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# **Volume 1**

## **Patient as Partner: Therapeutic Information Provision for People Suffering with Severe Mental Health Problems**

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## **ABSTRACT**

Few short-term psychosocial interventions have been devised for people in the acute stages of psychosis. The studies on psychoeducation for people with psychosis have focused on those in the chronic stages of illness. There is, however, increasing evidence to suggest that it is possible to intervene early in the course of a psychotic episode.

This study aims to assess the utility of a personalised psychoeducation package with a group of 16 inpatients diagnosed with acute psychosis. The scores of each participant were compared at three time points: prior to the intervention; post intervention and at six weeks follow-up. The five main areas assessed for change were: psychiatric symptomatology; insight; illness representations; compliance; and satisfaction.

There was evidence that this approach, together with routine care, may augment changes in psychiatric symptoms as measured by the Brief Psychiatric Rating Scale and the Brief Symptom Inventory. The findings of the study indicate that of those available for data collection, 46.15% significantly improved on Unusual Thought Content; 38.46% on Conceptual Disorganisation; and 38.46% on Paranoid Ideation. All change data was analysed using the Reliable Change Index.

In addition, the findings show that approximately 50% of the participants improved on at least one area of insight, as measured by the Scale to Assess Unawareness of Mental Disorder. The dimensions of insight measured



included awareness of having a mental disorder (53.85% of the participants available for data collection improved); awareness of the achieved effects of medication (46.15% improved); and awareness of the social consequences of having a mental disorder (53.85% improved). Approximately one third of participants improved and a further third deteriorated on one of the four illness representations measured using the Illness Perceptions Questionnaire-Revised. These included Consequences, Personal Control, Treatment Control and Illness Coherence. Only one participant improved on compliance with treatment, as operationalised for the purpose of this study. The majority of participants (78.57%) reported satisfaction with their care, as measured by the UKU-ConSat.

The useful elements of this psychoeducation package appear to be an individualised approach, a collaborative therapist-patient relationship and a brief number of sessions. These seem to allow participants to learn active means of controlling their illness.

This study is a useful preliminary investigation of a new personalised psychoeducation package for participants in the acute stages of psychosis. A larger scale randomised controlled trial, utilising a more robust design is advocated.

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For Jonny

## 1.0 INTRODUCTION

Psychosis is a confusing and frightening experience<sup>1</sup>. People with psychosis develop an alternative reality that can isolate them from society. Historically, medication has been the therapy of choice for treating psychosis. However, in recent times, more emphasis has been placed on interventions focusing on information provision.

*“...man does have a need to know, and more than that, a need to understand” (Maslow, 1963, p. 111).*

Maslow's (1963) general view that people have a desire and also a right to understand their conditions has been an important foundation for several therapeutic approaches. People with psychosis may believe that they both know and understand their experiences, however, this is often clouded by complex delusional systems. Specific guidance is required to inform these people of their illness and allow them to develop means of coping. This study has considered methods of helping people with psychosis to reappraise their views of illness and reconsider their beliefs and choices that can lead to maladaptive behaviours.

Yalom (1975) suggested that useful explanations of behaviour and illness are those that seem credible to the patient. He argued in favour of a “believable story” for each patient and stressed that conceptualisations of the patient's

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<sup>1</sup> The term “psychosis” will be used in the singular throughout this thesis. However, it refers to a range of psychotic disorders, including Schizophrenia, Brief Psychotic Disorder, Psychotic Disorder Not Otherwise Specified, amongst others. Please see DSM-IV (American Psychological Association, 1994) for further information.

situation should be tailored for each individual. These are only useful if the patient can identify his or her own experiences within the ideas being suggested. Furthermore, Yalom stated that complicated interpretations are not useful if the patient cannot comprehend them or connect them with his or her own experiences and thoughts. This study aimed to incorporate some of Yalom's ideas by taking into account the participants' perspectives of their experiences before offering a "credible alternative".

As has been highlighted above, it is not just the delivery of information that is important. There is a necessity to present a personalised account of the idiographic experiences of each patient. This study has created a brief intervention for patients with acute psychosis. It aimed to help them to not only know about psychosis, but to understand their own psychotic experiences. Furthermore, it attempted to provide them with ways in which they could control their illnesses and build for the future.

This Introduction is divided into five sections. The first will consider the biopsychosocial model of psychosis. The second will discuss the concept of "Patient as Partner". The third section will review the research on psychoeducation, including a number of outcome variables and factors when administering this type of treatment package. The fourth section will consider the use of a model of Health Psychology to understand patients' conceptualisations of having psychosis and the impact that this may have on treatment. Finally, the fifth section will relate the research discussed to a new personalised psychoeducation package that was designed for this study and

outline the research questions. This Introduction will not provide an exhaustive review of all literature related to psychoeducation for people with psychosis, but will consider the research relevant to this study.

### **1.1 What is Psychosis? – A Biopsychosocial Model**

Schizophrenia, the most common psychotic disorder, is defined in DSM-IV (American Psychological Association, 1994) as two or more symptoms persisting for at least six months. Symptoms include: delusions, hallucinations, disorganised behaviour, catatonic behaviour and/or negative symptoms (e.g. anhedonia and apathy). In addition, DSM-IV stipulates that symptoms must affect the individual's functioning in areas of work, social contact and self-care.

It is interesting to note that the DSM-IV criteria do not only include the medical view of the symptoms required to meet a diagnosis, but also consider the psychosocial functioning of the individual. This view is known as the 'Biopsychosocial Model' and was originally introduced by Engel (1977):

*"Boundaries between well and sick are not clear and never will be clear, for they are diffused by cultural, social and psychological considerations" (p.129).*

The Biopsychosocial Model takes an idiographic perspective of the individual's experience of the illness. It is defined as the impact of the biological changes on the person's psychological and social functioning. In

the case of psychosis, an individual may have a genetic predisposition to develop the illness. When activated, there are significant changes in the person's belief systems and interaction with others. The biopsychosocial model therefore takes a holistic perspective of the effects of an illness on all areas of a person's functioning.

It could be argued that this model is useful not only to gather a full assessment, but also in targeting interventions. However, within the field of psychosis, psychosocial interventions have been somewhat neglected and patients are treated primarily with medication (Goldberg & Huxley, 1992). Although drug therapy is imperative in managing the symptoms of psychosis, there has been limited and inconclusive research on psychosocial interventions (as will be described in detail below). This study aimed to develop a useful psychoeducation package that may be used as an adjunct to medication.

## **1.2 Patient as Partner**

The National Institute of Clinical Excellence (NICE), a government body, has outlined guidelines of care for various conditions. In 2002, a document regarding the care of people with Schizophrenia was published. It emphasised the importance of providing individuals with "clear and intelligible information" about Schizophrenia and its possible causes (guideline 1.1.4.2). It also stated,

*“The provision of information is essential to routine treatment and management of Schizophrenia” (Guideline 1.1.6.1).*

The timing of the provision of information was suggested to be “towards the end of the acute episode of Schizophrenia”. This had the intention of allowing patients to recover from the most severe symptoms in order that they would be more able to attend to the information delivered than when they were acutely ill. It also had the purpose of intervening sufficiently early to minimise the development of hopelessness regarding the future. The guidelines were devised with the aims of lessening the disability caused by Schizophrenia by instilling hope for the future and helping patients to reintegrate back into society; reducing risk of relapse by increasing insight into illness; and improving quality of life. In particular, the guidelines stated that local resources and services should be identified and the individual should be offered advice about drug treatments (guideline 1.3.3).

The process by which this information should be disseminated to individuals with Schizophrenia remains unclear. As is noted in the review below, much of the research on psychoeducation for people with psychosis has indicated that although knowledge increases, insight and treatment compliance have not been shown to consistently improve.

### **1.3 Psychoeducation**

Psychoeducation for people with severe mental illness is a broad, ill-defined term. It has been used to refer to a number of different approaches, including



education packages for families, behavioural management programmes and social skills training. This has made comparisons between different studies difficult (Gibbons, Hogan & McGauran, 1999). Glick, Burti, Okonogi and Sacks (1994) stated,

*“Psychoeducation as a technique in clinical practice can be defined as the systemic administration by the physician of information about symptoms, aetiology, treatment and course, with the goals of increasing understanding and changing behaviour” (p. 104).*

Often, psychoeducation has been referred to as an educational package aimed at providing information with regards to the aetiology of Schizophrenia, neuroleptic medication and relapse prevention (e.g. Smith, Birchwood & Haddrell, 1992; Atkinson, Coia, Gilmour & Harper, 1996). Studies of psychoeducation expect increases in the participants' knowledge of psychosis, compliance with medication, insight, social functioning, quality of life and satisfaction. Decreases in outcome measures of psychiatric symptomatology and relapse rates are expected, although the mechanisms involved in this decrease are not yet understood. If psychoeducation were found to be effective for people with psychosis, it would be a useful and inexpensive addition to medication treatment.

Merinder (2000) conducted a review of studies of psychoeducation for people with psychosis. There were three categories of studies: randomised controlled trials (RCTs) involving people with Schizophrenia only; naturalistic

(i.e. non-RCTs) of people with Schizophrenia; and RCTs of patients from mixed psychotic populations. The review excluded studies involving complex interventions of social skills training; interventions aimed at families alone; naturalistic studies of mixed psychotic samples; and those studies that used ill-defined outcome measures. This is a useful review of patient education programmes and will be referred to on several occasions throughout this Introduction.

Merinder (2000) noted that most studies demonstrated that knowledge could be improved by educational intervention. However, it was not possible to conduct a meta-analysis because there was a low number of methodologically sound studies; many studies did not provide sufficient details of the psychoeducation package used; and a wide range of outcome measures were used. In an earlier study, Merinder et al. (1999) stated that the few psychoeducation studies that have been published used a variety of interventions, outcome measures and follow-up periods. Furthermore, flaws in the research designs compromised the validity and generalisability of these studies. These included a lack of randomisation and the use of non-validated assessment instruments (Merinder et al., 1999).

In Merinder's (2000) review, of the 19 studies included, 14 were based on group interventions and the remaining 5 were based on individualised programmes. The sessions used a range of outcome variables, including knowledge, medication compliance, insight, satisfaction and level of symptomatology.

In summary, different researchers have used varying definitions of psychoeducation and have delivered education to patients in a range of ways. However, the outcome measure that has been consistently found to improve following psychoeducation is knowledge (e.g. Smith et al., 1992). These authors reported that knowledge gains following a psychoeducation programme allowed participants to normalise their experiences. Furthermore, participants were able to gain knowledge of coping strategies. Smith et al. concluded that despite an increase in knowledge, it was not clear whether participants were able to apply this information to their own personal circumstances. The clinical relevance of an increase in knowledge is therefore debatable. Below is a review of a number of other outcome measures following psychoeducation programmes.

#### 1.3.1 Psychoeducation and symptomatology

The links between symptom change and psychoeducation are unclear. In a review, Merinder (2000) mentioned five studies (written in English) that have measured symptom changes following psychoeducation. Of the five studies, two found a change in symptomatology (Goldman & Quinn, 1988; Kelly & Scott, 1990) and three found no change following a psychoeducation programme (Atkinson et al., 1996; Merinder et al., 1999; Browne et al., 1996). Each of these studies is detailed below.

#### 1.3.1.1

#### *Studies finding change in symptomatology following psychoeducation*

Goldman and Quinn (1988) conducted the first randomised controlled trial to study the effect of psychoeducation on variables other than knowledge. All participants had a diagnosis of Schizophrenia. They measured positive and negative symptoms in a sample of inpatients before and after an intensive three-week group programme. They found that the intervention group had significantly fewer negative symptoms following the programme than the controls, although positive symptom levels remained unchanged.

The authors hypothesised that psychoeducation served to improve participants' self-esteem and reduced the fear caused by symptoms. Furthermore, they suggested that the provision of practical ideas regarding resources increased hope for the future. These aspects of psychoeducation may have led to a decrease of negative symptoms.

However, the authors highlighted a number of limitations, which prevented generalisability of the findings. These included significant differences between the intervention and control groups in terms of gender and knowledge about Schizophrenia at baseline. Moreover, they did not measure long-term effects of the programme. As changes were found in negative symptoms and not positive symptoms, the authors concluded that different psychopathological processes are involved in the development of each symptom group.

The other study mentioned by Merinder (2000) that found change in symptoms following psychoeducation was that of Kelly and Scott (1990). They conducted a four-year trial that involved 418 outpatients with varying diagnoses of psychosis. Each participant underwent a six-month course of psychoeducation. This study aimed to develop “individualised compliance plans” in order to overcome the idiosyncratic problems of treatment compliance as identified by the individual’s family members and the researcher. Participants were either seen at home, at the clinic or both at home and the clinic and results were compared with that of a control group who received treatment as usual. Measures of psychiatric symptomatology were taken pre-intervention and at six months follow-up. This study found significantly lower scores for depression, paranoid ideation, psychoticism and Schizophrenia in all intervention groups when compared to the control group.

Kelly and Scott (1990) noted that the study was limited by a large drop-out rate of 35% of the sample at follow-up. Many of the participants who did not complete the programme had co-morbid diagnoses of alcohol and substance misuse. Kelly and Scott stated that the results of the study must therefore be restricted to patients without these co-diagnoses. Perhaps these results are indicative of a need to treat alcohol and substance misuse prior to providing information regarding psychosis.

In summary, both Goldman and Quinn (1988) and Kelly and Scott (1990) found decreases in levels of psychiatric symptomatology following a course of psychoeducation. However, the samples were different: Goldman and

Quinn used psychiatric inpatients suffering from Schizophrenia and Kelly and Scott used outpatients with a range of psychotic disorders. Furthermore, the content of the packages was different: Goldman and Quinn focused on knowledge about the illness and Kelly and Scott individualised their programmes with the aim of improving treatment compliance. The designs of the studies were also different as Kelly and Scott (1990) had a six-month follow-up phase, whereas Goldman and Quinn (1988) had no follow-up period.

In terms of positive and negative symptoms, Goldman and Quinn (1988) found changes in negative symptoms only, whereas Kelly and Scott (1990) found changes in both positive and negative symptoms. However, Kelly and Scott used briefer measures of symptomatology (Brief Symptom Inventory, Derogatis & Spencer, 1982 and the Schizophrenia Symptom Severity Scale, which has not been published. The latter is a self-report 14-item scale).

Goldman and Quinn used more comprehensive scales (Experiential World Inventory - EWI, El-Meligi & Osmond, 1970; Scale for the Assessment of Negative Symptoms - SANS, Andreasen, 1983). The EWI is a 400-item self-report measure used to assess distress, but Goldman and Quinn (1988) reported that it mainly measured positive symptomatology. The SANS is a well-researched and widely used tool to assess negative symptoms.

As can be seen, due to the differences in samples, measures, designs and interventions, it is not possible to conclude that psychoeducation packages for people with psychosis reduce psychiatric symptomatology.

1.3.1.2      Studies finding no change in symptomatology following psychoeducation

Atkinson et al. (1996) studied a sample of 146 outpatients with Schizophrenia. They randomly allocated the participants to either a psychoeducation group or a control group, which ran a placebo intervention. The intervention lasted for 20 weeks. Sessions alternated between providing information about Schizophrenia and problem solving. Participants' symptomatology was measured using the Brief Psychiatric Rating Scale - BPRS (Overall & Gorham, 1962). Measures were repeated pre-test, post-test and at nine months follow-up. The authors found no significant differences between groups at any of the time points.

Browne et al. (1996) conducted a study of 19 patients in a rehabilitation programme. They all met criteria for Schizophrenia and volunteered to participate in the study. The programme was of 16 weeks duration and involved education about Schizophrenia with particular emphasis placed on medication compliance and the prodromal signs of relapse. Psychiatric symptomatology was measured using the SANS and the Scale for the Assessment of Positive Symptoms – SAPS (Andreasen, 1984). Pre and post-test measures were used and there was no follow-up assessment. The authors found no significant differences in scores on SANS or SAPS. The limitations of the study were that there was a small sample size and the groups differed significantly in age and duration of illness. All participants had volunteered to participate in the study. The authors suggested that the results might have therefore been biased towards those with a good prognosis. They

offered no suggestion regarding the lack of change in levels of symptomatology. It may have been that the period of assessment (i.e. 16 weeks) was too short to have found a change in symptomatology. Perhaps a follow-up assessment would have found different results.

The final study not to have found symptom change mentioned in the review by Merinder (2000) is that of Merinder et al. (1999). This was a randomised controlled trial of an eight-session psychoeducation programme for 23 inpatients with Schizophrenia. Psychiatric symptoms were measured using the BPRS. Measures were repeated pre-test, post-test and at one year follow-up. Although these authors found one significant result, (a decrease in the Schizophrenia subscale of the BPRS), they concluded that the intervention did not affect symptomatology. This study was limited due to the small sample size. Merinder et al. noted that the mechanisms for the decrease in symptoms found by Goldman and Quinn (1988) and by Kelly and Scott (1990) are complex and have not been fully explained in those papers. Merinder et al. concluded that the main aim for any psychoeducation programme should be to improve knowledge.

In summary, the three studies that did not show symptom change following psychoeducation vary considerably in sample size and intervention.

However, two of the studies (Atkinson et al., 1996 and Merinder et al., 1999) were consistent in using the BPRS. As can be seen from this section, the literature is inconclusive with regards to whether or not psychoeducation programmes can reduce psychiatric symptomatology.



### 1.3.2 Psychoeducation and satisfaction

Amongst those reviewed by Merinder (2000), only two studies measured participants' satisfaction with the intervention (i.e. Kelly & Scott, 1990; Merinder et al., 1999). Both studies used different measures of satisfaction: Merinder et al. (1999) used the Verona Service Satisfaction Scale (Ruggeri & Dall'Agnola, 1993). This measure included seven scales, one of which considered the participants' satisfaction with their relatives' involvement in the intervention. The intervention used by Merinder et al. (1999) involved both participants and relatives. The authors found a change in satisfaction in the scale for relative involvement only. This scale therefore may only be suitable for interventions that involve family members. Kelly and Scott (1990) used the Slater Satisfaction with Mental Health Care scale (Ellsworth, 1975). However, they found no change in satisfaction following the administration of their intervention.

To understand the reasons for the lack of improvement in satisfaction in the above studies, literature from Health Psychology may be useful. Ley (1988) found that patients with physical health problems who felt dissatisfied with medical communications were less likely to comply with treatment recommendations. Areas of dissatisfaction included a lack of empathy and interest from the health professional to the patient's concerns. Furthermore, patients were dissatisfied when the clinician did not involve them in the decision-making process regarding their care.

In terms of the literature on psychosis, patient dissatisfaction with consultations by health professionals may explain why compliance is often not improved by psychoeducation (e.g. Macpherson, Jerrom & Hughes, 1996; Atkinson et al., 1996; Merinder et al., 1999). It is suggested that when psychoeducation is delivered as a blanket treatment, not personalised to each individual case and not negotiated with the patient, dissatisfaction and failure to adhere to treatment regimens may arise. In cases of physical health problems, Weinman and Petrie (2000) noted that patient dissatisfaction was often associated with insufficient information, poor understanding of medical advice and subsequent reluctance to follow recommended treatment guidelines. These issues are pertinent for people with psychosis, particularly as they may have difficulty receiving information due to the existence of positive symptoms. It is useful to consider the literature from Health Psychology regarding the components of patient satisfaction and to include these in clinical practice.

Isen, Rosenzweig and Young (1991) suggested that doctors' use of positive verbal and non-verbal behaviour and "partnership building" improved patient satisfaction. Weinman and Petrie (2000) described "partnership building" as the doctor's use of open questions and appropriate responses to signs of distress in the patient. When relating this literature to individuals with psychosis, it could be hypothesised that their satisfaction with care may improve following a psychoeducation intervention in which the clinician focuses on "partnership building". However, the studies of psychoeducation and psychosis to date have shown little evidence of participant satisfaction.

This may be associated with a didactic style of teaching, as used by Merinder et al. (1999). It would be interesting to determine whether or not a more collaborative approach in which the participant felt like a valued partner in understanding his or her symptoms may be more effective in increasing satisfaction. Furthermore, appropriate responding by the clinician to the patient's emotional needs may also improve satisfaction.

In summary, patient satisfaction following psychoeducation is rarely measured. The literature from patients with physical illnesses has indicated that the main implication of patient dissatisfaction is treatment non-compliance. Furthermore, previous research has indicated that strong "partnership building" is a contributing factor to satisfaction in physical health patients. In terms of patients with psychosis who receive psychoeducation, there has been little evidence of partnership building. The findings of psychoeducation studies point to a move away from didactic delivery of information to more involvement of the patient. This may increase patient satisfaction of psychoeducation programmes. One area that may contribute to partnership building is personalisation of information delivered to patients. This literature will be reviewed below.

### 1.3.3 Personalising Psychoeducation

In an extensive critique of psychoeducation for patients suffering from first-episode psychosis, McGorry (1995) suggested that the patient, as a consumer of mental health services, has a basic right to receive information about his/her diagnosis. McGorry further stated that psychoeducation has a

number of objectives. These include promoting a speedy recovery; aiding the person to accept future treatment; facilitating appropriate coping strategies; and finally, reducing the risk of early relapse. McGorry (1995) further stated that in order for psychoeducation to be effective, the information has to be provided “flexibly and sensitively” to each individual. This approach is in contrast to the methodology of many of the studies described in the review by Merinder (2000) in which group approaches employing didactic lecturing were frequently utilised.

Kilkku, Munnukka and Lehtinen (2003) conducted a qualitative analysis of the meaning of information provision to people experiencing their first episode of psychosis. Although the authors are vague about the type of psychoeducation delivered, it seems that it was factually based with little personalising of the information. They found that the individuals' own experiences of psychosis affected the way in which information was interpreted. Information was received with feelings of worthlessness, relief or confusion. The study concluded that it is important to take into account the experiences of the individual and tailor the information accordingly, rather than to use a blanket approach for all participants.

Tarrier and Barrowclough (1986), in a study designed for families, described psychoeducation as an interactive process between the patients, their families and health professionals. They commented on the “interaction model”, which takes into account the personalised lay models of illness held by the patient and family. It stated that information received from the health

professional by the patient and family is “assimilated, organised and possibly rejected” on the basis of whether or not it contradicts the patient’s and relatives’ internalised illness models. The authors suggested that information should be carefully tailored to each person’s symptoms and experiences, rather than focusing on psychopathology in general. Tarrier and Barrowclough (1986) suggested that patients and relatives should be questioned extensively regarding their beliefs about the patient’s illness prior to the delivery of information. They stated,

*“...information is not given in a vacuum” (p. 462).*

Similarly, McGorry (1995) suggested that individuals are more likely to recall information regarding their own symptoms and experiences than more general facts about psychosis.

In summary, although researchers have indicated that information regarding diagnoses should be personalised and delivered flexibly, this has not been the case in the psychoeducation literature. It is suggested that an individually tailored psychoeducation package may be a useful intervention for a group of psychotic patients. The review will now consider whether or not the effectiveness of a treatment of this nature is altered by the stage of the illness.

### 1.3.4 Duration of Illness and Psychoeducation

#### 1.3.4.1 *Psychoeducation and early intervention*

Studies of psychoeducation treatment protocols for people with severe mental health problems have generally focused on patients with chronic, treatment-resistant Schizophrenia. There has been little research on patients with recent-onset or acute symptoms (Haddock et al., 1999). McGorry (1995) stated that psychoeducation should be offered as early as possible to be most effective.

Birchwood, McGorry and Jackson (1997) stated that the time between the onset of psychotic symptoms and the individual's presentation to services is approximately one year. These authors emphasised the importance of intervening with both medication and psychological therapy as soon as the person is diagnosed with a psychotic disorder. This defines "early intervention" and implies that treatment is offered whilst the individual is suffering from florid psychotic symptoms (i.e. during the acute stage of psychosis).

Birchwood et al. (1997) speculated that the early phase of psychosis is influential in terms of the biological, psychological and social development of the individual. Furthermore, they suggested that long-term outcome is predicted in the early course of the illness. However, they did not assess this directly and based their opinions on some previous evidence together with their clinical opinions. They emphasised that it is critical to intervene at the

early phases of psychosis in order to minimise further deterioration. One key area of intervention that they proposed was psychoeducation.

Tarrier and Barrowclough (1986) suggested that the longer the duration of a psychotic episode, the more time the individual has to form personalised lay models of the symptomatology (i.e. believing that their positive symptoms are reality and not part of an illness). These authors therefore advocated providing psychoeducation at an early stage of psychosis. They defined the optimal time for intervention as being soon after an episode has begun.

Some literature on psychoeducation for people with psychosis has concluded that it is important to intervene during the early phases of a psychotic episode. Further studies have been conducted using Cognitive-Behavioural Therapy and have addressed the question of whether or not to intervene during the acute phases of psychosis. As some of the components of psychoeducation and CBT are similar (including the development of a collaborative therapeutic relationship), CBT studies of the acute phases of illness are informative when considering a psychoeducation approach. Some of these will be explored below.

#### 1.3.4.2 *CBT and early intervention*

Haddock et al. (1999) conducted a pilot study of 20 patients (11 in the CBT group and 9 in the supportive counselling / psychoeducation group - SC) over a one-year period. Participants received between 3 and 18 sessions. The sample used in this study was defined as having had first treatment for

psychosis less than 5 years previously. Furthermore, they were all inpatients on an acute psychiatric ward at the time of the study. Suitable, potential participants were approached within 10 days of admission to hospital by a Psychiatrist to obtain consent.

Haddock et al. (1999) found that the number of relapses and the time until recurrence of psychosis was lower in the CBT group than the SC group. They also found that both groups reduced significantly on levels of symptomatology, according to scores on the BPRS. A key limitation of this study was the small sample size. It was not possible to calculate the optimal number of sessions of CBT that should be offered. The authors also noted that the lack of a no-treatment control group limited the conclusions that could be drawn regarding the suitability of CBT for acutely ill patients. Despite these difficulties, Haddock et al. (1999) concluded that it is possible to intervene with people in the acute stage of psychosis.

This study was later followed-up by a large randomised controlled trial (Lewis et al., 2002). They randomly assigned a group of 309 inpatients with Schizophrenia-related diagnoses to CBT or supportive counselling. Potential participants were screened within 14 days of admission and written consent was obtained soon after. The CBT group received a mean of 16.1 sessions over a 10-week treatment period. They found that those treated with CBT showed a trend towards faster weekly improvement over the treatment period than the control group. The authors concluded that it is possible and effective to deliver psychological treatments to people with acute psychosis.



Loebel et al. (1992) also commented on treating patients in the acute stages of psychosis. They suggested that long periods of untreated illness are associated with increased risk of relapse and treatment resistance. In another randomised controlled trial of CBT for acute psychosis, Drury, Birchwood, Cochrane and MacMillan (1996a, b) stated that delusions originating in this stage of illness are likely to recur or persist over the next 2 to 8 years. They indicated that it is appropriate to consider the acute phase as the source of symptoms that remain over the long-term and are difficult to shift. They therefore advocated early intervention to attempt to modify delusional beliefs and minimise their presence over time.

In summary, there is a growing body of research (mainly CBT) indicating that interventions should take place when patients are in the acute phase of psychosis. However, most studies of psychoeducation have been conducted with chronically ill participants (i.e. those who have had recurrent episodes). It has been suggested that early intervention allows patients to form realistic, rather than personalised lay models of illness. Furthermore, it has been hypothesised that the acute phase of psychosis predicts future outcomes in terms of residual symptoms and psychological, biological and social changes. Early interventions may allow patients to cope with difficult symptoms and to make sense of the experience.

The CBT interventions mentioned above have been lengthy. This is not always appropriate for patients residing in inpatient settings. Perhaps a treatment that intervenes when the participant is acutely ill, but is short in

duration may be helpful. Moreover, the utility of psychoeducation in the early stages of illness has rarely been researched.

#### 1.3.5 Insight

This review will briefly consider the literature on insight in psychosis. As was mentioned above, one of the outcome measures of psychoeducation has been insight. This section will consider the means by which insight has been defined; the problems this entails; and finally, the literature regarding psychoeducation and insight.

##### 1.3.5.1 *Problems with the definition of insight*

The definition of “insight” is complex and controversial. It has been most commonly used with patients who have psychosis as a means of describing their mental state. However it is an ill-understood concept with varying definitions and measures. In a comprehensive review, Marková and Berrios (1995) suggested that the lack of a consistent definition of insight and the use of different measures has resulted in contradicting and confusing results. This therefore causes difficulty in drawing valid conclusions and appropriate comparisons between studies.

Amador and Kronengold (1998) suggested that there is a spectrum of perspectives in defining insight. It has frequently been defined in terms of its absence. Amador and Kronengold reported that some authors believe that lack of insight is a psychological defence to cope with the frightening experiences of psychosis. Others considered lack of insight as a cognitive

deficit caused by the psychosis. Aside from theoretical differences, Amador and Kronengold (1998) suggested that the definition of absence of insight that transcends all perspectives is:

*“An individual’s perception of him or herself that is grossly at odds with that of his or her community and culture” (p. 16).*

This is the definition that will be adopted in this study.

The concept of insight has evolved over time from having been studied as a categorical, unitary idea (i.e. it is either present or absent) to being considered as a continuous, multidimensional phenomenon (Marková & Berrios, 1995).

#### 1.3.5.2 *Categorical perspectives of insight*

Categorical studies suggested that patients’ insight into their conditions is either present or absent. For example, Lin, Spiga and Fortsch (1979) defined insight as:

*“... recognition of existence of problems and the need for medical intervention” (p. 430).*

This and other categorical definitions of insight have been critiqued in a number of studies (e.g. Amador & Seckinger, 1997). These authors suggested that categorical definitions do not take into account those patients

who recognise that they have some difficulties or unusual experiences, but do not attribute these to illness. Furthermore, there are patients who accept medical intervention but who deny that they have a condition that needs to be treated. These problems with categorical definitions led to the consideration of insight as a continuous scale.

#### 1.3.5.3 *Continuous perspectives of insight*

It has been widely accepted in recent years that insight is a multidimensional concept (e.g. Marková & Berrios 1995; David, 1998; Amador & Kronengold, 1998). However, the specific components of insight continue to be debated. David (1990) stated that insight has three related parts: recognition of having a mental illness; treatment compliance; and the ability to label unusual symptoms as being part of an illness.

Amador et al. (1993) suggested that insight is a multidimensional concept consisting of awareness of having a mental disorder, awareness of the achieved effects of medication and awareness of the social consequences of having a mental disorder. They suggested that both current and retrospective views should be assessed in terms of insight.

It may be argued that the most appropriate measure of insight to use depends on the individual's status at the time of testing, specifically in relation to compliance with medication. In cases where patients are hospitalised and have been sectioned under the Mental Health Act (1983), they have no choice about whether or not they take medication. This would

render a measure of treatment compliance (e.g. David, 1990) inaccurate. In this case, it is suggested that the conceptualisation of Amador et al. (1993) would be more useful as this examines the individual's perception of the effects of medication, rather than compliance.

In terms of the other components of insight, as operationalised by Amador et al. (1993), (awareness of having a mental disorder and the social consequences this entails), it is argued that these are appropriate when assessing insight in patients detained in hospital. Both of these components are emphasised to inpatients by the fact that they have been hospitalised and removed from their communities. A poor level of insight is indicated in patients whose awareness does not improve during hospitalisation.

Amador and Seckinger (1997) indicated that multidimensional definitions allow for interventions to be focused on one particular area of insight. These authors concluded that all types of insight together comprise an important domain of psychopathology that has been neglected in the research and treatment of psychotic patients. The debate about the exact definition and means of measuring the concept is ongoing.

In summary, the literature on insight into psychosis is vast and this review has briefly outlined the main points in relation to the present study. A major difficulty with comparing studies of insight has been that a variety of definitions have been used. The modern perspective on insight is that it is a multidimensional and not a categorical scale. This allows interventions to be

tailored according to specific areas of insight. This study has adopted the definition of Amador and Kronengold (1998) mentioned above and has operationalised insight according to Amador et al. (1993). As was explained above, this definition and conceptualisation were chosen because they account for the involuntary detention of patients in hospital under the Mental Health Act (1983). A review of the literature on psychoeducation for patients with psychosis and whether or not this has been found to increase levels of insight is considered below.

#### 1.3.5.4 *Psychoeducation and insight*

Few studies have been conducted into the effect of psychoeducation on an individual's level of insight. Macpherson et al. (1996) used an individualised package, which was tailored to the particular symptoms of each participant. The study used a chronic sample with a mean age of 45.2 years and mean years since first admission of 23.4 years. Participants were randomly assigned to a control group, or to one or three sessions of psychoeducation. Insight was measured using the Schedule for Assessment of Insight (David, 1990). This is a multidimensional scale, which considers subscales of treatment compliance, awareness of illness and ability to label psychotic symptoms as being part of a mental illness.

Macpherson et al. (1996) reported global scores of insight. They found that insight increased significantly at one-month follow-up for the group that had received three sessions of psychoeducation, but not for those who had received one session. These authors concluded that a structured,

individualised, interactive education programme of three sessions was useful in promoting insight. It is suggested that this format is particularly useful with inpatients who are unlikely to reside in hospital for sufficient time to conduct a long-term intervention.

Merinder et al. (1999) did not find insight to improve following an eight-session group intervention involving patients who had lengthy illness histories and their relatives. They used the Insight Scale, (Birchwood et al., 1994) which rates insight according to three factors: awareness of illness; need for treatment; and attribution of symptoms. However, they did not comment on the individual scores of each of the subscales. Merinder et al. (1999) studied a chronic sample (mean age of 35.9 years; mean duration of illness of 8.2 years). They concluded that the baseline measure of insight was high, allowing little chance of measuring improvement over time. They also stated that the brevity of the programme might have made changes in insight difficult to achieve. However, they provided five more sessions than Macpherson et al. (1996) who found an improvement in insight. It is suggested that the key difference between the above studies was that Macpherson et al. (1996) used an individualised approach and Merinder et al. (1999) used a group approach. The personalisation of information in the individualised packages (Macpherson et al., 1996) possibly led to a better outcome.

In summary, there is a lack of studies that have considered the effects of psychoeducation on the insight of patients with psychosis. Furthermore,

although these studies have used multidimensional tools to measure insight, the subscale scores were rarely reported and insight was conceptualised as one global construct. As was highlighted in the above section, it may be misleading to formulate insight in this way, as there is no unifying definition of this construct. The literature on psychoeducation and insight is sparse and the results remain inconclusive. This would suggest that a study to consider the effects of psychoeducation on each individual component of insight would be useful.

#### 1.3.5.5 *Risks of Insight*

Although studies have aimed to increase insight, certain risks of heightened awareness of psychosis must be highlighted. Amador et al. (1996) stated that increased insight leads to higher rates of depression and elevated risks of suicide. This occurs when the individual realises that they have a long-term, potentially recurring condition with numerous psychosocial consequences (including on relationships and jobs). Similarly, Iqbal, Birchwood, Chadwick and Trower (2000), in a study examining Post-Psychotic Depression (PPD), found that those with greater insight into their illness were more likely to develop PPD than those with less insight. They concluded that PPD is dependent on the appraisals that the individual makes about psychosis and its implications on his / her sense of self, feelings of loss, entrapment and humiliation.

Despite these risks, it could be argued that the benefits of increased insight, including treatment compliance, outweigh the costs.



### 1.3.6 Medication Compliance

This section will review some of the literature of psychoeducation and medication compliance and will introduce 'Compliance Therapy', which utilises components of psychoeducation in trying to improve medication compliance. A critique of this model is offered at the end of this section.

A contributing factor to the readmission of many patients is non-compliance with medication (Bebbington, 1995). It has been found that psychoeducation (delivered didactically) had limited effectiveness in increasing medication compliance (e.g. Smith et al., 1992). In a review by Merinder (2000), it was found that most studies measured compliance. Of these studies, one found an improvement in compliance (Boczkowski, Zeichnar & Desanto, 1985) and three found a reduction in compliance (Macpherson et al., 1996; Atkinson et al., 1996; Merinder et al., 1999). However, compliance has been a difficult construct to measure.

Kemp, Kirov, Everitt, Hayward and David (1998) stated that the measurement of compliance poses a methodological issue for research. They noted that pill counts have been used in past studies, but these are time-consuming and labour intensive. Furthermore, they stated that pill counts are not suitable for inpatient studies where medication is administered by staff, nor for studies involving participants who are on depot medication. Kemp et al. (1998) stated that urine tests could also be used to measure compliance, but that these have a tendency to overestimate compliance as anti-psychotics have a long half-life.

In the studies reviewed by Merinder (2000), there was no consistent means of measuring compliance. Boczkowski et al. (1985) measured compliance using a self-report scale for participants and their relatives. Furthermore, this sample self-administered medication and pill counts were undertaken. This method of measuring compliance is clearly relevant only for outpatient populations. Macpherson et al. (1996) and Merinder et al. (1999) measured compliance within insight measures and did not have a separate compliance measure. Atkinson et al. (1996) measured compliance at the nine-month follow-up only for patients who were on depot medication. They calculated the percentage of injections received and elicited this information from the medical notes.

As is highlighted above, the construct of compliance is difficult to measure, particularly in the case of inpatients and, specifically, for those detained under the Mental Health Act (1983). This study has considered these difficulties and has operationalised the construct of compliance accordingly. This operationalisation consists of insight into the achieved effects of medication and attitudinal changes of the extent to which medication can cure an illness and the degree of personal control that can be exerted over the illness.

#### 1.3.6.1 *Compliance Therapy*

In light of the evidence that psychoeducation delivered didactically has limited effectiveness, Kemp and colleagues designed a brief intervention, entitled, 'Compliance Therapy' (Kemp, Hayward, Applewhaite, Everitt &

David, 1996a; Kemp & David, 1996b; Kemp et al., 1998). This approach included components of motivational interviewing (Miller & Rollnick, 1991) and emphasised a collaborative relationship between therapist and patient. It was conducted over the course of 4 to 6 sessions in three phases. On average, participants spent three hours with the researcher. The first phase involved the therapist ascertaining the patient's stance towards treatment. Then, the patient's ambivalence towards treatment was explored in the second phase. Finally, the third phase considered maintenance of treatment regimes. Kemp and David (1996b) noted that in the third phase, patients frequently asked about the meaning of their diagnostic labels, psychotic symptoms and physiological brain changes during psychosis. The authors emphasised the importance of making the information directly relevant to the individual rather than discussing these issues abstractly.

Kemp et al. (1996a) assessed patients within one week of admission and randomly assigned them to the intervention group or the control group (supportive counselling). There were 25 and 22 participants in each group respectively. Nurses rated compliance blind to the intervention group using a seven-point scale. This assessment was conducted at initial assessment, following the intervention, at discharge, after three months and after six months. At three-month and six-month follow-ups, the scale was corroborated with as many sources as possible, including relatives, the Psychiatrist, the Community Psychiatric Nurse and the GP.

Kemp et al. (1996a) found that Compliance Therapy improved insight, attitudes to medication interventions and compliance. These changes remained largely intact at 6-month follow-up. Kemp et al. also found that increased insight did not lead to higher rates of depression and elevated suicide risk (as was indicated by Amador et al., 1996). Kemp and David (1996b) reflected that the lack of increase in depression (and associated suicide risk) following increased insight was an important and unique finding. The authors hypothesised that the focus on improving self-esteem in the treatment package had prevented depression from increasing. This is a concept that has been incorporated into the psychoeducation package utilised in this study. The authors also reported that participants appreciated being asked their opinion of their illness and that this was an unusual occurrence in routine care. They emphasised the importance of allowing patients this opportunity.

The results of Kemp et al. (1996a) and Kemp and David (1996b) were encouraging and the study was repeated using a more robust design (randomised controlled trial) to ascertain whether or not the findings were upheld over an 18-month follow-up period. Kemp et al. (1998) recruited a total of 74 participants: 39 in the treatment group and 35 in the control group. This was an extended sample and included those in the Kemp et al. (1996a) study. They found that the improvements in compliance, insight and attitudes to medication in the intervention group were indicated at the post-test stage and these gains were maintained over the follow-up period. It is suggested that a brief, individualised approach is a useful means of increasing insight

and compliance. These principles have been incorporated into the design of the current study.

In summary, Compliance Therapy, a brief intervention aimed at improving medication compliance, has been shown to be effective for psychiatric inpatients. Although this study found positive outcomes, it emphasised the control of psychosis through medication, but did not provide the patient with any other ideas of how to deal with his or her illness (e.g. through occupation, socialising, exercising). It is argued that this defines psychosis as an illness in which the patient is passive in terms of taking medication and cannot take an active role in managing his or her difficulties. However, the research into Compliance Therapy has provided important indicators about ways to develop psychoeducation programmes. These include personalising information; allowing patients the chance to discuss their experiences in a non-threatening environment; a collaborative patient and therapist approach; and a brief number of sessions. These elements have been utilised in the current study.

#### 1.3.7 Collaborative Therapist-Patient Relationship

The concept of a collaborative therapist-patient relationship has been discussed in the literature of CBT for psychosis as an important factor in motivating people to participate in therapy. It has also been discussed in the area of information provision to people with severe mental illness. A collaborative therapist-patient relationship may be utilised in the delivery of psychoeducation. Some of the research in this area will be outlined below.

Kuipers (1996) noted the importance of a “partnership or treatment alliance” in which a collaborative, rather than didactic, approach should be considered. Similarly, Kingdon (1998), in a review of engagement of patients with psychosis, found that a collaborative relationship is imperative when working with people who have psychosis. He outlined that there are two major components to achieving this level of engagement: firstly, understanding why the patient holds his or her beliefs and secondly, providing credible alternatives.

Prior to literature on CBT for psychosis, Greene (1984) reflected that clinicians have been reluctant to inform patients with Schizophrenia of their diagnoses because they believe that the diagnosis implies ongoing deterioration of both positive and negative symptoms. However, Greene commented that some patients can recover from Schizophrenia and the outlook is not necessarily bleak. He therefore encouraged open communication between therapists and patients in order that the patient may be motivated to manage the illness effectively. Furthermore, he speculated that open communication would allow the patient to feel comfortable to talk about his or her fears regarding psychiatric symptomatology. Greene speculated that this openness could be the beginning of a functional therapeutic relationship.

In summary, a brief educational package for patients with psychosis in which a collaborative approach is utilised may be a useful adjunct to routine care in

inpatient psychiatric settings. This study has devised a programme with these issues in mind.

#### 1.3.8 Importance of goals for the future

Often people who have had a psychosis have difficulties reintegrating into society. Research has suggested that following a psychotic episode, the individual may have low self-esteem and may mourn the loss of the previous self (e.g. Birchwood, Iqbal, Chadwick & Trower, 2000). Furthermore, people who have recovered from psychosis can feel as though they have no means of preventing a future episode, other than by taking medication. This perspective can be disempowering and does not take into account the biopsychosocial view of psychosis. The NICE guidelines (2002) recognised this issue and recommended that clinicians should direct people who have had a psychosis to local resources and services following discharge from hospital.

In personalising information, McGorry (1995) firmly stressed that it is important to provide the individual with hope for the future. He suggested that patients should be provided with strategies that can help to resolve the current psychotic episode and reduce the rate of relapse. McGorry stated that a useful model to empower the individual is the “Stress / Vulnerability Model” (Zubin & Spring, 1977). This is widely acclaimed and suggests that people who experience Schizophrenia have an underlying vulnerability to the illness. Although it has its critics (e.g. Morrison, Renton, Dunn, Williams &

Bentall, 2004), it provides a useful platform for helping patients to understand and cope with their experience of illness.

The Stress / Vulnerability model suggests that the risk of a psychotic episode emerging is mediated by the amount of stress experienced by the individual and his / her means of coping. Zubin and Spring (1977) suggested that this framework underpins all other theories of Schizophrenia, including genetic, developmental and psychosocial. The importance of the Stress / Vulnerability model is that it empowers people with Schizophrenia to take an active role in controlling relapse by maintaining low stress levels. This contrasts with the medical model, which encourages the individual to take a passive role of consuming medication to control symptoms and relapse.

Birchwood et al. (1997) commented that many people suffering from first-episode psychosis are young and value independence, employment and the youth culture. They stated that psychosis can exclude these individuals from their peer group and can prevent them from fulfilling their aspirations.

Birchwood et al. (1997) stated that it is important for clinicians to be aware of these losses and to take a positive approach to reintegrating the individual back into society. They advised that a vocational outcome should be a central aim of the recovery process.

Following the acute phase of psychosis, there is a risk that increased insight will lead to Post-Psychotic Depression. Iqbal et al. (2000) found that those who developed PPD believed that their future roles would be of lower status



than if they had not had a psychosis. These authors noted that work is a highly valued social role and recommended that services focus on helping people who have had a psychosis to reintegrate into the workforce at a suitable level. They hypothesised that this may be a useful way of reducing the individual's feelings of low self-worth, loss, entrapment and humiliation following a psychotic episode and may prevent the onset of depression.

In summary, it is important to instil goals for the future into people with psychosis. This is a means of empowering these individuals to control the emergence of future episodes of illness by taking medication, by being occupied (through work or education) and by socially reintegrating back into society. It is suggested that by having goals and instilling hope for the future, the individual can protect against Post-Psychotic Depression. The intervention described in this study has attempted to incorporate recommendations for the future in terms of a biopsychosocial perspective of psychosis.

#### **1.4 Illness Representations**

When developing a new psychoeducation package, it is important to consider factors that aid in patients' ability to cope with their illnesses. However, the literature considering mental health patients' coping responses is sparse. In an extensive review of models of illness in severe mental health, Lobban, Barrowclough and Jones (2003) noted that research into individuals' responses to physical health problems are useful in understanding coping styles of those with mental health difficulties. Specifically, they believed that

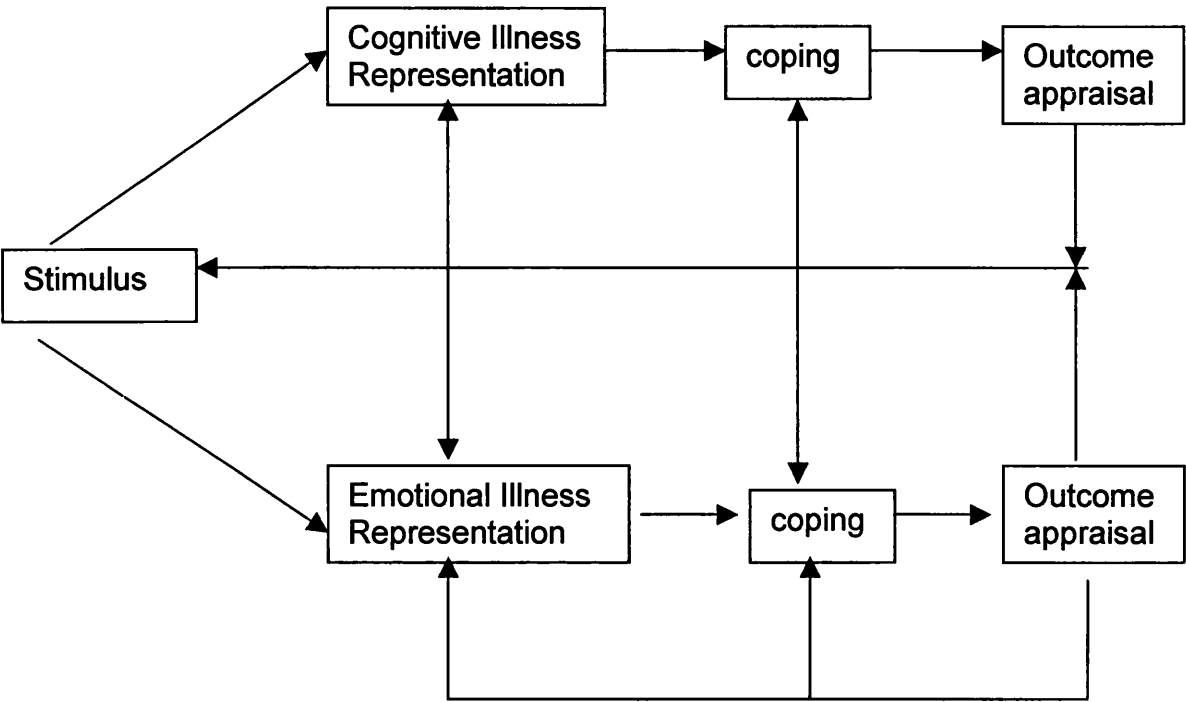
the Self-Regulation Model (Leventhal, Nerenz & Steele, 1984) could be usefully applied to those with mental health problems<sup>2</sup>.

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<sup>2</sup> Please see Figure 1.1.

**Figure 1.1    Self-Regulation Model, Leventhal et al. (1984)**

Social Environment



#### 1.4.1 *Self-Regulation Model*

This model assumes that people actively problem-solve and use health-related behaviours to try to shift from their present health status to a desired future goal. They use coping strategies to reach their future goals, which are based on their interpretation and evaluation of their illness. The outcome of these strategies is fed back into the model and used to further amend coping techniques.

Leventhal et al. (1984) suggested that cognitive representations guide an individual's responses. These consist of five specific components: the individual's perceptions of the *identity*, *consequences*, *causes*, *timeline* and *cure / control* of the illness. Moss-Morris et al. (2002) have further examined these components. Amongst other changes, an additional component of *illness coherence* has been suggested. This is the extent to which the individual believes that s/he understands the illness. Additionally, the *cure / control* component has been sub-divided into *personal control* (i.e. the extent to which the individual believes that s/he can exert control over the illness) and *treatment control* (i.e. the degree to which the individual believes that treatment, medication or otherwise, can cure the illness).

In addition to the cognitive representations of illness, Leventhal et al. (1984) suggested that emotional representations (i.e. the feelings that the individual attributes to having the illness) also lead to the development and appraisal of coping strategies.

#### **1.4.2 *Self-Regulation Model and Severe Mental Illness***

Although the Self-Regulation Model has been used to conceptualise severe mental illness, there have been few validation studies. Lobban et al. (2003) provided a detailed overview of research that supported each of the five components of cognitive representations. They concluded that the Self-Regulation model is a potentially useful model for understanding mental illness. Furthermore, they stated that it is crucial to examine each individual's appraisal of his or her mental illness in order to ascertain goals for intervention. On a clinical level, the Self-Regulation Model seems appropriately used to understand the beliefs of people with psychosis. Their cognitive and emotional representations may lead to inaccurate assumptions about their environments. It may be possible for these beliefs to be manipulated through the use of appropriate interventions. A personalised psychoeducation package may serve this purpose.

#### **1.5 The Present Study**

This pilot study is centred on the development of an approach that blends together those elements thought most likely to increase the chances of a positive outcome. These include a personalised approach using a collaborative therapist-patient relationship; intervention during the acute phase of illness; and information about local resources to help reintegration to society.

Similar to Compliance Therapy, a three-session intervention has been designed for this study. The literature described above indicated that there is

no pattern to the number of sessions offered to participants who have psychosis. Factors such as the type of setting; the usual duration of admission; and the number of staff members involved in administering the treatment affect the number of sessions that can be offered. These are issues that will be particularly pertinent to the current study. The participants will be acutely ill inpatients residing in a Psychiatric Intensive Care Unit. The duration of stay is variable, but mainly patients are discharged to open wards within six weeks of admission. The main researcher will be the only staff member to administer the intervention. A three-session intervention was therefore deemed attainable.

The sample of this study will be similar to that of Haddock et al. (1999) who recruited 21 participants from four admission wards over a one-year period. These authors concluded that their study did not have sufficient power to withstand “methodological rigour” and they found no significant differences between the intervention and control groups. The current study has the potential of recruiting proportionally similar numbers to Haddock et al. over an 8-month period. It was decided that when taking into account the small numbers, it would be most helpful to use an open trial without a control group, with each participant serving as his own control. This will allow for detailed examination of the effects of the intervention, together with routine care, on a number of outcome variables.

### 1.5.1 Outcome Variables

The review above has highlighted four outcome variables that have remained inconclusive in the psychoeducation literature. These are psychiatric symptomatology, insight, compliance and patient satisfaction. The only outcome measure to have been found to consistently improve following psychoeducation is knowledge. As this is a robust finding, it will not be measured in the present study.

#### 1.5.1.1 *Psychiatric Symptomatology*

Previous research has been inconclusive regarding changes in psychiatric symptomatology following psychoeducation. This study aims to examine positive and negative symptoms together with general ratings of psychiatric symptomatology. This involves a thorough examination of the key symptoms of psychosis and whether or not these symptoms alter following a brief course of psychoeducation. In particular, it is hoped that there will be reductions in anxiety, depression, suspiciousness and hostility as these symptoms are related to confusion caused by psychosis regarding the environment and other people. A reduction may also be found in a range of positive symptoms after participants have been provided with an explanation of their experiences.

#### 1.5.1.2 *Insight*

The research on psychoeducation and insight is sparse and inconclusive. A major problem with measuring insight in general is that there is no common definition across studies. It is now widely accepted that insight is a

multidimensional phenomenon, but this has not been utilised in previous studies of psychoeducation and insight. This study aims to consider different facets of insight, including awareness of having a mental disorder, awareness of the achieved effects of medication and awareness of the social consequences of having a mental disorder. In addition, the study will consider participants' self reports of their levels of insight. Improvements in all areas of insight are anticipated.

#### 1.5.1.3 *Compliance*

Some studies have found that personalised psychoeducation (in the form of Compliance Therapy) leads to improved compliance. This study will utilise many of the components of Compliance Therapy, including a brief number of sessions, personalising of information and a collaborative approach.

Although Compliance Therapy has been useful in improving medication compliance, it is suggested that it educates participants about passive means of managing their illnesses (i.e. by taking medication), rather than active ways that they might prevent or delay a future episode (e.g. social and occupational activities). This study aims to extend the brief of Compliance Therapy to include active roles that patients could utilise in order to control their psychosis.

However, there has been no standard measure of compliance, other than invasive and inaccurate tests (e.g. urine tests). Compliance is a difficult construct to measure when patients are detained involuntarily and they have no choice about taking medication. This study will consider compliance in



terms of insight into the achieved effects of medication and cognitive representations of personal control and treatment control of illness, as indicated in the Self-Regulation Model. This operationalisation will consider attitudinal changes towards compliance.

#### 1.5.1.4 *Patient Satisfaction*

Patient satisfaction has rarely been measured in studies of people with severe mental health problems. However, the physical health studies have shown that patient dissatisfaction often leads to treatment non-compliance. This is an important consideration when working with patients who have psychosis. The research into physical health has also indicated that satisfaction increases when information is personalised and the therapist attempts to build rapport with the patient. Furthermore, research into CBT for psychosis has indicated that collaborative approaches improve engagement.

In the present study, the concept of “partnership building” will be central to the intervention. Participants will be asked their opinions of their experiences and these will be incorporated into the intervention. The literature on Compliance Therapy also suggests that patients value the rare opportunities they have to tell clinicians about their experiences. This is one of the main goals of the present study. It is hoped that this will improve patient satisfaction.

This study incorporated the guidelines of the National Institute of Clinical Excellence (2002), which stated that patients should be provided with

information regarding their illnesses. Furthermore, they should be directed towards local resources and services. It is hoped that this approach to psychoeducation in people with psychosis will be beneficial in terms of decreasing symptomatology and improving satisfaction, aspects of insight and compliance. The specific research questions of this study are outlined below.

As this study will investigate the utility of a new intervention, it is deemed appropriate to carry out a pilot study. The results will be considered as hypotheses for future work.

#### 1.5.2 Research Questions

This section will highlight research questions and not hypotheses. As this study is an exploratory investigation of a new treatment package and does not have a comparison group, it is appropriate to state research questions. Hypotheses for future research will be borne out of this study.

This study aims to answer the following questions:

1. Does a personalised psychoeducation approach alter psychiatric symptomatology in people with psychosis?

Psychiatric symptomatology will be measured using observer-rated and self-report tools. Specifically, anxiety, depression, hostility, suspiciousness and a range of positive symptoms will be examined for change.

2. Having received this intervention, do participants change in particular areas of insight, namely, awareness of having a mental disorder, awareness of the achieved effects of medication and awareness of the social consequences of having a mental disorder?

This study will consider the construct of insight in terms of its facets and not as a global phenomenon. It is the aim of the study to understand the effect of the intervention on the dimensions of insight.

3. Does a personalised psychoeducation approach alter participants' perspectives on the cognitive representations of their illnesses?

This study aims to consider specific cognitive representations of illness and whether the intervention will alter these representations. The study will consider participants' beliefs regarding the consequences of illness; the extent to which they believe they have personal control over the illness; the degree of control that they believe their treatment has over their psychosis; and whether they feel that they have developed a coherent understanding of their illness.

4. Following receipt of this psychoeducation intervention, do participants change in areas of treatment compliance, namely, awareness of the achieved effects of medication; feelings of personal control over psychosis; and the attitude that treatment will improve their illness?

This study has operationalised the construct of compliance in terms of insight and cognitive representations of illness and therefore overlaps with research questions 2 and 3. It aims to examine whether or not compliance will change following this treatment package.

5. What are participants' feelings regarding their satisfaction with treatment following receipt of a personalised psychoeducation package?

This study will be unable to provide a quantitative analysis of changes in satisfaction following the administration of this psychoeducation programme. However, hypotheses of the most helpful aspects of the intervention will be drawn from some of the comments made by participants during a semi-structured interview regarding satisfaction with care.

## **2.0 METHOD**

This section will provide details of the participants of the study, the measures used, the design of the research and information regarding ethical approval.

### **2.1 Participants**

Participants<sup>1</sup> recruited were inpatients at a low secure psychiatric intensive care unit<sup>2</sup>. The base unit is rurally located and serves two counties. It consists of two wards, each with 16 beds. Patients are referred from one of two sources: court and prison diversions in which the individual is sent to the base unit for assessment and treatment of a deteriorating mental state; or from local Mental Health Units for patients whose illnesses are too acute to be managed on an open unit (due to absconding or threats of violence). The base unit is a controlled environment where most patients are restricted and under a section of the Mental Health Act (1983). All participants of this study were acutely psychotic at the time of recruitment and all were detained involuntarily under a section.

Over the course of data collection (eight months), 84 people were admitted to the ward. Of these, 16 participants were recruited. Figure 2.1 illustrates the recruitment of the study. Table 2.1 below outlines the demographic details and information regarding illness for the sample.

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<sup>1</sup> Please note that when referring to participants, the pronoun, "he" will be used for ease of reading, as the vast majority of participants were male.

<sup>2</sup> This will be referred to as the "base unit" for the remainder of this thesis.

**Figure 2.1**

**Flow Chart of Recruitment to Study**

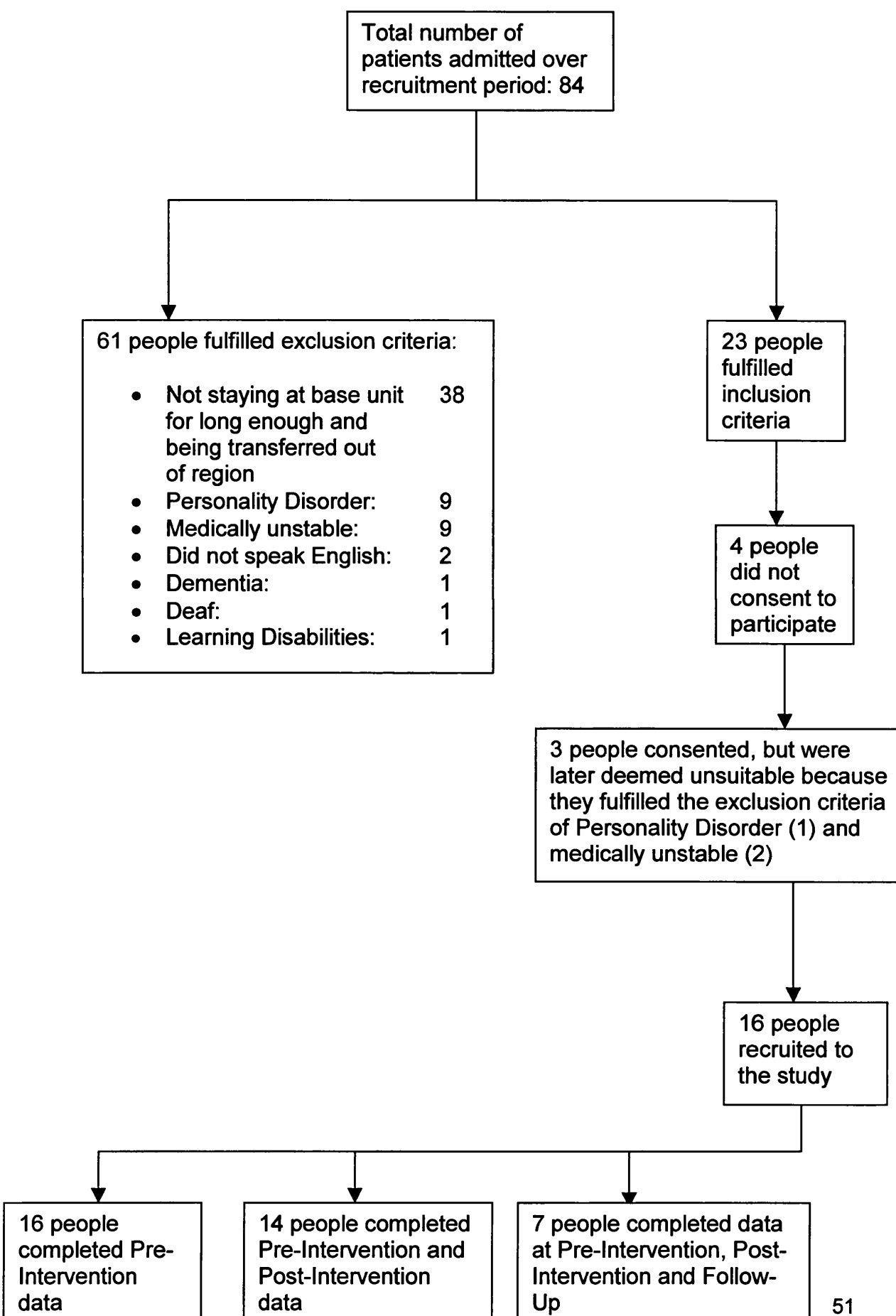


Table 2.1 Demographics and Illness Details

Gender	15 Male; 1 Female
Diagnosis	15 Schizophrenia; 1 Unspecified Psychosis
Age	20-42 years (Mean: 27.94; sd: 6.18)
Ethnicity	10 White; 3 Black or Black British; 2 Asian or Asian British; 1 Mixed
Marital Status	14 Single; 2 Married
Duration of Illness	0-14 years (Mean: 5.32; sd: 4.51)
Number of Previous Episodes of Illness	0-15 (Mean: 3.33; sd: 3.96)
Number taking anti-psychotic medication	16

There were two participants who dropped out of the study after Pre-Intervention and a further five who dropped out after Post-Intervention<sup>3</sup>. The table below highlights information regarding demographics and illness of the group of participants who dropped out throughout the study.

<sup>3</sup> There were three time points in this study – they will be termed Pre-Intervention, Post-Intervention and Follow-Up throughout this thesis.

**Table 2.2 Demographics and Illness Details of Participants who Dropped Out**

Gender	6 Male; 1 Female
Diagnosis	7 Schizophrenia
Age	20-35 years (Mean: 27.43; sd: 5.44)
Ethnicity	4 White; 2 Black or Black British; 1 Asian or Asian British
Marital Status	6 Single; 1 Married
Duration of Illness	0.67-13 years (Mean: 5.38; sd: 4.22)
Number of Previous Episodes of Illness	1-3 (Mean: 1.75; sd: 0.96)
Number taking anti-psychotic medication	7

### **2.1.1 Inclusion and Exclusion Criteria**

Inclusion criteria for this study were:

- Ability to give informed consent, as rated by a Psychiatrist independent of the study.
- Admission for acute psychosis (irrespective of diagnosis).
- A high probability (as decided by the Multi-disciplinary team) that the participant would remain on the unit for a period of at least 6 weeks (i.e. sufficient time to complete the intervention).
- The participant to be transferred to a local unit where it would be possible to collect follow-up data (i.e. not an out of region referral).



The Independent Psychiatrist made the decision regarding capacity to consent following a detailed interview. The potential participant was deemed capable of giving consent on the basis of four criteria as mentioned by Berghmans (2001). These are:

*" (i) the capacity to make and express a choice; (ii) the capacity to understand relevant information; (iii) the capacity to evaluate the character of the situation and possible consequences; and (iv) the capacity to handle information rationally" (Berghmans, 2001, p.4).*

Exclusion criteria of this study were:

- Personality Disorder as the primary diagnosis
- Dementia as the primary diagnosis
- Insufficient ability in the English language
- Learning disability
- Hearing Impairment
- Medically unstable

### 2.1.2 Obstacles to Recruitment

Admission figures for the previous three months were considered prior to the start of the study. It was identified that there were, on average, two admissions per week, which would have fulfilled the inclusion criteria for this study. On this basis, it was estimated that in the time available (i.e. six to seven months of data collection), two groups of 26 people (control versus

intervention) would be recruited. This sample size was in line with the power analysis.

However, over the course of the first ten weeks of data collection, a total of five participants had completed the intervention (and not 20, as had originally been predicted). Only two patients per month (who fulfilled inclusion criteria) were being admitted. It would therefore have taken approximately 26 months to collect the appropriate amount of data for an experimental design. This was beyond the scope of the time restraints of this study. The difference in admissions in comparison to the previous three months seemed to be that there were far more admissions of people with Personality Disorder over the recruitment phase of this study than there had been previously. These patients were unsuitable for this study.

Due to the recruitment problems mentioned above, the design was changed to an open trial without a control group, with each participant serving as his own control. Chairman's Action was obtained from the Local Ethics Committee to pursue this amended version of the research. The duration of data collection was extended to eight months and it was calculated that 16 participants would be obtainable, on the basis of two suitable admissions per month.

## 2.2 Measures

This section will outline details of all the measures used in this study.

### 2.2.1 Brief Psychiatric Rating Scale – BPRS (Overall & Gorham, 1962)<sup>4</sup>

This tool was designed to measure levels of general psychopathology. The authors suggested that trained clinicians should rate the BPRS. In this study, either the Psychiatrist or Consultant Clinical Psychologist fulfilled this role. Symptom severity is rated following a standard clinical interview, which can take between 10 and 40 minutes depending on the interviewer's familiarity with the participant (Lukoff, Liberman & Nuechterlein, 1986).

The BPRS is the most established scale for a rapid assessment of psychopathology (Hafkenscheid, 1991). It consists of 18 items rated on a seven-point severity scales (from zero, "Absent" to six, "Extremely Severe"). Items include Conceptual Disorganisation, Unusual Thought Content and Depression.

Van Riesen and Segal (1988), cited in Morlan and Tan (1998), evaluated the BPRS together with other general psychopathology rating scales. They found the BPRS to be superior in terms of resolution, sensitivity and simplicity. In addition, they recommended that the BPRS be used in all studies of people with Schizophrenia. A meta-analysis of studies involving the BPRS noted that 10 out of 13 studies reported reliability coefficients of .80 or greater for total pathology score, indicating high reliability (Hedlund & Vieweg, 1980).

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<sup>4</sup> Please see Appendix 1 for a copy of the BPRS.

Flemenbaum and Zimmerman (1973) published test-retest reliability figures for every item on the BPRS. These ranged from -.05 (Excitement) to .91 (Grandiosity).

In terms of validity, a meta-analysis found that BPRS scores over time have consistently reflected treatment changes that are corroborated and supported by other clinical ratings (Hedlund & Vieweg, 1980). The analysis used required information regarding Standard Deviations. These were obtained from Morlan and Tan (1998) and ranged from 0.92 (Conceptual Disorganisation) to 1.50 (Anxiety).

#### 2.2.2 Brief Symptom Inventory - BSI (Derogatis, 1993)

The BSI is a self-report inventory and was developed to measure nine primary symptom dimensions: somatisation, obsessive-compulsiveness, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism. In addition, it provides a global score. It is scored from zero ('not at all') to four ('completely').

The BSI is a clinically accepted instrument (Morlan & Tan, 1998). Francis, Rajan and Turner (1990) reported that it is easy to administer, takes little time to complete and has had extensive validation. Furthermore, Piersma, Reaume and Boes (1994) noted that it is relatively non-intrusive.

In terms of reliability, the BSI has been extensively investigated and shows good internal consistency and test-retest reliability. Coefficients range from

.68 for somatisation to .91 for phobic anxiety (Derogatis, 1993). The global rating shows excellent test-retest reliability at .90 (Derogatis, 1993). The analysis used required information regarding Standard Deviations. These were obtained from Morlan and Tan (1998) and ranged from 9.50 (Depression) to 12.46 (Paranoid Ideation).

In order to help participants to use this measure, the Assistant Psychologist read out the items and provided them with a card of the various responses. This was particularly useful with participants who had trouble concentrating due to their psychotic symptoms.

### 2.2.3 Scale to Assess Unawareness in Mental Disorder – SUMD (Amador, et al., 1993)<sup>5</sup>

This measure conceptualises insight as a multidimensional rather than categorical construct. It includes items of awareness of having a mental disorder; insight into the achieved effects of medication; awareness of the social consequences of having a mental disorder; and awareness of having a number of psychiatric symptoms. These include hallucinations, delusions and poor social judgment. Items are rated for current and past insight and on a scale from one ('aware') to five ('unaware'). A score of zero is given to patients who cannot be assessed or if the item is not relevant.

This study utilised the first three items only (i.e. awareness of having a mental disorder, the achieved effects of medication and the social

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<sup>5</sup> Please see Appendix 2 for a copy of the SUMD.

consequences of having a mental disorder). Furthermore, only current (not past) awareness was assessed as it was deemed problematic to assess insight in the past without corroborator information. As participants had a number of different symptoms, the individual symptom ratings were not included in the study. This allowed for ease of comparison between participants.

The measure was scored following a clinical interview conducted by a trained clinician (the Consultant Clinical Psychologist or Psychiatrist). Amador et al. (1993) reported inter-rater reliability correlations of .89, .75 and .68 for each of the three items (respectively). There have been no studies of test-retest reliability.

#### 2.2.4 The Insight Scale (Marková & Berrios, 1992)<sup>6</sup>

This is a self-report scale of insight designed for psychiatric inpatients. It incorporates both quantitative and qualitative features. The scale includes patients' perceptions of changes within themselves and within their environments, their recognition of being ill and their acknowledgement of needing help. The scale has 32 items. Thirty-one of the items are rated "yes", "no" or "don't know". The remaining item is a series of reasons for having to come into hospital and the participant is required to circle the ones that best describe his situation. The items are divided into "Positive insight", (i.e. if answered positively would indicate greater insight) and "Negative insight" (i.e. if answered positively would indicate less insight).

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<sup>6</sup> Please see Appendix 3 for a copy of the Insight Scale.

Marková and Berrios (1992) found the test-retest reliability coefficient to be .71 and stated that this was adequate. They also found that scores on the scale were inversely correlated with the severity of the patients' disorders. The analysis used required information regarding Standard Deviations. Marková and Berrios (1992) reported a standard deviation of 3.50 for Positive insight and a standard deviation of 1.80 for Negative insight.

#### 2.2.5 Illness Perception Questionnaire – Revised, IPQ-R (Moss-Morris et al., 2002)<sup>7</sup>

The IPQ-R is a measure of cognitive and emotional representations of illness as described in Leventhal's Self-Regulatory model (Leventhal et al., 1984). The components of illness representations that it considers are identity, timeline (acute / chronic), timeline (cyclical), consequences, personal control, treatment control, illness coherence and emotional representations. The IPQ-R is a 56 item self-report measure. Each item is rated on a five-point scale from “strongly disagree” to “strongly agree”. Similar to the BSI, the Assistant Psychologist read the items to the participant as he held a card with all of the possible responses.

Test-retest reliability has been used from patients on renal dialysis (Moss-Morris et al., 2002). The dimensions of the IPQ-R showed good stability over time with correlations ranging from .46 to .88. Evidence was also provided for internal reliability: the Cronbach alphas ranged from .79 (timeline cyclical) to .89 (timeline acute / chronic). The analysis required information regarding

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<sup>7</sup> Please see Appendix 4 for a copy of the IPQ-R.

Standard Deviations. The authors reported standard deviations for a chronic pain sample. These were utilised in this study and ranged from 3.36 (Treatment Control) to 4.78 (Illness Coherence).

In this study, it was deemed that the most relevant illness representations to assess for change over time were Consequences, Personal Control, Treatment Control and Illness Coherence. It was felt that these four subscales best characterised the illness representations that were expected to change following the receipt of a psychoeducation programme.

#### 2.2.6 Udvalg for Kliniske Undersøgelser (Committee for Clinical Trials)

##### Consumer Satisfaction - UKU-ConSat (Ahlfors et al., 2001)<sup>8</sup>

This scale was used to assess participants' overall satisfaction with care in the base unit, with later specific questions regarding their satisfaction with the psychoeducation package. The UKU-ConSat consists of six items related to the structure and process of treatment / care and two items related to outcome and well-being. The scale is administered as a brief semi-structured interview. The authors suggested that a person who is not directly involved in the treatment / care of the patient should conduct the interview. In this study, the Assistant Psychologist fulfilled this role. Whilst carrying out the interview, the Assistant Psychologist noted comments made by each participant regarding the psychoeducation package.

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<sup>8</sup> Please see Appendix 5 for a copy of the UKU-ConSat.



A total score of between –24 and +24 is obtained for this measure. The authors stated that any score below zero represents a degree of dissatisfaction and any score above zero is indicative of satisfaction. There have been no studies of test-retest reliability for this measure.

## **2.3 Procedure**

This section will outline the procedures adopted for informing each participant of the study, obtaining consent and collecting data.

### **2.3.1 Selection for the study**

Patients' suitability for this study was discussed at the weekly Multi-disciplinary team meeting. Each potential participant was then approached by an Assistant Psychologist who explained the study and provided a Patient Information Sheet. After reading this, the patient was asked to sign the Consent Form if he agreed to participate<sup>9</sup>.

### **2.3.2 Collection of data**

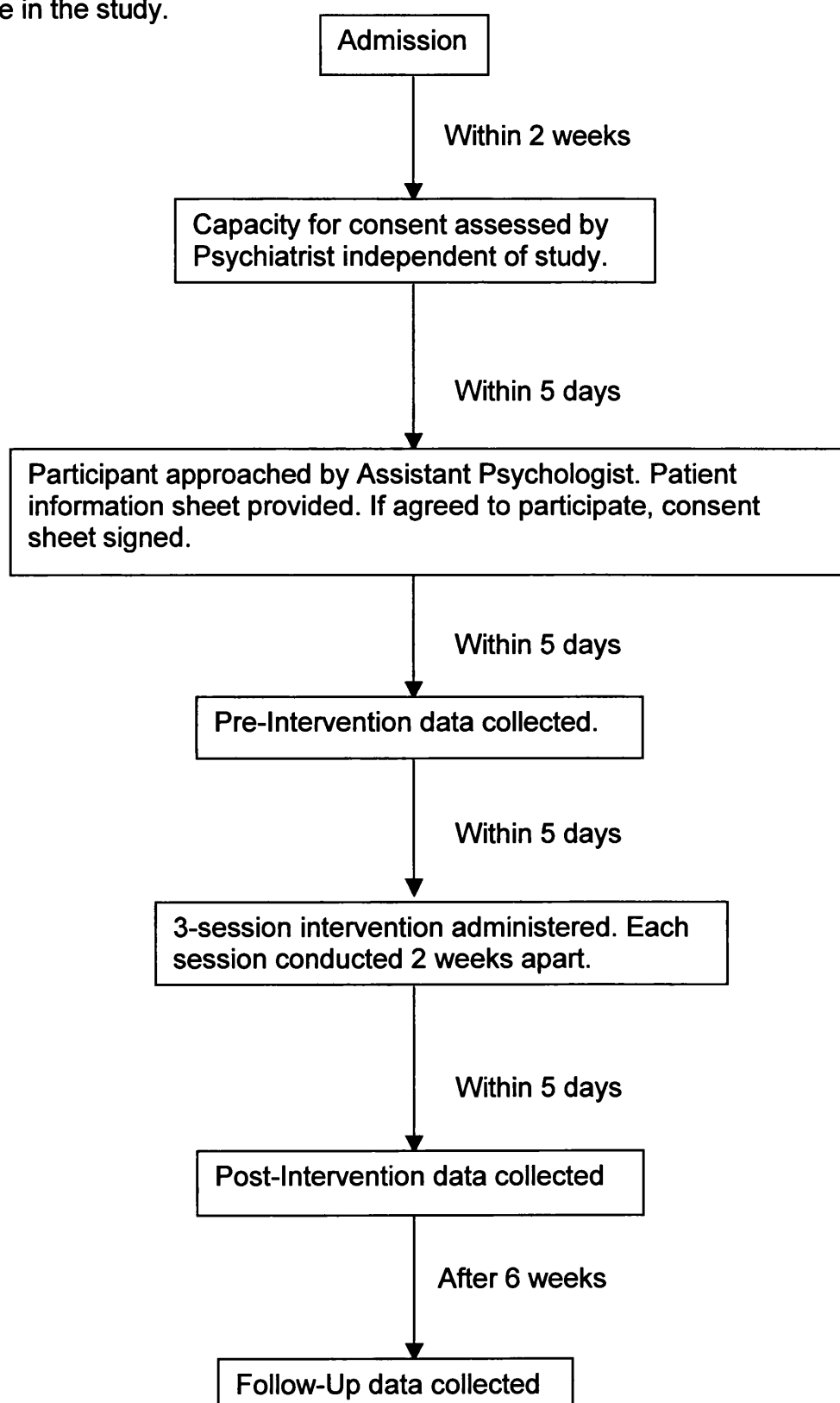
Data was collected at three time points: Pre-Intervention, Post-Intervention (following the intervention) and Follow-Up (six weeks after the completion of the intervention).

The figure below illustrates the process of data collection adopted by the study.

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<sup>9</sup> Please see Appendix 6 for the Patient Information Sheet and the Consent Form.

Figure 2.2 Flow Chart of data collection process for patients who consented to participate in the study.



After obtaining consent, the Assistant Psychologist returned within the next five days to collect baseline data. This consisted of the BSI; the IPQ-R; and The Insight Scale.

The Psychiatrist also visited the participant within five days of consent. A psychiatric interview was conducted and ratings were completed on the following measures: the BPRS and the SUMD. Following the collection of all relevant baseline data, the researcher administered the intervention at approximately 2, 4 and 6 weeks post admission.

Within five days of the final session of the intervention, the Assistant Psychologist and Psychiatrist again administered the same measures as Pre-Intervention (referred to as the Post-Intervention stage). In addition, the Assistant Psychologist also administered the UKU-Consat. Six weeks after the final intervention session, the Assistant Psychologist and Psychiatrist again administered the same measures that were used at Post-Intervention in the Follow-Up stage.

The Assistant Psychologist administered all psychological measures (i.e. BSI, IPQ-R, The Insight Scale and the UKU-ConSat). This maintained consistency for all participants. The Psychiatry measures (i.e. BPRS and SUMD) were completed by one of two people: a Psychiatrist or the Consultant Clinical Psychologist. It was ensured that the same clinician completed all three-time points with each participant in order to maintain consistency of rater.

Data was generally collected at the base unit in order to maintain consistency of setting. However, some participants were transferred during the course of the intervention and data was collected from the units in which they were residing. After completing Post-Intervention data, all participants who had been discharged from the base unit were sent a letter to offer an appointment time for collection of Follow-Up data. As this study was clinically based, it was not possible to maintain all participants within the same setting for the duration of data collection.

## 2.4 Design

The design of this study was an open trial without a control group. When developing a new intervention, Barker, Pistrang and Elliot (2002) recommended the use of a simple design. They stated that,

*“In clinical research it is often a good first step to use a simple design such as a one-group pretest-posttest to demonstrate that a gross effect exists at all” (p.149).*

The gross effect is the effect that can be attributed to the intervention i.e. the overall effect minus the confounding variables (Rossi, Freeman & Lipsey, 1999). Barker et al. (2002) suggested that if no effect has been found from a simple design, then there would be no purpose in carrying out a randomised controlled trial. They therefore stated that a simple design is an important initial study when evaluating a new intervention. Halpern, Karlawish and

Berlin (2002) similarly reported that one of the few types of study in which a small sample is acceptable is in early-phase trials of a new drug or device.

#### 2.4.1 Power

In terms of power, the original experimental design needed 26 participants in each group at  $\alpha=.80$  (assuming a large effect size similar to those expected for therapy and waiting list controls). As the study has changed in order to pursue a simple design, power is not relevant. Findings can therefore be described as hypotheses and not as firm conclusions due to the lack of power in this study.

#### 2.5 **Ethical Approval**

Permission to carry out the study was obtained from the Local Research Ethics Committee. After 10 weeks of data collection, Chairman's Action was granted to alter the design to an open trial without a control group<sup>10</sup>.

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<sup>10</sup> Please see Appendix 7 for confirmation of Ethical Approval and a copy of the Chairman's Action letter.

### 3.0 INTERVENTION

The intervention is designed based on three facets: theory; general clinical knowledge of those working in this field; and information that is readily available to patients in the base unit. It has been developed in line with NICE (2002) guidelines for delivering information regarding diagnosis to patients with Schizophrenia whilst they are in the acute stages of illness. By intervening early, this treatment attempts to allow participants to alter their trajectories regarding the long-term influences of their psychotic symptoms and help them to develop coping strategies (as suggested by Birchwood et al., 1997). The paragraphs below outline literature that contributed to the development and design of the intervention.

The recommendations of Kemp and David (1996b) were influential in the development of the intervention. These authors specified the importance of personalising information (in accordance with McGorry, 1995); the need to allow participants to discuss their experiences in a non-threatening environment; the collaborative therapy relationship (as is suggested by Kingdon, 1998); and a brief number of sessions. As is indicated in detail below, the intervention involves a process of eliciting participants' beliefs regarding their psychosis; empowering them to share these experiences through the lack of challenging in the initial assessment; and negotiating the details outlined in the manual<sup>1</sup>. These principles are an attempt to fulfil the first three of the recommendations mentioned by Kemp and David above.

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<sup>1</sup> Each participant received a manual regarding their experiences. This is detailed in the sections below.

The final criterion of a brief number of sessions was implemented and three were offered to each participant.

A key contributing factor in the design of the intervention is the objectives for delivering psychoeducation as indicated by McGorry (1995). Firstly, a “speedy recovery” is promoted through information regarding symptoms and ways of dealing with psychosis (medication and otherwise). Secondly, the psychoeducation package aims to present psychosis as a long-term, but manageable illness with the use of treatment. This fulfils McGorry's aim of aiding the person to accept future therapy. Thirdly, as directed by McGorry, appropriate coping strategies are discussed in the intervention, with an emphasis on avoidance of illicit substances and encouragement to partake in healthy activities (e.g. exercise and socialising). Finally, as McGorry recommended, the risk of early relapse is addressed through discussion of the key symptoms that would be likely to re-emerge in the prodromal stages of psychosis. Furthermore, the healthcare professionals and family members whom the participant may contact are highlighted.

This chapter will provide details about the ways in which this psychoeducation package was delivered. The sections below will include information regarding the initial assessment and the format of the intervention. Subsequently, the procedure of delivery of the intervention is specified.

### 3.1 Initial Assessment

In an attempt to take into account the experiences of each participant (as directed by Kilcku et al., 2003) and subsequently personalise each psychoeducation package, a detailed assessment was undertaken. The aim of the initial assessment is to obtain each participant's views of his circumstances without challenging by the main researcher. This is in line with the suggestions of Yalom (1975), who stipulated that patients' views must be considered before "credible alternatives" are offered.

The design of the initial assessment is also influenced by the literature on patient satisfaction. Weinman and Petrie (2000) highlighted that "partnership building", involving open questioning and appropriate responses to signs of distress increased satisfaction. The initial assessment was designed accordingly.

A semi-structured interview was devised which attempts to elicit the beliefs of each participant regarding: detention in the base unit; symptoms experienced; history of drug and alcohol misuse; and plans for the future<sup>2</sup>. The interview incorporates components from biological, psychological and social aspects of each individual. The assessment and intervention were designed within a biopsychosocial framework.

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<sup>2</sup> Please see Appendix 8 for Initial Assessment.



## 3.2 Format of Intervention

The intervention centres on the development and provision of a shared, personalised view of the key factors of each participant's illness. Participants are more likely to retain information that is personalised to their condition and not delivered as abstract concepts (e.g. McGorry, 1995). In order to achieve this standard, limited jargon and professional shorthand are used throughout the manual. Information is delivered where possible in the participant's own words (as was suggested by Tarrier & Barrowclough, 1986)<sup>3</sup>. The paragraphs below outline the content of each page of the manual.

### 3.2.1 Views of participant – Page 1

The first part of the manual reiterates the information collected in the semi-structured interview conducted in the first session. This includes beliefs regarding admission; precipitating events to admission; and the views of doctors and family or friends.

### 3.2.2 Introduction of the term 'psychosis' – Page 2

Towards the end of the first section of the manual, the term "psychosis" is introduced and the definition is provided. The definition was obtained from the Collins English Dictionary (1998). This stated

*"A psychosis is a condition in which the person's contact with reality is lost or highly distorted".*

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<sup>3</sup> Please see Appendix 9 for the template of the manual and Appendix 21 for a sample manual. In Appendix 21, details have been changed to protect confidentiality.

It is important to begin this section with a definition that is easily accessible to all readers. This section then tries to normalise the experience of having a psychosis by stating,

*“Many people who have a psychosis don’t believe they are suffering from an illness in the early stages”.*

The text aims to relate the experiences of the participant to the symptom and to personalise the information, e.g.

*“You mentioned that you hear voices telling you to kill yourself. This symptom is called a hallucination and often seems to occur out of nowhere. Hearing voices that other people can’t hear is the most common type of hallucination.”*

### 3.2.3 Summary of participant's beliefs and alternative explanations – Page 3

As pages 1 and 2 of the manual are often lengthy, the aim of page 3 is to include a summary table of the beliefs that the participant was experiencing together with associated symptoms. Please see the table below for an example:

Your Belief	Alternative Explanations
<ul style="list-style-type: none"> <li>• Your water was poisoned</li> </ul>	<ul style="list-style-type: none"> <li>• This belief seems to be true to you, but can make you feel alone because other people don't believe you.</li> <li>• Although you believe this very strongly, we think these feelings are due to a symptom called a delusion.</li> <li>• Delusions are a common symptom of psychosis.</li> </ul>

#### 3.2.4 Causes of Psychosis – Page 4

This section begins with biological, developmental or genetic reasons for the development of psychosis. It introduces the participant to the concept of organic causes of psychosis. In cases where the participant reports a difficult birth or pregnancy, this is linked as being a possible cause of psychosis. For those patients who have a family history of mental illness, the genetic characteristics of psychosis are highlighted as a possible cause.

The Stress-Vulnerability model is then introduced (Zubin & Spring, 1977). Information from the initial interview is used to ascertain the stressful experience that the participant had been experiencing prior to the onset of illness. This is then directly related to the model. In this section, a diagram is used to help to condense the information and better explain the model.

This page then informs the participant of the problems that can be encountered when taking drugs (for those participants who admitted to taking drugs). It is extremely common for people with psychosis to take drugs, usually cannabis (Negrete & Gill, 1999). These authors stated that cannabis

is the third most commonly used substance by people with psychosis, following tobacco and alcohol. They reported that the use of cannabis has the effect of unblocking dopamine pathways, heightening the risk of a further psychotic episode and possible hospital readmission.

This section aims to introduce to the participant that a degree of control over psychosis is attainable and by refraining from illicit substances, the likelihood of hospital readmission is lessened (Negrete & Gill, 1999). This section is the first of several designed to empower the participant to take an active role in controlling his psychosis.

### 3.2.5 Theories to understand symptoms – Page 5

This page aims to outline relevant theories in a simplistic way whilst relating them directly to the experiences of the individual. In cases where the participant is struggling with delusions, theories by Garety and colleagues are used (e.g. Garety, Hemsley & Wessley, 1991). These authors suggested that people who have delusions are likely to switch their judgments rapidly and draw on less firm conclusions. The manual firstly re-states the delusion that was mentioned by the participant in the first session, then provides information regarding the theory.

The next section is headed “How this relates to you” in which alternative explanations of reasons for experiencing the specific delusion are provided, including,

*“You believe that people who are close to you do not care about your welfare, when, in fact, there may be many other explanations, like there is a chemical imbalance in your brain that causes you to think this way. You may not have much evidence for believing your family doesn’t care for you. Instead, your psychosis causes you to think this way.”*

In order to include a balanced perspective, Bentall’s theory is also provided (e.g. Bentall, 1990). This suggested that delusions, particularly persecutory in nature, serve the function of defending self-esteem and minimising negative affect. Similar to the above format, the information is presented as a brief, accessible outline of the theory. This is followed by a section entitled, “How this may relate to you”, in which the particular delusion of the participant is referred to and an alternative explanation is offered, e.g.

*“Your experiences of attacking others may be examples of blaming other people for your symptoms. In your case, you become paranoid and then engage in violent behaviour, e.g. you stabbed a man in 1982, you threatened to hit a member of staff and you attacked another patient. These people may not have been trying to upset you, your psychosis may have been making you misinterpret your environment and feel this way. So, you blamed others for your behaviour, instead of feeling sad about being unwell.”*

In cases where auditory hallucinations are the main symptom, various theories to explain the experience to the participant were utilised. The format is the same as that described above for delusions, i.e. each section stated the theory and then related it to the individual.

Baddeley's (1986) theory of "disturbances of inner speech" is included which suggests that the articulatory loop (the short-term verbal store component of working memory) operates without adequate monitoring of the source of the stimulus, i.e. the person experiences thoughts as occurring from outside his head. An example of the section of "How this may relate to you" is,

*"The difficult thoughts that you have about killing yourself are generated from your own anxieties about the world. They are your own thoughts that are interpreted as coming from outside your head."*

The 'Input Theory' (Bentall & Slade, 1986) is also included. This theory suggests that an external stimulus might be misperceived, thereby giving a false perception. These authors suggested that disturbances are likely to occur due to a combination of poor signal discrimination and biases of perception. An example of the way in which this theory is related to a participant is highlighted below:

*"You sometimes become confused about noises from outside your head and misinterpret these as voices and telepathic messages."*

Finally, Frith's (1992) theory of 'Disturbances of Self Monitoring' is utilised.

This suggests that auditory hallucinations are caused by the failure to monitor the intention to produce inner speech, i.e. the source of the thought. In this case, an example of the section entitled "How this may relate to you" is,

*"The thoughts originate from inside your head, but because of a disturbance of self monitoring, you do not realise that you had intended to think them, so you perceive them as voices coming from outside your head."*

The main symptoms described in the first session interview by all participants were either delusions or auditory hallucinations. It is for this reason that theories of these symptoms have been documented only.

### 3.2.6 Metaphor to understand symptoms – Page 6

A metaphor from Acceptance and Commitment Therapy (ACT) is incorporated to allow the participant to begin to externalise psychosis (Hayes, Strosahl & Wilson, 1999). ACT is based on the premise that maladaptive behaviours are produced by attempts to suppress thoughts, feelings and symptoms. Bach and Hayes (2002) found ACT to be particularly helpful in reducing hospital readmission of psychotic patients. The first aim of ACT is to identify and abandon internally oriented control strategies. It uses metaphors to remove the focus directly from the patient and to help him to begin to think more laterally about problem solving strategies he employs that may be failing to help.

The metaphor used in the present intervention is called “Tug of war with a Monster”<sup>4</sup>. Following reading this metaphor, each participant is asked how he feels it relates to his own life circumstances. For those who find it a difficult idea to conceptualise, the “monster” is identified as psychosis and the rope (for the “tug of war”) is likened to all the strategies that the participant has used to deal with the “monster”, including taking drugs, having little structure in the day and stopping medication. It is suggested to the participant that the metaphor states that he should “drop the rope”, i.e. stop using these strategies, because the “monster” or psychosis is becoming worse, or “winning”, as the metaphor suggested. The researcher and participant then engage in a discussion about the metaphor and the personal relevance of the image to the participant.

### 3.2.7 Ideas to improve symptoms – Page 7

This section informs the participants of the biopsychosocial factors involved in psychosis and attempts to provide them with relevant information regarding control over symptoms. In terms of biology, it provides the participant with a rationale to continue to take medication, i.e. that it acts on the dopamine in the brain and can help to reduce many of the symptoms of psychosis. This section aims to improve the participants’ insight into the achieved effects of medication.

Further to the biological control of psychosis, this section emphasises the importance of avoiding illicit substances. It reinforces the connection between

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<sup>4</sup> Please see Appendix 21 (sample manual), page 6.



increased dopamine caused by illegal drug taking and the onset of psychosis as a result (Negrete & Gill, 1999).

In terms of the psychosocial aspects of psychosis, the importance of reducing stress and creating a daily routine are highlighted. This is in accordance with the Stress-Vulnerability model (Zubin & Spring, 1977).

Finally, for those participants whose social network increases the likelihood of returning to illicit drug taking, alcohol misuse and of remaining unemployed, they are encouraged to think about the dangers of socialising with these people and the consequences for their future mental health.

Several researchers have stated that it is important for patients with psychosis to have structure to their lives in order to reduce the frequency of relapse (e.g. Iqbal et al., 2000).

### 3.2.8 Relapse prevention – Pages 8 and 9

This section begins by reminding the participant of the aspirations that they stated in the initial assessment. Attempts are made to instil hope in the participants in order that they might be able to pursue those avenues in the future. This is in accordance with Birchwood et al. (2000), who stated that a vocational approach is appropriate when attempting to reintegrate patients with psychosis into society.

This section then emphasises the importance of remaining well in terms of a biopsychosocial perspective, including continuing to take medication, eating healthily, exercising and socialising. With regards to medication, this section

informs the participant that if he were to stop taking medication, the symptoms would be likely to re-emerge. It then mentions the symptoms that the participant may be likely to re-experience in the prodromal stages of psychosis. These symptoms are discussed with the participant in the second intervention session and are incorporated into the final draft of the manual. This is another example of personalising information to each participant by increasing awareness of personal relapse patterns. This approach is in line with literature on CBT for relapse prevention (e.g. Morrison et al., 2004).

Although the above issues were covered in an earlier part of the manual, it was deemed important to reiterate information that could empower the participant. Furthermore, it is known that people with psychosis may have difficulties in concentrating and that it is useful to repeat information (e.g. Lindsay & Powell, 1994).

The participant is then reminded of the importance of contacting his GP, Psychiatrist, CPN or Social Worker if he begins to notice his symptoms re-emerging. In session 2, the participant is asked the names of these individuals and these are included in the final draft. This helps to further personalise the manual.

Finally, this section informs the participant of the likelihood of further prescriptions of medication if symptoms re-emerge. It also reiterates the number of professionals available to help the participant should the need

arise. The aim of this section is to heighten the participant's awareness of the risk of relapse.

### **3.2.9 Plans for the future – Page 10**

On the basis of the hopes of participants as elicited in the initial assessment, information is given regarding possible contacts in a number of areas, including help with substance misuse, social and leisure activities, education, voluntary work and employment. Although the delivery of this information may seem premature whilst the participant remains acutely psychotic, it is in line with both NICE (2002) guidelines (regarding provision of contact details for local resources and services) and literature by Birchwood et al. (2000) and Iqbal et al. (2000).

## **3.3 Procedure of Intervention**

This section will describe the various stages of developing the intervention and will then outline the procedure used for administering the package.

### **3.3.1 Piloting of intervention**

The intervention was prepared as an anonymous letter and manual. Both versions were presented to 10 members of a Clinical Psychology department (five Clinical Psychologists, four Assistant Psychologists and one Psychotherapist) for review and comment. A pilot was conducted with three patients prior to the start of data collection for assessment of comprehension and face validity. In the final session, each was presented with the information as a letter and in a manual form. A brief questionnaire was

designed to assess the preference of formats<sup>5</sup>. The results indicated that all individuals preferred the manual format. This format was therefore used for the study.

### 3.3.2 Readability of the Manual

Each manual was checked for ease of reading using Flesch scores. This analysis is from 0 to 100 and states that the higher the score, the easier the document is to read and understand. Standard documents should obtain scores between 60 and 70. All manuals had scores of this range. On occasion, there were some participants who had some difficulties in reading. In these circumstances, both the manual and an audio taped version were presented to the participants. This occurred on two occasions.

### 3.3.3 First session / Initial Assessment

The emphasis in the first session was on building the therapeutic alliance. It was important for the participants to feel safe enough to reveal their beliefs without feeling judged. The researcher created this atmosphere by explaining to the participant that he would be questioned about his beliefs, but that the researcher would not be imposing her views.

At the end of the first session, each participant was informed that he would be meeting the researcher again in two weeks time. It was also explained that, at that time, he would be given a manual. It was indicated that this would incorporate both his views and those of the researcher (and the Multi-

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<sup>5</sup> Please see Appendix 10 for a sample letter and Appendix 11 for the questionnaire used in pilot study.

disciplinary team) about the symptoms he was experiencing. This session usually lasted between 45 minutes and 1 hour.

#### 3.3.4 Second Session

In this session, each participant was presented with a manual. As can be seen in Appendix 21, the manual was held together without staples. This avoided the risk of self-harming behaviour with the use of staples.

The session was introduced to the participant as his opportunity to discuss the manual and to amend the parts with which he strongly disagreed.

Specifically, the researcher would amend errors in the documentation of the participant's beliefs surrounding the events leading up to admission to the base unit. The researcher was not able to amend parts of the manual that related to theories explaining psychotic symptoms. This session usually lasted between 30 and 45 minutes.

Although the researcher focused closely on the text, time was spent discussing the various parts of the manual with each participant. At the end of this session, each participant was reminded that the researcher would be returning in two weeks for the final session and at that time, the participant would be presented with the amended version of the manual.

At the end of sessions 2 and 3, the participant was given his own colour copy of the manual. As it contained a large amount of information, it was deemed

important for the participant to have the opportunity to look through the information again whilst alone in order to aid comprehension.

#### 3.3.5 Final Session

The amended version of the manual was presented to the participant and was read through by the researcher. At various points, the researcher encouraged the participant to engage in discussion regarding his views. This session usually lasted approximately 20 to 30 minutes.

## 4.0 RESULTS

This study employed an open trial without a control group. A total of 16 people were considered suitable for the study. Of these 16, two participants dropped out after the Pre-Intervention stage due to the destabilisation of their mental states. Following the intervention, a further five people dropped out prior to the Follow-Up as they had been discharged from hospital and chose to withdraw.

### 4.0.1 Data Analysis

This study utilised the Reliable Change Index (developed by Jacobson, Follette & Revenstorf, 1984; amended by Christensen & Mendoza, 1986; cited in Jacobson & Truax, 1991), an analysis that defines whether or not a single case has statistically changed across two time points. This analysis considers the difference between each participant's pre-test and post-test scores<sup>1</sup> and compares this against the standard error of the measurement, as calculated using test-retest reliability figures.

Jacobson and Truax (1991) stated that in cases where the RCI is greater than 1.96, the post-test score is statistically significantly greater than the pre-test score, that is, "real change" is indicated. This assumes a probability of a 5% chance that the observed change is due to the unreliability of the measurement.

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<sup>1</sup> In the case of this study, Pre-Test is referred to as Pre-Intervention and Post-Test as Post-Intervention.

The Reliable Change Index will be used to analyse research question 1 (Psychiatric Symptomatology), question 3 (Illness Representations) and question 4 (Compliance). Question 2 (Insight) will compare results by subtracting Post-Intervention and Follow-Up scores from Pre-Intervention scores. Question 5 (Satisfaction) will report total scores and quote participants' comments regarding the psychoeducation package. Appendix 12 indicates the Standard Error and Standard Error of Difference between two test scores for each measure that was analysed using the Reliable Change Index.

#### 4.0.2 Analysis of data across 3 time points

Data was analysed by comparing Pre-Intervention to Post-Intervention and Pre-Intervention to Follow-Up scores, i.e. the analysis considered whether any improvement at Post-Intervention was upheld at Follow-Up. It was therefore deemed superfluous to requirements to analyse Post-Intervention to Follow-Up.

A total of 14 out of 16 participants (87.50%) completed the intervention (i.e. Pre-Intervention and Post-Intervention) and 7 out of 16 participants (43.75%) completed a full data set (i.e. Pre-Intervention, Post-Intervention and Follow-Up). Appendix 13 outlines each participant's recruitment over the three time points and states when missing values were used. Appendix 14 provides raw data for each participant on all of the variables analysed for this study.



## 4.1 Psychiatric Symptomatology

This study aimed to answer the following question:

*Does a personalised psychoeducation approach alter psychiatric symptomatology in people with psychosis?*

The study considered both positive and negative symptoms. The specific symptoms of interest were: anxiety, depression, hostility, suspiciousness, unusual thought content, conceptual disorganisation, psychoticism and paranoid ideation.

Appendices 15 and 16 show the Reliable Change Indices for each participant from Pre-Intervention to Post-Intervention and from Pre-Intervention to Follow-Up for the BPRS and BSI respectively (labelled A to P for purposes of confidentiality). Table 4.1 below indicates the number of participants whose scores, according to the Reliable Change Indices, were found to significantly improve, significantly deteriorate and those who showed no change across the time points. The table is divided into two halves: the first highlights Pre-Intervention to Post-Intervention data (i.e. any changes occurring during the active stage of intervention); the second indicates Pre-Intervention to Follow-Up (i.e. changes sustained over six weeks following the intervention). The table shows individual figures for BPRS and BSI ratings. Each cell includes the number of participants who had changed significantly. The time points Pre-Intervention and Post-Intervention have been abbreviated to Pre- and Post- in Table 4.1. It is noted that of the 16 participants, at Post-Intervention,

13 were available for assessment using the BPRS and 14 were assessed using the BSI. At Follow-Up, 8 were available for assessment of the BPRS and 9 for the BSI. Those available for assessment will be referred to as “responders”.

Table 4.1      Number of Participants with Significant Changes across Time  
on Psychiatric Symptomatology

	Pre-	to	Post-	Pre-	to	Follow- Up
	<i>Deteriorate</i>	<i>No</i>	<i>Improved</i>	<i>Deteriorate</i>	<i>No</i>	<i>Improved</i>
	<i>Change</i>			<i>Change</i>		
<b>BPRS</b>						
Anxiety	0	13	0	0	8	0
Depression	0	12	1	0	7	1
CD *	0	8	5	0	5	3
UTC *	0	10	6	0	4	4
Hostility	0	12	1	0	8	0
Suspiciousness	0	10	3	0	5	3
<b>BSI</b>						
Anxiety	0	12	2	0	7	2
Depression	0	10	4	0	7	2
Paranoid	2	7	5	1	5	4
Ideation						
Psychoticism	0	10	4	0	6	3
Hostility	1	11	2	0	7	2

\* CD = Conceptual Disorganisation

\* UTC = Unusual Thought Content

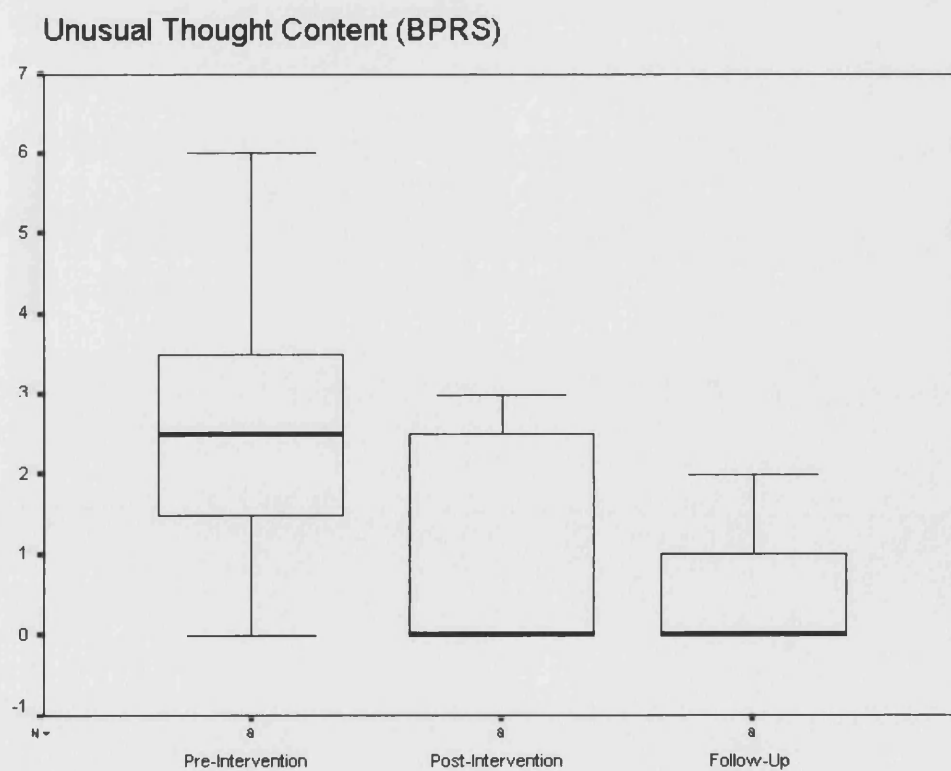
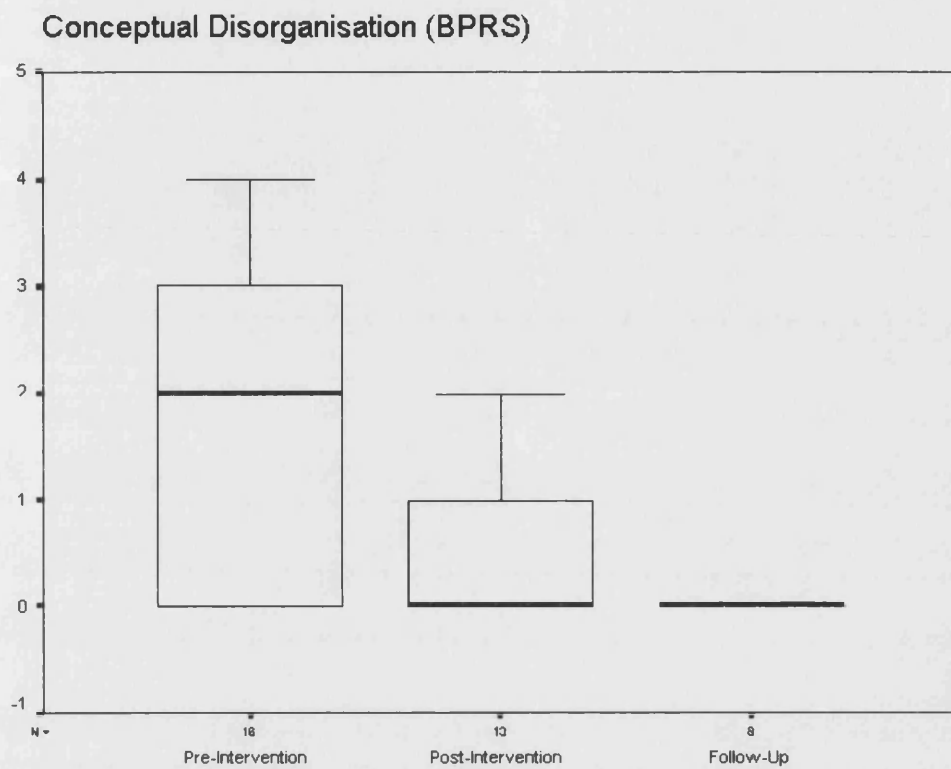
The shaded areas in Table 4.1 above indicate the three symptoms that were found to have the highest proportion of significant changes over the three time points.

During the active phase of the intervention (i.e. Pre-Intervention to Post-Intervention), the variables found to have the highest number of significant improvements were Unusual Thought Content (six participants, i.e. 46.15% of responders), Conceptual Disorganisation (five participants, i.e. 38.46% of responders) and Paranoid Ideation (five participants, i.e. 38.46% of responders). A number of other variables showed smaller numbers of participants who had significant differences in the active intervention stage. These included Psychoticism (four participants, i.e. 28.57% of responders); Depression – as rated in the BSI (four participants, i.e. 28.57% of responders); and Suspiciousness (three participants, i.e. 23.08% of responders). However, some variables that were measured showed few significant differences in the active treatment stage. These included Anxiety (no participants, i.e. 0% in BPRS and two participants, i.e. 14.29% in BSI) and Hostility (one participant, i.e. 7.69% in BPRS and two participants, i.e. 14.29% in BSI).

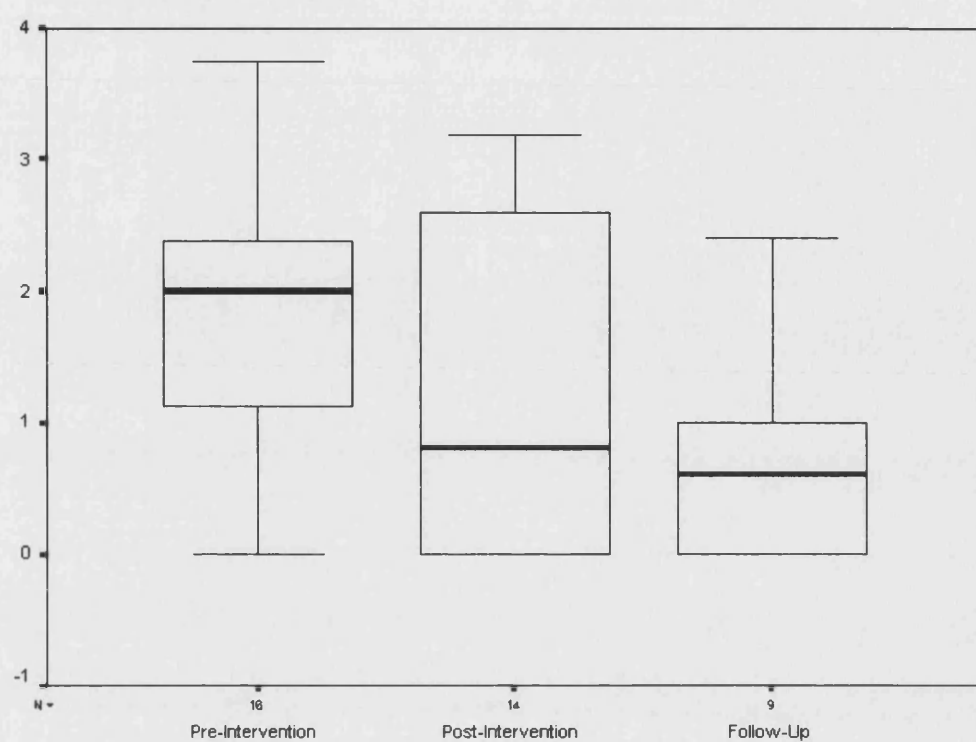
At Follow-Up, of the 8 participants available using the BPRS, four showed gains on Unusual Thought Content and three had gains on Conceptual Disorganisation from Post-Intervention. In terms of the 9 participants available for Follow-Up on the BSI, four had gains on Paranoid Ideation.

The box plots below (Figure 4.1) illustrate the changes found in these symptoms over the three time points. The graphs show that the median of the variables decreased over the three time points for Conceptual Disorganisation and Paranoid Ideation. In the cases of Conceptual Disorganisation and Unusual Thought Content, the median at Post-Intervention reached 0 and this was maintained at Follow-Up.

Figure 4.1 Box Plots of Psychiatric Symptomatology with Most Significant Changes



### Paranoid Ideation (BSI)



In summary, this study found that three positive symptoms (Unusual Thought Content, Conceptual Disorganisation and Paranoid Ideation) showed the highest number of participants who had significant changes during the active phase of treatment. These changes were maintained at Follow-Up in many of the responders. However, changes in Anxiety and Hostility were not found. Only moderate changes were found in the remaining symptoms that were measured. These included Depression, Psychoticism and Suspiciousness.

## 4.2 Insight

The second research question posed by this study was:

*Having received this personalised psychoeducation package, do participants change in particular areas of insight, namely, awareness of having a mental disorder, awareness of the achieved effects of medication and awareness of the social consequences of having a mental disorder?*

The results will be described below according to the two measures (SUMD and Insight Scale) respectively.

### 4.2.1 Scale to Assess Unawareness in Mental Disorder

The SUMD was analysed by subtracting Post-Intervention scores from Pre-Intervention scores and Follow-Up scores from Pre-Intervention scores. The study recognised that any decrease from a high score to a lower score represented some improvement in insight.



Appendix 17 outlines the change in scores from Pre-Intervention to Post-Intervention and from Pre-Intervention to Follow-Up in each of the 16 participants. Table 4.2 below indicates the number of participants found to decrease in scores over time for each of the three items. The table is divided into two halves: the first indicates changes from Pre-Intervention to Post-Intervention; the second denotes changes from Pre-Intervention to Follow-Up. The headings for each of the items have been condensed from “awareness of having a mental disorder” to “Mental Disorder”; “awareness of the achieved effects of medication” to “Medication”; and “awareness of the social consequences of having a mental disorder” to “Social Consequences”. It is noted that 13 participants were available for data collection at Post-Intervention and 8 were available at Follow-Up. These participants will be referred to as “responders”.

**Table 4.2      Number of Participants to have improved in insight on SUMD**

	<b>Pre-Intervention to Post-Intervention</b>	<b>Pre-Intervention to Follow-Up</b>
Mental Disorder	7	5
Medication	6	5
Social Consequence	7	4

Table 4.2 above indicates that, during the active phase of treatment, 53.85% of participants (7 out of 13 responders) improved on awareness of having a mental disorder (i.e. from Pre-Intervention to Post-Intervention). At Follow-Up, of the eight available participants, five were found to have improved. It is

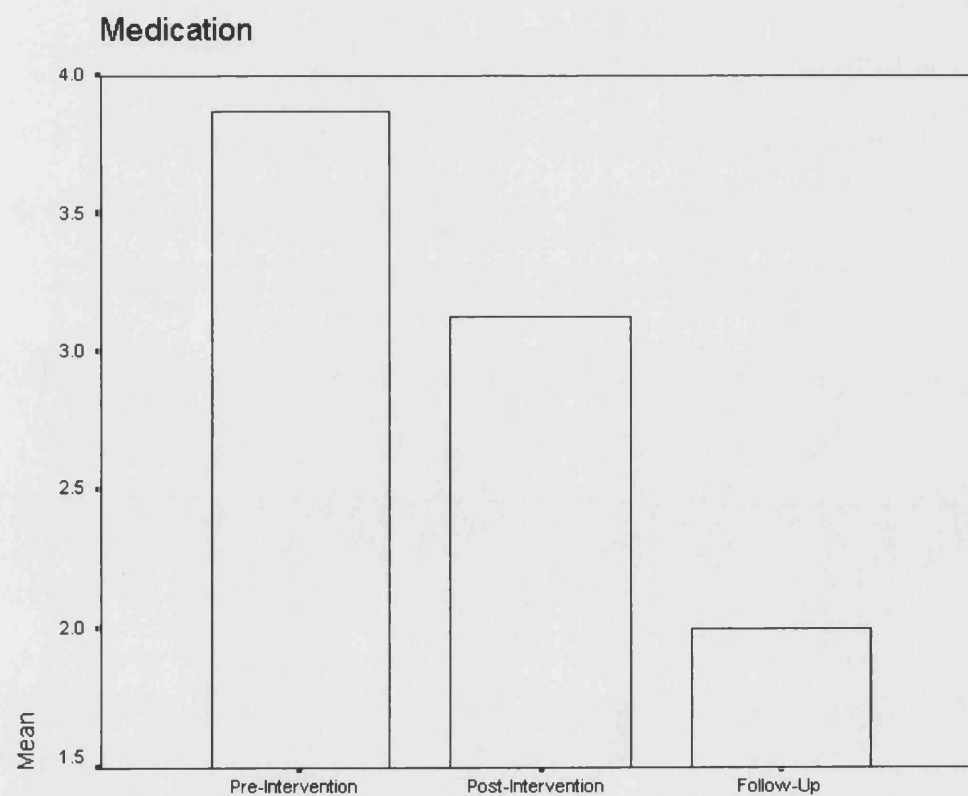
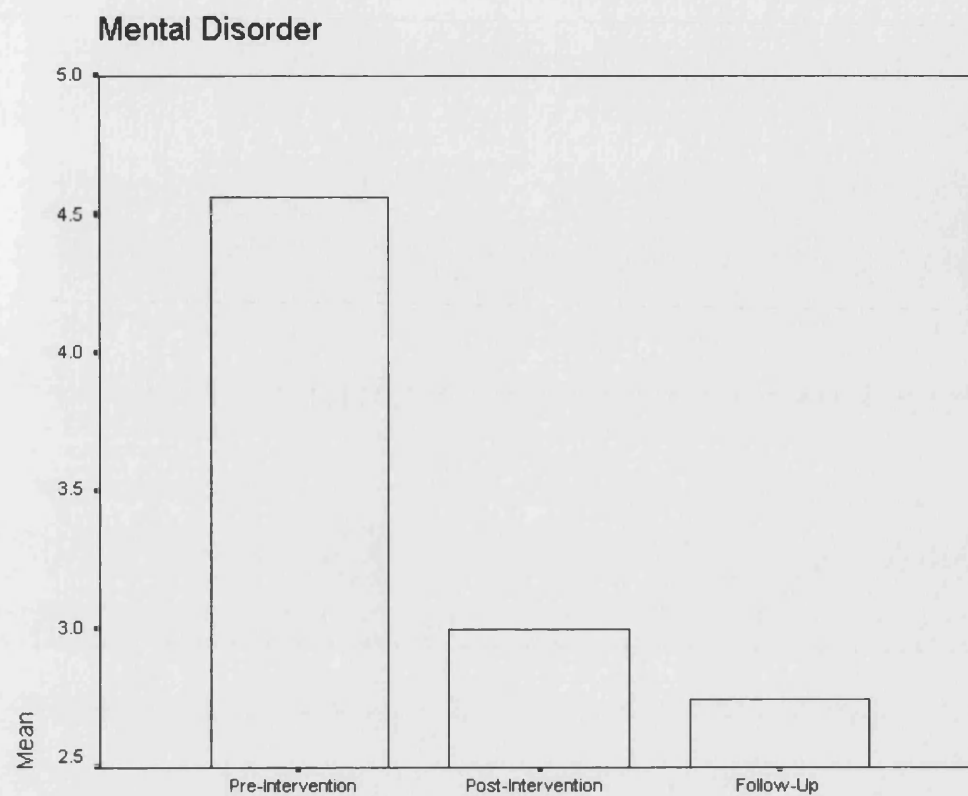
noted that all participants had a degree of unawareness of having a mental disorder at Pre-Intervention.

In terms of awareness of the achieved effects of medication, 46.15% of participants (6 out of 13 responders) improved from Pre-Intervention to Post-Intervention. At Follow-Up, this gain was found in five of the eight responders. Participant O sustained full awareness of the achieved effects of medication across the three time points.

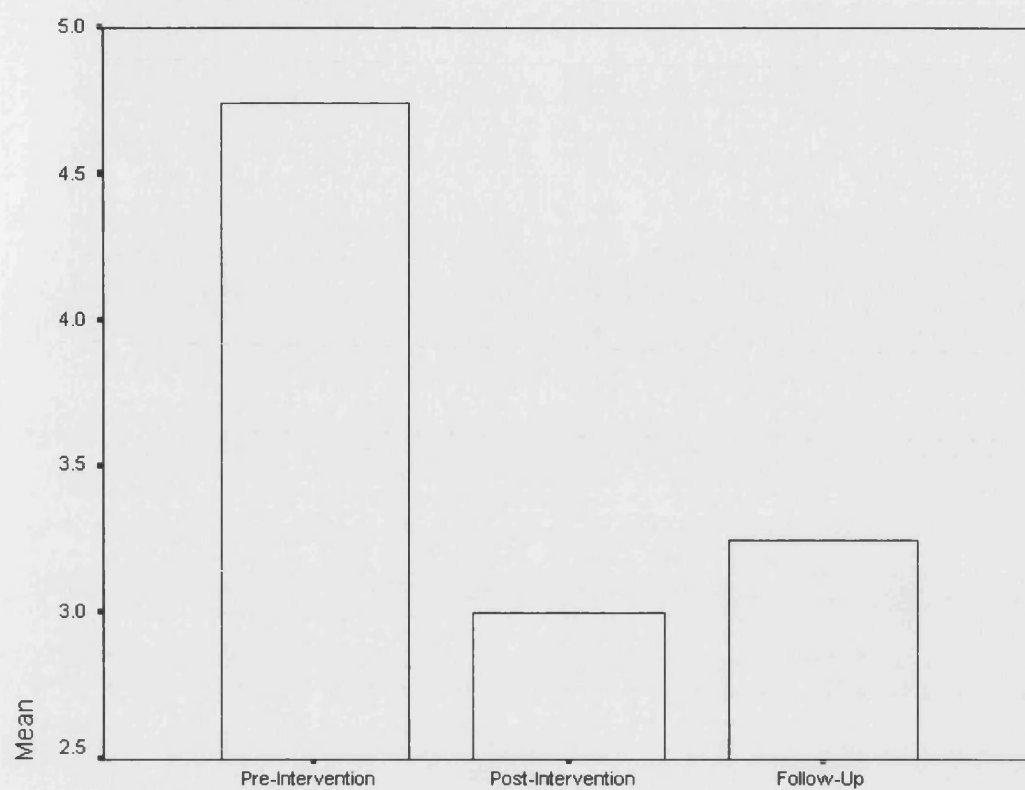
Finally, with regards to awareness of the social consequences of having a mental disorder, 53.85% of participants (7 out of 13 responders) improved from Pre-Intervention to Post-Intervention. This was upheld in four of the eight participants available at Follow-Up.

The bar graphs in Figure 4.2 below illustrate the change of scores over the three time points. They show the mean scores of all responders for each of the three time points. As can be seen, in the cases of awareness of having a mental disorder and awareness of the achieved effects of medication, the mean score consistently decreased over time. However, in the case of awareness of the social consequences of having a mental disorder, the mean at Follow-Up was slightly higher than at Post-Intervention, although the amount of change is negligible (i.e. 0.02 points on the scale).

Figure 4.2 Bar Graphs of Means of SUMD Items



### Social Consequences



It has been illustrated above that approximately 50% of participants improved on insight in at least one area following the psychoeducation intervention.

#### 4.2.2 The Insight Scale

This questionnaire was analysed using the Reliable Change Index. The differences between scores from Pre-Intervention to Post-Intervention and from Pre-Intervention to Follow-Up were considered. Appendix 18 states each participant's Reliable Change Index for both Positive and Negative Insight. The significant findings are illustrated in Table 4.3 below.

Table 4.3     Number of Participants with Significant Changes on the Insight Scale

	<b>Pre-Intervention to Post-Intervention</b>	<b>Pre-Intervention to Follow-Up</b>
Positive Insight	2	2
Negative Insight	1	0

The results show that two participants (A and C) had significant gains in Positive Insight from Pre-Intervention to Post-Intervention (RCI = 2.62 and RCI = 5.24 respectively). This was upheld on the Pre-Intervention to Follow-Up comparison for Participant C (RCI = 3.00). In addition, Participant F was found to have significant improvements on Positive Insight at Follow-Up (RCI = 3.00). Participant A's data was recorded as missing at Follow-Up due to his deteriorating mental state.

In terms of Negative Insight, Participant G's scores were found to significantly increase when comparing Pre-Intervention and Post-Intervention (RCI = 3.51). Participant G dropped out after Post-Intervention and missing data was recorded. As can be seen in Appendix 18, Participant J's scores were found to significantly decrease on Negative Insight from Pre-Intervention to Follow-Up (RCI = -2.34).

In response to the research question of whether insight changes following the administration of a personalised psychoeducation package, the results indicate that in the three facets of insight, as assessed by the SUMD (awareness of having a mental disorder, awareness of the achieved effects of medication and awareness of the social consequences of having a mental disorder) all significantly improved for approximately 50% of the participants over time. The results of the Insight Scale confirm, but add little to this finding.

#### **4.3 Illness Representations**

This study aimed to answer the following question:

*Does a personalised psychoeducation approach alter participants' perspectives on the cognitive representations of their illnesses?*

The specific cognitive representations of illness that were examined in this study were Consequences, Personal Control, Treatment Control and Illness Coherence. The direction of results that signified a positive change for all of

the above sub-scales was Post-Intervention scores higher than Pre-Intervention scores, or Follow-Up scores higher than Pre-Intervention scores. Appendix 19 details the Reliable Change Indices for each of the 16 participants on the IPQ-R.

Table 4.4 below highlights the number of participants who were found to have improved significantly from Pre-Intervention to Post-Intervention and from Pre-Intervention to Follow-Up. Furthermore, the table identifies each significant participant. As is illustrated, very few participants were shown to have any significant change. There were 13 participants available for data collection at Post-Intervention and 8 at Follow-Up. They will be referred to as “responders”.

**Table 4.4**      Number of Participants found to have Significant Findings in IPQ-R

	<b>Pre-Intervention to Post-Intervention</b>	<b>Pre-Intervention to Follow-Up</b>
Consequences	1 (D)	0
Personal Control	2 (F, H)	1 (F)
Treatment Control	1 (F)	1 (F)
Illness Coherence	2 (D, E)	1 (B)

Table 4.4 above indicates that a total of five out of 13 participants (38.46% of responders) showed significant changes on at least one sub-scale of the IPQ-R. Participant F had significant changes on more sub-scales than any

other participant (Personal Control and Treatment Control). These findings were maintained at Follow-Up. Of note is the finding of Illness Coherence as this does not seem to relate to increased insight. Neither Participant D nor E was found to increase on any area of insight as measured by the SUMD.

Appendix 19 also indicates participants who showed significant deterioration (i.e.  $RCI < -1.96$ ) on the four subscales. These results are presented in Table 4.5 below.

**Table 4.5**      **Number of Participants who Significantly Decreased on Sub-Scales of the IPQ-R**

	<b>Pre-Intervention to Post-Intervention</b>	<b>Pre-Intervention to Follow-Up</b>
Consequences	4 (A, B, L, O)	1 (O)
Personal Control	0	0
Treatment Control	1 (O)	0
Illness Coherence	1 (F)	0

A total of five out of the 13 responders (38.46%) significantly decreased on at least one sub-scale of the IPQ-R. Two of these Participants (B and F) significantly increased in some of the sub-scales. However, the sub-scales are measuring different cognitive representations and do not correlate (Moss-Morris et al., 2002).



In response to the research question of whether this psychoeducation programme altered participants' perspectives of the cognitive representations of their illnesses, the results of this study have been inconclusive. Five participants (i.e. 38.46% of responders) showed significant increases in their scores on at least one cognitive representation. However, the same number significantly deteriorated on at least one cognitive representation.

#### **4.4 Compliance**

This study aimed to answer the following research question:

*Following receipt of this psychoeducation intervention, do participants change in areas of treatment compliance, namely, awareness of the achieved effects of medication; feelings of personal control over psychosis; and the attitude that treatment will improve their illness?*

The concept of "Compliance to Treatment" was operationalised for the purpose of this study. It included the item entitled, "current awareness of the achieved effects of medication" from the SUMD; and two items from the Illness Perception Questionnaire – Revised (IPQ-R): "Treatment Control" and "Personal Control". Appendices 17 and 19 detail each participant's scores on these items. In terms of the research question mentioned above, participants had to show significant improvements in all three items to be considered compliant with treatment.

Only one participant, F, showed significant improvements in all of the above variables. These findings were maintained at Follow-Up. Table 4.6 below details the results of Participant F.

Table 4.6 Overview of Participant F's results for Compliance

	<b>Pre-Intervention to Post-Intervention</b>	<b>Pre-Intervention to Follow-Up</b>
Achieved Effects of Medication	2* (shift from unaware to somewhat aware)	4* (shift from unaware to aware)
Treatment Control	RCI = 2.78**	RCI = 2.42**
Personal Control	RCI = 2.42**	RCI = 2.43**

\* improvement in insight

\*\* significant finding (i.e. RCI >1.96)

As can be seen, Participant F fulfilled the criteria for improvement in compliance. It is suggested that the administration of the psychoeducation package contributed to this improvement.

One other participant, H, fulfilled two out of three criteria to meet compliance (current awareness of the achieved effects of medication and Personal Control). Significant changes were found between Pre-Intervention and Post-Intervention. However, Participant H dropped out after Post-Intervention. The table below outlines the results for Participant H. It is suggested that Participant H partially fulfilled criteria for improved compliance, as operationalised for this study.

Table 4.7 Overview of Participant H's results for Compliance

	Pre-Intervention to Post-Intervention	Pre-Intervention to Follow-Up
Achieved Effects of Medication	4* (shift from unaware to aware)	-
Treatment Control	RCI = 0.35	-
Personal Control	RCI = 2.42**	-

\* improvement in insight

\*\* significant finding (i.e. RCI >1.96)

- missing data

In response to the research question regarding whether participants change on compliance following the administration of this personalised psychoeducation package, the results have shown that only one participant in the sample of 16 improved on compliance over the course of treatment. One further participant partially improved on compliance. The study has therefore found that the majority of participants do not improve on compliance following the receipt of psychoeducation.

#### 4.5 Satisfaction

The final question posed by this study was:

*What are participants' feelings regarding their satisfaction with treatment following the receipt of a psychoeducation programme?*

The design of this study did not allow for comparisons of satisfaction Pre-Intervention to Post-Intervention as satisfaction was not measured at Pre-Intervention. The total scores of the measure used will be reported (regarding overall satisfaction of care in the unit), together with quotes from participants regarding their experiences of the psychoeducation package.

Appendix 20 indicates the scores of each participant on the UKU-ConSat. At Post-Intervention, the mean total score was 2.29 (sd = 7.00). At Follow-Up, the mean of the total score was 2.00 (sd = 7.26). The means of scores at both Post-Intervention and Follow-Up were positive, indicating some satisfaction with overall care at the base unit.

Table 4.8 below indicates the participants who were dissatisfied with the treatment they received whilst residing at the base unit.

**Table 4.8 UKU-ConSat Scores for Participants who were Dissatisfied with Care**

	<b>Post-Intervention</b>	<b>Follow-Up</b>
D	-10	-10
G	-12	-
P	-4	-
J	3	-2
- missing data		

There were 14 participants in the sample assessed for satisfaction at Post-Intervention as two had dropped out after Pre-Intervention. A total of nine participants were available for assessment at Follow-Up. These participants will be referred to as “responders”.

The results indicate that, immediately following the active phase of treatment, 11 of the 14 responders (78.57%) were satisfied with their overall care whilst at the base unit and only 3 participants (21.43% of responders) were dissatisfied. At Follow-Up, 7 of the 9 responders expressed a degree of satisfaction with their care and only two were dissatisfied.

As can be seen in Table 4.9 (Case Summary), there was no common area of improvement amongst the four participants who were dissatisfied with their care. However, three of the four participants (D, G and P) did not improve on any aspect of insight as measured by the SUMD.

Whilst administering the UKU-ConSat, information was recorded regarding participants' satisfaction of the psychoeducation package (separate from routine care). These have been grouped into two broad themes of “Positive Feedback” and “Negative Feedback”. Themes have been elicited from each of these broad categories and are highlighted below in the form of quotations. Examples of participants' comments in each theme are cited below.

#### 4.5.1 Positive Feedback regarding Psychoeducation Package

- *This approach should be accessible to all patients*

“I think everyone should get it. It clarifies to people where they are, where they’ve come from and where they’re going in terms of their illness and treatment”. (Participant F)

“It should be given to everyone. It’s better to talk to *name of researcher* than just to patients – you give better advice”. (Participant L)

- *Information regarding local resources and services was useful*

“It was very useful. Especially the telephone numbers like the Citizens Advice Bureau”. (Participant L)

“The practical advice was the most helpful. Especially the contact details for the Personal Advisor Service. It’s good to know where to get help with getting a job”. (Participant J)

- *The benefits of being able to express views to a member of staff*

“They actually tell you what is wrong with you. *Name of researcher* explains the reasons why you feel like you do. She tells you stuff the doctors don’t tell you.” (Participant P)

“The best thing about it was to be understood by a member of staff, although it was difficult and uncomfortable at times”. (Participant J)

#### 4.5.2 Negative Feedback regarding Psychoeducation Package

- *Problems in feeling understood*

“It was frustrating at first, trying to get my message across”. (Participant J)

“Some of the information in the booklet was a bit muddled. For example, she wrote the wrong information about what happened in *name of previous inpatient unit* – I know it happened”. (Participant D)

▪ Problems in retaining the information in the booklet

“I can’t remember much of what she talked about. I haven’t read the booklet since”. (Participant I).

“Its early days. I don’t know if it will be useful”. (Participant I)

Of note in the above quotes is the comment by Participant P regarding the benefits of being able to express himself to a member of staff. Participant P’s total scores for the UKU-ConSat described a degree of dissatisfaction in his overall care at the base unit (as is noted in Table 4.8). However, he was enthusiastic about his experiences of receiving the psychoeducation package and had clearly processed this as a separate entity to his overall care.

In response to the research question concerning participants’ feelings regarding their satisfaction of treatment following receipt of this psychoeducation package, the results suggest that the majority of responders (78.57%) showed a degree of satisfaction with their care at the base unit in general. Satisfaction with overall care was also found in the majority of responders at Follow-Up. When considering the comments of participants regarding the psychoeducation package specifically, results were mixed. There were both positive and negative comments.

## 4.6 Case Summaries

Although it is not possible to draw general conclusions of the utility of this psychoeducation programme due to the small sample size and lack of control group, it is useful to consider the outcomes for each individual participant.

This section will be divided into two parts: firstly it will provide a summary table detailing gains by each participant in the five outcome areas. Secondly, it will provide two brief case illustrations: one of Participant F who arguably obtained the best outcomes in comparison to the rest of the sample; and Participant D who responded the least well of those who completed data at all three time points.

### 4.6.1 Gains in the Five Outcome Areas

Table 4.9 below provides a summary of each individual participant and highlights whether or not significant changes or positive results (i.e. in the case of satisfaction) were found in at least one sub-scale of the five main areas assessed. In the case of Compliance, positive results have been indicated if the participant fulfilled all three criteria. For those who obtained positive results in one or two of the three criteria of compliance, their gains are indicated as Illness Representations or Insight. The table is organised in ascending order of those who obtained the most improvement to those who did not improve. It is noted that Participants K and N dropped out after Pre-Intervention and therefore no gains have been found.



The first column of the table states the confidential label of each participant.

The second column indicates each participant's gender. The column labelled, "Illness Reps" is an abbreviation of "Illness Representations".

Table 4.9 Case Summary

		<i>Ethnicity</i>	<i>Psychiatric</i>	<i>Insight</i>	<i>Compliance</i>	<i>Illness</i>	<i>Satisfaction</i>
			<i>Symptoms</i>			<i>Reps</i>	
F	Male	White	*	*	*	*	*
A	Male	Black	*	*	-	*	*
B	Male	White	*	*	-	*	*
H	Male	White	*	*	-	*	*
L	Male	White	*	*	-	*	*
O	Male	Mixed	*	*	-	*	*
C	Male	Asian	*	*	-	-	*
M	Male	Black	*	*	-	-	*
E	Male	Black	-	-	-	*	*
I	Male	White	-	*	-	-	*
J	Male	White	*	*	-	-	-
D	Male	White	-	-	-	*	-
G	Male	White	*	-	-	-	-
P	Male	Asian	*	-	-	-	-
K	Fem	White	-	-	-	-	-
	ale						
N	Male	White	-	-	-	-	-

\* denotes significant change on at least one sub-scale.

Table 4.9 above indicates that 6 participants (37.50% of the sample) were found to significantly improve or show positive results on at least one sub-scale of all four areas; two improved in three areas (12.50% of the sample); three improved in two areas (18.75% of the sample); three improved in one area (18.75% of the sample); and two (12.50%) did not improve in any area. In summary, 87.50% of the sample improved in at least one sub-scale of one area of outcome, although it is noted that change in only one sub-scale may be viewed as having occurred by chance alone.

#### 4.6.2 Brief Case Illustrations

This section will provide brief case illustrations of Participants F and D for the purposes of understanding both their improvement and lack of improvement in greater detail. Demographic and personal details have been altered in order to protect confidentiality.

##### 4.6.2.1 *Participant F*

Participant F is a White, single man in his early 40s. He has had a diagnosis of Paranoid Schizophrenia for 14 years. He was admitted to hospital due to non-compliance with medication and physical attacks on another patient in a Community Centre. At the initial assessment, Participant F stated that prior to his admission, he was having difficulty in sleeping, he was neglecting his self-care and he was unable to look after his home. He reported that he felt that at this time, he was either going through a “Psychological Evolution”, in which his thinking became clearer and faster, or he had a mental illness.

Participant F had a history of violent behaviour and had stabbed a man approximately 20 years prior to his present admission. He believed that this man was trying to extort money from Participant F.

In terms of his future goals, Participant F was keen to work. He believed that he should begin to earn his own money and to stop relying on benefits.

When asked about his diagnosis at the initial assessment, Participant F said that he had been told that he had Paranoid Schizophrenia, but that he disagreed with this and felt that his problems were “a lack of discipline, lack of self-regulation and self-denial”. During data collection, Participant F informed the researcher that he was undergoing his longest period of being compliant with medication since he received his diagnosis.

When relaying information from his personalised booklet to him, Participant F did not argue with the researcher, but instead questioned some of the information and showed interest in the responses. It seemed that he was keen to take on an alternative perspective to his previously held beliefs regarding his mental state.

In the case of Participant F, prior to the start of the intervention, he reported that he considered that he might have had a mental illness. He was therefore prepared to engage in discussions regarding psychosis. He showed improvement in all areas of insight, in his Personal and Treatment Control of illness, but not in the Consequences and Illness Coherence representations.

It may have been that the increase in insight in Participant F led to uncertainty in his beliefs about his illness and its consequences.

#### 4.6.2.2 *Participant D*

Participant D is a White, single man in his mid-thirties. He has had a diagnosis of Paranoid Schizophrenia for the past 7 years. He had had four previous episodes prior to his present admission.

At the initial assessment, Participant D reported that he was at the base unit for “security purposes”. He stated that he had witnessed a drug operation and that he was under surveillance as a result. Participant D also informed the researcher, “All NHS workers are army trained” and that he felt unsafe in the base unit. The time of the assessment coincided with President Bush’s visit to the UK. Participant D attributed his surveillance and heightened security to this visit.

Prior to his admission, Participant D reported that he had been working throughout the night and had been getting little sleep. Furthermore, he stated that he smoked six or seven “joints” of cannabis per week.

When asked about his diagnosis, Participant D stated that he was not unwell. He said that his Psychiatrist had told him that he had Paranoid Schizophrenia, but that a private Psychiatrist had disagreed.

Whilst delivering the psychoeducation package, Participant D was highly critical of all suggestions made regarding psychosis. He felt sure that he knew why he was at the base unit, the consequences of his admission and his goals for the future. Participant D's views did not shift over the course of the three-session intervention.

Participant D denied the existence of any illness for the duration of the intervention. His delusional system was complex and he used any evidence available to him (e.g. President Bush's visit to the UK) to erroneously confirm his beliefs. He was therefore not amenable to suggestions proffered during the psychoeducation package.

In terms of his results, of note is that Participant D significantly improved on both Consequences and Illness Coherence in the IPQ-R. However, he showed no improvement on any area of insight over the three time points. This suggests that Participant D's engagement was minimal and that he was not socialised to the process of psychoeducation.

In conclusion, it is suggested that the intervention was offered at the optimal time for Participant F and not for Participant D. Participant F was able to engage, develop a relationship with the researcher and both were working towards shared goals. It is accepted that the assessment of the most appropriate time for intervening with acutely psychotic patients is beyond the scope of this study.

## 5.0 DISCUSSION

This study aimed to assess the utility of a novel personalised psychoeducation approach for a group of inpatients in the acute stages of psychosis. This study recognises that the conditions that lead to therapeutic change in psychosis are not fully understood. The goal of the psychoeducation package was to socialise acutely ill patients to the therapy environment and allow them to make small gains in areas including insight, symptom reduction and compliance. Furthermore, this psychoeducation package may be seen as a precursor to future, in-depth therapies for this population. This study accepts that the design utilised does not have the methodological rigours to control for threats to internal validity, including regression to the mean, endogenous change and interfering events (Cook & Campbell, 1979). It was considered that a simple design was appropriate for assessing the utility of a new intervention. More sophisticated designs will be required in the future to illuminate key variables.

The results below are discussed in a style that describes the preliminary signs of clinical utility of the psychoeducation package, whilst acknowledging the limitations of the design. The results of the study are mixed. However, signs of positive change did occur in approximately one third of participants in at least one sub-scale of the five main outcome areas: psychiatric symptomatology, insight, compliance, illness representations and satisfaction. The approach was only successful in augmenting change on all outcome measures for one participant. In terms of insight, approximately a half of the participants available for data collection increased in at least one

dimension of insight. However, the results suggest that only one participant could be considered to be compliant with treatment. Furthermore, over a quarter of participants showed significant changes in at least one of their illness representations of psychosis. Finally, satisfaction with overall treatment on the base unit was found in three quarters of participants. The results must be reviewed in the context of the impact of this psychoeducation package together with routine clinical care, as it is not possible to separate the effects of each.

This Discussion is divided into four sections. The first will consider the above results in more detail and comment on their relationship to previous literature. The second section will outline some methodological considerations and limitations of the present study. The third section will detail both preliminary scientific and clinical implications of the present research. The final section will outline the main conclusions of the study.

## **5.1 Overview of Results**

A review of the five main outcome areas will be detailed below.

### **5.1.1 Psychiatric Symptomatology**

Approximately one third of participants' scores were found to significantly decrease on the following positive symptoms: Conceptual Disorganisation, Unusual Thought Content and Paranoid Ideation.



The common aspect of these three symptoms is disordered thought processing. They are all contained within the category of “positive symptoms” (Andreasen, 1984) and form part of the psychotic experience.

In reference to the literature on psychoeducation, only two studies have reported changes in psychiatric symptomatology. These were Goldman and Quinn (1988) and Kelly and Scott (1990). The changes found in this study were similar to those found by Kelly and Scott, in terms of the decrease in positive symptoms.

Kelly and Scott (1990) provided an individualised psychoeducation package, personalised to each participant, all of whom were outpatients. This differed from Goldman and Quinn (1988) who administered group sessions of psychoeducation to inpatients. It may be that the provision of personalised information regarding specific symptoms allows the participant to reappraise, review and reconceptualise them, thereby decreasing their intensity. However, the mechanisms by which symptom reduction may occur remain unclear.

Whether these results are due to the psychoeducation package or the effects of medication remains unanswered. Lewis (2002) stated that negative symptoms are rarely modified by anti-psychotic medication and that positive symptom change is often observed early when anti-psychotic medication is administered. All of the participants in the present study were compliant with taking anti-psychotic medication (as monitored in a hospital setting).

In a study investigating early symptom change following the initiation of anti-psychotic medication, Correll, Malholtra, Kaushik, McMeniman and Kane (2003) found that the first factor of the BPRS to show change was “thought disturbance”. This factor includes both Conceptual Disorganisation and Unusual Thought Content. When comparing the findings of Lewis (2002) and Correll et al. (2003) to this research, it may be argued that the symptom changes found in this study might be due to anti-psychotic medication alone. Thus, it is not possible to state whether the psychoeducation package contributed to the reduction in positive symptoms in up to approximately one third of participants.

In summary, although the findings of this study support those of Kelly and Scott (1990), research into the effects of anti-psychotic medication on people with psychosis suggested that the reduction found in positive symptoms might be due to medication alone. As the sample size is small, it is not possible to deliver firm conclusions in this area.

#### 5.1.2 Insight

The findings of this study indicated that approximately a half of participants improved on at least one area of insight. These results are similar to those of Macpherson et al. (1996), who found improvement in insight following a three-session intervention. The approach utilised by these authors was an individualised psychoeducation package. Conversely, Merinder et al. (1999) did not find an increase in insight following an 8-session group format. It may again be suggested that the individualised approach offered in this study and

in that by Macpherson et al. (1996) contributed to the increase of insight in some of the participants.

The psychoeducation package delivered in this study focused strongly on reviewing participants' views of their illness before offering alternatives (see Kingdon, 1998; Tarrier and Barrowclough, 1986; Yalom, 1975). It could be argued that the package fulfilled this principle successfully and allowed participants' insight into psychosis to increase over time. However, as the sample is small, it is stressed that these results may also be due to the effects of medication or of the hospital environment.

In summary, the finding of this study that insight significantly improved for approximately 50% of participants in at least one area is similar to a previous finding by Macpherson et al. (1996). The increases found in insight may have evolved from the personalised approach proffered to participants.

### 5.1.3 Illness Representations

The results of this study indicated that approximately one third of participants altered their illness representations in at least one area. These included the long-term consequences of having psychosis; the extent to which the individual could use personal control to cope with the illness; the degree to which the individual believed that treatment (medication or otherwise) could be helpful in controlling the illness; and the participant's perceived ability to comprehend the illness.

A possible explanation for the lack of change in illness representations over time is that many participants denied that they had an illness. This resulted in participants answering items on the Illness Perception Questionnaire – Revised (Moss-Morris et al., 2002) as if they did not have an illness. Pre-Intervention scores were therefore low for several participants.

An interesting finding of this study is that those who significantly decreased from Pre-Intervention to Post-Intervention on Illness Coherence and Consequences were those who scored better on insight measures than those who increased from Pre-Intervention to Post-Intervention on these illness representations. A suggested reason for these changes is that those who have more insight over time become less certain of the course of their illness. This argument is strengthened when considering one of the participants whose scores on Illness Coherence increased from Pre-Intervention to Post-Intervention (Participant D). He had a firm delusional system and responded to items on the Illness Coherence subscale at Post-Intervention with certainty.

Similar to the above scenario, in reference to the Consequences subscale, those who increased in scores from Pre-Intervention to Post-Intervention had less insight than those who decreased from Pre-Intervention to Post-Intervention. It is suggested that the psychoeducation package may have had the effect of allowing those with more insight to feel empowered about their futures than those with less insight. This may have led to them feeling less certain about the negative consequences of psychosis.

In summary, the results of this study have found that equal numbers of participants significantly improved and significantly deteriorated in their illness representations over time. A possible explanation of this may be that changes in the Illness Coherence and Consequences variables may be related to both deterioration and improvement in insight, dependent on whether or not participants accepted the existence of an illness.

#### 5.1.4 Compliance

This study found that only one participant fulfilled all of the criteria of compliance (as operationalised for this study). It could be argued that the follow-up period of this study was too short to find distinct changes in cognitive representations of illness for the majority of participants.

Furthermore, all the participants resided in hospital throughout the administration of the psychoeducation package and were all under a section of the Mental Health Act (1983). It was therefore difficult to accurately measure compliance whilst medication was not being independently controlled, but rather was given by nursing staff. In addition, if participants had refused medication, it would have been forced on them due to their legal status. The measurement of compliance by attitudinal changes was therefore deemed most appropriate for the sample and the clinical setting. It is difficult to compare the findings regarding compliance from this study to previous studies due to differing means of operationalising the construct.

In summary, it is argued that the follow-up period for this study was too short to measure changes in compliance accurately. Furthermore, in retrospect, it

was unrealistic to assume that participants would change their attitudes towards compliance in a short period of time and whilst in hospital. A longer follow-up period may have found different results.

#### 5.1.5 Satisfaction

This study found that approximately three quarters of participants were satisfied with the overall care that they received at the base unit.

Furthermore, this study quoted participants' views of the psychoeducation package. These comments were broadly categorised into positive and negative feedback. Within the positive feedback, themes emerged regarding the accessibility of the package, the utility of information about local resources and the valued experience of being listened to by a member of staff. The negative feedback category included themes of not feeling understood and problems in retaining information from the booklet.

It is important to note that in some cases, the total score on the UKU-ConSat did not correlate with the comments made by the participant. An example of this was Case P. He scored -4 at Post-Intervention and Follow-Up on the UKU-ConSat. This is suggestive of a degree of dissatisfaction. However, when asked specifically about his views of the psychoeducation package, he said,

*"They actually tell you what is wrong with you. [Name of researcher] explains the reasons why you feel like you do. She tells you stuff the doctors don't tell you".*

This highlights that some participants viewed their overall care at the base unit as separate and different from participating in this study.

In reference to previous literature, the comments by Case P and others that they valued the personal contact from a member of staff and the chance to disclose their beliefs about their experience are similar to those found by Kemp and David (1996b). It is suggested that this was created through the use of a collaborative therapist-patient relationship, as was advocated by Kuipers (1996) and Kingdon (1998).

It is not possible to compare the results of this study to previous research considering psychoeducation and satisfaction. The construct was measured differently to the present study, making comparisons impossible (see Merinder et al., 1999; Kelly & Scott, 1990).

The development of the psychoeducation package relied heavily on the findings of satisfaction studies involving medical outpatients. Although this study is unable to determine whether or not satisfaction increased from Pre-Intervention to Post-Intervention, it is able to conclude that the majority of participants described a degree of satisfaction with their care at Post-Intervention. It is suggested that the attempt of this psychoeducation package to empower each participant, show empathy and involve him in designing the final manual led to a degree of satisfaction in most cases (see Ley, 1988).

In summary, this study did not compare ratings of satisfaction from Pre-Intervention to Post-Intervention, but found that approximately three quarters of participants showed a degree of satisfaction with their care at Post-Intervention. The use of research on physical health patients' satisfaction with healthcare has been imperative in the design and delivery of this psychoeducation package.

## **5.2 Methodological Considerations / Limitations**

This section of the Discussion will evaluate the design of this study; highlight considerations regarding some of the measures; and review the statistical analysis used.

### **5.2.1 Design**

This study employed an open trial without a control group, with each participant serving as his own control. It is considered efficient to use a simple design, such as the one used in this study, when testing a new intervention prior to investing in a large-scale study. Furthermore, Barlow and Hersen (1984) noted a range of advantages in using a simple design, including avoiding the ethical issue of withholding the intervention from a control group. They further argued this by stating that in many clinical settings, professionals use any treatment, no matter how inadequate, for patients who are visibly struggling with their illness. It is therefore more appropriate to assess the utility of the treatment package on a small group than to administer the intervention without any examination of its validity.



However, the limitations of undertaking a simple design must be considered.

One problematic area is the inability of this type of design to generalise findings, i.e. across participants, therapists and settings (Barlow & Hersen, 1984). This indicates weak external validity. It is noted that it is not possible to identify the usefulness of the intervention if conducted by therapists other than the main researcher of this study or if administered in different settings. The results must be considered within these restrictions.

Furthermore, this design does not allow for consideration of the effects of the intervention separate from routine care, as there was no control group. All patients on the base unit were administered with anti-psychotic medication, received support from nursing staff and therapeutic interventions from Occupational, Art and Drama Therapists. The results must therefore be considered in the context of the effects of the psychoeducation package together with routine care and not in isolation.

A further limitation is that this study cannot make firm conclusions about the suitability of the psychoeducation package for certain individuals in terms of their age, gender, diagnosis, duration of illness or number of previous episodes of illness. However, it is possible to hypothesise and suggest the direction of future studies on the basis of the findings (Kiesler, 1971).

As a result of the difficulties of recruiting and engaging participants with acute psychosis, a number of compromises of the design and methodology of the study were undertaken. It would have been preferable to recruit both

intervention and control groups, but soon after data collection began, it became clear that this would not be possible. An alternative design would have been a multiple single case study, assessing multiple baselines following each intervention session and comparing this with Post-Intervention and Follow-Up scores. However, it was felt that it would be both impractical and unethical to take more intrusive measures with acutely ill participants. It was therefore decided that an open trial without a control group, with each participant serving as his own control was the most appropriate means of assessing the effects of this intervention, together with routine care, on this sample.

In summary, it is argued that the use of an open trial without a control group was appropriate in this study as it creates research questions for future larger scale studies. However, limitations of this design must be taken into consideration when interpreting results, including lack of generalisability; the combination of the intervention and routine care; and the inability to conclude the suitability of the personalised psychoeducation package to specific individuals.

### 5.2.2 Sample

The sample was a group of consecutively referred patients to a Psychiatric Intensive Care Unit. Although only one participant did not have a diagnosis of Schizophrenia and another was the only female member of the sample, these participants were included as the sample was deemed to be clinically relevant and represented the reality of the setting. The drop-out rate at

Follow-Up was high. This was partly a function of the majority of participants being discharged or transferred from the base unit. However, every effort was made to contact all participants for the Follow-Up. In the two cases when participants dropped out after Pre-Intervention, letters were sent to offer them the opportunity to debrief about their experiences. These participants chose not to meet again with the researcher.

A number of limitations of the sample must also be highlighted. Firstly, the sample was somewhat heterogeneous, in terms of age, number of previous episodes of psychosis and duration of illness. Due to the small sample size, it has not been possible to consider which of these variables best predicts good outcome following the psychoeducation package.

Secondly, those who refused to participate in the study may have responded differently to the intervention to those who agreed. This is described as a type of sampling bias that may have affected the results. It is speculated that those who were willing to participate may have had higher levels of insight and satisfaction prior to the intervention than those who declined to be recruited to the study. These limitations have contributed to the lack of external validity of this study. Results must only be considered in the context of those who participated and cannot be generalised to the entire target population (i.e. all people with acute psychosis in psychiatric intensive care units).

### 5.2.3 Measures

Some strengths of this study are that a range of different measures and a variety of methods of assessment were used, including observer-rated, self-report and semi-structured interviews. Barker et al. (2002) stated that it is important to use different methods of assessment as the same methods have a tendency to correlate together, even when they are assessing different constructs. This sub-section will review each of the measures in turn and comment on their utility in this study.

#### 5.2.3.3 *Brief Psychiatric Rating Scale (Overall & Gorham, 1962) and Brief Symptom Inventory (Derogatis, 1993)*

Both of the above measures are well known and widely utilised in Psychological and Psychiatric literature. They have been used in a number of studies on psychoeducation for people with psychosis (e.g. Kelly & Scott, 1990; Atkinson et al., 1996). The use of both observer-rated and self-report measures of psychiatric symptomatology was a strength of this study.

A limitation of this study is that two members of staff rated the BPRS (a Psychiatrist and a Consultant Clinical Psychologist) and inter-rater reliability scores were not obtained. There is therefore a risk that some participants were rated as being less acute than others when this may not have been the case. However, the Psychiatrist rated the majority of participants (12 participants were rated by the Psychiatrist and 4 were rated by the Consultant Clinical Psychologist). This allowed for a degree of consistency amongst most participants.

In summary, this study utilised two highly reported measures, using different methods, to assess psychiatric symptomatology. It is limited in the lack of inter-rater reliability between assessors of the BPRS.

#### 5.2.3.2 *Scale to Assess Unawareness in Mental Disorder (Amador et al., 1993)*

The SUMD assesses insight as a multidimensional phenomenon. It is suggested that this multidimensional perspective of insight has been useful in this study. In particular, this study was able to use scores of awareness of the achieved effects of medication as part of the operationalisation of the construct 'Compliance'.

A possible limitation of the SUMD is that it is reliant on the view of one rater and scores are calculated on the basis of a brief interview. Perhaps it would have been useful to incorporate corroborative reports from nursing staff, who have the most regular contact with participants in comparison with all other members of the Multi-disciplinary Team. This would have acted as inter-rater reliability of the results.

In summary, the SUMD has been a valuable tool in the assessment of both insight and compliance in this study. However, it is scored on the basis of the subjective experience of the rater following a brief interview.

### 5.2.3.3 *The Insight Scale (Marková & Berrios, 1992)*

The Insight Scale was included in this study as it is one of the few self-report measures of insight available. The findings from the Insight Scale have added little to the results from the SUMD. This section will consider the Insight Scale in further detail and possible reasons for the lack of participants showing improvements on this measure.

Constable, Lopez-Ibor, Kemp and David (1998), when comparing a number of insight measures, found that the Insight Scale by Marková and Berrios (1992) did not correlate with any other scale. It seems therefore that this scale measures a different construct to the SUMD by Amador et al. (1993).

The Insight Scale scores insight as either positive or negative. Positive insight items included, "My condition can be treated by medicines" and "I understand why other people think I should be in hospital". Negative items included, "Mental illness does not exist" and "Someone is controlling my mind". It could be argued that the positive items indicate some degree of insight, whereas the negative category highlights lack of insight. This therefore suggests that the Insight Scale is failing to measure insight as a multidimensional phenomenon, but considers it as a unitary concept, based on the number of items in the positive category answered appropriately. It is suggested that Positive insight may be a similar construct to "awareness of having a mental disorder" in the SUMD. This study found that two participants improved on positive insight. These participants also improved on "awareness of having a mental disorder" in the SUMD.

The disadvantages of measuring insight as a categorical, or unitary concept are that it is not possible to assess whether participants can attribute their unusual experiences to a mental illness, despite accepting anti-psychotic medication. In this study, participants who showed significant increases on Positive insight on the Insight Scale may therefore have only partial awareness into their difficulties. However, in using the Insight Scale, it is not possible to identify the specific aspects of insight of which the participants are aware. This is a limitation of using the Insight Scale with this sample.

Since developing this study, a revised version of the Insight Scale has been published (Marková et al., 2003). The present study had been finalised by the time of publication of the revised scale and it was too late to include it in this study. Marková et al. (2003) found that the revised scale correlated with the insight scale incorporated in the Present State Examination (Wing, Cooper & Sartorius, 1974, cited in Marková et al., 2003). The revised version of the Insight Scale appears to be a more robust measure than the original scale. It would have been interesting to determine whether or not different results would have been found from this study with the use of the new version.

In summary, although Marková and Berrios (1992) stated that the Insight Scale considers a multidimensional concept of insight, it has been argued above that this scale does not cover the concept adequately.

#### 5.2.3.4 *Illness Perception Questionnaire – Revised (Moss-Morris et al., 2002)*

The IPQ-R is a tool to assess the Self-Regulatory Model (Leventhal et al., 1984). Although it has not previously been used on a sample of people with psychosis, Lobban et al. (2003) suggested that the Self-Regulatory Model could appropriately be attributed to psychosis. Furthermore, a modified version of the IPQ (Weinman, Petrie, Moss-Morris & Horne, 1996) was used in a study to assess illness perceptions of carers of people with Schizophrenia (Barrowclough, Lobban, Hatton & Quinn, 2001).

Intuitively, the IPQ-R seemed to be a useful tool to use with a group of inpatients with psychosis. In retrospect, the follow-up period of this study (six weeks) was possibly too short to find change in any of the illness representations. It is suggested that a longer follow-up period in which participants move from the acute stages of illness to more stability may have found alternative results.

#### 5.2.3.5 *UKU-ConSat (Ahlfors et al., 2001)*

The UKU-ConSat was used in this study as it was validated on a large group of psychiatric patients who had been discharged from hospital in the previous three days to completing the measure. Although not the same, this sample was similar to that of the present study as they had all recently been inpatients and a proportion of them had a diagnosis of a psychosis (22.20%). It also provided the participants with the opportunity to express their views



regarding the psychoeducation package, as the tool is administered as a semi-structured interview and not as a questionnaire.

Limitations of the scale should be considered when interpreting results. One main concern is that Ahlfors et al. (2001) have not provided clear information regarding the means and standard deviations of scores. It is therefore not possible to compare results from the present study to those of Ahlfors et al. (2001). Malm and Lewander (2001) stated that the UKU-ConSat has a range from -24 (low satisfaction) to +24 (high satisfaction). Furthermore, these authors stated that any score above 0 should be considered as a degree of satisfaction. This scoring cut-off was used to assess satisfaction in this study, although it is clearly broad and inclusive.

In summary, the results must be considered within the context of the restraints imposed by the methodological concerns of the measure, mentioned above. However, the use of a semi-structured interview to obtain participants' views of the psychoeducation package added meaning to raw scores.

#### 5.2.4 Statistical Analysis: Reliable Change Index

This study employed the Reliable Change Index (Jacobson & Truax, 1991) to assess change in individual cases. This analysis tests whether differences in scores between two time points for individual cases are significantly greater than the error expected from the outcome measure. As it considers each participant's scores separately, it does not rely on the sample size. It was

decided to use the Reliable Change Index to analyse the data, as the sample of this study was small and there was no control group.

In a review of this statistical approach, Hafkenscheid (2000) compared seven different methods of Reliable Change indices. The method employed was the assessment of a sample of psychiatric inpatients on the BPRS over two time points. The approach by Jacobson and Truax (1991), originally developed by Jacobson et al. (1984), was termed as a “classic approach” because it uses raw scores to assess Reliable Change. Hafkenscheid stated that the approach by Jacobson et al. (1984) was one of the most sensitive methods as it utilised the most stringent significance level ( $p < .05$ ) of all the Reliable Change indices.

Hafkenscheid (2000) concluded that the classic approach is a safe procedure to use as it produces the lowest estimates of treatment efficacy, due to the use of stringent statistical levels. This allows the researcher to be confident that significant results were not derived by chance. Furthermore, Hafkenscheid stated that the classic approach has fewer statistical assumptions than other Reliable Change indices, as it does not require information from the whole sample to calculate population parameters, as do some other methods. Instead, the approach by Jacobson et al. (1984) relies solely on the standard error of the outcome measure which is calculated by using the test-retest reliability and standard deviation of the population on which the tool was developed.

The Reliable Change Index has some limitations. Primarily, the analysis is dependent on the accessibility of good quality validation studies in order to obtain test-retest reliability scores and standard deviations. This information is not always practically accessible and must be taken into account when designing a small sample study (Jacobson & Truax, 1991). In terms of the present study, effort was made to obtain the best quality validation studies.

In summary, the Reliable Change Index, as cited in Jacobson and Truax (1991) was the most appropriate method of analysis for this study. It provided stringent and therefore realistic results of treatment efficacy as it is a “classic approach”. However, there are some limitations of obtaining appropriate validation studies that must be taken into consideration.

### **5.3 Implications**

This section will firstly discuss the scientific implications of the study, with regards to the research questions, followed by a reflection on administering the intervention. It will then consider the clinical implications of the study.

#### **5.3.1 Scientific Implications**

Due to the small sample size, the lack of a control group and the lack of power, it is not possible to reach any firm conclusions about the utility of this psychoeducation package. Alternatively, this study has been able to generate some hypotheses on the basis of the results. These include that a personalised psychoeducation package may be able to improve some positive psychiatric symptoms over time (within a framework of traditional

treatment delivery systems). It is also hypothesised that the psychoeducation programme may be able to increase insight in specific areas, including that of having a mental disorder, of the achieved effects of medication and of the social consequences of having a mental disorder. Finally, it is hypothesised that a personalised psychoeducation programme may be able to increase patients' satisfaction of treatment care. The results of this study do not allow for hypotheses regarding the connection between receiving psychoeducation and compliance with medication, nor with altered illness representations.

The scientific implications of this study point to the need for a control group and an open trial design. This would allow the researcher to ascertain whether or not improvements made in the areas of positive symptomatology, insight and satisfaction are due to the effects of the psychoeducation package or the routine care received on a Psychiatric Intensive Care Unit. Following the implementation of an open trial (with a control group), results may support a further randomised controlled trial (see Barker et al., 2002).

Despite advocating a larger scale study, the clinical utility of the present study must not be overlooked. In order to complete an open trial (i.e. implementing control and intervention groups) and to assess results using multivariate analyses, it is suggested that a total of 64 participants per group would be required to find a medium effect size at  $p < .05$  (see Cohen, 1992). As the groups would be similar in nature, residing in the same environment and in receipt of the same routine care, a suitable sample to find a small effect size would be desirable. This would require 393 participants per group

at  $p < .05$  (according to Cohen, 1992). Clearly, to find even a medium effect size, the study would have to run for several years if recruitment rates were similar to those of the present study. It is suggested that a multi-centre trial would be required to recruit appropriate numbers of participants. However, this design would have the ethical dilemma of restricting many patients from an intervention that may be clinically useful whilst a large study is completed. It is argued that the design that was employed in this study was appropriate in assessing the utility of this intervention for this sample and in delivering the package to as many participants as possible over a short period of time.

A longer follow-up period is suggested for future studies to further assess the areas that were not shown to improve following the psychoeducation package (i.e. medication compliance and illness representations). These attitudinal changes are likely to emerge beyond a six-week follow-up period. This is indicated in previous studies of medication compliance. Boczkowski et al. (1985), who found an effect of psychoeducation on medication compliance, had a 3-month follow-up period, that is, double the duration of the follow-up period of this study. Furthermore, many of the studies of medication compliance used outpatients who had control of their medication. In this study, all participants were inpatients and were given their medication by nursing staff. This study therefore provided a new operationalisation of medication compliance. It is suggested that future studies may consider assessing the utility of this way of measuring compliance.

In summary, future studies incorporating more robust designs than this study are indicated to assess the effect of this personalised psychoeducation package on psychiatric symptoms, different dimensions of insight and satisfaction. Furthermore, the findings of this study imply that future studies with a longer follow-up period of at least 3 months are needed in order to assess the effects of this psychoeducation package on medication compliance and illness representations. Specifically, a randomised controlled trial could be implemented in which intervention and control groups (receiving routine care) would be compared. The data could be analysed using multivariate analyses to compare between groups. In addition, multiple regression analyses may be utilised to predict the outcome variables most likely to be related to participants' improvement (e.g. as measured by time between admission and discharge) following the receipt of the psychoeducation package.

### **5.3.2 Reflections of the Personalised Psychoeducation Manual**

Although this psychoeducation package had a strong basis in literature, on reflection, future studies may consider revising some aspects. Firstly, the manual is fairly lengthy. At times, it was difficult to read through with participants who were easily distracted. As low concentration is a common feature of people who have psychosis (Lindsay & Powell, 1994), this is not a surprising occurrence. Any revised version of the current psychoeducation package should consider shortening the length of the manual.

Secondly, any revision should consider the way in which information regarding symptoms is delivered. The package attempted to provide a collaborative therapeutic experience through the use of the initial assessment procedure and the opportunity for participants to amend the first version of the manual. However, it is suggested that although the manual clearly stated the beliefs of the participants, it presented opposing views and labelled each individual's experience as being part of psychosis. Examples of this are presented in Appendix 21, page 2. After having reiterated the experiences of the participant in his own words, the manual then states that his experiences are "common for people who have a psychosis". In the following paragraph, the experiences are re-labelled as symptoms of psychosis. It could be suggested that the method of delivery of this information moved away from a collaborative therapist-patient relationship of compromise to an authoritarian position by the therapist. Alternative means of modifying beliefs are suggested below.

Chadwick and Lowe (1990), in a study considering modification of delusional beliefs, found that delusions arise out of personalised thinking processes in reaction to specific experiences. They found that modification of delusions was more likely if this process was explained to the participants than if they were told that their beliefs were a result of a mental illness. This study did not incorporate the findings of Chadwick and Lowe. Some of the quotes from the UKU-ConSat indicated participants' dissatisfaction with this part of the psychoeducation package. This included,

*"It was frustrating at first, trying to get my message across".*

This quote suggests that the participant was definite in his beliefs regarding his delusions and that he assumed that the way in which his symptoms were conveyed in the manual were evidence of the researcher's lack of understanding. This may have arisen as a result of direct challenging of symptoms and labelling of them as part of a mental illness, rather than by modifying them in the way suggested by Chadwick and Lowe above. This may be considered in a revised version of the psychoeducation package.

A further consideration is that the development of participants' beliefs may have been more closely examined through the use of the Causal Belief Questionnaire (Whittle, 1996b). Whittle suggested that causal beliefs regarding the emergence of psychiatric disorder evolve from "Psychosocial", "Biological", "Structural" and "Stress" beliefs and that these help patients to obtain some control through their understanding of their illnesses. Whittle (1996a) suggested that the lay beliefs that clients (and their relatives) hold with regards to mental disorder will have a bearing on their expectations for treatment and therapy. The use of the Causal Belief Questionnaire in the present study may have been useful in further understanding the lay beliefs of each participant and in enhancing the personalisation of the psychoeducation package.

Finally, this study utilised the definition of insight from Amador et al. (1993) as a multidimensional phenomenon. These authors suggested that the



assessment of insight as a number of different facets could be used to target interventions. This function has not been utilised in this study, but may be considered in future work.

In summary, the length of the package, the way in which beliefs were challenged and the lack of targeting the intervention to tackle particular areas of insight were reflected above. These may be considered in a revised version of the psychoeducation package.

### 5.3.3 Clinical Implications

A number of clinical implications have evolved. Firstly, this study has supported the idea of personalising psychoeducation programmes as opposed to running them in groups. This approach relates to previous literature (e.g. Macpherson et al., 1996) and appears to lead to an improvement in some areas of insight.

Secondly, similar to the findings of Kemp and David (1996b), participants positively reported that they appreciated the chance to express their views to a member of staff. This implies that initially, rapport may be built between staff and patients if staff members do not offer alternative explanations of patients' beliefs. Later, when a strong therapy relationship has been built, patients may be challenged about their psychotic ideas.

Thirdly, several participants mentioned that they valued being given information regarding local resources. It is suggested that this approach, in

line with NICE guidelines, was empowering for participants and allowed them to begin to positively contemplate their futures. This was an example of the aim of the psychoeducation package to move away from the medical model towards a biopsychosocial perspective. It is argued that this aim was achieved and proved successful for many participants.

Finally, the personalised psychoeducation package designed for this study can be viewed as a possible precursor stepped care approach to CBT. It is short in duration and could be administered by any member of the Multi-Disciplinary Team. It could therefore be widely accessible to patients with acute psychosis. However, a larger sample and a robust design are needed prior to determining the exact effects of this intervention. Furthermore, additional research is indicated to investigate whether this psychoeducation package is able to increase collaboration with the therapist and positively impact on a future course of CBT.

In summary, a range of clinical implications has been highlighted above. These included the individualisation of psychoeducation; providing patients with the opportunity to discuss their experiences; the useful provision of information regarding local resources; and using psychoeducation as a stepped care approach prior to CBT.

## **5.4 Conclusions**

In reference to the quote at the beginning of this thesis (Maslow, 1963), this study has found that the provision of the appropriate information allows

patients with psychosis to fulfil “the need to understand”. By utilising a collaborative approach and a biopsychosocial perspective, participants of this study were provided with the opportunity to feel empowered in being able to control their psychosis. Furthermore, the delivery of information regarding local resources and services offered participants some hope for their futures.

This study has contributed to the literature on psychoeducation for people with psychosis, but gaps remain. These include information regarding the mechanisms by which psychiatric symptomatology change, other than by taking medication. In addition, the ways in which people who have psychosis conceptualise their illness representations is unclear. The construct of compliance to treatment (medication and otherwise) also remains ill defined. Future studies are needed to determine if these results can be generalised beyond this sample and setting.

In conclusion, on the basis of these preliminary findings of a new psychoeducation package, a larger scale study is indicated. This would compare the effectiveness of this approach with treatment as usual. It would also assess whether or not this type of package can be usefully implemented during the acute stages of psychosis, prior to the delivery of more in-depth therapies. This study has contributed to the field of psychosocial interventions for people with acute psychosis, but further work must now be conducted.

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**Appendix 1:                    Brief Psychiatric Rating Scale**

### BPRS Score Sheet

0	1	2	3	4	5	6
Absent	Very Mild	Mild	Moderate	Moderate/ Severe	Severe	Extremely Severe

ITEM	SEVERITY SCORE
Somatic Complaint	
Anxiety	
Emotional Withdrawal	
Conceptual Disorganisation	
Guilt Feeling	
Tension	
Mannerism and Posturing	
Grandiosity	
Depressive Mood	
Hostility	
Suspiciousness	
Hallucinations	
Motor Retardation	
Unco-operativeness	
Unusual Thought Content	
Blunted or Inappropriate Affect	
Elation Euphoria	
Disorientation	

**Appendix 2:     Scale to Assess Unawareness in Mental Disorder**

Assessment of Insight in Psychosis  
Amador, Strauss, Yale, et al

The scale requires that the subject have a mental disorder with one of the symptoms listed below. For each symptom item on the scale, it must first be ascertained that the subject has exhibited the particular symptom during the period under investigation. The severity of the symptom is not relevant, only that it is clearly present. The symptom checklist must be completed prior to filling out the scale, in order to determine which symptom items are relevant. The three nonsymptoms "summary items" are usually relevant and should be completed if this is the case.

In the "Current" column, rate the highest level of awareness obtained at the time of the interview for current psychopathology.

In the "Past" column, rate the present level of awareness for each item occurring during the period of time preceding the current period of investigation. In other words, when questioned about a particular episode in the past, would the subject currently say s/he was delusional, thought disordered, asocial, mentally ill etc at that time?

Longer or shorter time periods may be used to assess the current and retrospective awareness and attributions, depending on the goals of the investigation.

Following each symptom item (numbers 4-20), you are asked to rate the subject's understanding of the cause of the symptom (i.e. attribution). NOTE for any symptom attribution items are rated only if the subject received a score between 1 and 3 on the awareness item.

---

## General items

### 1. *Awareness of mental disorder*

In the most general terms, does the subject believe that he / she has a mental disorder, psychiatric problem, emotional difficulty etc.?

C	P	
0	0	Cannot be assessed
1	1	Aware: subject clearly believes that he/ she has a mental disorder
2	2	
3	3	Somewhat: is unsure whether he / she has a mental disorder but can entertain the idea that he / she might
4	4	
5	5	Unaware: believes that he / she does not have a mental disorder

### 2. *Awareness of achieved effects of medication*

What is the subject's belief regarding the effects of medication? Does the subject believe that medications have lessened the intensity or frequency of his / her symptoms (i.e. if applicable)?

C	P	
0	0	Cannot be assessed or item not relevant
1	1	Aware: subject clearly believes medications have lessened the intensity or frequency of his / her symptoms
2	2	
3	3	Somewhat: is unsure whether medications have lessened the intensity or frequency of his / her symptoms but can entertain the idea
4	4	
5	5	Unaware: believes that medications have not lessened the intensity or frequency of his / her symptoms



3. Awareness of the social consequences of mental disorder

What is the subject's belief regarding the reason he / she has been admitted to the hospital, involuntarily hospitalised, arrested, evicted, fired, injured, etc.?

C	P	
0	0	Cannot be assessed or item not relevant
1	1	Aware: subject clearly believes that the relevant social consequences are related to having a mental disorder
2	2	
3	3	Somewhat: is unsure whether the relevant social consequences are related to having a mental disorder
4	4	
5	5	Unaware: believes that the relevant social consequences have nothing to do with having a mental disorder

**Appendix 3:     The Insight Scale**

INSTRUCTIONS PLEASE RING REPLY AS REQUIRED:			
1. I have come into hospital for a rest	yes	no	Don't know
2. I have never been so ill in my life	yes	no	Don't know
3. Mental illness does not exist	yes	no	Don't know
4. I am here because I was asked to come	yes	no	Don't know
5. My condition can be treated with medicines	yes	no	Don't know
6. Why have you come to hospital (you can ring more than one)			
a) My doctor asked me to			
b) I am ill and need treatment			
c) My wife/husband might leave me if I didn't			
d) I feel nervous but not ill			
e) I was forced			
7. Should anyone be here instead of you?	yes	no	Don't know
8. To feel well I only need some advice and talking to.	yes	no	Don't know
9. I have been having some silly thoughts.	yes	no	Don't know
10. Nothing is the matter with me.	yes	no	Don't know
11. The mind cannot become ill, only the body.	yes	no	Don't know
12. I shall sue the hospital if I am not allowed out.	yes	no	Don't know
13. No one believes I am ill.	yes	no	Don't know
14. Something very strange is happening to me.	yes	no	Don't know
15. My neighbours are after me.	yes	no	Don't know
16. I feel my mind is going.	yes	no	Don't know
17. I know that my thoughts are silly but I cannot help it.	yes	no	Don't know
18. I cannot stop worrying about things	yes	no	Don't know
19. The voices I hear are not in my mind.	yes	no	Don't know
20. Someone is controlling my mind.	yes	no	Don't know
21. All I need is to pull myself together.	yes	no	Don't know
22. I feel different from my normal self.	yes	no	Don't know
23. I am losing contact with my environment.	yes	no	Don't know
24. I am losing contact with myself.	yes	no	Don't know
25. I understand why I am in hospital.	yes	no	Don't know
26. I understand why other people think I should be in hospital.	yes	no	Don't know
27. I feel in control of my thoughts.	yes	no	Don't know
28. I feel in control of my feelings.	yes	no	Don't know
29. I could have prevented this situation.	yes	no	Don't know
30. I find it difficult to explain how I feel.	yes	no	Don't know
31. I want to know what is happening to me.	yes	no	Don't know
32. I want to know why I am feeling like this.	yes	no	Don't know

## **Appendix 4: Illness Perception Questionnaire - Revised**

# ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

Name.....

Date.....

## YOUR VIEWS ABOUT YOUR ILLNESS

Listed below are a number of symptoms that you may or may not have experienced since your illness. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your illness.

	I have experienced this symptom <i>since my illness</i>			This symptom is <i>related to</i> <i>my illness</i>	
	Yes	No		Yes	No
Pain					
Sore Throat					
Nausea					
Breathlessness					
Weight Loss					
Fatigue					
Stiff Joints					
Sore Eyes					
Wheeziness					
Headaches					
Upset Stomach					
Sleep Difficulties					
Dizziness					
Loss of Strength					

We are interested in your own personal views of how you now see your current illness.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP1*	My illness will last a short time					
IP2	My illness is likely to be permanent rather than temporary					
IP3	My illness will last for a long time					
IP4*	This illness will pass quickly					
IP5	I expect to have this illness for the rest of my life					
IP6	My illness is a serious condition					

IP7	My illness has major consequences on my life					
IP8*	My illness does not have much effect on my life					
IP9	My illness strongly affects the way others see me					
IP10	My illness has serious financial consequences					
IP11	My illness causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my illness gets better or worse					
IP14	The course of my illness depends on me					
IP15*	Nothing I do will affect my illness					
IP16	I have the power to influence my illness					
IP17*	My actions will have no affect on the outcome of my illness					
IP18*	My illness will improve in time					
IP19*	There is very little that can be done to improve my illness					
IP20	My treatment will be effective in curing my illness					
IP21	The negative effects of my illness can be prevented (avoided) by my treatment					
IP22	My treatment can control my illness					
IP23*	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My illness is a mystery to me					
IP26	I don't understand my illness					
IP27	My illness doesn't make any sense to me					
IP28*	I have a clear picture or understanding of my condition					
IP29	The symptoms of my illness change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My illness is very unpredictable					
IP32	I go through cycles in which my illness gets better and worse.					
IP33	I get depressed when I think about my illness					
IP34	When I think about my illness I get upset					
IP35	My illness makes me feel angry					
IP36*	My illness does not worry me					
IP37	Having this illness makes me feel anxious					
IP38	My illness makes me feel afraid					

## CAUSES OF MY ILLNESS

We are interested in what you consider may have been the cause of your illness. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your illness rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your illness. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A Germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my illness					
C11	Overwork					
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused **YOUR** illness. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

## **Appendix 5: UKU-ConSat**



# UKU-ConSat (Consumer Satisfaction Rating Scale)

Patient name/initials:

Interviewer:

Date of birth:

Date of interview:

Gender: Male ☐ Female ☐Evaluation period: ..... - .....  
date dateInterviewer involved in the treatment/care of the patient: Yes ☐ No ☐Assessment of Inpatient care ☐ Daycare ☐ Outpatient care ☐Compulsory care ☐ Voluntary care ☐

## A. Structure and process

### 1. Availability of treatment/care

Possibility to get care when needed. Note positive/negative factors, that has affected hospitalisation or outpatient consultation, time on waiting list, etc.

Subtract 1 point for disapproval of compulsory treatment/care or pressure to seek care.

Add 2 points for approval of coercive measures taken.

However, the entered rating should not exceed -3 or +3.

### 2. Environment and services

The atmosphere of the ward or office, respectively; arrangements, level of service, attitude and interaction with personnel.

### 3. Availability of various treatment modalities

Opportunity for psychotherapy and other treatment modalities.

Availability and continuity of personnel.

### 4. Information

Availability of spontaneous or requested information regarding planning of treatment/care, its nature and contents, e.g. decisions made, diagnostic methods, participation in decisions.

### 5. Drug treatment

Subjective opinion regarding the properties of the drugs, mode of administration, effects, side effects. NB! If no drugs given, enter dash (-) \*.

### 6. Psychosocial interventions

Social skills training, help with family problems, offered and effectuated social measures that might affect e.g. the private economy, employment or living conditions.

NB! If no psychosocial measures needed, enter dash (-) \*.

Subtotal, items 1 - 6 \_\_\_\_\_

## A. Outcome

### 7. Usefulness of the treatment/care

Achieved or no subjective usefulness of the treatment/care, respectively.

### 8. General well being

Satisfaction with life as a result of the treatment/care provided; at ease or sick at heart; optimistic or pessimistic.

Subtotal, items 7 - 8 \_\_\_\_\_

Total score: \_\_\_\_\_

\*) For scoring - see the Manual

## UKU-ConSat (Consumer Satisfaction Rating Scale)

### MANUAL

The assessment shall be based upon the subjective opinion of the patient, but be performed in the form of an interview. The interviewer, who preferably should not be directly involved in the treatment/care of the patient, scores according to the contents of the patient's answers. The interview should be structured according to the standard form:

"How satisfied are you with ...?".

Complementary questions may be asked especially when there are problems with understanding. The evaluation should be done independently from psychopathological factors according to the following:

- 3 = Completely negative attitude to the contents of the treatment/care, the outcome, environment or other factors, e.g. worthless treatment or mainly adverse effects of drugs. Not even details are looked upon positively. Subjectively the condition has deteriorated to a considerable degree during the treatment period.
- 2 = Negative attitude to the contents and outcome of the treatment/care. Only isolated and unimportant details are reported positively, e.g. regarding the environment or opportunities for interaction with the personnel. Drugs are without effect, or harmful in some respect. Subjectively, the condition has deteriorated during treatment.
- 1 = Somewhat negative attitude to the contents, outcome of the treatment/care, the environment or other factors. The main attitude is negative, even though the patient acknowledges positive details. Too small an effect of the medication or adverse effects that are not markedly troublesome. Subjectively, the condition has not improved during the treatment/care.
- 0 = No specific subjective assessment or vague answers that are difficult to rate.
- +1 = Somewhat positive attitude to the contents and outcome of the treatment/care, or other factors. The main attitude should not be negative. Negative points of view may be expressed regarding details, e.g. aspects of the medication or the ward atmosphere, but the mildly positive attitude predominates. Subjectively, the condition has improved somewhat.
- +2 = Positive attitude to the contents and outcome of the treatment/care, or other factors. Minor, less important negative points of view may be expressed, but the attitude is mainly positive. Subjectively, the condition has improved to a considerable degree.
- +3 = Extraordinary positive attitude to the contents of the treatment/care, environment, personnel, etc. Marked satisfaction or gratitude. Subjectively, the patient has recovered as a result of the treatment/care.

**NB!** If Drugs have not been given (Item 5), or Psychosocial interventions have not been undertaken (Item 6), the mean scores of the remaining endorsed ratings shall be used.

## APPENDIX 6

### PATIENT INFORMATION SHEET

#### **Study Title**

Patient as Partner: Therapeutic Information Provision for People Suffering with Severe Mental Health Problems

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.

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

The Clinical Psychology Team at the <name of base unit> feel that it is important to share as much information as possible about your illness while you are a patient on the ward. We have therefore put together an information and skills pack that we hope will help you to understand your difficulties in more detail. We believe that this will help you to get better quicker and stay better for longer.

Many people often feel that they are not being listened to when they first come into hospital. Three essential parts of our approach are:

1. To help us understand how you see your difficulties
2. To work together on the beliefs about your illness that may keep you stuck
3. To work together on a shared understanding of unusual or upsetting things that you have experienced while you were unwell.

The study will be looking at how effective this pack is in helping you to understand your symptoms.

#### **Why have I been chosen?**

You have been chosen for this study because you are a new patient of the <name of base unit>. We will be asking a total of 16 people, who are also new patients, to join in with this study.

#### **Do I have to take part?**

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

**What do I have to do?**

The study will involve you meeting with a member of the Clinical Psychology team on three separate occasions. Each meeting will last approximately 30 minutes. The meetings will be arranged at 2-week intervals after your admission to the *<name of the base unit>*.

**What are the possible disadvantages and risks of taking part?**

We do not expect there to be any risks from taking part in this study. However, if you feel distressed during the study, you are free to withdraw. In this case, you will be offered access to the most appropriate support for you, through either the nurses, the Clinical Psychologist or your Psychiatrist.

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

We hope that this treatment will help you to gain a better understanding of your symptoms. However, this cannot be guaranteed. The information we get from this study may help us to treat future patients with mental health difficulties better.

**Will taking part in this study be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the *<name of base unit>* will have your name and address removed so that you cannot be recognised from it.

**What will happen to the results of the research study?**

The results of the study will be published as the doctoral thesis of Judith Friedman for the qualification of Doctorate in Clinical Psychology at University College London. This will be published in June 2004. We also intend to submit the results in a suitable academic publication. If you would like a copy of the results, this can be obtained from Judith Friedman in June 2004. You will not be identifiable in any publication.

**Who is organising and funding the research?**

The research is being organised by Gary Kupshik and Judith Friedman. No funding has been requested for this research. No professional involved in this study is being paid specifically to carry out this research.

**Who has reviewed the study?**

This study has been reviewed by the *<name of the local Ethics Committee>*. It has also been peer reviewed by the Research Sub-Committee at the Sub-department of Clinical-Health Psychology.

**Contact for Further Information**

We are happy to discuss the study further with you if you have any questions. Please contact either Judith Friedman or Gary Kupshik at the addresses below:

Mrs Judith Friedman  
Trainee Clinical Psychologist  
Sub-Department of Clinical-Health Psychology  
University College London  
Gower Street  
London WC1E 6BT  
Telephone: 0207 679 5699

Dr Gary Kupshik  
Consultant Clinical Psychologist  
Department of Clinical Psychology  
<address>

You will be given a copy of the information sheet and a signed consent form to keep.

Thank you for taking the time to read this information sheet.

## APPENDIX 6

### CONSENT FORM

Name\_\_\_\_\_

- I give my consent to participate in the study
- I understand the information given in the handout explaining the purpose of the research.
- I understand that the results of the study may be shared with other clinical staff, including nurses, doctors, Occupational Therapists and any other professional involved in my care.
- I understand that the results of the study may be published but that I will not be identifiable in any way.
- I understand that I can withdraw from the study at any time should I wish to, without giving an explanation.
- This form will not influence the treatment that I would ordinarily receive from the *<name of base unit>*.

Signature\_\_\_\_\_ Date\_\_\_\_\_

Witnessed by (signature)\_\_\_\_\_ Date\_\_\_\_\_

## **Appendix 7:**

## **Ethical Approval and Chairman's Action**

Details of the base unit have been erased to protect confidentiality

## SOUTH BEDFORDSHIRE LOCAL RESEARCH ETHICS COMMITTEE

Chairman: Mr. R. Driver  
Administrator: Mrs. D. Chapman

Lewsey Road  
LUTON  
LU4 0DZ

Facsimile: 01582 564543  
E-mail: [Debbie.Chapman@ldh-tr.anglox.nhs.uk](mailto:Debbie.Chapman@ldh-tr.anglox.nhs.uk)

Switchboard: 01582 491122

To: Dr. G. A. Kupshik, Consultant Clinical Psychologist, Department of Psychology,

Copy to:

Date of Approval: 29.08.03

### Members of the LREC:

Mr. R. Driver, Chairman: Dr. J. Dove, Vice Chairman: Mrs M. Turton (Community Health Council):  
Dr. J. Ana (General Practitioner): J. Ang (Community Health Care Trust): Mr. D. Fairclough (Lay  
Member): Dr. W. Matta (General Practitioner): Dr. S. Stein (Consultant Child Psychiatrist): B.  
Thatcher (Pharmacist): P. Davies (Senior Nurse): Elizabeth Bradley (Lay Member): Dr. C. Travill  
(Director of Research and Development – as an observer)

Title of study: **Patient as Partner: Therapeutic Information Provision for People  
Suffering with Severe Mental Health Problems**

**SBLREC Ref: May03/4c**

***please quote this reference on all correspondence***

Study considered for first time by the Committee	
Study reviewed by the Committee	XX
Study examined by Chairman (preliminary)	
Chairman's action, following examination by the full committee, and subsequent modifications	
Chairman's action only; examination by committee not necessary	

OUTCOME:	Study APPROVED (WITH COMMENT)	XX
----------	-------------------------------	----



The South Bedfordshire Local Research Ethics Committee conforms to the ICH Guidelines on Good Clinical Practice.
--

**ADDITIONAL COMMENT:**

1. Page 4: ... *The decision regarding the capacity to give consent would be the responsibility of the RMO, Dr. \_\_\_\_\_, who is independent of this study* ... Members would like a letter from Dr. \_\_\_\_\_ to say that he would be happy to do this.

This study is **approved** subject to the above condition.

**DOCUMENTS CONSIDERED:**

Protocol No/Date:

Version No.:

Patient Information:

Consent Form:

Questionnaire:

**ONE OF THE CONDITIONS OF THIS APPROVAL IS THAT YOU SUBMIT TO THE COMMITTEE ANNUAL REPORTS ON THE PROGRESS OF THE STUDY. A REMINDER LETTER WILL BE SENT TO YOU A MONTH BEFORE THE FIRST REPORT IS DUE.**

***FAILURE TO PROVIDE REPORTS MAY RESULT IN APPROVAL BEING WITHDRAWN***

Signed \_\_\_\_\_ (Chairman/Vice-Chairman)

Date 21/8/03

Correspondence to:  
Mrs D. Chapman  
L.R.E.C. Administrator



**South Bedfordshire Local Research Ethics Committee**

Luton and Dunstable Hospital NHS Trust  
Lewsey Road  
Luton  
Bedfordshire  
LU4 0DZ

Tel: 01582 497420  
Fax: 01582 564543

*(please quote this reference on all correspondence)*

07 November 2003

Mrs Judith Friedman  
Trainee Clinical Psychologist

Dear Mrs Friedman

**Re: Patient as Partner: Therapeutic information provision for people suffering with severe mental health problems**

Thank you for your letter dated 29 October 2003. The amendment you wish to make, involving contacting about 16 participants 6 weeks after completing the last intervention session, has been approved by Chairman's Action on behalf of the Committee.

<b>The South Bedfordshire Local Research Ethics Committee conforms to the ICH Guidelines on Good Clinical Practice.</b>
---

One of the conditions of this approval is that you submit to the Committee Annual Reports on the progress of the study. A reminder letter will be sent to you a month before the first report is due.

*Failure to provide reports may result in approval being withdrawn.*

Yours sincerely

*gr* **Mr. Ron Driver**  
**Chairman - South Bedfordshire Local Research Ethics Committee**

## Appendix 8

### First Session Interview

*Thank you for agreeing to participate in this research. My name is Judith Friedman and I am a Trainee Clinical Psychologist. As you are aware, I will be using the information that I obtain today as part of a research project. The purpose of today's session is to find out a little about why you think you're at the <name of base unit> and what difficulties you feel you have.*

*I would like to start the session by asking you a few questions. Before I begin, do you have any questions you'd like to ask me?*

1. Can you tell me the reasons why you are in the <name of base unit>?
2. What do you think is wrong with you at the moment?
3. What do you think will help you to get better?
4. What do you think will stop you from getting better?
5. What do you think could make you get worse?
6. What have you been told is wrong with you (by doctors, nurses, family, friends etc)?
7. What are the most difficult / troublesome symptoms that you experience?

8. What do you think has made you feel this way?
9. What do you think is wrong with you?
10. Have you ever seen or heard anything that other people can't see or hear?
11. Please take a moment to think back to life before you came to the <name of base unit>. Can you describe a typical day to me?  
*If participant doesn't respond, prompt by asking what time s/he would normally awaken; what s/he would do in the morning etc.*
11. How much alcohol did you used to drink?
12. Did you take drugs? If so, what drugs? How often did you take drugs?
13. Is there anyone in your life who would notice if you weren't feeling well? If so, who are they? What do they think is wrong with you just now
14. When did you first notice that you weren't feeling like your usual self?

15. Thinking back, when you have felt unwell in the past, what have you been able to do to make yourself feel better? Has this worked?

16. Do any of your relatives suffer from the difficulties that you have?

17. Do you know of any problems your mother had when she was pregnant with you?

Were there any problems during your birth?

Did you have any problems at school?

18. What would you like to achieve whilst you're at the <name of the base unit>?

19. What do you hope to do in the future? Where do you hope to live? Do you intend to work? If so, what would you like to do?

20. In the future, if you feel unwell again, what do you think you would do? Who would you go to for help?

*Thank you for answering these questions. I will meet with you again in 2 weeks. At that time, I will be able to give you a shared description of what you think your problems are and of what I think your problems are. We will then have a chance to discuss this further.*

*Do you have any further questions?*

*If you realise there is something else that you would like to ask, feel free to ask me or Gary Kupshik, Consultant Clinical Psychologist. We will be happy to answer any queries.*

## Appendix 9

### Template for Manual

#### 1. What the participant thinks is wrong

Insert paragraph about what the patient generally thinks is wrong with them, e.g. they are being watched by others; they are being spoken to by the devil etc.

Include the participant's account of the incidents that led to admission.  
Include information regarding what the patient has been diagnosed with in the past and whether or not he agrees.

#### 2. General information about Psychosis

The experiences that you are having, like *<include symptoms mentioned by participant>* are common for people who have a psychosis. A psychosis is a condition in which the person's contact with reality is lost or highly distorted. *<In cases where participant has been diagnosed with Schizophrenia, state, "One illness in which people suffer from psychosis is Schizophrenia">*. Many people who have a psychosis don't believe that they are suffering from an illness in the early stages.

#### Hallucinations

In our discussion, you mentioned that you *<insert hallucination, e.g. sometimes hear people talking to you; see things that others can't>*. These symptoms are called **hallucinations** and often seem to occur out of nowhere. Hearing voices that other people can't hear is the most common type of hallucination. In your case, the voices *<describe your activities; carry on a conversation; give you orders; warn of dangers>*.

*In cases of auditory, tactile or olfactory hallucinations, include details of symptom and state that they are part of psychosis.*

#### Delusions

You mentioned that you believe *<insert delusion e.g. you believe that someone is following you; that you are an important person; that your neighbour is spying on you; that people on television are sending you special messages; that your thoughts are being broadcast out loud to others>*. These beliefs seem to be true to you and can make you feel very frightened. They can make you feel alone because other people don't believe you. This is a symptom of psychosis and is called a delusion. Delusions are a common symptom of psychosis.

#### Thought disorder

You mentioned that you are having difficulty in *<insert person's description, e.g. thinking straight; making sense of your thoughts etc>*. This can make it difficult for you to have a conversation and can make you feel isolated and lonely. This symptom is called "thought disorder" and is common for people who have psychosis.

### Blunted affect

In our discussion, you said that it is difficult to *<insert, e.g. get out of bed; motivate yourself etc>*. You're no longer interested in the things you used to enjoy. Sometimes you can spend days doing nothing at all. You find it difficult sometimes to wash or dress yourself. This is another symptom common to people who have **psychosis** and is called "blunted or flat affect".

### 3. Summary of symptoms

*Insert table summarising participant's belief and alternative explanation (for delusions). Change to "Your Experience" and "Alternative Explanations" for other symptoms.*

Your Belief	Alternative Explanations

### 4. What causes psychosis?

#### Brain factors

It is likely, but not certain, that you and other people who have psychosis have imbalances in your brain. These imbalances are in the chemicals that send messages around your brain. The main chemical involved in psychosis is called **dopamine**.

#### Vulnerabilities

##### Genetic factors

You mentioned that your *<insert relative who had psychotic episodes>* also had symptoms like the ones you're experiencing now. Psychosis is known to run in families.

##### Developmental factors

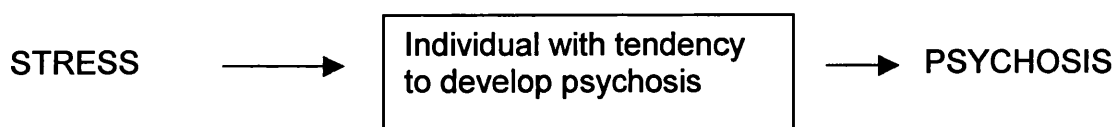
You mentioned that *<insert complication, e.g. your mother's pregnancy with you was difficult; your mother had a virus when she was pregnant; your birth was complicated and difficult>*. It may be that this difficulty was one of the causes that led you to develop psychosis.

#### Stressors

##### Behavioural factors

You mentioned that for a while *<insert stressor, e.g. you have not been getting enough sleep; you have been particularly stressed; you have been taking <insert illicit drug>>*. Researchers called Dr Zubin and Dr Spring wrote in 1977 and said that people, like you, who have a tendency to develop psychosis, and who do things that puts stress on their bodies, like *<insert stressor>* are more likely to develop symptoms of psychosis than if they didn't do those things.

*Insert diagram below:*



## Drugs

You mentioned that you sometimes take *<insert name participant used to describe drug>*. Your use of drugs is not unusual. *<If participant uses cannabis, then state, "Cannabis is one of the three substances most frequently misused by people with mental health difficulties like you">*. We feel that your use of *<name of drug(s)>* needs to be moderated significantly, if not stopped altogether. Researchers think that cannabis should be seen as something which can precipitate further episodes of illness. Other Doctors, like *<name of lead Psychiatrist at base unit>* feel that cannabis increases the risk of hospital readmission.

Drugs cause worsening of your symptoms and can trigger a further episode of psychosis. We know that the medication that you have been prescribed will block an important neurochemical called dopamine. We think that drugs have the effect of unblocking or enhancing dopamine pathways that cause *<name of symptom that participant experiences>*.

## 5. How do we understand your symptoms?

### Delusions

You talked about feeling *<insert delusion>*. This seems to be real to you. We understand this in a different way.

Dr. Garety and her colleagues think that your symptoms are caused by your wish to make sense of these strange things happening to you, so you grasp the first conclusion you come to, even though this may not be the right one. So, in your case, you believe *<insert delusion>* when, in fact, there may be many other explanations, like there is a chemical imbalance in your brain that causes you to think this way.

Dr Bentall in Manchester has also written about what delusions are. He thinks that if you think someone is trying to get you *<only insert if there is persecutory delusion>* then you won't feel depressed about all the things that you haven't done in your life, because you'll be able to blame it on someone else.

Dr Frith in London has another different idea about delusions. He thinks that it is difficult for you to understand that other people may be thinking something different from you. This leads you to become confused about whether a bad thought is coming from your own mind or is coming from someone else *<insert delusion, e.g. like the devil>*.

### Hallucinations

In our discussion, you mentioned that you sometimes hear voices that other people can't hear. There have been many Psychologists who have thought about why someone like you hears these voices. Dr Baddeley thinks that you have a fault in the way that you hear information. This means that you are not always sure if a thought has come from inside your head or from someone else. This is called a disturbance of inner speech.



Dr Bentall and Dr Slade also think that sometimes you become confused with noises that you hear and think that those noises are voices when they are not. This is called an input theory.

Dr Frith thinks that you have some difficulties in realising that you had intended to think something. The result of this is that you think that the thought has come from somebody else, but it has actually come from inside your head. This is called a disturbance of self-monitoring.

## 6. Metaphor

A useful way to think about your symptoms is to use the following metaphor. It's about a tug of war:

"The situation you are in is like being in a tug-of-war with a monster. In between you and the monster is a pit, and so far as you can tell, it is bottomless. If you lose this tug-of-war, you will fall into this pit and will be destroyed. So you pull and pull, but the harder you pull, the harder the monster pulls, and you edge closer to the pit.

The hardest thing to see is that our job here is not to win the tug-of-war.....Our job is to drop the rope".

In this metaphor, think about the rope as the problems in your life. It says that if you keep using the same strategies to manage your difficulties, then drop the rope because they're making things worse. How might this apply to you?

## 7. What can be done to improve your symptoms

### Medication

You have been asked by your doctor to take anti-psychotic medication, *<insert name of medication>*. This is one of the most helpful ways of getting rid of psychosis. The medication acts on the dopamine in your brain. It cannot "cure" your psychosis, but it take away many of your symptoms or make them milder. In some cases, they can shorten the course of an episode of psychosis as well.

### Other ways to control Psychosis

Taking your medication regularly is an important way of controlling psychosis, but not the only way. You can also look after yourself better by taking regular exercise, eating healthily and avoiding stressful situations.

The other important way of controlling your psychosis is not to take street drugs. You mentioned that you take *<insert name of drug>*. You are much more likely to have a bad reaction to street drugs than someone who doesn't have psychosis.

### Psychosocial environment

In our discussion you told me that the people who you mix with also like to take drugs and don't have jobs. You mentioned that you find it difficult to say

“no” when they offer you drugs. Sometimes being with these people can make you feel worse. You mentioned that you began to notice that your symptoms came out again when you were with these people. You may think about changing your friends in the future if you want to stay well.

#### Previous daily routine

You told us that when you started having your symptoms, you didn't have much to do during the day. You didn't have a job and you didn't have much money. You were bored. We think that this lifestyle made it easy for your symptoms to come out. In the future, you may plan to do other things with your life. You may even try to get a job. These things will help you to control your difficult psychotic symptoms.

#### 8. Relapse Prevention

In our meeting, you said that before you became ill you used to *<insert daily activities, including job, hobbies, people they used to see etc>*. We hope that you are able to return to doing those things again.

The most important way of making sure that you become well is to keep taking your medication. When medication is stopped, people who have psychosis often relapse and suffer from their hallucinations and delusions again.

Another way of making sure that you don't relapse is to get enough sleep. When you notice that you haven't been getting much sleep, speak to your *<insert keyworker, doctor, social worker etc>*.

Keep away from street drugs to make sure you don't relapse. *<insert name of drug patient takes>* affects the dopamine in your brain. This is the chemical involved in psychosis.

Another way of staying healthy is to try to keep stress at bay. If you become stressed, your psychotic symptoms may emerge. Ways of keeping stress at bay are to exercise, to socialise and to eat healthily *<insert specific activities that person used to engage in>*.

#### 9. What should I do if my symptoms start again?

When you know that your symptoms are starting again, the most important thing for you to do is tell someone. One person you could tell is *<insert name of Social Worker and phone number>* or you may choose to tell a family member.

It is likely that your doctor will prescribe you some anti-psychotic medication. It is really important that you take this to reduce the uncomfortable feelings.

Remember, your psychosis is an illness. It can be treated. You can make it better by taking your medication, staying stress-free and by not taking street drugs. There are lots of people around to help you. You're not alone.

#### 10. Plans for the future

It's great that you want to *<insert participant's words, e.g. get a job, go to college, do some volunteer work etc.>*.

It may be helpful for you to contact *<insert names and telephone number of relevant organisations, e.g. Citizens' Advice Bureau; local college; supported working schemes; volunteer projects>/*

*If participant admitted to misusing drugs, insert:*

If you find you are again having problems with drugs, you may either want to contact your doctor (GP or Psychiatrist). You may also find it helpful to contact Drugline to talk to someone about your difficulties. Their phone number is *<insert phone number>*.

#### Useful phone numbers

*Insert all names and phone numbers mentioned above again.*

I hope you have found this helpful,

Yours sincerely,

Judith Friedman  
Trainee Clinical Psychologist

## Appendix 10: Intervention as a Letter

Headed paper with Trust Logo

Psychology Department  
Address of Base Unit

Date

### CONFIDENTIAL

Joe Bloggs  
Ward Name

It was good to meet you on the *<insert dates of first and second sessions>*. In the first session, we were discussing the reasons why you are in the Orchard Unit and what you feel your difficulties are at the moment. In the second session, I gave you a letter with a shared idea of your understanding of what is happening to you right now and my understanding. In that session, you had the chance to change any aspects that you did not agree with. This letter is the amended version of the last letter.

In our meeting, you told me that you are in the *<name of base unit>* because you stopped taking your medication. You were also feeling stressed and upset because you were having difficulties with your relationship and because a good friend of yours committed suicide. You began to re-experience symptoms, including hearing voices and having “telepathic communications” from your friend who died. These messages were telling you to throw yourself in front of a train. When I met you the second time, you said that you were hardly getting any of these symptoms. You told me this was because the medication had started to work.

I asked you about what the doctors feel is wrong with you at the moment. You told me that they have told you that you have Paranoid Schizophrenia. You told me that you have had this in the past, but that you do not believe that you have it now.

Over the course of our session, you mentioned several times that you had been treated unfairly because of your Schizophrenia. You seemed to feel that other people are against you because of your illness.

The experiences that you are having, like receiving telepathic messages and hearing voices are common for people who have a psychosis. A psychosis is a condition in which the person’s contact with reality is lost or highly distorted. One illness in which people suffer from psychosis is Schizophrenia. Many people who have a psychosis don’t believe that they are suffering from an illness in the early stages. In your case, you told me that you are not sure at

the moment whether or not you are ill, but feel that in a few weeks, you will look back on this experience and realise that you are ill.

You mentioned that you have telepathic communications from the dead telling you to kill yourself. You also hear voices. These symptoms are called **hallucinations** and often seem to occur out of nowhere. Hearing voices that other people can't hear is the most common type of hallucination. In your case, the voices give you orders to kill yourself.

You mentioned that you feel that everyone knows that you have Schizophrenia and think badly of you because of this. This belief seems to be true to you and can make you feel very frightened. It can make you feel alone because other people don't believe you. This symptom is a **delusion** and is a common symptom of psychosis.

#### What Causes this Illness?

It is likely, but not certain, that you like other people who have a psychosis, have imbalances in your brain. These imbalances are in the chemicals that send messages around your brain. The main chemical involved in psychosis is called dopamine.

You mentioned that before your admission to *<name of base unit>*, you felt stressed because of the death of your friend and because you had been having relationship difficulties. In addition, you had stopped taking your medication.

Dr Zubin and Dr Spring wrote in 1977 and said that people, like you, who have a tendency to develop a psychosis and who experience extreme stress are more likely to develop a psychosis than if they had not had this stress.

You mentioned that you used to abuse many street drugs, including cocaine, heroin, crack, cannabis and speed. Your use of drugs is not unusual. Cannabis is one of the three substances most frequently misused by people with mental health difficulties like you. We feel that your use of cannabis and other drugs needs to be moderated significantly, if not stopped altogether. Researchers consider that cannabis should be seen as something which can precipitate further episodes of illness. Other Doctors like *<name of Psychiatrist at base unit>* feel that cannabis increases the risk of hospital readmission.

Drugs cause worsening of your symptoms and can trigger a further episode of psychosis. We know that the medication that you have been prescribed will block an important neurochemical called dopamine. We think that drugs have the effect of unblocking or enhancing dopamine pathways, which cause paranoid thinking, delusions and hallucinations.

#### How do we understand your symptoms?

In our discussion, you mentioned that sometimes you hear voices that other people can't hear and believe that people are against you because you have

Schizophrenia. There have been many Psychologists who have thought about this.

Dr Baddeley suggested that your symptoms are caused by a fault in the way that you hear information. This means that you are not always sure if a thought has come from inside your head or from someone else. This is called a disturbance of inner speech.

This means that the difficult voices that you hear about killing yourself are generated from your own anxieties about the world (for example, about people around you dying or leaving you). They are your own thoughts that are interpreted as coming from outside of your head.

Dr Frith at University College London said that people like you may have some difficulties in realising that you had intended to think something. The result of this is that you think that the thought (or voice) has come from somebody else, but it has actually come from inside your head. This is called a disturbance of self-monitoring.

This means that the thoughts of wanting to throw yourself in front of a train originate from inside your head, but because of a disturbance of self-monitoring, you do not realise that you had intended to think them, so you perceive them as voices coming from outside of your head.

Dr Bentall in Manchester said that if people think that others are conspiring against them, then they won't feel depressed about all the things that they haven't done in their lives, because they'll be able to blame it on someone else.

For you, this means that your experiences of feeling that others are persecuting you for having Schizophrenia may be a symptom of Schizophrenia. The theory suggests that you can blame others for you having Schizophrenia as you have found this difficult to accept yourself. This stops you from feeling depressed about the Schizophrenia, but instead ends up with you being angry with others.

A useful way to think about your symptoms is to use the following metaphor. It's about a tug of war:

'The situation you are in is like being in a tug-of-war with a monster. In between you and the monster is a pit, and so far as you can tell it is bottomless. If you lose this tug-of-war, you will fall into this pit and will be destroyed. So you pull and pull, but the harder you pull, the harder the monster pulls, and you edge closer to the pit.

**The hardest thing to see is that our job here is not to win the tug-of-war.....Our job is to drop the rope.'**

In this metaphor, think about the rope as the problems in your life. It says that if you keep using the same strategies to manage your difficulties, then drop the rope because its making things worse. How might this apply to you?

#### What can be done to improve your symptoms?

You have been asked by your doctor to take anti-psychotic medication, called Clozaril. This is one of the most helpful ways of getting rid of psychosis. The medication acts on the dopamine in your brain. It cannot cure your psychosis, but it can take away many of the symptoms and make them milder. In some cases, they shorten the course of an episode of psychosis as well.

The other important way of controlling your psychosis is not to take street drugs. You mentioned that you take many different drugs and you know that these help to get rid of your symptoms in the short-term, but make them worse in the long term. This is because they interfere with the dopamine in your brain, that we talked about before.

One way of controlling your symptoms is to look after yourself by taking regular exercise (like going to the gym and kick-boxing, that you enjoy), eating healthily and avoiding stressful situations.

In our discussion, you told me that some of the people that you mix with also like to take drugs and don't have jobs. Sometimes being with these people can make you feel worse. You also told me that you have two circles of friends: those who take drugs and those who do not. You said that you are going to try to avoid the friends who take drugs to help you to stay off them. We also encourage you to do this.

#### Relapse Prevention

In our meeting, you told me that, in the future, you are keen to get a job that you enjoy, e.g. engineering or mechanical work. We very much hope that you will be able to take up this lifestyle.

The most important way of making sure that you become well is to keep taking your medication. When medication is stopped, people who have a psychosis often relapse and suffer from their delusions and hallucinations.

#### What should I do if my symptoms start again?

When you know that your symptoms are starting again, the most important thing for you to do is to tell someone. You could tell your Social Worker <name>, your GP <name>, your Psychiatrist <name> or your CPN <name>.

It is likely that your doctor will prescribe you some medication. It is really important that you take this to reduce the uncomfortable feelings.

Remember, your psychosis is an illness. It can be treated. You can make it better by taking your medication and by staying stress-free. There are lots of people around to help you. You're not alone.

Another way of making sure that you don't relapse is to get enough sleep. When you notice that you haven't been getting enough sleep, speak to your Social Worker <name> or GP <name> or CPN <name>.

When we talked about how you were feeling before you came to hospital, you said:

- Feeling lethargic
- Having no motivation
- Feeling depressed
- Hearing voices
- Receiving telepathic messages

These symptoms were probably the signs that your psychosis was coming back. This is called "Relapse". When you start to experience these symptoms, it is important that you contact your Social Worker, CPN or doctor immediately.

Finally, a key way of staying healthy is to keep stress at bay. If you become stressed, your symptoms, including delusions and hallucinations, may emerge. Ways of keeping stress at bay are to exercise (including kick boxing and going to the gym), to socialise and to eat healthily.

#### Plans for the Future

It's great that you want get a job, e.g. engineering or mechanics.

You may want to get some advice about your future career by calling the Citizens Advice Bureau. Their phone number is <local branch>. Also, there is a Personal Advisor Service that you may find useful in thinking about your career. The phone number is free and is <telephone number>.

You may want to go to college to train in engineering or mechanics. The local college that has this sort of course is <name> and you can contact them on <number>

If you find that you are again having problems with drugs, you may either want to contact a doctor (your GP or Psychiatrist) or you may also find it helpful to contact Drugline to talk to someone about your difficulties. Their phone number is <insert telephone number>.

I hope you have found this helpful.

Yours sincerely,

Judith Friedman  
Trainee Clinical Psychologist



## Appendix 11

### QUESTIONNAIRE

We are currently undertaking a research study in an inpatient ward and would appreciate your feedback. We are investigating the usefulness of a psychological therapy for patients suffering from psychosis, in which the patients are provided with information regarding their illness. We have developed two possible formats in which to present the information to the patient and are interested as to which you believe would be more useful. We would appreciate it if you would take a few minutes to look at the two manuals and then answer the questions listed below, using the rating scale provided. Thank you!

Judith Friedman – Trainee Clinical Psychologist  
Anna Hames – Assistant Psychologist

Very much so	Reasonably so	Satisfactory	Poor	Not at all
Rating Scale: 1	2	3	4	5

1. Is the manual easy to read?

Manual 1	1	2	3	4	5
Manual 2	1	2	3	4	5

2. Is the manual appealing to look at?

Manual 1	1	2	3	4	5
Manual 2	1	2	3	4	5

3. Is the information in the manual easy to understand?

Manual 1	1	2	3	4	5
Manual 2	1	2	3	4	5

4. Is the information in the manual accessible?

Manual 1	1	2	3	4	5
Manual 2	1	2	3	4	5

5. What improvements would you make to the layout of the manual?

Manual 1.....

.....

Manual 2.....

.....

6. Overall, which manual do you prefer?

Manual 1 ☐

Manual 2 ☐

Please could you explain your reasons.....

.....

.....

.....

THANK YOU VERY MUCH FOR YOUR TIME

## Appendix 12      Reliable Change Index Information

SE is the standard error of measurement

$S_{diff}$  is the standard error of difference between the two test scores. It describes the spread of distribution of change that would be expected if no actual change had occurred (Jacobson & Truax, 1991).

The SE and  $S_{diff}$  scores for each sub-scale of the measures amenable to the Reliable Change Index are highlighted below.

### BPRS

	SE	$S_{diff}$
Anxiety	1.14	1.61
Depression	0.98	1.39
Hostility	0.99	1.40
Suspiciousness	0.80	1.13
Unusual Thought Content	0.59	0.83

### BSI

	SE	$S_{diff}$
Anxiety	0.52	0.74
Depression	0.48	0.68
Hostility	0.40	0.57
Paranoid Ideation	0.45	0.64
Psychoticism	0.45	0.64

### The Insight Scale

	SE	$S_{diff}$
Positive	1.89	2.67
Negative	1.21	1.71

### IPQ-R

	SE	$S_{diff}$
Consequences	1.98	2.80
Personal Control	2.93	4.14
Treatment Control	2.04	2.88
Illness Coherence	3.01	4.26

## Appendix 13 Case Summary of Recruitment

The table below illustrates a case summary of those who dropped out of treatment and where missing values were used.

Case Summary of Intent to Treat Analysis

Case	Completer	Drop-Out
A	—	Missing values for Psychology data at Follow-Up. Participant had deteriorated in mental state.
B	—	Missing values for Psychiatry data at Follow-Up.
C	*	
D	*	
E	*	
F	*	
G	—	Participant dropped out after Post-Intervention. Missing values for Psychiatry and Psychology data at Follow-Up.
H	—	Participant dropped out after Post-Intervention. Missing values for Psychiatry and Psychology data at Follow-Up.
I	*	
J	—	Missing values for Psychiatry data at Follow-Up. Participant's mental state had deteriorated and he refused to engage in Psychiatric interview.
K	—	Participant dropped out after Pre-Intervention. Missing values for Psychiatry and Psychology data at Post-Intervention and Follow-Up.
L	*	
M	—	Participant dropped out after Post-Intervention. Missing values for Psychiatry and Psychology data at Follow-Up.
N	—	Participant dropped out after Pre-Intervention. Took illicit substances whilst on leave and mental state deteriorated. Missing values for Psychiatry and Psychology data at Post-Intervention and Follow-Up.
O	*	
P	—	Participant accepted Psychiatry and Psychology data at Pre-Intervention and Psychology data only at Post-Intervention. Missing values for Psychiatry data at Post-Intervention and Follow-Up and for Psychology data at Follow-Up.

\* denotes that participant completed data at all three time points.

## Appendix 14: Raw Data

Detailed below is the raw data for each participant on all of the variables analysed for this study.

### Participant A

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	1	2	0
Depression	1	1	0
Conceptual Disorganisation	3	1	0
Unusual Thought Content	6	0	0
Hostility	0	0	0
Suspiciousness	5	0	1
<b>BSI</b>			
Anxiety	0.50	1.17	-
Depression	1.33	0.83	-
Paranoid Ideation	2.25	0.80	-
Psychoticism	1.33	0.33	-
Hostility	0.25	0.40	-
<b>SUMD</b>			
Mental Disorder	5	1	1
Medication	5	2	1
Social Consequences	5	1	3
<b>Insight Scale</b>			
Positive Insight	19	7	-
Negative Insight	5	26	-
<b>IPQ-R</b>			
Consequences	27	19	-
Personal Control	24	20	-
Treatment Control	16	19	-
Illness Coherence	14	19	-
<b>UKU-ConSat</b>	- missing data	5	-

## Participant B

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>		0	-
Anxiety	3	0	-
Depression	2	0	-
Conceptual Disorganisation	0	0	-
Unusual Thought Content	0	0	-
Hostility	1	0	-
Suspiciousness	0	0	-
<b>BSI</b>			
Anxiety	2.67	0	0.83
Depression	0.67	0	0.50
Paranoid Ideation	1.00	0	0
Psychoticism	1.33	0	0.40
Hostility	1.75	0	0
<b>SUMD</b>			
Mental Disorder	5	1	-
Medication	5	1	-
Social Consequences	1	5	-
<b>Insight Scale</b>			
Positive Insight	19	22	20
Negative Insight	8	11	8
<b>IPQ-R</b>			
Consequences	23	16	20
Personal Control	23	22	22
Treatment Control	25	20	20
Illness Coherence	5	10	16
<b>UKU-ConSat</b>		13	13

- missing data

## Participant C

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	3	1	0
Depression	0	0	0
Conceptual Disorganisation	0	0	0
Unusual Thought Content	4	0	0
Hostility	2	0	0
Suspiciousness	4	1	0
<b>BSI</b>			
Anxiety	0.17	0	0
Depression	0	0.17	0
Paranoid Ideation	2.25	0	0.60
Psychoticism	1.33	0.33	0.40
Hostility	0.75	0	0.20
<b>SUMD</b>			
Mental Disorder	5	1	3
Medication	5	1	1
Social Consequences	5	1	5
<b>Insight Scale</b>			
Positive Insight	9	23	17
Negative Insight	7	10	5
<b>IPQ-R</b>			
Consequences	17	20	21
Personal Control	23	21	21
Treatment Control	13	18	18
Illness Coherence	14	20	19
<b>UKU-ConSat</b>		4	0

## Participant D

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	0	2	0
Depression	0	0	0
Conceptual Disorganisation	2	3	2
Unusual Thought Content	2	0	2
Hostility	0	3	0
Suspiciousness	3	4	3
<b>BSI</b>			
Anxiety	0.17	0.50	0.17
Depression	0.17	1.17	0.67
Paranoid Ideation	1.50	2.60	1.00
Psychoticism	0.33	0.33	0
Hostility	0.25	0.20	0.20
<b>SUMD</b>			
Mental Disorder	5	5	5
Medication	5	5	5
Social Consequences	5	5	5
<b>Insight Scale</b>			
Positive Insight	18	15	19
Negative Insight	8	8	7
<b>IPQ-R</b>			
Consequences	12	19	7
Personal Control	26	24	20
Treatment Control	10	10	12
Illness Coherence	5	15	11
<b>UKU-ConSat</b>		-10	-10

## Participant E

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	0	0	0
Depression	0	0	0
Conceptual Disorganisation	0	0	0
Unusual Thought Content	3	3	3
Hostility	3	2	2
Suspiciousness	3	3	3
<b>BSI</b>			
Anxiety	1.00	0	0
Depression	0.50	0.50	0.17
Paranoid Ideation	2.00	0.60	0.60
Psychoticism	1.33	0.67	0.20
Hostility	1.25	0.20	0.20
<b>SUMD</b>			
Mental Disorder	5	5	5
Medication	5	5	5
Social Consequences	5	5	5
<b>Insight Scale</b>			
Positive Insight	15	15	15
Negative Insight	12	8	8
<b>IPQ-R</b>			
Consequences	10	10	8
Personal Control	14	16	14
Treatment Control	13	15	13
Illness Coherence	5	15	9
<b>UKU-ConSat</b>		4	4



## Participant F

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	2	0	0
Depression	3	0	0
Conceptual Disorganisation	0	1	0
Unusual Thought Content	0	0	0
Hostility	0	0	0
Suspiciousness	0	0	0
<b>BSI</b>			
Anxiety	2.17	0	0
Depression	1.33	0	0
Paranoid Ideation	2.75	0	0.40
Psychoticism	2.33	0.33	0.60
Hostility	0	0	0
<b>SUMD</b>			
Mental Disorder	3	5	1
Medication	5	3	1
Social Consequences	3	1	1
<b>Insight Scale</b>			
Positive Insight	12	17	20
Negative Insight	6	6	7
<b>IPQ-R</b>			
Consequences	25	23	29
Personal Control	20	30	30
Treatment Control	17	25	24
Illness Coherence	20	10	15
<b>UKU-ConSat</b>		12	12

## Participant G

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	0	0	-
Depression	0	0	-
Conceptual Disorganisation	3	0	-
Unusual Thought Content	3	0	-
Hostility	1	0	-
Suspiciousness	1	0	-
<b>BSI</b>			
Anxiety	0	0.67	-
Depression	0	0.67	-
Paranoid Ideation	0.67	2.60	-
Psychoticism	0	1.00	-
Hostility	0	0.60	-
<b>SUMD</b>			
Mental Disorder	5	5	-
Medication	5	5	-
Social Consequences	5	5	-
<b>Insight Scale</b>			
Positive Insight	13	14	-
Negative Insight	3	9	-
<b>IPQ-R</b>			
Consequences	-	-	-
Personal Control	-	-	-
Treatment Control	-	-	-
Illness Coherence	-	-	-
<b>UKU-ConSat</b>		-12	-

- missing data

## Participant H

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	0	0	-
Depression	2	3	-
Conceptual Disorganisation	2	0	-
Unusual Thought Content	3	1	-
Hostility	0	0	-
Suspiciousness	2	0	-
<b>BSI</b>			
Anxiety	1.67	1.00	-
Depression	3.00	1.67	-
Paranoid Ideation	2.50	1.80	-
Psychoticism	0.67	0.33	-
Hostility	2.25	2.20	-
<b>SUMD</b>			
Mental Disorder	5	1	-
Medication	5	1	-
Social Consequences	3	1	-
<b>Insight Scale</b>			
Positive Insight	22	20	-
Negative Insight	8	8	-
<b>IPQ-R</b>			
Consequences	24	20	-
Personal Control	11	20	-
Treatment Control	14	15	-
Illness Coherence	20	12	-
<b>UKU-ConSat</b>		3	-

- missing data

## Participant I

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	3	3	0
Depression	2	2	3
Conceptual Disorganisation	0	0	0
Unusual Thought Content	1	0	1
Hostility	1	1	0
Suspiciousness	0	0	0
<b>BSI</b>			
Anxiety	1.83	1.33	1.33
Depression	0.33	0.33	0
Paranoid Ideation	0.25	0	0
Psychoticism	0	0.33	0.60
Hostility	0.25	0.40	0
<b>SUMD</b>			
Mental Disorder	4	3	1
Medication	3	3	1
Social Consequences	5	3	1
<b>Insight Scale</b>			
Positive Insight	18	22	22
Negative Insight	7	8	5
<b>IPQ-R</b>			
Consequences	23	21	20
Personal Control	22	19	19
Treatment Control	17	16	17
Illness Coherence	20	21	19
<b>UKU-ConSat</b>		5	7

## Participant J

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	1	1	-
Depression	2	1	-
Conceptual Disorganisation	4	1	-
Unusual Thought Content	3	0	-
Hostility	3	0	-
Suspiciousness	2	0	-
<b>BSI</b>			
Anxiety	2.17	1.67	1.17
Depression	2.00	1.17	1.33
Paranoid Ideation	1.25	0.80	2.20
Psychoticism	3.33	2.33	0.60
Hostility	0.50	1.40	0.40
<b>SUMD</b>			
Mental Disorder	5	1	-
Medication	5	1	-
Social Consequences	5	3	-
<b>Insight Scale</b>			
Positive Insight	16	21	11
Negative Insight	8	6	4
<b>IPQ-R</b>			
Consequences	-	20	21
Personal Control	-	25	23
Treatment Control	-	16	18
Illness Coherence	-	15	23
<b>UKU-ConSat</b>		3	-2

- missing data

## Participant K

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	4	-	-
Depression	1	-	-
Conceptual Disorganisation	4	-	-
Unusual Thought Content	5	-	-
Hostility	6	-	-
Suspiciousness	6	-	-
<b>BSI</b>			
Anxiety	4.00	-	-
Depression	2.83	-	-
Paranoid Ideation	3.75	-	-
Psychoticism	2.33	-	-
Hostility	1.75	-	-
<b>SUMD</b>			
Mental Disorder	5	-	-
Medication	5	-	-
Social Consequences	5	-	-
<b>Insight Scale</b>			
Positive Insight	20	-	-
Negative Insight	6	-	-
<b>IPQ-R</b>			
Consequences	16	-	-
Personal Control	23	-	-
Treatment Control	22.50	-	-
Illness Coherence	10	-	-
<b>UKU-ConSat</b>		-	-

- missing data

## Participant L

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	2	2	2
Depression	0	0	0
Conceptual Disorganisation	3	3	0
Unusual Thought Content	2	2	0
Hostility	0	0	0
Suspiciousness	2	3	0
<b>BSI</b>			
Anxiety	2.17	3.33	2.67
Depression	2.17	2.17	2.00
Paranoid Ideation	1.75	3.20	2.40
Psychoticism	2.33	1.67	2.20
Hostility	0.25	1.40	0.20
<b>SUMD</b>			
Mental Disorder	3	1	5
Medication	2	5	1
Social Consequences	5	5	5
<b>Insight Scale</b>			
Positive Insight	19	20	20
Negative Insight	9	10	8
<b>IPQ-R</b>			
Consequences	26	20	23
Personal Control	22	22	27
Treatment Control	20	19	20
Illness Coherence	13	20	12
<b>UKU-ConSat</b>		4	7

## Participant M

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	2	0	-
Depression	1	0	-
Conceptual Disorganisation	2	2	-
Unusual Thought Content	2	1	-
Hostility	0	0	-
Suspiciousness	3	0	-
<b>BSI</b>			
Anxiety	2.00	0.67	-
Depression	2.67	1.33	-
Paranoid Ideation	3.50	3.00	-
Psychoticism	0.67	1.33	-
Hostility	0.25	0	-
<b>SUMD</b>			
Mental Disorder	5	5	-
Medication	5	5	-
Social Consequences	3	4	-
<b>Insight Scale</b>			
Positive Insight	26	26	-
Negative Insight	11	10	-
<b>IPQ-R</b>			
Consequences	25	22	-
Personal Control	12	14	-
Treatment Control	15	17	-
Illness Coherence	18	21	-
<b>UKU-ConSat</b>		4	-

- missing data



## Participant N

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	0	-	-
Depression	0	-	-
Conceptual Disorganisation	0	-	-
Unusual Thought Content	1	-	-
Hostility	0	-	-
Suspiciousness	2	-	-
<b>BSI</b>			
Anxiety	0.83	-	-
Depression	1.67	-	-
Paranoid Ideation	0	-	-
Psychoticism	1.33	-	-
Hostility	1.25	-	-
<b>SUMD</b>			
Mental Disorder	3	-	-
Medication	1	-	-
Social Consequences	1	-	-
<b>Insight Scale</b>			
Positive Insight	13	-	-
Negative Insight	8	-	-
<b>IPQ-R</b>			
Consequences	19	-	-
Personal Control	19	-	-
Treatment Control	6	-	-
Illness Coherence	9	-	-
<b>UKU-ConSat</b>		-	-

- missing data

## Participant O

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	0	2	2
Depression	0	0	0
Conceptual Disorganisation	3	0	0
Unusual Thought Content	3	0	0
Hostility	0	0	0
Suspiciousness	3	2	0
<b>BSI</b>			
Anxiety	0.67	0.83	0
Depression	2.00	1.00	0.33
Paranoid Ideation	2.25	1.20	0
Psychoticism	1.67	0.33	0
Hostility	3.25	0.80	0
<b>SUMD</b>			
Mental Disorder	5	1	1
Medication	1	1	1
Social Consequences	5	3	1
<b>Insight Scale</b>			
Positive Insight	21	23	19
Negative Insight	9	8	6
<b>IPQ-R</b>			
Consequences	28	14	17
Personal Control	23	19	20
Treatment Control	25	15	22
Illness Coherence	15	16	10
<b>UKU-ConSat</b>		1	1

## Participant P

	Pre-Intervention	Post-Intervention	Follow-Up
<b>BPRS</b>			
Anxiety	0	-	-
Depression	0	-	-
Conceptual Disorganisation	1	-	-
Unusual Thought Content	0	-	-
Hostility	3	-	-
Suspiciousness	2	-	-
<b>BSI</b>			
Anxiety	1.50	1.33	-
Depression	3.00	1.17	-
Paranoid Ideation	2.00	0.60	-
Psychoticism	2.67	1.33	-
Hostility	1.25	0.40	-
<b>SUMD</b>			
Mental Disorder	5	-	-
Medication	5	-	-
Social Consequences	5	-	-
<b>Insight Scale</b>			
Positive Insight	21	-	-
Negative Insight	10	-	-
<b>IPQ-R</b>			
Consequences	21	17	-
Personal Control	21	23	-
Treatment Control	15	15	-
Illness Coherence	13	20	-
<b>UKU-ConSat</b>		-4	-

- missing data

## Appendix 15 BPRS – Reliable Change Indices

The tables below indicate the Reliable Change Index values for each individual when comparing results from Pre-Intervention to Post-Intervention and Pre-Intervention to Follow-Up on the BPRS.

### Pre-Intervention to Post-Intervention

	Anxiety	Depression	Conceptual Disorganisation	Unusual Thought Content	Hostility	Suspiciousness
A	-0.62	0	3.08 *	10.17 *	0	4.42 *
B	1.86	1.44	0	0	0.71	0
C	1.24	0	0	6.78 *	1.43	2.65 *
D	-1.24	0	-1.54	-1.69	0	-0.88
E	0	0	0	0	0.71	0
F	1.24	2.16 *	-1.54	0	0	0
G	0	0	4.62 *	5.08 *	0.71	0.88
H	0	-0.72	3.08 *	3.39 *	0	1.77
I	0	0	0	1.69	0	0
J	0	0.72	4.62 *	5.08 *	2.14 *	1.77
K	-	-	-	-	-	-
L	0	0	0	0	0	-0.88
M	1.24	0.72	0	1.69	0	2.65 *
N	-	-	-	-	-	-
O	-1.24	0	4.62 *	5.08 *	0	0.88
P	-	-	-	-	-	-

\* significant finding (i.e. RCI >1.96)

- missing data

### Pre-Intervention to Follow-Up

	Anxiety	Depression	Conceptual Disorganisation	Unusual Thought Content	Hostility	Suspiciousness
A	0.62	0.72	4.62 *	10.17 *	0	3.54 *-
B	-	-	-	-	-	-
C	1.86	0	0	6.78 *	1.43	3.54 *
D	0	0	0	0	0	0
E	0	0	0	0	0.71	0
F	1.24	2.16 *	0	0	0	0
G	-	-	-	-	-	-
H	-	-	-	-	-	-
I	1.24	1.44	0	1.69	0.71	0
J	-	-	-	-	-	-
K	-	-	-	-	-	-
L	0	0	4.62 *	3.39 *	0	1.77
M	-	-	-	-	-	-
N	-	-	-	-	-	-
O	-1.24	0	4.62 *	5.08 *	0	2.65 *
P	-	-	-	-	-	-

\* significant finding (i.e. RCI >1.96)

- missing data

## Appendix 16 BSI – Reliable Change Indices

The tables below indicate the Reliable Change Index values for each individual when comparing results from Pre-Intervention to Post-Intervention and Pre-Intervention to Follow-Up on the BSI.

### Pre-Intervention to Post-Intervention

	Anxiety	Depression	Paranoid Ideation	Psychoticism	Hostility
A	-0.90	0.74	2.27 *	1.56	-0.26
B	3.60 *	0.98	1.56	2.08 *	3.07 *
C	0.23	-0.25	3.52 *	1.56	1.32
D	-0.45	-1.47	-1.72	0	0.09
E	1.35	0	2.19 *	1.04	1.84
F	2.93 *	1.96 *	4.30 *	3.13 *	0
G	-0.90	-0.98	-3.02 ^	-1.56	-1.05
H	0.90	1.96 *	1.09	0.52	0.09
I	0.68	0	0.39	-0.52	-0.26
J	0.68	1.23	0.70	1.56	-1.58
K	-	-	-	-	-
L	-1.58	0	-2.27 ^	1.04	-2.02 ^
M	1.80	1.96 *	0.78	-1.04	0.44
N	-	-	-	-	-
O	-0.23	1.47	1.64	2.08 *	4.30 *
P	0.23	2.70 *	2.19 *	2.08 *	1.49

\* significant finding (i.e. RCI >1.96)

^ significant deterioration (i.e. RCI <-1.96)

- missing data

### Pre-Intervention to Follow-Up

	Anxiety	Depression	Paranoid Ideation	Psychoticism	Hostility
A	-	-	-	-	-
B	2.48 *	0.25	1.56	1.46	3.07 *
C	0.23	0	2.58 *	1.46	0.96
D	0	-0.74	0.78	0.52	0.09
E	1.35	0.49	2.19 *	1.77	1.84
F	2.93 *	1.96 *	3.67 *	2.71 *	0
G	-	-	-	-	-
H	-	-	-	-	-
I	0.68	0.49	0.39	-0.94	0.44
J	1.35	0.98	-1.48	4.27 *	0.18
K	-	-	-	-	-
L	-0.68	0.25	-1.02	0.21	0.09
M	-	-	-	-	-
N	-	-	-	-	-
O	0.90	2.45 *	3.52 *	2.60 *	5.70 *
P	-	-	-	-	-

\* significant finding (i.e. RCI >1.96)

^ significant deterioration (i.e. RCI <-1.96)

- missing data

## Appendix 17 SUMD – Changes in Scores Over Time

The tables below indicate the change in scores for each individual when comparing Pre-Intervention to Post-Intervention and Pre-Intervention to Follow-Up.

### Pre-Intervention to Post-Intervention

	Awareness of having a Mental Disorder	Awareness of the Achieved Effects of Medication	Awareness of the Social Consequences of having a Mental Disorder
A	4 *	3 *	4 *
B	4 *	4 *	-4
C	4 *	4 *	4 *
D	0	0	0
E	0	0	0
F	-2	2 *	2 *
G	0	0	0
H	4 *	4 *	2 *
I	1 *	0	2 *
J	4 *	4 *	2 *
K	-	-	-
L	-2	-3	0
M	0	0	-1
N	-	-	-
O	4 *	0	2 *
P	-	-	-

\* denotes improvement in insight

- missing data

### Pre-Intervention to Follow-Up

	Awareness of having a Mental Disorder	Awareness of the Achieved Effects of Medication	Awareness of the Social Consequences of having a Mental Disorder
A	4 *	4 *	2 *
B	-	-	-
C	2 *	4 *	0
D	0	0	0
E	0	0	0
F	2 *	4 *	2 *
G	-	-	-
H	-	-	-
I	3 *	2 *	4 *
J	-	-	-
K	-	-	-
L	-2	1 *	0
M	-	-	-
N	-	-	-
O	4 *	0	4 *
P	-	-	-

\* denotes improvement in insight

- missing data

**Appendix 18      The Insight Scale – Reliable Change Indices**

The tables below indicate the Reliable Change Index values for each individual when comparing results from Pre-Intervention to Post-Intervention and Pre-Intervention to Follow-Up on the Insight Scale.

**Pre-Intervention to Post-Intervention**

	Positive Insight	Negative Insight
A	2.62 *	1.17
B	1.12	1.75
C	5.24 *	1.75
D	-1.12	0
E	0	0
F	1.87	0
G	0.37	3.51 *
H	-0.75	0
I	1.50	0.58
J	1.87	-1.17
K	-	-
L	0.37	0.58
M	0	-0.58
N	-	-
O	0.75	-0.58
P	-	-

\* significant finding (i.e. RCI > 1.96)

- missing data

**Pre-Intervention to Follow-Up**

	Positive Insight	Negative Insight
A	-	-
B	0.37	0
C	3.00 *	-1.17
D	0.37	-0.58
E	0	0
F	3.00 *	0.58
G	-	-
H	-	-
I	1.50	-1.17
J	-1.87	-2.34 ^
K	-	-
L	0.37	-0.58
M	-	-
N	-	-
O	-0.75	-1.75
P	-	-

\* significant finding (i.e. RCI >1.96)

^ significant deterioration (i.e. RCI <-1.96)

- missing data

## Appendix 19 IPQ-R – Reliable Change Indices

The tables below indicate the Reliable Change Index values for each individual when comparing results from Pre-Intervention to Post-Intervention and Pre-Intervention to Follow-Up on the IPQ-R.

### Pre-Intervention to Post-Intervention

	Consequences	Personal Control	Treatment Control	Illness Coherence
A	-2.73 ^	-0.97	1.04	1.17
B	-2.39 ^	-0.24	-1.74	1.17
C	1.02	-0.48	1.74	1.41
D	2.39 *	-0.48	0	2.35 *
E	0	0.48	0.69	2.35 *
F	-0.68	2.42 *	2.78 *	-2.35 ^
G	-	-	-	-
H	-1.37	2.17 *	0.35	-1.88
I	-0.68	-0.72	-0.35	0.23
J	-	-	-	-
K	-	-	-	-
L	-2.05 ^	0	-0.35	1.64
M	-1.02	0.48	0.69	0.70
N	-	-	-	-
O	-4.78 ^	-0.97	-3.47 ^	0.23
P	-1.37	0.48	0	1.64

\* significant finding (i.e. RCI >1.96)

^ significant deterioration (i.e. RCI <-1.96)

- missing data



# Pre-Intervention to Follow-Up

	Consequences	Personal Control	Treatment Control	Illness Coherence
A	-	-	-	-
B	-1.07	-0.24	-1.74	2.58 *
C	1.43	-0.48	1.74	1.17
D	-1.79	-1.45	0.69	1.41
E	-0.71	0	0	0.94
F	1.43	2.42 *	2.43 *	-1.17
G	-	-	-	-
H	-	-	-	-
I	-1.07	-0.72	0	-0.23
J	-	-	-	-
K	-	-	-	-
L	-1.07	1.21	0	-0.23
M	-	-	-	-
N	-	-	-	-
O	-3.93 ^	-0.72	-1.04	-1.17
P	-	-	-	-

\* significant finding (i.e. >1.96)

^ significant deterioration (i.e. <-1.96)

- missing data

## Appendix 20      UKU-ConSat (total scores)

The table below indicates the total score for each individual on the UKU-ConSat at Post-Intervention and Follow-Up.

	Post-Intervention	Follow-Up
A	5	-
B	13	13
C	4	0
D	-10	-10
E	4	4
F	12	12
G	-12	-
H	3	-
I	5	7
J	3	-2
K	-	-
L	4	7
M	4	-
N	-	-
O	1	1
P	-4	-

- missing data

## **Appendix 21:   Personalised Psychoeducation Manual**

This is a sample manual. Details have been changed to protect confidentiality.

TRUST LOGO



**CONFIDENTIAL**

**PERSONALISED INFORMATION BOOKLET**

**Joe Bloggs  
Final Session**

***Date***

PSYCHOLOGY DEPARTMENT  
ADDRESS

Date

Dear Joe,

It was good to meet you on the *<insert dates of first and second sessions>*. In the first session, we were discussing the reasons why you are in the *<name of unit>* and what you feel your difficulties are at the moment. In the second session, I gave you a letter with a shared idea of your understanding of what is happening to you right now and my understanding. In that session, you had the chance to change any aspects that you did not agree with. This letter is the amended version of the last letter.

In our meeting, you told me that you are in the *<name of base unit>* because you stopped taking your medication. You were also feeling stressed and upset because you were having difficulties with your relationship and because a good friend of yours committed suicide. You began to re-experience symptoms, including hearing voices and having "telepathic communications" from your friend who died. These messages were telling you to throw yourself in front of a train. When I met you the second time, you said that you were hardly getting any of these symptoms. You told me this was because the medication had started to work.

I asked you about what the doctors feel is wrong with you at the moment. You told me that they have told you that you have Paranoid Schizophrenia. You told me that you have had this in the past, but that you do not believe that you have it now.

Over the course of our session, you mentioned several times that you had been treated unfairly because of your Schizophrenia. You seemed to feel that other people are against you because of your illness.

The experiences that you are having, like receiving telepathic messages and hearing voices are common for people who have a psychosis. A psychosis is a condition in which the person's contact with reality is lost or highly distorted. One illness in which people suffer from psychosis is Schizophrenia. Many people who have a psychosis don't believe that they are suffering from an illness in the early stages. In your case, you told me that you are not sure at the moment whether or not you are ill, but feel that in a few weeks, you will look back on this experience and realise that you are ill.

You mentioned that you have telepathic communications from the dead telling you to kill yourself. You also hear voices. These symptoms are called **hallucinations** and often seem to occur out of nowhere. Hearing voices that other people can't hear is the most common type of hallucination. In your case, the voices give you orders to kill yourself.

You mentioned that you feel that everyone knows that you have Schizophrenia and think badly of you because of this. This belief seems to be true to you and can make you feel very frightened. It can make you feel alone because other people don't believe you. This symptom is a **delusion** and is a common symptom of psychosis.

Your Experience	Alternative Explanations
<ul style="list-style-type: none"> <li>Receiving telepathic messages from your friend who died telling you to kill yourself.</li> </ul>	<ul style="list-style-type: none"> <li>This belief seems true to you, but can make you feel alone because other people don't believe you and don't have the same communications</li> <li>We think these feelings are due to a symptom called a hallucination.</li> <li>Hallucinations are a common symptom of psychosis.</li> </ul>

Your Belief	Alternative Explanations
<ul style="list-style-type: none"> <li>You believe that everyone around you knows that you have Schizophrenia and thinks badly of you because of this.</li> </ul>	<ul style="list-style-type: none"> <li>Although you believe this very strongly we think these feelings are due to a symptoms called a delusion</li> <li>Delusions are a common symptom of psychosis.</li> </ul>

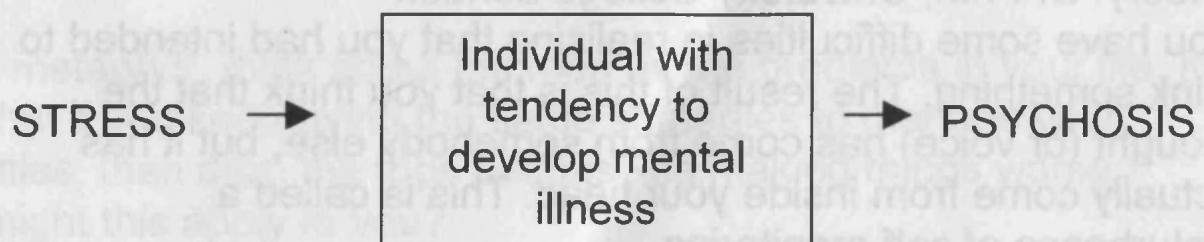
## WHAT CAUSES THIS ILLNESS?

It is likely, but not certain, that you like other people who have a psychosis, have imbalances in your brain. These imbalances are in the chemicals that send messages around your brain. The main chemical involved in psychosis is called dopamine.

You mentioned that before your admission to <name of base unit>, you felt stressed because of the death of your friend and because you had been having relationship difficulties. In addition, you had stopped taking your medication.

### Theory: Dr Zubin & Dr Spring, 1977

People, like you, who have a tendency to develop a psychosis and who experience extreme stress are more likely to develop a psychosis than if they had not had this stress.



You mentioned that you used to abuse many street drugs, including cocaine, heroin, crack, cannabis and speed. Your use of drugs is not unusual. Cannabis is one of the three substances most frequently misused by people with mental health difficulties like you. We feel that your use of cannabis and other drugs needs to be moderated significantly, if not stopped altogether.

Researchers consider that cannabis should be seen as something which can precipitate further episodes of illness. Other Doctors like <name of Psychiatrist at base unit> feel that cannabis increases the risk of hospital readmission.

Drugs cause worsening of your symptoms and can trigger a further episode of psychosis. We know that the medication that you have been prescribed will block an important neurochemical called dopamine. We think that drugs have the effect of unblocking or enhancing dopamine pathways, which cause paranoid thinking, delusions and hallucinations.



## HOW DO WE UNDERSTAND YOUR SYMPTOMS?

In our discussion, you mentioned that sometimes you hear voices that other people can't hear and believe that people are against you because you have Schizophrenia. There have been many Psychologists who have thought about this.

**Theory: Dr Baddeley**

Your symptoms are caused by a fault in the way that you hear information. This means that you are not always sure if a thought has come from inside your head or from someone else. This is called a disturbance of inner speech.

**HOW THIS MAY RELATE TO YOU:** The difficult voices that you hear about killing yourself are generated from your own anxieties about the world (for example, about people around you dying or leaving you). They are your own thoughts that are interpreted as coming from outside of your head.

**Theory: Dr Frith, University College London**

You have some difficulties in realising that you had intended to think something. The result of this is that you think that the thought (or voice) has come from somebody else, but it has actually come from inside your head. This is called a disturbance of self-monitoring.

**HOW THIS MAY RELATE TO YOU:** The thoughts of wanting to throw yourself in front of a train originate from inside your head, but because of a disturbance of self-monitoring, you do not realise that you had intended to think them, so you perceive them as voices coming from outside of your head.

**Theory: Dr Bentall, Manchester**

If people think that others are conspiring against them, then they won't feel depressed about all the things that they haven't done in their lives, because they'll be able to blame it on someone else.

**HOW THIS MAY RELATE TO YOU:** Your experiences of feeling that others are persecuting you for having Schizophrenia may be a symptom of Schizophrenia. The theory suggests that you can blame others for you having Schizophrenia as you have found this difficult to accept yourself. This stops you from feeling depressed about the Schizophrenia, but instead ends up with you being angry with others.

A useful way to think about your symptoms is to use the following metaphor. It's about a tug of war:

'The situation you are in is like being in a tug-of-war with a monster. In between you and the monster is a pit, and so far as you can tell it is bottomless. If you lose this tug-of-war, you will fall into this pit and will be destroyed. So you pull and pull, but the harder you pull, the harder the monster pulls, and you edge closer to the pit.

**The hardest thing to see is that our job here is not to win the tug-of-war.....Our job is to drop the rope.'**

In this metaphor, think about the rope as the problems in your life. It says that if you keep using the same strategies to manage your difficulties, then drop the rope because its making things worse. How might this apply to you?

## WHAT CAN BE DONE TO IMPROVE YOUR SYMPTOMS?

You have been asked by your doctor to take anti-psychotic medication, called Clozaril. This is one of the most helpful ways of getting rid of psychosis. The medication acts on the dopamine in your brain. It cannot cure your psychosis, but it can take away many of the symptoms and make them milder. In some cases, they shorten the course of an episode of psychosis as well.

The other important way of controlling your psychosis is not to take street drugs. You mentioned that you take many different drugs and you know that these help to get rid of your symptoms in the short-term, but make them worse in the long term. This is because they interfere with the dopamine in your brain, that we talked about before.

One way of controlling your symptoms is to look after yourself by taking regular exercise (like going to the gym and kick-boxing, that you enjoy), eating healthily and avoiding stressful situations.

In our discussion, you told me that some of the people that you mix with also like to take drugs and don't have jobs.

Sometimes being with these people can make you feel worse. You also told me that you have two circles of friends: those who take drugs and those who do not. You said that you are going to try to avoid the friends who take drugs to help you to stay off them. We also encourage you to do this.



## RELAPSE PREVENTION

In our meeting, you told me that, in the future, you are keen to get a job that you enjoy, e.g. engineering or mechanical work. We very much hope that you will be able to take up this lifestyle.

The most important way of making sure that you become well is to keep taking your medication. When medication is stopped, people who have a psychosis often relapse and suffer from their delusions and hallucinations.

Another way of making sure that you don't relapse is to get enough sleep. When you notice that you haven't been getting enough sleep, speak to your Social Worker <name> or GP <name> or CPN <name>.

When we talked about how you were feeling before you came to hospital, you said:

- Feeling lethargic
- Having no motivation
- Feeling depressed
- Hearing voices
- Receiving telepathic messages

These symptoms were probably the signs that your psychosis was coming back. This is called "Relapse". When you start to experience these symptoms, it is important that you contact your Social Worker, CPN or doctor immediately.

Finally, a key way of staying healthy is to keep stress at bay. If you become stressed, your symptoms, including delusions and hallucinations, may emerge. Ways of keeping stress at bay are to exercise (including kick boxing and going to the gym), to socialise and to eat healthily.

## WHAT SHOULD I DO IF MY SYMPTOMS START AGAIN?

When you know that your symptoms are starting again, the most important thing for you to do is to tell someone. You could tell your Social Worker <name>, your GP <name>, your Psychiatrist <name> or your CPN <name>.

It is likely that your doctor will prescribe you some medication. It is really important that you take this to reduce the uncomfortable feelings.

Remember, your psychosis is an illness. It can be treated. You can make it better by taking your medication and by staying stress-free. There are lots of people around to help you. You're not alone.

## PLANS FOR THE FUTURE

It's great that you want get a job, e.g. engineering or mechanics.

You may want to get some advice about your future career by calling the Citizens Advice Bureau. Their phone number is *<local branch>*. Also, there is a Personal Advisor Service that you may find useful in thinking about your career. The phone number is free and is *<telephone number>*.

You may want to go to college to train in engineering or mechanics. The local college that has this sort of course is *<name>* and you can contact them on *<number>*

If you find that you are again having problems with drugs, you may either want to contact a doctor (your GP or Psychiatrist) or you may also find it helpful to contact Drugline to talk to someone about your difficulties. Their phone number is *<insert telephone number>*.

### Useful phone numbers

**Citizens Advice Bureau:** *insert phone number*

**Personal Advisor Service:** *insert phone number*

**Name of local college:** *insert phone number*

**Drugline:** *insert phone number*

I hope you have found this helpful.

Yours sincerely,

Judith Friedman  
Trainee Clinical Psychologist