and it was deemed that this was a sufficiently large enough sample for a qualitative study. Of the 25 approached, three people declined to take part; two said they did not want to be involved in research and one did not want to be tape-recorded. Two further people who initially consented did not complete the interview, as they did not feel capable on the agreed interview day.

Twenty people participated in the study. Table 1 presents brief details of the participants; further information is not provided here in order to preserve anonymity. The participants' ages ranged from 18 to 33, with a mean age of 24. 13 males and 7 females took part. Six people described themselves as White British, five as White Other and the rest as Black British, Asian, Black African, Greek-Cypriot, mixed race or other (using standard NHS rating system). The 20 participants represented a broad range of the EIS clients, in terms of socio-demographics, but also in terms of severity of symptoms, duration of untreated illness, and level of engagement with the service. Participants were interviewed between two and ten months after their initial referral to the EIS, so in most cases participants were in the early stages of recovery when they were interviewed. All were deemed well enough to give informed consent to the interview by the EIS staff working with them.

### **Semi-Structured Interview**

A semi-structured interview schedule was used in order to elicit participants' stories of their experiences and perceptions about what had happened to them (see appendix D). The interview schedule was based on previous exploratory research carried out with this client group by members of the research team (Gould, Johnson, Billings, Pilling, Bebbington et al., 2005, unpublished) and other qualitative research about illness experiences and beliefs conducted with other populations (e.g. Clements, Sharpe, Simkin, Borrill & Hawton, 1997; Green, Payne & Barnitt, 2004). Pilot interviews were conducted with two participants (not included in the final sample) who had also recently experienced a first episode of psychosis, and minor refinements were made to the interview schedule based on the feedback from these two interviewees.

**Table 1. Participant information**

Participant	Age	Gender	Ethnic Group	Hospital admission
P1	18	Female	Black British	Yes - informal
P2	23	Male	White British	Yes - sectioned
P3	18	Female	White Other	Yes - informal
P4	19	Male	White British	Yes - sectioned
P5	22	Male	Other	Yes - sectioned
P6	31	Male	White British	Yes - informal
P7	30	Male	White Other	No
P8	22	Female	White British	No
P9	26	Male	White Other	Yes – sectioned
P10	20	Male	Mixed White & Black Caribbean	Yes - sectioned
P11	22	Female	White British	Yes – sectioned
P12	33	Female	White Other	Yes – sectioned
P13	26	Male	White British	Yes - informal
P14	23	Female	Black British	Yes – sectioned
P15	27	Female	Asian Bangladeshi	No
P16	28	Male	Asian Indian	Yes – sectioned
P17	20	Male	White Other	No
P18	18	Male	Black African	Yes – sectioned
P19	29	Male	Greek-Cypriot	Yes - informal
P20	23	Male	Asian Bangladeshi	Yes - sectioned

The interview schedule covered a number of areas, including experiences of the onset of psychotic symptoms, initial experiences of interacting with mental health services and current beliefs about their “illness”. (Additional questions pertaining to experiences and opinions of the specific specialist early intervention service were also included at the request of the service, although these were not analysed in the present study).

The style of the interview was one of “directed conversation” (Pidgeon & Henwood, 1996) and was intended to be as flexible and open-ended as possible, so as to allow participants to tell their own story and share their perceptions in their own words. Further prompts were included as needed, to further guide the discussion and to offer more structure to those participants who found it difficult to talk at length and in detail.

All interviews took place individually, in the setting most convenient to the participant, including the EIS offices, hospital wards and participants’ own homes. Interviews lasted between 30 and 90 minutes (average 50 minutes), were audiotaped with the participant’s consent, and then transcribed verbatim. (An excerpt from an interview is included in appendix E).

### **Qualitative Data Analysis**

The transcripts of the interviews were analysed according to the principles of interpretative phenomenological analysis (IPA: Smith, Jarman & Osborn, 1999; Smith & Osborn, 2003). IPA is an inductive, qualitative form of analysis, in which themes are systematically identified from the data. It is “phenomenological” in that

it is concerned with eliciting and exploring individual, personal accounts of an experience, but it is also “interpretative” in recognising that research is a dynamic process which necessarily involves the researcher’s own interpretation of the data.

IPA was chosen as the most appropriate method of analysis in this study as, consonant with the aims and priorities of the phenomenological paradigm, it facilitates an exploration of participants’ experiences, cognitions and meaning-making (Smith, 1996) and also offers a systematic approach to analysing qualitative data with clearly described procedures.

The analysis followed a number of stages as outlined by Smith and Osborn (2003). The first stage involved a detailed reading and re-reading of each transcript in order to identify the sorts of ideas that were being expressed. At this stage, each individual transcript was annotated in the margin to record emerging issues, points and processes (see Appendix F). The second stage involved re-reading the annotated transcripts and identifying tentative categories, or themes, which could be applied to the text and which were again annotated on each individual transcript (see Appendix G). The third stage of analysis involved making connections between these categories and comparing them across transcripts, resulting in a final set of themes, which were then applied to all the data (see Appendix H). Consonant with the inductive and iterative process of IPA, as the analysis evolved, earlier transcripts were reviewed in the light of new themes emerging, and instances of, or contradictions to, the theme from the earlier transcripts included in the ongoing analysis. This final stage of the analysis was facilitated by the use of the QSRN6 computer software for analysing qualitative data (QSR, 2002), which aided in the

management and organisation of the large amount of data, by copying and pasting 'chunks' of text to various themes and sub themes.

The final themes were organised within three broad domains. The domains were not themes in themselves but rather a framework to help order the data (Barker, Pistrang & Elliott, 2002). The domains were partly pre-determined by the research questions and interview schedule, but also reflected the issues raised by the participants themselves in their narratives and the chronology of their experiences and attempts at sense making.

### **Credibility Checks**

In line with "good practice" guidelines for qualitative research (Elliott, Fischer & Rennie, 1999; Smith, 1996; Yardley, 2000) credibility checks of the analysis were undertaken at several points to ensure that the themes generated adequately represented the data. Two supervisors were involved in examining transcripts of the interviews, discussing evolving themes and refining theme labels to best capture the interview data. The supervisors were also involved in conducting an "audit of the paper trail", as recommended by Smith (1996), checking that a coherent chain of argument ran from the raw data to the final list of themes.

## **RESULTS**

The participants described a range of experiences, explanations and beliefs about first episode psychosis. There were also several processes and dilemmas that repeatedly appeared in the participants' narratives, with most accounts marked by

uncertainty, confusion and contradiction as the participants sought to make sense of what had happened to them.

The interpretative phenomenological analysis yielded nine key themes, grouped within three broad domains (see Table 2). Each theme is presented in turn and illustrated by quotations from the participants. (The source of each quotation is indicated by the participant’s number). Where quotes have been edited for brevity, missing words are denoted by “...”.

**Table 2. Domains and Themes**

<b>Domain</b>	<b>Theme</b>
Experiences and understanding of the onset of psychosis	1. Evolution, escalation and breakdown 2. This can’t be happening to me: normalising, minimising and denial 3. What’s going on?
Experiences and understanding of mental health services	4. Where am I? Confusion and uncertainty 5. Mistrust and suspicion 6. Other patients: threat vs support
Beliefs about “illness”	7. Can I make sense of this? 8. Just an experience? 9. Derailment and getting back on track

**Experiences and Understanding of the Onset of Psychosis**

The themes in this domain reflect the initial stories that people told of experiencing the onset of psychotic symptoms, what that was like for them, and how they tried to make sense of it at the time.

## ***1. Evolution, escalation and breakdown***

All of the participants recognised having had some subjective, psychological problems at the time of the onset of psychotic symptoms, albeit not usually labelled as psychosis. Many described some prior awareness of these problems; others had identified them in retrospect.

*“I just felt that things were getting really bad, at home, my surroundings, my physical health was deteriorating, not sleeping, not eating properly, um, just feeling that there were things wrong at home and with my surroundings...and I decided to go to the hospital and tell them what I was going through...just a general feeling that things were not as they should be.” (P19)*

*“I wouldn’t be able to tell you exactly about the first instance when I felt ill, I think I just assumed that prior to me actually going into hospital that I wasn’t that ill, that I didn’t notice it, but um, as far as I can remember, I started just feeling a little bit, bit odd, a few questions started coming into my head, questions about life, and stuff like that.” (P5)*

Participants reported a range of subjectively noticed symptoms, including feeling paranoid, not sleeping, thinking strangely, seeing or hearing strange things, arguing with others, feeling stressed or just not feeling like themselves. They also reported a range of emotions associated with experiencing psychotic symptoms for the first time. Most described themselves as having felt “scared”, “distressed”, “suspicious” and “fearful”. A small number also reported other complicated emotions, often felt

alongside those above, including having felt “good at times”, “excited”, “strong”, “powerful”, “invincible” and “important”.

Some participants felt that their problems had come on very suddenly, others more slowly. Several described how their symptoms had evolved out of problems in their current life context.

*“I was bullied, I just grew up with it and I just coped with it until I was, maybe I was sixteen and it just started to get worse and I started to get stressed, so I became ill and I started taking drugs, it just got worse and worse and I started getting paranoid that people were coming after me.” (P18)*

*“I got really stressed out because there were many rumours about me...the rumours were, were the original cause...and then the voices in my head were built on these rumours, so in a way the reason why I couldn't get out or didn't seek help at first was because this was built on the rumours and so for me it was very hard to distinguish the rumours from the reality...because I wasn't even sure, but now I know that the voices didn't just appear out of nowhere, they were sort of like a continuation of the original negative situation.” (P3)*

Some participants described a specific triggering event, or catalyst, that they felt provided a turning point between reality and psychotic experience.

*“It was me speaking to my landlord about a girl in the house, there was lots of conflict with this person so I asked him if he could get the girl to leave ...and when I was speaking to him I just experienced this really weird thing, I was*

*really, really stressed, I could feel my face getting hot and red and then afterwards I couldn't return to a relaxed state, um, it was like I sort of geared up to speaking to him, but in my brain it carried on gearing itself up in front of me... it just really snowballed." (P9)*

Nearly all of the participants had experienced a period of “escalation” or of their problems “snowballing”, whether over days, weeks or months, until reaching a period of crisis, “breakdown” or “breaking point”.

*“The first time someone made a noise, I just got really stressed about it, and I was just like, really worried about what it was that made me jump, it wasn't a bad noise it was just a noise, and I jumped and got really scared...but it just escalated...I think as well once something minor happened to me, I blew it up out of proportion, cos I didn't have anyone to talk to me, like make me feel better about what was going on, so it escalated and got really bad.” (P8)*

*“I've always said that it's due to me coming into a new area, not being used to the area, not knowing anyone, being all like stressed, I'd lost my job about the same sort of time...so it was around that time that I got sick...I think it was just the stress and strain, just got to breaking point and then that was it.” (P13)*

## ***2. This can't be happening to me: normalising, minimising and denial***

The participants' stories of first experiencing psychotic symptoms were permeated with attempts to normalise, minimise and deny the significance of the phenomena they were experiencing.

*“I didn’t really look at it I didn’t really go into it you know, I just thought that’s just normal everyday life...being a teenager, you just expect that, just a normal thing really.” (P1)*

Attempts at coping tended to follow from these normalising and minimising initial responses, with people either just trying to carry on as normal and ignore their experiences, or resorting to drug and alcohol use.

*“I just carried on really just doing what I was doing, stressing myself out further, just ignoring how I was feeling, just getting on with it you know. I just got on with things, just carried on and just hoped for the best.” (P1)*

*“To be honest with you, I preferred not, just to ignore the voices and to continue with my life. I realise now that I look back...there was one situation where I would be reading and hearing voices at the same time and I am shocked with myself that I didn’t go to the doctors, instead I was just concentrating on being able to read and ignore the voices at the same time.” (P3)*

*“I drank alcohol, it’s an easy option to just drink and be happy with it rather than stressful with it. Because some of the other things I was thinking about were really stressful.”(P11)*

The responses of others also mirrored this pattern, with friends and family members initially minimising and normalising strange behaviour.

*“I did speak to one friend...I’d tell her that I had an argument with my mum...and that I’m finding it stressful at work... and I’ll just have a little natter with her and she’ll tell me like, you know, how she’s stressed out too. But she didn’t have an idea of where this was heading and I didn’t have an idea at all.”*  
(P1)

*“I talked to one, a good friend of mine, but the problem was I had sleeping problems and my friend said that a person has a tendency to have hallucinations if he or she doesn’t have enough sleep and so I didn’t go to the doctor because I thought that these problems were occurring because I had little sleep and so I thought that if I had enough sleep they would just disappear.”* (P3)

For several of the participants, there had been a point of subjective realisation of something more serious being wrong, although still not knowing what it was.

*“I thought that, I honestly thought that there were people out to, you know, get me and then I started, because, the nurse, the staff nurses were so flippant and stuff like that, they were um, I started to distrust them and then once I started to distrust them, it was like, even my family started to question my sanity...and then once my family started to question my sanity, it was like, you know, hang on a sec, am I a bit over the top here?”* (P4)

*“At that particular time I knew I needed help but I didn’t know exactly who from or where from.”* (P6)

Even when confronted with the realisation that something more serious was wrong, several participants still expressed a strong desire to resist the idea that this could happen to them.

*“I thought it would be something that would never happen to me, I was quite strong, I couldn’t ever imagine being depressed or having anxiety, being afraid of things.” (P9)*

*“I was just shocked because I think of this stereotype in society that everybody who has some kind of psychological illness has something terribly wrong with them and that their lifestyle will be changed forever. So I thought, I just couldn’t believe that this was true, I thought something, something has to be wrong but at the outset I didn’t want to take any medication whatsoever because I thought this is just, this just can’t be happening to me.” (P3)*

### **3. What’s going on?**

Following on from having had some awareness of subjective difficulties, most of the participants did appear to engage in some initial search for an explanation of their experiences. These attempts at understanding were, however, characterised by uncertainty, confusion and an oscillation between different possible explanations.

Some participants initially drew on explanations in terms of other psychological problems, such as stress, depression or anxiety. Several had attributed their symptoms to drug use. At some point all of the participants had believed in the

reality of their experiences. Some participants talked about how their psychotic experiences had felt even more real than normal reality.

Participants' narratives captured a sense of their struggling to make sense of what was happening to them; what was 'real' and what was 'not real'; what was genuinely happening to them and what could be explained in other ways. Some participants oscillated between multiple possible explanations.

*"I wasn't really sure what was going on at the time...when I was at the police station the psychiatrist asked me a few questions and I, up to that point, thought maybe this was something, well something to do with me being a joke for my friends, you know, that they were all going to jump out and this was a big joke, but then I thought maybe this had something to do with the free masons, but things have been intertwined because I wasn't sure what was going on, so I was a bit confused, or very confused." (P2).*

Others attributed parts of their experiences to psychological problems and other parts to reality.

*"I thought to myself, I need to see a psychiatrist anyway, not about the stalking cos that's true, but about my other problems...then they said a lot of people hear voices and they've got psychosis...and amongst other things, people with psychosis have too many thoughts going on in their brain...I knew that that wasn't me, cos the things I'm hearing, they're not in my head, they are real, but I thought, cos it says people who have too many thoughts in their head, and I thought yeah, I did have a lot of thoughts going around in my head, so maybe*

*their medication will help so I agreed to take the medication they gave me for psychosis.” (P8)*

Yet others appeared to be struggling with where reality ended and more subjective experiences took over.

*“Everything can be taken out of context, but that’s one thing, I’m not delusional to the point where its just in my mind, and I’m not actually, you know seeing things that ain’t there, I mean everything is there, its just a question of perception, and even like when [those people]walked past me and one of them said he’s a dead man, they could have been talking about somebody else, but the fact I’m standing there and hearing it is freaking me out so those are the reasons, those are the kind of tangible things that set me off.” (P4)*

This confusion and oscillation tended to carry on into the early stages of recovery and in the initial stages of contact with mental health services.

*“Since I started taking the medication its like things have started slowing down a bit more, I kind of believe in certain things but I don’t believe in certain things, I’m sort of confused.” (P15)*

One participant also talked about the dilemma of giving up the idea that his experiences might be real. Whilst an explanation in terms of psychosis came as a possible relief to him, preferred to the alternative that people wanted to kill him, he felt that he couldn’t give up his initial ideas, just in case they were right.

*“If I thought I’m mad, if I actually thought I was mad then that would probably be a comforting thing, almost because of what the alternative is if I’m right...the alternative if I’m right is that there really are people out to get me, so I would like to have believed at that time that I was sort of mentally unwell, but I couldn’t bring myself to believe that, and therefore I was still paranoid...its better to be safe than sorry, the alternative is wait to be stabbed or shot.” (P4)*

## **Experiences and understanding of mental health services**

The themes within this domain describe the experiences that the participants recounted of having come into contact with mental health services for the first time, what this was like for them, and how they tried to make sense of this.

### ***4. Where am I? Confusion and uncertainty***

Contact with mental health services was precipitated for most participants by their problems having escalated to some form of crisis point. Some then presented themselves at services, some were taken to A&E by family members, and others were referred to mental health services by other agencies and assessed at home. Many participants were vague and uncertain about what had happened to them during this period of crisis. Some found it hard to remember what had happened to them, others could remember but their accounts captured their confusion and uncertainty as to what was happening to them at the time.

*“One day there was an incident with a couple of boys, they were making trouble and they were stealing from a shop and they stole something from a woman and I*

*was walking down the street and they thought I was involved with them, they didn't give me the chance to speak. They arrested me and handcuffed me and put me in a cell. I didn't know what was going on, I was so confused. They thought I was really ill.” (P18)*

*“We got into the cab anyway and obviously my things were packed and they must have said...that we were going to the clinic, but for some strange reason I was thinking something completely different...I thought I was going to see my dad for some really strange reason, I haven't got a clue why I would have thought that, why that would have happened, but I knew he lived in that area so I kind of had that kind of thought even though I'd clearly been told by these people that I was going somewhere else.” (P1)*

For several this experience of not knowing what was happening to them and then ending up in hospital was a particularly negative and traumatic event, which was further experienced as an infringement on their normal rights and likened by some to going to prison.

*“I was taken there [to the hospital] and by that point I was very confused still. I was taken in and held down by several people because, um, well I was really worried because I wasn't sure what was going on so they took me into the hospital and I struggled because I was like this is a joke and not really sure what was going on so, and I was injected I think, it was something, I wasn't sure what, and taken into the hospital.” (P2)*

*“At that stage I didn’t understand why I was in hospital anyway, um, as far as I was kind of concerned, what I was living was real so I didn’t understand, it felt like some form of, err, some form of sentence, to go on to be restricted from doing certain things and I just couldn’t understand.” (P6)*

For some participants, there was a sense of not wanting, or being able, to question what was happening. Most, however, felt that they had wanted and needed more information and explanations.

*“I suppose I must have been ill to have to be admitted but I just didn't feel like, like looking back I felt like there was really no one, well the nurses were there to talk to us but I just felt like um, I still feel like I haven't really been given a good decent explanation about why it happened. No one really knows why it happened, you know, ideas about what things contributed to it and what might have happened and that's one thing that annoyed me when I was in hospital that no one was taking the time to explain things to me properly and we just kept, it just felt like that I was just piled with medication the whole time.” (P14)*

However, there was also an acknowledgement that professionals may have made attempts to explain their situation to them, but that they had not been able to understand, retain or believe information at this time of crisis.

*“I was still really confused. No one really sat me down and told me what was going on when I was transferred. I think X might have done, that was one of the social workers, but if I believed him, that’s a different story.” (P2)*

Participant 11 also captured a sense of the difficulties of trying to communicate with professionals at a time of such uncertainty.

*“I didn't really have anyone to talk to at that time. What happened, why I felt like that. I did have a doctor but all they were saying was I was hearing voices in my head and as soon as I heard that I thought no, I don't want to talk about nothing, but I think I wasn't able to talk about anything because things weren't clear in my head. Things weren't clear in my head myself so I don't know how I could have sat down and be able to talk about it.” (P11)*

### **5. Mistrust and suspicion**

Participants' initial experiences of services tended to be characterised by mistrust and suspicion. It seemed the nature of the many participants' initial contact with mental health services, full of confusion and uncertainty as described above, fed into the paranoia and suspicion they were already experiencing.

*“As soon as the police got here I started believing everything, I started seeing that people were talking about me, so then I started feeling I am an important person, they're trying to track me, they're trying to get me.” (P5)*

Being admitted to hospital was an event particularly likely to exacerbate feelings of paranoia.

*“I was really worried, I didn't know what was going on, I didn't really have a clear idea of why I was being held. I thought it was a big joke or by that point I*

*thought it was by the free masons that, they were trying to teach me a lesson for some reason.” (P2)*

Participants also acknowledged often having been mistrustful and suspicious of having contact with mental health workers in the community. For example, Participant 1 described her confusion and suspicions over evening home visits by members of the local Crisis Resolution Team.

*“My mum contacted the crisis team...and then they came round a couple of times, quite often, and they were giving me, they prescribed me medication to take...and for some strange reason I didn't take it...but at this point I really didn't know who they were, I had this, I don't know if it was in my mind but I sort of had these thoughts that maybe they were trying to poison me...they did try to explain to me...but I was still suspicious you know cos they never really seemed like who they were, I don't think they were even in uniform, it was just like two people who would come round at some time during the evenings.” (P1)*

Similarly, Participant 15 described her fears about early intervention service workers who came to her house to conduct a home assessment.

*“There was a part of me that thought that [they] were part of a mental hospital, looking for patients, you know when you have one of those hospital vans outside, with the injection...that's what I thought [they] were.” (P15)*

Some participants retained their mistrust, especially of the hospital environment, but most described a process of beginning to invest at least some trust in the health professionals working with them.

*“Once I was put in the hospital and once I sort of slept for a night, because at the time I was put into the hospital I didn’t sleep for three days, but I had my sleep and I had my food and realised that something was really serious...and I realised that actually I had to trust my doctors and not my own judgement.” (P3)*

It seemed that given these levels of mistrust and suspicion, it had taken participants quite a leap of faith to trust the mental health care professionals working with them and accept treatment.

*“When I started taking the risperidone, I was a bit hesitant because I thought the doctor was poisoning me or something, if I took it my mind would totally be lost, or, I just was suspicious, I was always wondering why does X all of a sudden want to persuade me to take these tablets...what is it about these tablets, I wonder if they are planning something or if they contact a chemist that I’d been to and deliberately told them you know to give me different tablets, you know, I was just really wondering.” (P15)*

#### **6. Other patients: threat vs support**

Being with other patients in a hospital environment also appeared to elicit mixed responses. For some participants, being around other people with mental health

problems, especially when feeling so vulnerable, was a particularly distressing experience, further increasing feelings of paranoia.

*“I was fearing for myself when I went in there. It was like I was put in a strange environment...I was paranoid, I was fearful, you know just strangers being around me. They stuck you in with about fifteen, twenty other people, who are all mentally ill and all spouting complete rubbish to me and it just wasn't an ideal situation and that freaked me out twice as bad.” (P4)*

Other participants talked about other patients having been a significant source of support and insight.

*“some of the people in here um, some of the people that were patients themselves kind of helped me realise what I was. They said little things that made me feel better, so I think that was good to be with people like myself cos I'm not mad or mental or anything but it was nice to come here and meet people like myself who've had a breakdown.” (P11)*

*“people who use the service, they've made me feel like I'm not alone and I'm not the only person who's been through what I've been through.” (P18)*

Stigmatising preconceptions of psychiatric patients were apparent in many narratives. For some, particularly those who had recounted negative experiences of being around other people, these views were corroborated, although most participants described their experiences having changed their views about people with mental illness.

*“A lot of the people...they seemed a lot more normal than what I'd imagined I thought people would be really kind of crazy and saying weird things and acting really strangely, but they seemed more like people that were just really down on their luck rather than having mental health problems. Some of the people there, some of the people that I kind of spoke to or became friendly with, they seemed really normal and really helpful as well, which I didn't expect. (P14)*

*“[I thought they'd be] really abnormal people, schizophrenics, depressives, people completely out of touch with reality, I never thought I'd be one of them...but now...just that they are ordinary people who need health services in order to be ok.” (P15)*

Several participants remained curious about other people's experiences, suggesting that they would like to have the opportunity now to meet and interact with other young people who had been through experiences like themselves.

*“I just think it would be helpful to hear about other people's experiences first hand rather than reading about them and hear about how they are managing their situations and hear suggestions about what might be helpful for other people who have gone through it themselves. And just having someone of your own age who's been through the same things to be able to talk to them about it.” (P14)*

## **Beliefs about “Illness”**

The themes within this domain describe the participants’ perceptions of their experiences at the time of the interview, how they had labelled them, how significant they thought they were, the impact they felt that had had on their lives and what they thought might happen in the future.

### ***7. Can I make sense of this?***

All participants were aware that they had been given a diagnosis of an episode of psychosis. Some had clearly accepted this label by the time of the interview and talked about their experiences of psychosis as an “illness”. Others remained more openly rejecting of this label. Several used the terms “ill” or “psychotic” but still appeared uncertain or unconvinced as to how it applied to them. All participants accepted and spoke about having experienced some form of psychological difficulty.

When asked if their experiences now made sense to them, only one participant said he felt he fully understood what had happened to him. Most other accounts were characterised by continuing confusion and a marked ambivalence: a struggle to still try to make sense of what had happened alongside a desire to move on and forget about what they had experienced.

*“I’m still a little bit lost about what kind of happened anyway, rather like some form of bad film, it’s like I watched the film, you know, didn’t enjoy it, but again didn’t understand it either...I think in some ways I need to understand, but I don’t ...I can see how I ended up in hospital but I still don’t understand why I*

*was that bad...I've never experienced anything like that whatsoever...it was just so real, I just, I'm having trouble to remember, I'm just trying to forget.” (P6)*

Nearly all the participants appeared at some point to have considered what might have caused them to go through these experiences. Many had isolated a few possible causal factors, of which the most frequently cited were drug use, stress and difficult life events. Others seemed to hold ideas as to several potentially contributing factors, but remained uncertain as to which were more likely to have been causal.

#### ***8. Just an experience?***

Nearly all of the participants said that their experiences had had a big impact on their lives. A minority described some positive aspects, such as having brought family members closer together, or feeling that they had become mentally more resilient as a result of these experiences, but for nearly all the experience was seen as a negative one.

Participants described the disruptive effects of having had these experiences on their work, study and relationships with friends, partners and family, as well as the personal and emotional impact of these experiences.

*“Having these experiences, it's shattered my life having these experiences.”*

*(P16)*

Despite the widely acknowledged impact of these events at the time, most participants didn't however seem to think that these experiences would have long-term consequences for them in the future.

*"What's happened in the past can't affect my future." (P10)*

What consequences participants thought there might be for the future mostly related to having been involved with mental health services, rather than having had the psychotic experiences per se. Some felt that having had help from mental health services was a positive consequence. Some were concerned that mental health services' involvement might hinder their future chances of employment.

Participants' accounts were also punctuated with an apparent struggle to resolve whether what they had been through was a meaningful and significant life event, an "epiphany", or whether it was "just an experience", just a "part of life", a "blip."

Some participants consistently sought to minimise the significance of their experiences.

*"I'm trying not to look at it as a negative, I'm just going to look at it as something that has happened, an experience, you know, everything in life is an experience, you just look at it as that, it may not have been the best, but that's how it goes really, you know, no one's life is perfect." (P1)*

Others believed that what they had been through was personally meaningful and truly life changing. For example, one participant described how his experiences had

brought him closer to religion, and two others talked about how, in retrospect, they felt that they had needed to reach such a breaking point in order to turn their lives around.

*“I have been up and down, up and down all my life, sometimes I feel really down and depressed...but this was quite a big discovery for me because I was thinking about what I did and to get to know where it all came from, like it was supposed to be, it was like destiny for me to go through that kind of breakdown.”(P11)*

*“I was convinced that something had happened on that particular date, but maybe it was just breaking point, I don’t know, maybe looking back on it that’s a feasible way of looking at it, maybe its just the fact that it was breaking point and I’d had enough and I was looking for an escape but I couldn’t find a way of escaping, of getting out of my dilemma of my problems.” (P7)*

Yet other participants still seemed to be trying to come to terms with whether what they had been through was meaningful, or whether it was just another life event to try to move on from. For example, Participant 7, as above, referred to the significance of his experiences at several points, yet at other points, labelled them as “just an experience”.

*“it was profound, it was like a landmark, or like a change...it was really strange, maybe, like coming of age...an epiphany” (P7)*

*“the way I see it, you know, I went through something, I don’t know what it was, um, maybe it was just a phase in my life” (P7)*

## ***9. Derailment and getting back on track***

A common and prominent metaphor in participants' accounts was of having been "derailed", and having "gone off the tracks". Concomitantly, participants also talked about "getting back on track" now.

The help of mental health services was appreciated for facilitating the process of "getting back on track", particularly in relation to returning to education or work, help with housing and benefits, and access to talking therapies. However, once "back on track", participants seemed to feel that they would no longer need the help of mental health services. Most participants appeared to feel that they would only need help for a period of a further few months, up to a couple of years. All were keen to take medication only in the short term.

In the meantime, participants were particularly conscious of stigma. Again it was the involvement of mental health services and concomitant labels that were seen as a risk of more enduring stigma than the experiences they had been through per se.

*"To be in contact with a form of mental health team or that kind of thing, straight away says that you have some form of mental dysfunction, which I don't like to put myself in those, in that kind of label." (P6)*

*"I think it's good as long as they don't think I'm mad. As long as they continue helping me and finding me a job they can help me sort out my problems." (P17)*

In line with participants' focus on "getting back on track" was a negative point expressed by two participants about ongoing contact with mental health services constantly being a reminder about what had happened to them.

*"I'm reminded about the experience I've had which can be quite upsetting cos obviously when I have to meet up, we have to go through the same, not the same things, but talk about certain things, and you now, its always referred back to that time...it feels like I want to move on but when I speak to them its like going back, time again, and going through certain things that were quite hard to talk about." (P1)*

Participants also expressed varying views about how much experiences like these could be controlled. Nearly all had experienced psychosis at the time as being out of control, of being unable to control their own mind and/or events around them. After the event, some participants now seemed convinced that they would have much more control over whether something like this would happen to them again. Others felt that they still had little control at all.

*"I've really tried to knuckle down and say hey this isn't real, this is mad and it's just me, I'm freaking out over nothing, and as much as I've tried to control it, it still doesn't, it's like, you're out of it, you can't control it, there's nothing you can do." (P4)*

Most again appeared to not yet have formed clear ideas as to how controllable these experiences ultimately were, either personally or through treatments offered to them by mental health professionals. Some participants appeared to believe that control

lay more within themselves, others deferred control to the mental health professionals around them.

Some participants did express concerns about their future mental health, and a small minority were worried about relapsing. However, most participants said that they hoped this would not happen to them again, and of these, most said that they did not believe it would. It seemed that where participants had been able to identify possible causes (e.g. stress, drug use) they felt that they could make changes in these areas and ultimately make it less likely for these experiences to recur. Some participants were explicit about not wanting to think about whether it might happen to them again in the future. Again the idea of drawing a line under the experience and moving on from it was prominent.

*“I think once I’m back on track I’ll be fine because I just want to move on with my life...things like housing, once I get my housing I’ll be fine, starting to rebuild a life, so there wont be any consequences because I’ll change that, anything that comes along I’ll now be able to change for the better.” (P11)*

## **DISCUSSION**

The 20 participants involved in this study recounted varied and personal stories of first episode psychosis. Qualitative analysis of these accounts revealed nine key themes related to the participants’ experiences and beliefs. The results of this study highlight a number of tensions and concomitant dilemmas, both for those experiencing first episode psychosis and also for the mental health professionals working with them.

## **Early Detection**

All of the participants identified some subjective changes or unusual experiences, albeit some in retrospect. Many were also aware of a subjective escalation in their problems, whether in days, weeks or months. The significance of these experiences was, however, often minimised or normalised, for example as usual teenage behaviour or psychosocial stress, by both participants and their friends and families.

The participants did also seek explanations for their experiences. However, participants' initial attempts at understanding and explaining their experiences were often complex and multidimensional, with many holding several competing explanations in mind at once. Some participants drew on explanations in terms of other psychological disorders such as anxiety and depression and many on psychosocial stressors and drug use. The process of the participants trying to explain the nature of their symptoms also seemed to evolve alongside the course of their experiences. Several participants appeared to have sought more "normal" explanations for their experiences at the very early stages, and then more psychotic explanations as time and symptoms progressed. For many this process then seemed to reverse later into treatment, with increasing, although gradual, awareness of other possible explanations again.

That these participants were able to identify something as "wrong", even if not labelled as psychosis, is helpful to clinicians in finding some common ground to work from. This finding also has important implications for early detection as it contrasts with the traditional view of prodromal and early psychosis, in which a total lack of insight is usually viewed as inherent to the disorder (ICD-10, 2003) and

people are seen as unlikely to seek help on their own behalf, as they are not aware of what is going on.

Even if people were to present themselves to primary care services, the processes of normalising and minimising of problems, both by people themselves and their friends and families, and the manner in which several people's psychotic symptoms evolved out of the context of other current life difficulties, still make identifying psychosis particularly difficult. Given that one tenet of the early intervention philosophy is to try to reduce duration of untreated psychosis (DoH, 2001), and early contact with primary care has been seen as vital in achieving this (Skeate, Jackson, Birchwood & Jones, 2002), front line health professionals are likely to need considerable support and training from specialist services in order to recognise early psychosis.

The resistance and denial expressed by several participants to labelling their experiences as a mental health problem is also likely to reflect the still considerable stigma in society surrounding mental illness generally and psychosis in particular (Crisp, Gelder, Rix, Meltzer & Rowlands, 2000). Adopting explanatory narratives around psychosocial stressors and drug use may therefore be relatively less stigmatising.

The difficulty participants had in making sense of their experiences and the processes of minimising and normalising are also likely to reflect a broader lack of knowledge about psychosis in society. Public education may have a vital role to play in increasing public knowledge about psychosis and reducing the stigma associated with it, and thereby facilitate early detection.

## **Service Intervention**

Nearly all of the participants experienced their first contact with mental health services as a confusing and anxiety-provoking event. Participants tended to find it particularly hard to coherently recall or understand events around the time of the crisis that usually precipitated their first contact with services. The manner in which most participants then came into contact with mental health professionals (through A&E, hospital ward or home visits from crisis or early intervention service workers) appeared to exacerbate feelings of paranoia symptomatic of the psychosis. However, many participants' feelings of mistrust and suspicion can also be understood more broadly as an understandable and non-psychotic response to suddenly being in such an alien and disempowering situation.

The nature of this initial contact with mental health services raises a difficult dilemma for professionals in balancing their duty to intervene, with obvious negative consequences on long-term engagement. The challenge remains for clinicians to manage these initial interactions in as clear, collaborative and non-invasive manner as possible.

## **Education and information**

Most participants were keen to be given explanations and information as to what was happening to them, both in terms of their immediate care and what explanations others had for the experiences they were going through. Several participants did, however, also acknowledge the difficulty of understanding, retaining and accepting this information at the time.

This finding is supported by the results of a small qualitative study carried out recently in Finland. Kikku, Munnukka and Lehtinen (2003) interviewed seven people who had recently had a first episode of psychosis to explore their experiences of information giving. The authors found that the meaning of the same psycho-educational information was met with a variety of responses, including feelings of worthlessness and confusion, or relief, confidence and coping, depending on the person's prior understanding and acceptance, or not, of their psychotic experiences so far.

This highlights the need for clinicians to give frequent and repeated reassurance and explanations, but to deliver this in a way that is as acceptable to the client as possible, and not construed as too immediately challenging or invalidating of the client's current experiences and views. Currently it is likely to remain a matter of sensitive clinical judgement as to when explanations in terms of medical and psychological symptoms may be experienced as helpful and a relief to clients, or when it is necessary to integrate information into the patients' existing model of their experiences. This dilemma does have clear practical implications for clinical practice and may warrant exploration in additional research.

### **Other patients**

Participants expressed mixed feelings towards their contact with other people in the care of mental health services. A significant minority reported very negative and stigmatising views of other patients, usually in relation to other in-patients. Other participants talked about the benefits of having shared this experience with other

young people like themselves. This finding supports that of Colton and Pistrang (2004), who also reported similar mixed findings about other patients in their study of young people's experiences of in-patient treatment, whilst being treated for eating disorders.

Peer support amongst individuals with severe mental illnesses has also been previously highlighted as a positive intervention (Davidson, Chinman, Kloos, Weingarten, Stayner, & Kraemer Tebes, 1999). That many participants in this study retained a marked curiosity about the experiences of other young people like themselves highlights a potential role for mutual support groups with this client group, which certainly warrants further investigation.

Dissatisfaction with existing in-patient mental health care has unfortunately been widely documented (Quirk & Lelliott, 2001) and contributed to Rethink's critique of traditional services as "youth insensitive" and "therapeutically pessimistic". An aim of specialist early intervention services is to keep more young people out of hospital and treat them in the community. However, a significant minority of early intervention clients are still likely to need admission to an in-patient facility at some point. Some of the pioneer early intervention services have included specialist early intervention wards for the sole treatment of young people with psychosis. This however does raise the issue of a particularly ill group of young people being held together on the same ward, as described by participants in the current study, with other acutely unwell people at times when they themselves are feeling very vulnerable. Such wards are likely to require staff with specialist training and extensive on-going support. Further research into the issues and pragmatics of running such specialist wards is needed.

Despite the generally very positive feedback from participants about the early intervention service, their preconceptions about mental health services were still clearly imbued with traditional representations of psychiatric institutions. There is evidently a lot of work for specialist early intervention services to do to override this pervasive stigma.

### **Beliefs, Coping and Recovery**

Participants' views and beliefs about their experiences were characterised by ambivalence: on a cognitive level, wanting to make sense of experiences versus wanting to move on from and forget them, and on a more emotional level, trying to reconcile whether what had happened was a personally significant event or just a life experience with no enduring meaning.

Further apparently contradictory processes were also evident, such as the finding that participants frequently acknowledged the extensive impact of the experience of psychosis on their work, social and personal lives, yet minimised the likelihood of it having longer-term consequences in their lives, outside perhaps of the stigma of having been involved with mental health services.

Illness belief models (as indeed nearly all cognitive models) are predicated on the assumption that individuals are driven by a need for coherence, to make sense of the world and the experiences that happen to them (Cameron & Leventhal, 2003). Most of the participants in this study did seem driven, at least at some points in their narratives, to try to make sense of the experiences that they had gone through.

However, at other points they also sought to forget about and move on from thinking about these experiences. Perhaps another normal psychological process is however also at play here: the desire to move on and try and forget about painful events. Considering the distressing nature of the experiences that most of the participants described, the wish to move on and forget about them can be conceived of as an understandable and normal process rather than as a sign of psychosis, or lack of insight into their psychosis, as has traditionally been the case. These competing, yet normal, psychological processes may explain such phenomena as why people ask for more information and explanations about what has happened to them, yet, as is clinically often the experience, are then not motivated to read it.

Consideration of these competing processes may also shed further light on literature related to coping styles in first episode psychosis. Traditionally, two forms of coping style have been identified in people recovering from psychosis: “sealing over”, which is a way of coping by minimising the significance of symptoms and impact of psychosis and showing a lack of curiosity about the experience; and “integration”, where individuals incorporate the psychosis into their wider life experience (McGlashan, 1987). An integrative coping style has been linked with generally better outcomes from first episode psychosis after 12 months (Thompson, McGorry & Harrigan, 2003), and also better engagement with services at 6 months (Tait, Birchwood & Trower, 2003). However, this style of coping has also been linked with higher short-term levels of depression, purportedly indicative of the individual becoming engulfed by the demoralisation and stigma that they associate with mental illness (Jackson, McGorry, Edwards, Hulbert & Henry et al., 1998).

Coping style has traditionally been conceived of as an enduring personality trait (McGlashan, 1987). However, recently Tait et al. (2003) found that individuals tended to shift from a coping style of integration to sealing over within the first three months of recovery after a first episode of psychosis. The findings of the present study support Tait et al.'s view that coping style can be seen as a more fluid concept rather than a static personality characteristic, but perhaps go even further as to suggest that "recovery style" may be the outcome of shifts in the balance of the competing psychological processes described above. It may be that the present study accessed several people at the point in their recovery where this transition was occurring. However, these results may also support the idea that the construct of "recovery style" is actually more malleable than previously conceived, and not necessarily simply a dichotomous concept, as may be indicated from the snapshot nature of most quantitative research.

### **Long-term engagement**

Participants' accounts of "derailment" and "getting back on track" also highlight perhaps why people are more willing to accept the help of services in the first few months after their problems have reached crisis point, but do not see the help of services as relevant to them in the long term. This gives rise to a particularly difficult dilemma for clinicians as to how to maintain "youth oriented" and "therapeutically optimistic" (Rethink, no date) services whilst being honest about future risks and relapse rates.

Current estimates vary, but indicate that approximately 15-35% of people with first episode psychosis will have relapsed within the first year, 30-60% within two years,

and 80% within five years (Robinson, Woerner, Alvir, Bilder, Goldman *et al.*, 1999; cited in Birchwood, 2002). Whilst specialist early intervention services have as an explicit aim to reduce these rates, any changes are likely to take time and still, realistically, involve the majority of clients having some form of relapse in the first few years. Services therefore face a significant challenge if they are to be realistic and honest about longer-term relapse risks and retain people on their caseloads and follow them up throughout the critical period of the first three years, in line with early intervention guidelines (DoH, 2001), and yet be a service that is acceptable to their clients and not pessimistic or risking disengagement.

### **Methodological Issues**

The findings of this study should be considered within the context of a number of methodological limitations. Firstly, participants were interviewed early in the course of recovery from their first psychotic episode. Whilst this enabled access to their experiences soon after the onset of psychosis, and to their beliefs early in their formation, it meant that some were still experiencing positive symptoms and three were still in-patients at the time of the interview. This may have impacted on the coherence of the interviews. This group may also have given different perspectives had they been interviewed later into their recovery. Secondly, because the participants were all on the caseload of a specialist early intervention in psychosis service, their accounts were inevitably shaped by the interactions they had already had with several mental health professionals. It is therefore difficult to disentangle what perceptions participants may have formed independently of their contact with mental health workers. People who had experienced an episode of psychosis, but had little, or no contact with mental health services, may have expressed very different

perspectives. Thirdly, whilst this study achieved very good response rates, and was able to access a range of clients in terms of socio-demographics, duration of untreated psychosis and level of engagement, it is difficult to know how transferable these findings would be out of a multi-cultural, inner city context. Finally, given the multi-cultural nature of the sample, it is difficult to ascertain how much some people's beliefs may have been influenced by their particular cultural and social backgrounds and further in-depth research in relation to the impact of these factors on beliefs about psychosis is warranted.

## **Conclusions**

Contrary to traditional views of early psychosis, the participants in this study did have some subjective awareness of problems. Help seeking, however, appeared to be hindered by processes of normalising and minimising these initial problems, a lack of knowledge about psychosis and stigma surrounding mental health in general. This highlights the need for front line mental health professionals to receive support and training in order to identify psychosis from these ambiguously presented symptoms, and also considerable work that needs to be done to increase public knowledge about psychosis and reduce the stigma associated with it.

Participants' experiences of their first contact with mental health services were often confusing and anxiety-provoking. Participants wanted more information and explanations as to what was happening to them, although also acknowledged how this information was difficult to understand, believe or retain at the time. Professionals face a challenge to provide assertive health care that is acceptable to their clients. Further research is also warranted into the potential role of mutual

support groups with this client group as well as the use of specialist early intervention wards.

This study has also established that people engage in a complex process of meaning making when faced with the experience of psychosis for the first time. Many of these processes seem apparently contradictory, reflecting the participants wanting to understand what had happened to them alongside their desire to forget about the painful experiences and move on and get on with the rest of their lives. These processes in turn appeared to be linked with the participants' way of coping and what they wanted from mental health services.

This qualitative, phenomenological study was able to access a variety of beliefs and experiences shared by participants. Further investigation of these beliefs about, and perceptions of, "illness" in relation to early psychosis would certainly seem warranted. Using the illness perceptions approach may offer a useful framework for future work in this area, although more qualitative work adapting the models for use in early psychosis is perhaps necessary in order to extend the framework to include some of the factors and processes raised by the participants in this study.

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## **PART 3**

### **CRITICAL REVIEW**

# **Making Sense of First Episode Psychosis: A Critical Review and Reflection**

## **Introduction**

This paper reviews and reflects on the process of conducting the empirical study described in part two of this thesis. Throughout the whole research process many issues and dilemmas arose, and choices had to be made, that ultimately shaped the results of the final study. In this paper these issues are discussed in relation to two central areas. Firstly, dilemmas related to conducting qualitative research with people with first episode psychosis are considered, and secondly, issues pertaining to the position of the researcher in relation to the research are discussed. Finally, these factors are summarised with respect to implications for researchers conducting further research in this area.

### **1. Conducting qualitative research with people with early psychosis**

This study involved interviewing people recently diagnosed as having had a first episode of psychosis early in the course of their illness. All of the participants interviewed were judged as able to give informed consent to the interview by the medical professionals treating them; however, some were still experiencing florid symptoms of psychosis and several were still in-patients at the time of the interview. As such, in this study I interviewed a group of people not conventionally considered to be “interviewable”.

By interviewing people early in the course of their psychosis I was able to hear stories of participants' early experiences that were still relatively recent and access beliefs about these experiences as they were being formed. Whilst most participants were able to share coherent and thoughtful reflections on their experiences so far, the nature of their psychotic illness did inevitably have a number of implications throughout the research process.

### ***Language and Labels***

Individuals who have been diagnosed by health professionals as having “psychosis” do not always, either at the time or subsequently, label themselves as having an “illness” or talk about “psychosis” (Fowler, Garety & Kuipers, 1995). Whether this is related to problems in insight intrinsic to the disorder (ICD-10, 2003), or due to other factors discussed in the preceding papers, this nevertheless raised a dilemma about being transparent and honest about the research aims whilst using language acceptable to the participants.

All of the clients who were recruited to this study were aware that they had been given a diagnosis of psychosis by the specialist team working with them. As discussed in the main paper, some participants clearly accepted this label, some openly rejected it, and many others were not sure as to how it applied to them. Not knowing in advance how participants related to their diagnosis had clear implications for the research, particularly in relation to developing the information sheet and the interview schedule, making the sensitive use of language and avoidance of labels pertinent.

All participants who were approached about the study were given an information sheet (see Appendix B) with details of the study entitled “Making Sense of First Episode Psychosis.” This may have immediately positioned the research as fitting within a standard psychiatric, diagnosis-led, view of mental illness, and led to participants making certain assumptions about what would be talked about in the interview. At this point, however, I made a deliberate decision to use the term “first episode psychosis” on the information sheet as this term would be used in writing up the study.

Later in the information sheet, participants were referred to as “people who have been diagnosed with psychosis by mental health services”, rather than “people with psychosis”, in an attempt to use language more acceptable to a variety of service users. Also, in the interview schedule, participants were asked about their “experiences”, rather than about “symptoms” or “illness”. Where the participants used terms such as “psychosis” themselves, they were asked what they meant by these, again to avoid assumptions about what this meant to them, and then the participants’ own language was used where possible.

These issues were discussed prior to the main study with both other mental health professionals, but also with the two participants involved in the pilot interviews. The feedback from these discussions was particularly helpful in thinking through the consequences of asking certain questions in certain ways. Nevertheless, questions asked by a non-mental health professional, and particularly by a service user

interviewer, may still have been considerably different and therefore shaped the research in different ways.

### ***Anonymity, Confidentiality and Flexibility***

As detailed in the main study, many of the participants were initially mistrustful and suspicious of mental health services, as well as unclear and uncertain as to what might be happening to them. Again, as discussed earlier, this may have been caused to various degrees by factors inherent to the psychosis or may have been an understandable reaction to going through strange experiences and the sudden and pervasive involvement of mental health services in their lives. Either way, this certainly had important implications for conducting the research interviews, which impacted particularly on anonymity, confidentiality and the need for flexibility.

In order to begin to establish trust and rapport, I normally met with each participant at least once prior to the research interview to talk informally about the research. Prior to conducting the interview I again discussed the purpose and process of the research with each participant, in order to make certain they had been able to understand and retain the information. With several participants it was also necessary to engage them in talking about informal matters before getting onto the “business” of the interview, again in order to relax them as much as possible.

Most participants reported being happy to be involved in research that would help to shape services. However, a significant minority expressed some concerns, most notably suspicions about the tape recording of the interview, who might hear it and

what would happen to it after the interview. It was therefore important to repeatedly assure participants of their anonymity and confidentiality as well as explain the process of the research including transcription, analysis and writing up. Participants were also invited to listen back to parts of the tape after the interview and asked if they would like to be sent a copy of the interview transcript. These measures seemed to alleviate most participants' concerns, and only one person requested a copy of the transcript from his interview.

Whilst most people approached via the above mechanisms gave consent to the research quite willingly, the pragmatics of completing the research interview still required considerable flexibility. I endeavoured in this study to recruit a wide range of clients including those who were still unwell, and those not so actively engaged with the early intervention service. This inevitably led, however, to the need for considerable assertiveness in recruitment and increased flexibility in terms of the time and place of interview, as well as being able to re-arrange the interview for participants who did not feel well enough, or had forgotten, on that day. Within the interview, it was also imperative to adopt a flexible, relaxed and conversational style, in order to encourage participants who might already be guarded or suspicious to not feel further persecuted by the personal and probing nature of interview questions.

Conducting qualitative interviews with young people with psychosis clearly necessitated a more flexible, tolerant and informal approach than may be adopted in research with other client groups. Spending so much time with participants prior to interviewing them is also clearly more time consuming than the usual process of research. However, as Smith and Osborn (2003) advocate, spending time carefully

setting up and making the research process transparent with all research participants is important to put people at ease prior to and during the interview to ensure good quality qualitative data. These issues may be especially pertinent to conducting good research with this client group.

### *Agendas and Ethics*

Asking young people with psychosis to talk extensively about often distressing and traumatic experiences, in a non-therapeutic, research setting, also raised ethical issues. Several participants did comment that they had found it helpful and interesting to share their story with someone, and for some, that this had provided an opportunity to reflect on events that they had not had so far. Some, however, also commented that it was difficult to talk about these often very traumatic experiences.

The research interview is very different from a therapeutic session, although this may be less clear to participants. Again, with this in mind, it was imperative to talk to participants about the nature, boundaries and confidentiality of research. It was particularly important to outline limits to confidentiality, for example if participants were to disclose information to me during the course of the interview that might indicate their putting themselves or others at risk. Whilst it is not the researcher's agenda to encourage participants to engage with a service, a researcher who is also a clinician will be very aware of their professional responsibility and clinical integrity, and not want to cause any negative impact from the research on their participants. In some cases during this study where participants revealed ongoing concerns, I encouraged them at the end of the interview to talk to members of the Early

Intervention Service. I also gave participants an e-mail address and work telephone number for them to contact me on if they had any questions or concerns following the research.

### ***Coherence and Validity***

Most of the participants were still in the very early stages of recovery at the point at which they were interviewed. Some were still actively experiencing psychotic symptoms and three were still in-patients at the time of their interview. This clearly had an impact on conducting the interview, as discussed above, but also affected the coherence of the final interview data, which in turn raises the question of whether or not their stories are valid accounts?

Most participants were able to describe their experiences in a coherent and thoughtful way. However, the narratives of a minority were more confused and thought disordered, although tended to still have some moments of greater clarity. I believed it was important to include these participants' experiences and views in the research if at all possible, and not exclude them on the basis of a lack of consistent coherence. In so doing I was hoping to achieve more inclusiveness and diversity in my sample, and not just represent the views of the most well recovered and articulate minority.

Including these narratives, however, raised certain dilemmas in terms of analysing the data. Inevitably subjective decisions had to be made throughout the analysis

process about what could or could not be made sense of in certain individuals' accounts and therefore what was to be included or excluded from the final analysis.

The interview data generated in this study was analysed according to the principles of Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2003). IPA is a methodology based within the broader phenomenological tradition, and as such aims to capture the quality and texture of individual experience and meaning making. IPA also, however, recognises that the researcher's own views and perspectives are necessarily involved in the *interpretation* of the participants' experiences in the research process (Willig, 2001). In a study such as this, perhaps the researcher's role can be construed as requiring a more actively interpretative component, than might be the case in research with other client groups.

Nevertheless, this still raises questions of whether the interpretations I made might have biased the research findings. However, it was my belief, and therefore my choice, that not including these participants would have biased the research more fundamentally.

The validity of retrospective accounts by people with psychosis has also been questioned (Yung & McGorry, 1996). However, this criticism is arguably applicable to retrospective methodologies conducted with all research participants. Again, this awareness of the limitations of retrospective accounts needs to be balanced with the benefits of hearing people's stories of their experiences and views told in their own words. In line with the focus on beliefs in this study, it could also be argued that it is not necessarily an objective record of the facts of someone's experience of psychosis

that we are trying to access, but rather their subjective experience of it, and beliefs about it, as it will be these that influence their subsequent behaviour.

### ***Generalisability***

It is not the aim of qualitative research to provide a representative sample from which generalisations can be made to other groups, as is the basis of quantitative research. Qualitative research, rather, is concerned with exploring individual experiences in their depth, detail and complexity (Barker, Pistrang & Elliott, 2002). Nevertheless, the findings of any one qualitative research study will be interesting to other researchers and clinicians reading it in terms of how usefully they think they can be transferred to the people they are working with.

As discussed above, concerted efforts were made in recruiting participants to this study to include a broad range of the early intervention service's clients, in terms of socio-demographics, severity of symptoms, duration of untreated illness, and level of engagement with the service. In so doing, I hoped to not just represent the views of those who were most articulate, had recovered most quickly or who were most engaged with the service. However, whilst the participants in this study may have been reasonably representative of the clients on the caseload of the service where the research was carried out, the extent to which these findings can be generalised outside of an inner city context, or to people who may have experienced a first episode of psychosis and not come into contact with specialist mental health services, is less clear.

As advocated by Elliott, Fischer and Rennie (1999), it is important to describe the research participants so that readers can decide for themselves how widely the findings of the study may apply. Attempts were made in this study to 'situate' the sample of participants, although again this had to be balanced with the need to preserve the participants' anonymity ensure that no one could be recognised by the local service.

## **2. The Position of the researcher**

This second area of reflection concerns the position of the researcher in relation to the research. As discussed above, the researcher plays an active role in interpreting qualitative data, and in so doing, their own ideas, values and assumptions necessarily impact on the research. In addition, methodologies such as IPA are not value free, but are also imbued with certain epistemological assumptions. Finally, this research took place within a real clinical setting, in which I was also on clinical placement, which raised issues about the dual position of the psychologist as researcher and clinician.

### ***Personal Reflexivity***

The researcher's own experience, assumptions and theoretical perspective inevitably permeate the research process at many stages. My decision to conduct research in the area of psychosis was related to my clinical interests and previous experience in this area. My interest in exploring people's experiences and beliefs was in turn related to my own belief that this was an important and under researched area. This was in turn

influenced by assumptions from my previous clinical work that people who have recently experienced a first episode of psychosis would be able to take part in a semi-structured qualitative interview, and that their accounts and views could contribute significantly to the development of services and research in this area.

Whilst having a personal belief in the value of using qualitative research to let mental health service users' own stories be heard, as someone who has not experienced psychosis personally, nor ever been a mental health service user, I could inevitably only understand so much of what the participants were able to relay to me. As a few participants commented, "you can only really know what it's like if you've been through it yourself."

The process of conducting research can also, in turn, affect and change the researcher. Some of my prior assumptions were confirmed by conducting this study (i.e. that people with first episode psychosis would have something significant to say and that they would be able to articulate this); however, other ideas I had previously held were challenged and refuted. For example, I was not expecting contact with mental health services to form such a central component of participants' stories, yet this appeared to be a key factor in leading people to define their experiences as "psychotic" as well as a prominent source of fear and stigma.

The stories that many of the participants told also impressed upon me how confusing and anxiety provoking the experiences of both becoming psychotic and coming into contact with mental health services for the first time could be. I hope to take this

understanding and use it to inform my future clinical practice with similar vulnerable client groups.

### ***Epistemological Reflexivity***

Epistemological reflexivity (Willig, 2001) relates to how the design of the study and method of analysis has shaped and constructed the data and the findings. IPA was chosen for this study as its central aim is to explore in detail how participants are making sense of their personal and social world (Smith & Osborn, 2003). This philosophy was consonant with the specific research questions in this study, namely what were people's experiences of psychosis and contact with mental health services and what were their understanding and beliefs about these experiences. The process of conducting IPA has also been well documented, and is relatively simple, logical and transparent. It therefore has considerably face validity for use in a study such as this.

IPA, however, only represents one way of working with qualitative data. Different results may well have been generated by this study if a different, more social constructionist, methodological paradigm had been applied to it. For example, using discourse analysis (Potter & Wetherall, 1987) may have revealed more about how participants constructed their experience through language. Alternatively, a more anthropological or social psychological approach, such as social representations theory (Farr & Moscovici, 1984) may have focused more in the social origins of the participants' ideas and beliefs.

Whilst IPA was perhaps best suited to answering the research questions originally set out in this study, these alternative approaches could provide a useful alternative perspective on the data obtained, or could be used in other qualitative studies to further inform our understanding and the research literature on first episode psychosis.

### ***The Psychologist as Scientist Practitioner***

Whilst conducting this research I was also on a six-month clinical placement with the Early Intervention Service. Working with the team certainly aided recruitment of participants to the study, as I was aware of eligible clients, was on hand to remind clinicians to mention the research to their clients, and was able to talk to potential participants informally myself either on the hospital wards or when they came to the service. Conducting research in a service at the same time as working there clinically did, however, raise several issues, which are particularly pertinent for clinical psychologists if they are to work as “scientist practitioners”, combining clinical and research activity in their clinical settings.

Being known to many of the participants as a clinician within the team as well as a researcher meant that participants inevitably positioned me as part of the mental health system. I sought to maximise participants’ openness in the interview by assuring them of confidentiality and anonymity, and encouraging them to share both positive and negative experiences, with the rationale of helping to develop mental health services that would be more acceptable to people like themselves. Nearly all of the participants did disclose both positive and negative experiences and views.

However, my position as a clinical psychologist, and moreover as a clinician in the team from which they were receiving most of their current help, is likely to have impacted on the stories that people shared with me. It would certainly be interesting to compare the data obtained in this study with similar interviews, for example conducted by a trained service user.

As raised earlier, clarity around anonymity and confidentiality was particularly important. However, conducting research in a team in which I was working clinically highlighted for me that preserving confidentiality is not always such a black and white matter.

Working with young people in the early stages of psychosis requires an intensive team approach, with daily handover meetings on each client. Having spent quite a long period of time with each participant I was often the most well informed clinician as to that client's mental state at that time. Whilst this did not involve divulging the content of any of the interviews, it still raised issues about how much other, general information I should clinically, and ethically, share with other clinicians.

I also found that working clinically myself with clients who had been research participants raised some dilemmas. A purist perspective on research might advocate not crossing any boundaries between what is discussed in a clinical setting and what is discussed in a research setting. However, clients themselves often referred to information that they had shared with me in one setting in another, and also expected me to remember and refer to this. Where this arose I directly discussed these issues

with the clients. Some seemed appreciative of preserving such clear-cut boundaries, although for others this appeared to be more of an arbitrary division, and one person commented on finding it strange that they had talked to the same person a few weeks previously, who then didn't immediately acknowledge some of the things that they had disclosed when they met with them again.

So, clinical psychologists are equipped with extensive research knowledge and skills and have direct access to clinical populations, which provides them with opportunities to conduct novel research that will contribute to the development of their own and other's clinical knowledge. However, the issues discussed above highlight that there may be more immediate and pragmatic issues for clinicians conducting research to consider, alongside the traditionally perceived barriers to clinical psychologists being scientist practitioners, such as simply having the time and resources to conduct research alongside their clinical work

### **Summary and implications for conducting further research**

This thesis has explored people's experiences and perceptions of a first episode of psychosis. In the literature review, the importance of conducting research into people's experiences of psychosis was highlighted and the illness perceptions model was discussed. This model would seem to offer a promising framework for exploring people's perceptions of psychosis, however, as emphasised by the few authors who have explored illness perceptions in relation to mental illnesses so far, more explorative, qualitative work is necessary in order to examine the validity of this model in relation to mental illnesses such as psychosis. The second part of this thesis

explored people's own spontaneously generated experiences of first episode psychosis, and their perceptions of these experiences. Several components of the participants' representations did appear to fit within the illness perceptions framework, although other aspects, such as stigma, and ambivalence, offered further important aspects which would need to be considered, and adapted into any illness perception measures for use with this client group. A further area for research would therefore be to consider more explicitly how to adapt the illness perceptions model to fit with the findings generated in the empirical part of this thesis.

This final part of the thesis has focused more explicitly on the issues and dilemmas that arose throughout the research process. Many tensions centred around attempts to adhere to a purist approach to the research alongside pragmatic demands inevitably made on a researcher conducting real world research, and often within a setting where the researcher is also a clinician.

The participants in this study were, for the most part, able to share thoughtful reflections on their experiences of psychosis and mental health services so far. It would certainly be worthwhile to conduct further qualitative research with this client group. It would also be interesting to compare the results of a similar study where the interviewer was a trained service user, to begin to explore some of the impacts of the principal researcher also being a clinician in a service currently used by participants.

Research with this client group, or indeed any potentially vulnerable population, is likely to require careful consideration and flexibility from the researcher. Thinking

about the language used in the interview may be important so as not to label or alienate participants. Spending time with participants both before and during the interview, and adopting a friendly and informal interview style may be important to put participants at ease and therefore contribute to obtaining good quality data. Ensuring that the research participants understand the purpose and nature of the research, as well as issues of anonymity and confidentiality is also imperative. This information may need to be repeated on more than one occasion, to ensure that potential participants have been able to understand and retain the information given to them.

Most of the participants who took part in this study were positive about being involved in research that would contribute to developing services to help people like themselves. Nevertheless, the researcher still has an ethical duty to ensure that participants are not left in any distress following the interview, and steps need to be taken to ensure that the research participants have somewhere to take any enduring questions or concerns.

The role of the researcher when conducting qualitative research with people in the early stages of psychosis may involve a more active interpretation than is the case in usual research. Given this, it is particularly important for the researcher to be aware of what values and assumptions they are bringing to their research. These may be tempered by discussion of the research with supervisors, colleagues or service users. However, human research must inevitably be a value laden tool, so the researcher can perhaps at best present details about their sample, their research procedures, the process of their analysis and provide evidence for their conclusions in the form of

participants' own quotations, and then let the reader decide for him or herself how useful the research is.

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# ***APPENDICES***

***Appendix A***

***LREC APPROVAL***

Camden and Islington   
Mental Health and Social Care Trust

Camden & Islington Community Health  
Services Local Research Ethics Committee  
Room 3/14  
Third Floor, West Wing  
St Pancras Hospital, 4 St Pancras Way  
London  
NW1 0PE

12 July 2004

Ms Joanne Billings  
Trainee Clinical  
Psychologist  
University College London  
Sub-Department of Clinical  
Health Psychology, UCL  
Gower Street, London  
WC1E 6BT

Dear Ms Billings,

***Full title of study: Making Sense of First Episode Psychosis: Personal narratives of understanding, explaining and adjusting to the onset of psychosis.***

***REC reference number:***

***Protocol number: 1***

Thank you for your letter of 10 July 2004, responding to the Committee's request for further information on the above research.

The further information has been considered on behalf of the Committee by the Chair and Dr Gill Livingston.

**Confirmation of ethical opinion**

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

The favourable opinion applies to the following research site:

Site: Camden and Islington Mental Health and Social Care Trust.

Principal Investigator: Ms Joanne Billings

**Conditions of approval**

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

## **Approved documents**

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

Document Type: Application  
Version: 1  
Dated: 11/03/2004  
Date Received: 11/03/2004

Document Type: Investigator CV  
Version:  
Dated: 11/03/2004  
Date Received: 11/03/2004

Document Type: Protocol  
Version: 1  
Dated: 28/11/2003  
Date Received: 11/03/2004

Document Type: Covering Letter  
Version:  
Dated: 10/03/2004  
Date Received: 11/03/2004

Document Type: Peer Review  
Version:  
Dated: 12/12/2003  
Date Received: 11/03/2004

Document Type: Interview Schedules/Topic Guides  
Version: 1.0  
Dated: 10/03/2004  
Date Received: 11/03/2004

Document Type: Participant Information Sheet  
Version: 2.0  
Dated: 10/07/2004  
Date Received: 12/07/2004

Document Type: Participant Consent Form  
Version: 1.0  
Dated: 10/03/2004  
Date Received: 11/03/2004

Document Type: Response to Request for Further Information  
Version: 1  
Dated: 10/07/2004  
Date Received: 12/07/2004

## **Management approval**

The study may not commence until final management approval has been confirmed by the organisation hosting the research.



***Appendix B***

***INFORMATION SHEET***

**Camden and Islington**   
Mental Health and Social Care Trust

**INFORMATION SHEET**

**Study Title: Making Sense of First Episode Psychosis**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

*Thank you for reading this.*

**Who is carrying out the research?**

A research team of staff working at University College London and Camden & Islington Mental Health and Social Care Trust.

**What is the purpose of the study?**

The purpose of this study is to find out more about the experiences and views of people who have recently been diagnosed as having had a first psychotic episode, and have come into contact with mental health services for the first time.

**Why have I been asked to take part?**

We are particularly interested in your story of your experiences so far. We have also asked the health professionals who you have had contact with if they were happy with you being approached about this study.

**Do I have to take part?**

It is up to you to decide whether or not you would like to take part. If you decide to take part you will be given this information sheet and asked to sign a consent form. If you do decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive now, or in the future.

**What will happen to me if I take part?**

You will be invited to meet with a researcher who will ask you some questions. She will probably spend around an hour with you, although the time taken really depends how much you have to say about the topics to be discussed. The interview will be arranged at a time and location most convenient to you.

Areas covered in the interview will include what led up to your current difficulties, what have been your experiences, how you have made sense of these experiences, how are you coping now, and how have you experienced your contact with mental health services so far.

In order to record peoples' responses accurately and to assist with analysis of the information obtained, we will need to record all the interviews on audio-tape. The audio-tapes will then be transcribed. All the tapes and transcripts will be anonymised, so you will not be identifiable from either. The tapes and transcripts will be held by the research team at the Early Intervention Service base, and will not at any stage be available to anyone outside of the research group. Once the research report has been completed, all the audio-tapes will be destroyed.

You may stop the interview at any time, without giving any reason, without your medical care or legal rights being affected.

### **What are the possible benefits of taking part?**

We will pay you £10 in acknowledgement for your time given up to take part in this research.

The information gained from the study will also be used to inform the development of mental health services, like the Camden & Islington Early Intervention Service, to help people like yourself in the future.

### **What are the possible disadvantages of taking part?**

Many people feel it is helpful to talk about their experiences, however some people may find discussing some aspects of their personal experience distressing. If you find any topic upsetting and you wish to pause or stop the interview at any point you will be free to do so.

### **What happens to the results of the research study?**

The information collected will be anonymised and written up in a report. The report will not contain any personal information from which you could be identified. The results may also be published in a journal read by people planning and researching mental health services. If you are interested in the study, a copy of the report will be made available to all participants and service users.

### **What if I am unhappy with the research?**

If you have any concerns about the way you have been treated during the course of the research, the research team will of course be very happy to discuss this with you. Their contact details are below. If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should also be available to you.

### **Will my taking part be kept confidential?**

All information that is collected about you during the course of the research will be kept strictly confidential. No information identifying you in any way will leave the Early Intervention Service building. When we report on the research, it will not be in any way possible to identify you from the report.

The only limit to confidentiality would be if during the course of the interview, you were to say something that led the researcher to believe that you may be in danger of placing yourself, or those around you, at serious risk of harm. In this case the researcher would be required to inform the Early Intervention team immediately.

**Who has reviewed the study?**

The study has been reviewed by Camden & Islington Community Health Services Local Research Ethics Committee.

**Contact for further information:**

If you require any further information or have any questions not answered by this information sheet, or if you have any comments or concerns, please do not hesitate to contact a member of the research team.

The research team are:

**Ms Joanne Billings**

Trainee Clinical Psychologist, University College London, Gower Street, London, WC1E 6BT.

**Dr Sonia Johnson**

Consultant Psychiatrist & Senior Lecturer, University College London

**Ms Kate Theodore**

Research & Audit Worker, University College London

***Thank you for taking part in this study***

***Appendix C***

***CONSENT FORM***

Camden and Islington **NHS**  
Mental Health and Social Care Trust

Participant Identification Number: .....

Date: .....

**CONSENT FORM**

**Research Project: Making Sense of First Episode Psychosis**

Please tick box

- 1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
- 3. I understand that sections of my medical notes may be looked at by the research team. I give permission for these individuals to have access to my records
- 4. I agree to take part in the above study.
- 5. I agree to the tape recording of the interview.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

1 for participant; 1 for researcher; 1 for file

## ***Appendix D***

### ***INTERVIEW SCHEDULE***

## Interview Guide

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- Intros & warm up
  - Purpose and nature of interview
  - Confidentiality, anonymity and use of info
  - Tape recording
- 

### 1. Onset

*Going right back to the beginning, can you tell me about when you first noticed that something was going on, and what you thought was happening?*

- What kind of difficulties did you have?
- At the time, what did you think was happening/how did you explain it?
- Did you talk to anyone else about what you were experiencing?
- What did they think?
- How did you try and cope?
- What made it better/worse?

### 2. Early experiences of help seeking

*When you first noticed these problems, what did you do, if anything, to get help?*

- Who did you see? (e.g. GP, psychiatrist, school etc)
  - What happened?
  - What was it like to see this person/people?
- What was helpful/unhelpful?
- What if anything, were you told about what was happening to you?
  - What did you think of this?
- Was there anyone else you thought of seeing?

### 3. Early experiences of treatment

*What types of help did you receive initially and what was that like for you?*

- What sort of services did you have contact with initially? (e.g. hospital admission, crisis team intervention etc.)
  - What was this like for you?
- What was your understanding of these services?
- What did they say to you about what was going on?
  - What did you think about this?
- What was helpful/unhelpful?

### 4. First contact with specialist EI service

*Can you remember back to when you first met the people from the team here. What happened, and what was that like for you?*

- When did you first come into contact with the team here?
  - What happened?
  - What was this like for you?
- What was your understanding of what this service was about?
- What did they say to you about what was going on?
  - What did you think about this?
  - Did you find the way things were explained helpful?

- What specific types of help have you been offered so far?
- What did you think of this/these?
- What have been the best/worst things about being involved with this team?
- Is there any other help that you would have liked but didn't get?
- Do you think you'll stay in touch with mental health services in the future? Why?

## 5. Current perceptions of illness

*Looking back now, what would you say about the experiences you've had and what sense have you managed to make of them?*

- What would you say were the causes of the problems you've been experiencing?
- Have you spoken to anyone or read anything useful that's helped you understand what's going on?
- What impact have these experiences had on your life currently?
- What do you think the consequences of having gone through this might be for you in the future?
- What do you think the consequences might be of having been in contact with mental health services?
- Have there been any good things about going through these experiences?
- Do you think you might go through experiences like this again in the future?
- How much control do you think you potentially have over these experiences?
- How much do you think the treatments you've been offered can help you control these experiences?
- How much do you feel like you now understand the experiences you've been through?
  - What parts make sense to you/what parts don't make sense?

## 6. Current perceptions of services

*Looking back now, what would you say about the experiences you've had so far of mental health services, and overall what do you think about them?*

- Was having contact with mental health services like you thought it might be?
  - In what ways was it like/different from how you thought it would be?
- What did you think people in contact with mental health services would be like?
  - How do you think about them now?
- Do you think the people you're working with share the same ideas as you about
  - What these experiences are about?
  - What can be done about them?
- If you could design your own service, to help people like yourself, what would it be like?
  - What makes you think that those kinds of things would help you?
  - In what ways is this similar/different from what you're getting at the moment?
- Can you think of anything else at all that could have made it easier for you, or people like you, to get help?

**THANK YOU**

***Appendix E***

***INTERVIEW EXCERPTS***

### Except from Interview with Participant 1

INT: Interviewer

P1: Interviewee

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INT: Ok I wonder if we could think right back to the beginning, and tell me about when you first noticed that something was going on, and what you thought was happening at the time.

P1: Ok um well say I first started to notice things weren't particularly right from about, probably about October, November of last year, um, at the time I was in college and I was working and I was doing extra curricular activities outside of the college and I just noticed that I was feeling pretty down and my thoughts were, not how they used to be, sometimes they would go fast, sometimes they would slow down, you know, I would feel, I don't know how to, its really, its so hard, I've been asked this so many times it's really hard to sort of try and break it down but I could tell that being me, myself, I wasn't you know, how I was before cos I'm usually quite a happy person, sociable, but all of a sudden I was just sort of very withdrawn and very stressed and you know, very, very much stressed and you know, I would think to myself, well, what is you know, what's the problem but I didn't really look at it, I didn't really go into it you know, I just thought that's just normal everyday life you know what I mean, um and then things, stuff like having more arguments with my mum, our relationship wasn't how it used to be that's another thing I kind of noticed but you know, being a teenager you just expect that's just a normal thing really, um and yeah, that was pretty much what I kind of noticed around that time you know those kind of things yeah, yeah.

INT: So at that time what did you think was happening? How did you explain those changes in behaviour?

P1: Um, see the thing is, I couldn't really explain these things cos I just thought they was just normal for me you know just a little phase you know, I couldn't, I mean I didn't really think anything of it, I couldn't really, I don't know, I just thought it was just normal really there's nothing I kind of, didn't think anything otherwise you know

INT: And did you talk to anyone at the time about how you were feeling?

P1: Um I did speak to one friend um I mean she my close friend anyway, I'd tell her that I had an argument with my mum, she's so this she's so that, and um I'm finding it stressful at work, I'm trying to, its stressful at work with all the overtime I'm doing and the hours that I'm doing and you know, I'm finding a lot of the courses that I'm doing quite stressful and you know, I'll just have a little natter with her and she'll tell me like you know how she's stressed out but she didn't have an idea of where this was heading and I didn't have an idea at all, just general conversation really, but I think I started to speak about it to my friend and then with my mum it was a bit difficult because as I said we will have, we would argue quite a lot. I tend to be very snappy, irritable and um, I mean, when I spoke to my mum I was just sort of saying things like mum, you know, I'm stressed, I can't be bothered to do this work and Waitrose, I used to work in Waitrose, um, this is you know, this is getting a little bit too much for me, they won't reduce my hours because they have some sort of system going on there where they couldn't reduce my hours or whatever and you know, she would, she would, she did you know, try and phone them to see if they could sort it out for me but, you know, like I said, nothing, I didn't really think any further to you know from that I thought you know its just stress, teenage life, you know what I mean, my mum had no other thoughts about it so it was just one of those things

INT: So at that stage your mum didn't think there was anything particularly wrong?

P1: No, not at all not at all

INT: Ok, so how did you try and cope with how you were feeling at that time?

P1: Um, I don't think I coped really well obviously, um, I just kind of carried on really, just doing what I was doing, stressing myself out further, just ignoring how I was feeling, just getting on with it you know, I just got on with things, just carried on and just hoped for the best that's basically all I was doing you know

INT: So you put it down to stress and you just got on with things

P1: Basically

INT: and just hoped it would work itself out

P1: pretty much, yeah, yeah

### Except from Interview with Participant 11

INT: Interviewer

P11: Interviewee

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INT: Can you think right back to the beginning, when you first noticed something was going on, and what did you think was happening at the time?

P11: Yeah, it was at my hostel and I was being treated unfairly and um, I thought something odd was going on because everything didn't make sense, like the way they were treating me, the way they were treating other women. So instead of getting upset and angry like I normally would have, I had a laugh about it and started drinking more than I usually do to try and block out the kind of facts that I wasn't going to get this settled seemingly I thought. So, um, which is from then and I started talking to myself, just to clear the air about what was happening in the hostel, so some of the doctors said to me when I got in touch with them, do I hear voices in my head, and I denied it because I thought that, you know, they're going to send me somewhere and keep me there for a long time, because they think something's wrong with me, so I kind of denied it but I didn't actually hear voices in my head, it was just um, just messages coming through and also, I just felt upset about my housing situation. So there was nothing really, that was going on at that time, but the first time I came into hospital I was scared because I listened to the radio a lot and I really thought that something was going to happen to me, but obviously it didn't.

INT: What did you think was going to happen?

P11: I thought I might be killed or might be impregnated with something. I don't know why I thought that at the time, but I think that, I thought of some films and that take over, some sort of conspiracy or something. So my thoughts were a bit all over the place at that time.

INT: That was just before you came into hospital the first time?

P11: The first time, yeah.

INT: You said the doctors asked you about whether you heard voices, did you go and see the doctor, did you ask for help?

P11 No, I didn't go and ask for help, he came to me but I denied hearing voices in my head because I didn't actually hear. You know that advert when you hear someone talking to them in their head, it wasn't like that.

INT: So who called the doctor do you think?

P11: Um, the people at my hostel, because I would talk to myself for hours and they were scared. So they were worried about me so they put the doctors on to me but I ran away and when they came down I just run away. But they caught up with me later and brought me in. I was drinking a lot of alcohol at the time, I didn't think it was that healthy of me to be drinking like that but I just carried on because it was affecting the neighbours as well, the neighbours were getting really upset about it, so that's why I, but I got discharged early, nothing was really explained to me by the doctors, nothing was really like, said that you are having a breakdown, I was pretty much left on my own to work it all out that I was actually having a breakdown.

INT: Did you know why you were in hospital?

P11: No, not really. All I knew is that I was talking a lot to myself and I thought some of the things I was saying was a bit about evil and um, I was actually talking about the system, how unfair it is and everything. So I thought it had something to do with that at first, I didn't actually think that there were people there to help me because I was having a breakdown. It was scary those times. I got discharged early, so I was happy about that but.

INT: And at that point you still weren't very sure about what had happened?

P11: No I still wasn't sure.

INT: Was there anyone you talked to about what you were going through and how you were feeling?

P11: Um, no. I didn't really have anyone to talk to at that time. What happened, why I felt like that. I did have a doctor but all they were saying was I hearing voices in my head and as soon as I heard that I thought no, I don't want to talk about nothing but I think I wasn't able to talk about anything because things weren't clear in my head. So things weren't clear in my head myself so I don't know how I could have sat down and been able to talk about it.

## ***Appendix F***

### ***ANALYSIS STAGE 1***

## IPA ANALYSIS STAGE 1

### Extract from Interview 1

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<ul style="list-style-type: none"> <li>▪ Things not particularly right</li> <li>▪ College, working, extra curricular activities</li> <li>▪ Feeling pretty down</li> <li>▪ Thoughts not how they used to be</li> <li>▪ Thoughts – different pace</li> <li>▪ Hard to break it down</li> <li>▪ Not myself</li> <li>▪ Withdrawn &amp; stressed</li> <li>▪ Think to myself, what’s the problem</li> <li>▪ Didn’t really look at it/want to go into it</li> <li>▪ Just normal everyday life</li> <li>▪ Arguments with mum</li> <li>▪ Relationships changed</li> <li>▪ Just normal for a teenager</li> </ul>	<p>P1: Ok um well say I first started to notice things weren’t particularly right from about, probably about October, November of last year, um, at the time I was in college and I was working and I was doing extra curricular activities outside of the college and I just noticed that I was feeling pretty down and my thoughts were, not how they used to be, sometimes they would go fast, sometimes they would slow down, you know, I would feel, I don’t know how to, its really, its so hard, I’ve been asked this so many times it’s really hard to sort of try and break it down but I could tell that being me, myself, I wasn’t you know, how I was before cos I’m usually quite a happy person, sociable, but all of a sudden I was just sort of very withdrawn and very stressed and you know, very, very much stressed and you know, I would think to myself, well, what is you know, what’s the problem but I didn’t really look at it, I didn’t really go into it you know, I just thought that’s just normal everyday life you know what I mean, um and then things, stuff like having more arguments with my mum, our relationship wasn’t how it used to be that’s another thing I kind of noticed but you know, being a teenager you just expect that’s just a normal thing really, um and yeah, that was pretty much what I kind of noticed around that time you know those kind of things yeah, yeah.</p>
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### Extract from Interview 11

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<ul style="list-style-type: none"> <li>▪ Didn’t have anyone to talk to</li> <li>▪ Doctors focusing on symptoms</li> <li>▪ Stigma of hearing voices</li> <li>▪ Scared to talk to doctors about voices</li> <li>▪ Things not clear in my head, so not able to talk to others</li> </ul>	<p>P11: Um, no. I didn't really have anyone to talk to at that time. What happened, why I felt like that. I did have a doctor but all they were saying was I hearing voices in my head and as soon as I heard that I thought no, I don't want to talk about nothing but I think I wasn't able to talk about anything because things weren't clear in my head. So things weren't clear in my head myself so I don't know how I could have sat down and been able to talk about it.</p>
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## ***Appendix G***

### ***ANALYSIS STAGE 2***

## IPA ANALYSIS STAGE 2

### Extract from Interview 1

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P1: Ok um well say I first started to notice things weren't particularly right from about, probably about October, November of last year, um, at the time I was in college and I was working and I was doing extra curricular activities outside of the college and I just noticed that I was feeling pretty down and my thoughts were, not how they used to be, sometimes they would go fast, sometimes they would slow down, you know, I would feel, I don't know how to, its really, its so hard, I've been asked this so many times it's really hard to sort of try and break it down but I could tell that being me, myself, I wasn't you know, how I was before cos I'm usually quite a happy person, sociable, but all of a sudden I was just sort of very withdrawn and very stressed and you know, very, very much stressed and you know, I would think to myself, well, what is you know, what's the problem but I didn't really look at it, I didn't really go into it you know, I just thought that's just normal everyday life you know what I mean, um and then things, stuff like having more arguments with my mum, our relationship wasn't how it used to be that's another thing I kind of noticed but you know, being a teenager you just expect that's just a normal thing really, um and yeah, that was pretty much what I kind of noticed around that time you know those kind of things yeah, yeah.

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- Aware something wrong
- Stress
- Feeling down
- Thoughts changed
- Hard to break it down now
- Not myself
- Withdrawn & stressed
- What's wrong vs not wanting to go into it
- Normalising
- Normalising - teenage life

### Extract from Interview 11

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P11: Um, no. I didn't really have anyone to talk to at that time. What happened, why I felt like that. I did have a doctor but all they were saying was I hearing voices in my head and as soon as I heard that I thought no, I don't want to talk about nothing but I think I wasn't able to talk about anything because things weren't clear in my head. So things weren't clear in my head myself so I don't know how I could have sat down and been able to talk about it.

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- No-one to talk to
- Scared
- Stigma
- Can't make sense of it
- Want explanations vs difficult to talk about it

## ***Appendix H***

### ***ANALYSIS STAGE 3***

### IPA ANALYSIS STAGE 3

#### Extract from Interview 1

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P1: Ok um well say I first started to notice things weren't particularly right from about, probably about October, November of last year, um, at the time I was in college and I was working and I was doing extra curricular activities outside of the college and I just noticed that I was feeling pretty down and my thoughts were, not how they used to be, sometimes they would go fast, sometimes they would slow down, you know, I would feel, I don't know how to, its really, its so hard, I've been asked this so many times it's really hard to sort of try and break it down but I could tell that being me, myself, I wasn't you know, how I was before cos I'm usually quite a happy person, sociable, but all of a sudden I was just sort of very withdrawn and very stressed and you know, very, very much stressed and you know, I would think to myself, well, what is you know, what's the problem but I didn't really look at it, I didn't really go into it you know, I just thought that's just normal everyday life you know what I mean, um and then things, stuff like having more arguments with my mum, our relationship wasn't how it used to be that's another thing I kind of noticed but you know, being a teenager you just expect that's just a normal thing really, um and yeah, that was pretty much what I kind of noticed around that time you know those kind of things yeah, yeah.

**Theme 3: What's going on?**

**Theme 2: This can't be happening to me: normalising, minimising and denial**

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#### Extract from Interview 11

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P11: Um, no. I didn't really have anyone to talk to at that time. What happened, why I felt like that. I did have a doctor but all they were saying was I hearing voices in my head and as soon as I heard that I thought no, I don't want to talk about nothing but I think I wasn't able to talk about anything because things weren't clear in my head. So things weren't clear in my head myself so I don't know how I could have sat down and been able to talk about it.

**Theme 4: Where am I? Confusion and uncertainty**

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## STAGE 3 CONT.

**Extracts Coded Under Theme 2: This can't be happening to me: normalising, minimising and denial****P1**

P1: I would think to myself, well, what is you know, what's the problem but I didn't really look at it, I didn't really go into it you know, I just thought that's just normal everyday life you know what I mean, um and then things, stuff like having more arguments with my mum, our relationship wasn't how it used to be that's another thing I kind of noticed but you know, being a teenager you just expect that's just a normal thing really, um and yeah, that was pretty much what I kind of noticed around that time you know those kind of things yeah, yeah.

P1: Um I did speak to one friend um I mean she my close friend anyway I'd tell her that I had an argument with my mum she's so this she's so that and um I'm finding it stressful at work I'm trying to its stressful at work with all the overtime I'm doing and the hours that I'm doing and you know I'm finding a lot of the courses that I'm doing quite stressful and you know I'll just have a little natter with her and she'll tell me like you know how she's stressed out but she didn't have an idea of where this was heading and I didn't have an idea at all just general conversation really

P1: Um I don't think I coped really well obviously um I just kind of carried on really just doing what I was doing stressing myself out further just ignoring how I was feeling just getting on with it you know, I just got on with things, just carried on and just hoped for the best, that's basically all I was doing you know

P1: Um see the thing is I couldn't really explain these things cos I just thought they was just normal for me you know just a little phase you know, I couldn't, I mean I didn't really think anything of it I couldn't really, I don't know I just thought it was just normal really, there's nothing I kind of, didn't think anything otherwise you know

P1: it was a bit difficult because as I said we will have we would argue quite a lot, I tend to be very snappy, irritable, and um, I mean when I spoke to my mum I was just sort of saying things like, mum, you know, I'm stressed, I can't be bothered to do this work and, Waitrose I used to work in Waitrose, um, this is you know, this is getting a little bit too much for me, they won't reduce my hours because they have some sort of system going on there where they couldn't reduce my hours or whatever and you know, she would, she would, she did you know, try and phone them to see if they could sort it out for me but, you know, like I said, nothing, I didn't really think any further to you know, from that I thought you know, its just stress, teenage life you know what I mean, my mum had no other thoughts about it, so it was just one of those things

P1: to the GP yeah, I went to the GP on my own and um, you know, my mum didn't say anything but my brother phoned, she phoned my brother, and he phoned me and asked me, you know, what's going on where are you, why are you at the doctors sort of thing, and um, I explained the whole story and he wasn't happy with me whatsoever he said to me why did you come home late, blah, blah, blah, blah, blaming it on me, and so anyway he told me you know what, don't see the doctor just come home so I came home now

**P13**

P13: I thought I was just, getting uptight about things, stressed cos I wasn't, I don't think I was working at the time, I was just looking after the kids

**P14**

P14: normal just happier, I didn't feel like I was ill and I don't think anyone around me thought I was ill they just thought I was in a good mood. We just did the whole holiday thing, shopping and touristy stuff

**P16**

P16: What's been happening is my medicine has been upped because I'm stressed, I'm very stressed thinking about my baby

**P3**

P3: yes, I talked to one, a good friend of mine, but the problem was I had sleeping problems and my friend said that a person has a tendency to have hallucinations if he or she doesn't have enough sleep and so I didn't go to the doctor because I thought that these problems were occurring because I had little sleep and so I thought that if I had enough sleep they would just disappear, and secondly, I was so busy and in my university, it just takes time to arrange an appointment and it's such a hassle I thought, I'm so busy I'll just wait until it passes and I won't seek medical help and, unless it was very, very necessary, so in a way I was in this vicious cycle, I was too busy to really stop and think what was going on and the biggest problem with me was because these voices were a continuation of real life situations, so for me it was really hard to make sense of what was going on.

**P6**

P6: I, to be honest, I couldn't really explain it to myself, it was more, it just felt so bad that it was not possible to explain it to myself that err, you know, that something was wrong, even though there was, um, it just felt like normal life really