Service Users' Construction of Relapse Experiences in Psychosis: A Grounded Theory Approach

&

Research Portfolio

PART ONE

(Part Two bound separately)

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Degree of Doctor of Clinical Psychology

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Chapter One

Service Based Evaluation

Improving communication: An audit of assessment letter content within Ayrshire and Arran Consulting and Clinical Psychology Services (CCPS).

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ABSTRACT

Effective communication within and between services is important in the development of multi-disciplinary collaboration, effective service delivery and satisfactory patient treatment. The primary aim of this study was to audit assessment letter content across three therapy disciplines within Ayrshire and Arran Consulting and Clinical Psychology Services (CCPS). A secondary aim was to audit content within the three therapy disciplines. The overall aim was to ascertain service implications based on the current letter standard. A random sample of sixty letters were audited, twenty written by Clinical Psychologists, twenty by Counselling Psychologists and a further twenty by CBT Psychotherapists. The results suggested overall content inclusion was of a high standard. However, there were some inclusion gaps in specific information pertaining to the themes of case complexity, reason for seeking assistance, previous psychiatric and medical history, maintaining factors and estimated treatment length. It was concluded that training should be conducted across the service to further develop communication within these areas.

Key Words

Assessment letter, content, inclusion, therapy discipline.

INTRODUCTION

Background to Service-Related Issue

Developing more effective shared care between primary and secondary services is a key feature of the National Service Framework for Mental Health.[1] However, it is acknowledged that communication difficulties are common both within and between primary and secondary mental health services. Several studies have explored these difficulties and attempted to find ways of improving communication.[2,3,4,5,6] The quality of care received by patients within the NHS relies, in part, on good communication,[7] thus monitoring and improving communication levels can effectively improve the service that is provided to the patient.

One of the most common forms of communication difficulties between and within services is inadequacies in letter content.[8] A review by Tattersall[6] which explored research on item inclusion in referral letters concluded that NHS specialists are dissatisfied with the quality and content of written communication. Indeed, one study by Farid[5] found that the quality of letters written within services has a direct impact on the patient and their treatment. For example high quality referral letters were associated with subsequent attendance to initial appointments and treatment, whereas lower quality referral letters were associated within non-attendance for initial appointment and subsequent treatment.

Accurate and comprehensive letter content provides improvements in communication between the referring agent and the mental health service and subsequently in their working relationships.[9] This may impact upon the development of effective collaboration, consultancy and further, the opportunity to understand other professional roles. If these competencies are developed between services, the level of communication is likely to be greater and more effective and ultimately services will be working in collaboration in order to provide the best treatment for the patient. These studies highlight the importance of improving letter content and suggest the implications that letter content has upon multi disciplinary collaboration, service delivery, and patient care.

Service-Related Aspects

This project explores the content of initial assessment letters written within a multidisciplinary primary care adult mental health service. Ayrshire and Arran Consulting and Clinical Psychology Services (CCPS) operate with a skill mix of professionals including clinical psychologists, counselling psychologists and CBT specialists. As part of a waiting list initiative the service uses an assessment triage system. The triage system aims to ensure patients are seen as soon as possible following referral, and also screened for appropriate discipline and type and length of intervention. Referrals received by CCPS are first placed on an initial assessment waiting list. The initial assessment is conducted by a therapist from the service skill mix, who based on one session with the patient writes an assessment letter which is sent to the referring agent and filed in the patient's case notes. The content of the assessment letter is important in terms of achieving the discussed collaborative approach between services that ultimately impacts upon the effectiveness of patient care, but also in terms of meeting the following specific service objectives. Firstly, order in to provide information on the presentation of the patient at the time of assessment. This information can then be disseminated and provides guidance to the therapist who takes on the case, the referring agent and the patients General Practitioner. Secondly, the content of the assessment letter allows appropriate cases to be selected for Trainee Clinical Psychologists and Assistant Psychologists. Finally, the content of the assessment letter should provide important information about the type of treatment and length of intervention required. This is particularly important in terms of ensuring that the most effective form of treatment is offered to the patient.

Based upon the first authors' clinical experience and through discussion with other therapists, difficulties meeting the described objectives are encountered when there is inadequate information within an assessment letter. Thus, as well as the evidence from the existant research literature, standard clinical practice has emphasised the importance of comprehensive assessment letter content.

Although several studies have explored communication problems within and between services, there appears to be a scarcity of literature defining appropriate levels of communication and in particular the appropriate content of assessment letters. The few studies that are available fail to specify what should be included in an assessment letter. For example Yellowlees[10] surveyed 80 Scottish GP's and 80 psychiatrists about the key

items to be included in referral and consultation letters and found inconsistencies between the two groups. GP's placed greater emphasis on the inclusion of diagnosis, treatment, follow-up and prognosis; whereas the psychiatrists rated main symptoms, reason for referral, psychiatric history, medication and family history as the most important.

In addition the CCPS department does not have set guidelines for the content of assessment letters. Based upon supervision, clinical training, and reflection on the literature and consistent with suggestions by Lindsay & Powell,[11] the current author proposes that the following categories of information should be included in a satisfactory assessment letter: presenting problems, personal background, formulation and treatment recommendations (a detailed content breakdown of these is included in the method section).

Research Aims

The study has two major aims. The primary aim is to explore the overall content of assessment letters across therapy disciplines within the service. This information will form the main basis for suggesting the overall inclusion rate of letter content and will subsequently highlight service implications in relation to the current standard across the service. Following this initial exploration, the secondary aim of the study is to explore the content of letters within therapy disciplines. This is important in order to identify whether there are specific training needs within individual therapy disciplines, the service can then ensure that any training resources they implement are targeted appropriately.

METHOD

Sample: A random sample of 60 adult mental health cases were selected, comprising 20 from the Clinical Psychology wait list, 20 from the Counselling Psychology wait list and 20 from the CBT Specialists wait list. Letters inspected were written following one initial assessment meeting with patients, and were written by three Clinical Psychologists, two Counselling Psychologists and three CBT Psychotherapists.

Procedure: Content analysis of each assessment letter was achieved by visual inspection, to denote presence or absence of the following items. These items are based

on the first authors experience in supervision, clinical training, and reflection on the literature and consistent with suggestions specified by Lindsay & Powell.[11]

Insert Table 1

A data collection sheet was designed to score each letter (see Appendix 1). The first author completed all content analyses. Content analysis for general category and for specific areas was examined (Table 1). The total number of letters which included each content item was then derived. These data were then converted to percentage score for ease of comprehension, indicating the pattern of item inclusion (general category and specific items) both across and within disciplines.

Data Analysis: Inter-rater reliability was checked by a qualified Clinical Psychologist colleague, who rated 6 assessment letters (10% of sample) using the above criteria. A quantitative descriptive data analysis of the results was then conducted.

Ethical Considerations:

The CCPS Clinical Governance Forum granted approval of the project and it was agreed ethical approval was not warranted. Procedures to anonymise case identity were considered, however, the Forum agreed this was not necessary because the case notes were only used for the purpose of the described data collection.

RESULTS

The inter-rater score for content of six letters totalled 77 in comparison to the first authors rating score of 75 (Kappa coefficient .96) suggesting high inter-rater reliability.

Primary Analysis: Content across all disciplines

Table 2 shows the percentage of item inclusion across the three disciplines. The four main category areas are highlighted in bold and a breakdown of inclusion of specific items within that category are also shown.

Insert Table 2

As is evident, the overall inclusion of the four category items is high. However, the percentage of specific item inclusion varies within these categories. A large proportion of the sample (98.4%) include a discussion of presenting problems, when documenting this, onset and duration are included by most therapists (83.4% and 65% respectively). However, frequency and severity and reason for seeking assistance are documented much less frequently (23.4% and 15% respectively). Although 80% of therapists included personal background, the percentage of specific items documented within this category were not overly high. In particular there are gaps in the inclusion of items pertaining to early experiences, 61.7% included family relationships, 41.7% included childhood and only 13.3% of therapists included education. A further finding within this category is that only 50% of the discipline sample included in their letters information regarding psychiatric and medical history. Ninety percent of therapists included a formulation within their letters, when documenting this the majority of therapists included a discussion of primary problems, predisposing and precipitating factors, however only a minority of 10% included a discussion of maintaining factors. One hundred percent of therapists within the sample included treatment recommendations and 98.4% documented the required intervention. However, only 8.4% included the estimated length of treatment.

Secondary analysis: Content inclusion per discipline

Tables 3-5 present the mean item inclusion per discipline and the main differences from the overall percentages of item inclusion (Table 2) are identified.

Insert Table 3

In agreement with the overall mean results across disciplines (Table 2), inclusion of the four category items is high amongst Clinical Psychologists. In further agreement smaller percentages of Clinical Psychologists include duration, frequency and severity and reason for seeking assistance, 55%, 15% and 10% respectively, however these inclusion levels are lower than the overall mean inclusion levels across disciplines. Within Personal Background 55% of Clinical Psychologists included a discussion of childhood, which is greater than the percentage of inclusion across disciplines. However, there were lower percentages of inclusion of social relationships and psychiatric and medical history within this therapy group. The inclusion of the formulation category is 100% within this therapy discipline and inclusion of specific

formulation items are higher than the overall mean inclusion levels across disciplines. However, in agreement with the overall results only a small percentage (15%) of Clinical Psychologists included maintaining factors. One hundred percent of this sample included treatment recommendations and required interventions, however only 5% included the estimated length of treatment, this is lower than the overall mean inclusion rate of 8.4% across disciplines.

Insert Table 4

One hundred percent of the sample of Counselling Psychologists included the four category areas. Within presenting problems 95% included the duration of the problem, this is higher than the overall mean inclusion rate of 65% across the disciplines. However only 5% of Counselling Psychologists included reason for seeking assistance, which is lower than the overall inclusion rate of 15%. When discussing personal background only 35% included a discussion of childhood information, however 65% included social relationships. Inclusions of formulation and treatment and recommendation items are high, however in agreement with the overall results across disciplines; only 10% of the sample include maintaining factors and estimated length of treatment.

Insert Table 5

In agreement with the overall mean inclusion levels, high percentages of CBT Psychotherapists include presenting problems and treatment and recommendations (95% and 100% respectively). However only 55% included personal background and 70% included formulation. Additionally as shown percentage of specific item inclusion within these categories suggests some gaps in information inclusion. In particular no CBT psychotherapists included education and within formulation smaller percentages of the sample included a discussion of primary, predisposing and precipitating factors in comparison to the mean inclusion level across all three disciplines. The 5% inclusion level of maintaining factors is similar to the overall low inclusion rate of this item across therapy discipline. One hundred percent of the sample included treatment and recommendations and within this 95% included required intervention and 10% included estimated length of treatment, this latter inclusion rate is higher than the overall percentage inclusion across discipline**.**

DISCUSSION

The primary aim of this study was to explore assessment letter content across three therapy disciplines within CCPS in order to identify service and training implications arising from the current standard of assessment letters. The secondary aim was to explore the content of letters written within therapy disciplines to enable the service to identify whether there are different training requirements within disciplines that would enable them to better target training resources.

An exploration of the primary study aim suggests that the content inclusion of assessment letters written by the Clinical Psychologists, Counselling Psychologists and CBT psychotherapists is of an overall high standard. The three therapy disciplines typically include a discussion of the four category items; presenting problems, personal background, formulation and treatment and recommendations. This result is positive, suggesting an overall high level of communication between therapists and also to secondary services. As suggested by the extant research, this may increase collaboration within working relationships[9] and in turn provide positive benefits to the patients' treatment process. However, although the study highlights a high inclusion rate of the four general category areas, within each category there are gaps in the inclusion of specific items. This lack of inclusion may result in service and wider implications as a result of information not being communicated to the referring agent, the patients General Practitioner (GP) and the therapist who takes on the case. A discussion of these gaps in information reflecting service implications and training needs shall now be presented.

The majority of therapists document presenting problems, however within this category the results highlight lower inclusive levels of frequency and severity and reason for seeking assistance. The lack of inclusion of frequency and severity may signify that the overall complexity of the case is not communicated to the referring agent, GP and treating therapist. For example they may not be informed of suicide ideation or the disabling nature of the patients presenting problems. This may have implications for the service in their selection of appropriate cases for training and also for the treating therapist and their initial understanding of the patients' difficulties. Furthermore, the wider implications may be that this gap in communication prevents the patients GP and referring agent from selecting treatment appropriate to the complexity of the case.

Omission of information regarding the patients' reason for seeking assistance may have implications for the treating therapists' awareness of the patients' motivation for attending therapy. If patients' motivation is more out of obligation than desire to change, this may result in lack of engagement. Communication of this information within the initial assessment letter will enable the therapist to consider the patients' likely engagement with therapy and address this in the first appointment. Ultimately this can help to maximise the efficient use of clinic time and may in turn impact upon waiting list times.

Although a large percentage of therapists across the disciplines included the category item of personal background, there are particular gaps in specific item inclusion within this category, in particular items pertaining to early experiences such as childhood, education and family relationships. This information is important in terms of enabling the treating therapist to have an understanding of how the patients' difficulties developed in order to form a tentative formulation of the likely maintaining beliefs held by the patient. If this information is communicated initially within an assessment letter, it provides the therapist with a basis to explore this aspect further with the patient at an early stage in therapy. Furthermore, psychiatric and medical histories are only included by half of the sample. This suggests a further gap in the communication of information that may influence the treatment provided by the treating therapist and also the GP. Lack of information in these areas may entail that treatment time is utilised for additional assessment, thus impinging upon clinic time efficiency and further on the speed of the patients' treatment progress.

Formulation is included by high percentage of therapists. Equally, primary problems and precipitating factors are included by the majority of therapists. However, there is a shortage of therapists who included a discussion of predisposing factors, this may relate to the previous finding of the gap in inclusion of early experiences. Additionally, a minority of therapists included maintaining factors. The present authors argue that this represents a significant gap within the discussion of a formulation in initial assessment letters. Irreversible factors that are maintaining the patients' problems play a central role in guiding the therapist's choice of intervention [12] and are subsequently one of the main targets for change. The lack of inclusion of this item suggests a key understanding of the underlying mechanisms has not been identified. This requires that the treating therapist makes a further assessment in this area and at this point the assessors'

recommendations for treatment type may have to be revised, thus impacting upon the patients therapy type and length and in turn waiting list times and possibly the patients level of satisfaction with the service.

Positively, one hundred percent of therapists included treatment and recommendations in their letters and within this category almost all therapists stated the required intervention. However, only a small minority included the estimated length of treatment. This may be problematic for therapists who take on the case as it does not indicate the length of treatment time that the patient may require which may prevent the therapist planning the management of their cases. This lack of information may also prevent the GP and referring agent from planning appropriate treatment in collaboration with the therapy received by the patient.

In terms of the secondary study aim, exploration of assessment letter content within individual therapy disciplines suggests there are few outliers in the results for each discipline. However, the individual discipline results suggest that the need for training may be greater for CBT Psychotherapists. In particular this group of therapists appear to be least inclusive in their documentation of personal background and formulation. Nevertheless, an argument for targeting training resources primarily at this group of therapists is not wholly supported by the results as this therapy group are the most inclusive in their documentation of reason for seeking assistance, an item which the other disciplines scored significantly poorer on. The authors therefore propose that CCPS apply training across the service, this would also provide the benefit of promoting continuing professional development for all therapists within the service.

White and Marriot[8] used evidence-based dissemination and implementation strategies to improve routine communication. They developed a 'decision support system'[13] in the form of a laminated A4 desktop reminder including the proposed content of an assessment letter. Based upon their positive findings of improvements in letter content at yearly intervals over a 3 years period, the current authors suggest the introduction of this training strategy. The first author shall disseminate the project findings and propose the introduction of laminated reminders for assessment letter content, including the information specified in Table 1.

Certain limitations in the methodology of this study require discussion. Firstly, content analysis was only conducted on sixty letters. Although this does not invalidate the results, it is a relatively small sample from which to make conclusive statements about the quality of assessment letters within the service. A further limitation is that the number of therapists conducting initial assessments and subsequently writing assessment letters was small, totalling only eight. Moreover, although therapists' initials were not coded for the purpose of anonymity, an observation from the data collection was that it was not possible to obtain equal numbers of letters written by each therapist. Therefore, there were unequal numbers of letters from each therapist. These findings may have implications for the value and generalisation of the results across the entire service. Finally, the assessment letters audited were written following one initial meeting with the patient, therefore it is relevant to suggest that to obtain a thorough assessment of all 20 items (Table 1) within one initial assessment can be difficult and may also be dependent upon the patient factors such as level of engagement and the complexity of presenting problems. Thus, there may be variables out with the therapists' control that may affect their ability to include all of the letter content items.

Despite these limitations, the study has highlighted implications for CCPS. Overall the content of assessment letter written by a sample of therapists across three disciplines is of a high standard. However, the study does highlight some pertinent gaps and training needs in relation to the themes of case complexity, reason for seeking assistance, previous psychiatric and medical history, maintaining factors and estimated treatment length. It has been argued that lack of communication of these factors in an initial assessment letter can have effects on clinic time efficiency, subsequent waiting list times, collaboration and in turn relationships between services, and ultimately in the treatment received by the patient and their satisfaction with this. It has been suggested that training should be conducted across the service through the dissemination of these findings and the introduction of laminated cards suggesting assessment letter content. Further audit could then be conducted to assess improvements in assessment letter content.

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Table 1. Letter items for content analysis

Presenting Problems
Onset
Duration
Frequency & Severity
Reason for seeking assistance
Personal Background
Family Relationships
Childhood
Education
Occupation
Social Relationships
Psychiatric & Medical History
Formulation
Primary Problem
Predisposing Factors
Precipitating Factors
Maintaining Factors
Treatment Recommendations
Required Intervention
Estimated length of treatment

Table 2. Mean Percentage of item inclusion within letters.

Item	Mean Percentage of item inclusion across the three therapy disciplines
Presenting Problems	**98.4%**
Onset	83.4%
Duration	65.0%
Frequency and severity	23.4%
Reason for seeking Assistance	15.0%
Personal Background	**80.0%**
Family Relationships	61.7%
Childhood	41.7%
Education	13.3%
Occupation	48.3%
Social Relationships	38.3%
Psychiatric and Medical history	50.0%
Formulation	**90.0%**
Primary Problems	86.7%
Predisposing Factors	53.4%
Precipitating Factors	70.0%
Maintaining Factors	10.0%
Treatment Recommendations	**100.0%**
Required Intervention	98.4%
Estimated length of treatment	8.4%

Table 3. Mean Percentage of item inclusion within letters written by Clinical Psychologists.

Item	Mean Percentage of item inclusion within letters written by Clinical Psychologists
Presenting Problems	**100.0%**
Onset	95.0%
Duration	55.0%
Frequency and severity	15.0%
Reason for seeking Assistance	10.0%
Personal Background	**85.0%**
Family Relationships	55.0%
Childhood	55.0%
Education	25.0%
Occupation	40.0%
Social Relationships	20.0%
Psychiatric and Medical history	35.0%
Formulation	**100.0%**
Primary Problems	95.0%
Predisposing Factors	65.0%
Precipitating Factors	80.0%
Maintaining Factors	15.0%
Treatment Recommendations	**100.0%**
Required Intervention	100.0%
Estimated length of treatment	5.0%

Table 4. Mean Percentage of item inclusion within letters written by Counselling Psychologists.

Item	Mean Percentage of item inclusion within letters written by Counselling Psychologists
Presenting Problems	**100.0%**
Onset	95.0%
Duration	95.0%
Frequency and severity	25.0%
Reason for seeking Assistance	5.0%
Personal Background	**100.0%**
Family Relationships	85.0%
Childhood	35.0%
Education	15.0%
Occupation	70.0%
Social Relationships	65.0%
Psychiatric and Medical history	75.0%
Formulation	**100.0%**
Primary Problems	100.0%
Predisposing Factors	65.0%
Precipitating Factors	90.0%
Maintaining Factors	10.0%
Treatment Recommendations	**100.0%**
Required Intervention	100.0%
Estimated length of treatment	10.0%

Table 5. Mean Percentage of item inclusion within letters written by CBT - Psychotherapists.

Item	Mean Percentage of item inclusion within letters written by CBT Psychotherapists
Presenting Problems	**95.0%**
Onset	60.0%
Duration	45.0%
Frequency and severity	30.0%
Reason for seeking Assistance	30.0%
Personal Background	**55.0%**
Family Relationships	45.0%
Childhood	35.0%
Education	0.0%
Occupation	35.0%
Social Relationships	30.0%
Psychiatric and Medical history	40.0%
Formulation	**70.0%**
Primary Problems	65.0%
Predisposing Factors	30.0%
Precipitating Factors	40.0%
Maintaining Factors	5.0%
Treatment Recommendations	**100.0%**
Required Intervention	95.0%
Estimated length of treatment	10.0%

Chapter Two

Systematic Literature Review

Psychosis, Interpersonal Experiences and Quality of Life: A Metasynthesis of Qualitative Research.

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Abstract

The impact of the experience of psychosis has been widely researched. There is an abundance of research to suggest the importance of the interpersonal atmosphere in terms of promoting recovery and adaptation from the experience of psychosis. This review aimed to appraise and assimilate findings from qualitative research that explored subjective experiences from three domains: i) the impact of psychosis, ii) quality of life experiences, iii) experiences of interpersonal relationships and supports. It was proposed that a synthesis of qualitative studies from these areas would provide an enriched account of interpersonal experiences, quality of life and the intersubjective dimensions of meaning and adaptation to psychosis. A metasynthesis approach was undertaken including both methodological critique and synthesis using a method of meta-ethnography (Noblit & Hare, 1988). The findings of the methodological critique suggested that most studies demonstrated a number of strengths and all studies represented the positive movement towards enabling the subjective experiences of individuals experiencing psychosis to be better understood. The synthesis produced five interacting themes: i) the interpersonal impact of living with psychosis, ii) the importance of interpersonal support, iii) gaining control over experiences, iv) affect – the reaction to the impact of experiences associated with psychosis, v) putting it all together: making meaning from experiences. The themes illuminated the intersubjective process of meaning making and it was observed that this process might mediate experience of recovery and adaptation. Theoretical and clinical implications are discussed.

Key words: psychosis, interpersonal experiences, quality of life, metasynthesis, intersubjective dimensions

Introduction

The experience of psychosis can have a multifaceted impact, affecting many areas of an individual's life (Tarrier, 2005). Research suggests individuals experiencing psychosis are vulnerable to secondary psychological difficulties. Several studies have explored depression following psychotic experiences (Rooke and Birchwood., 1998; Iqbal et al., 2000; Birchwood et al., 2000) and the association between psychotic experiences and the development of post-traumatic stress disorder (Shaw et al., 1997; Morrison et al., 2003; Shaw et al., 2002; Meyer et al., 1999; Harrison et al., 2004 & Jackson et al., 2004). High rates of suicidal thinking and behaviour have also been found amongst individuals experiencing psychosis (Tarrier, 2005). Research studies suggest that the appraisals and evaluative thinking style of individuals' who experience psychosis are instrumental in the development of secondary psychological difficulties (Chadwick et al, 1996; Drayton, 1995; Rooke & Birchwood, 1998 & Birchwood et al., 2000). It is argued that appraisals such as loss, entrapment and humiliation are grounded in the realities of psychotic experience that may include hospital admission, loss of employment and social role and residual symptoms. (Rooke & Birchwood, 1998). This body of research provides an initial orientation to the impact of psychosis and the challenges faced by individuals in their process of recovery.

The interpersonal atmosphere is a key factor in relapse of psychosis (Brown & Rutter, 1966; Leff & Vaughn, 1985). Studies of Expressed Emotion (EE: Brown & Rutter, 1966), a term that describes experiences within interpersonal relationships and patterns of communication that have consistently found to be implicated as predictors of poor clinical outcome and relapse in a range of psychiatric difficulties (Butzlaff & Hooley, 1998; Wearden et al., 2000), have suggested that the interpersonal atmosphere plays a key role in supporting individuals during their recovery process. Research by Barrowclough et al (2003) suggested that the immediate interpersonal environment, specifically high EE criticism from a family member, was associated with greater negative self evaluations and that such evaluations were associated with positive psychotic symptoms. They found that the impact of criticism was mediated by its association with negative self-evaluation. It is likely that these negative evaluations were embedded within the familial environment. In considering the development of meanings and appraisals it is therefore important to consider the familial environment.

This is supported by Lobban et al (2006) in their study that suggests the importance of understanding EE within a systemic framework.

Families are faced with the challenge of adapting to the changes in the behaviour of the individual such as withdrawal, psychotic symptoms, behavioural excesses and impaired social performance (Birchwood & Smith, 1987) and it is likely that this affects their appraisal of the individual and their relationship with them. Patterson et al (2005) found that the appraisal of loss was a key experience for relatives and was similar to loss appraisals experienced by individuals with psychosis. In their qualitative study, Osborne & Coyle (2002) explored parental responses to having a child diagnosed with schizophrenia. The authors found that three of the four parents described a sense of loss. One parent stated that she felt having a son with schizophrenia was like a *"bereavement because one felt one had lost the person one knew, almost like a living death"* (p311). These studies suggest that the impact of psychosis engenders similar loss reactions in key carers as it does for the individual with psychosis.

Considering experiences within the wider interpersonal environment, studies suggest that supportive networks for individuals with a diagnosis of schizophrenia are smaller, including a high percentage of family members as compared with nonfamily members. Further that these networks fail to provide necessary support and validation (Tolsdorf, 1976; Westermeyer & Pattison, 1981). There is evidence to suggest that individuals feel a sense of distance and disconnectedness from others in society (Arieti, 1974) and this would further limit their access to support. Furthermore, it has been suggested that the experience of social distance may coincide with the experience of stigma and that these are the most stressful events for individuals diagnosed with schizophrenia living in the community (Hicks, 1981). Schulze & Angermeyer (2003) conducted a focus group study exploring subjective experiences of stigma and found that a significant theme was interpersonal interactions; participants described reduced social contacts, distancing, negative reactions from others and feelings that their illness determined their identity.

These studies suggest that appraisals are not only grounded within specific experiences of psychosis such as hospitalisation (Birchwood & Rooke, 1998) but also within the familial (Barrowclough et al., 2003), systemic (Lobban et al, 2006), and wider interpersonal environment of individuals experiencing psychosis. Experiences in these areas are particularly important as they may reflect recovery from psychosis and

recovery style (Tait et al., 2004). It is hypothesised that a synthesis of qualitative studies sampled from the following three domains, i) the impact of psychosis, ii) quality of life experiences, iii) experiences of interpersonal relationships and supports, will provide an enriched account of interpersonal experiences, quality of life and the intersubjective dimensions of meaning and adaptation to psychosis.

Methodology

Triangulation in metasynthesis

By sampling the qualitative research from three domains, this study utilises a method of triangulation (Webb et al., 1966 & Denzin, 1978). This process captures the importance of looking at phenomena from several angles and will function as a strategy for improving the validity and reliability of the findings within the metasynthesis.

Selection Criteria of studies

Published studies were included in the research if they met the following criteria. The study adopted a qualitative approach (using grounded theory or interpretative phenomenological analysis) and explored individuals' subjective experiences within one or more of the three domains, i) the impact of psychosis, ii) quality of life experiences, iii) experiences of interpersonal relationships and supports. Participants included were adults diagnosed as having schizophrenia or adults who have experienced psychosis. Studies were included if they were published between the years 1990 and April 2007.

Studies were excluded if they were not included in peer reviewed scientific journals, were not written in the English language, were studies that did not include interviews with the individual experiencing psychosis or included quantitative analysis.

Search strategy

Several approaches were used to search for relevant studies:

Electronic Search

Four computerised databases were searched: Medline [1980 –2007], CINAHL [1982 – 2006], Embase [1980 –2007], PsycINFO [1985-2007]. Search terms included "schizophrenia" or "psychosis". This was combined with the methodology type that included denominations of "grounded theory" and "interpretative phenomenological

analysis". This in turn was combined with search terms that aimed to locate studies describing individuals "experience", the "impact" of psychosis and "quality of life" factors including "relationships", "supports" and "interpersonal" experiences. The final search strategy is presented in Table 1.

Insert Table 1 here

This electronic search produced 214 studies. At this stage 186 studies were excluded on the basis of their title alone. Abstracts were read for the remaining 28 articles and a further 7 articles were excluded (Corin & Lauzon, 1992; Newton et al., 2007; Barnable et al., 2006; Larsen, 2004; Milliken, 2001; Rose et al., 2002; Kulhara et al., 1986). The remaining 21 articles were read in full and a further article was excluded (Dearing, 2004). The remaining 20 articles were included in the review.

Hand searching

To further inform the sensitivity of the search strategy the *Journal of Mental Health* was hand searched from 1990 to 2007, however no further studies met criteria for inclusion. The references of the included studies were also manually reviewed to further inform the sensitivity of the search strategy. On the basis of the titles, 5 studies were read in full but did not meet the inclusion criteria.

Consultation with other qualitative researchers

Consultation with another qualitative researcher helped to identify a further article (Boyd & Gumley, 2007).

Therefore in total 21 studies were identified and reviewed (Angell, 2003; Barker et al., 2001; Beal, 1999; Beal et al., 2005; Boyd & Gumley, 2007; Browne & Courtney, 2005; Campbell & Morrison, 2007; Gee et al., 2003; Hirschfield et al., 2005; Humberstone, 2002; Knight et al., 2003; Leiphart & Barnes, 2005; McCann, 2002; McCann & Clark, 2003; McCann & Clark, 2004; Macdonald et al., 2005; Robertson & Lyons, 2003; Sayre, 2000; Ware et al., 2004., Watts & Priebe, 2002., Williams & Collins, 1999). These studies are summarised in Table 2.

Insert Table 2 here

Methodological review

The quality of any systematic review or meta-synthesis depends on the quality of the studies that it includes (Jones, 2004). Therefore, a methodological evaluation of the literature was completed prior to a synthesis of the research findings. There has been some debate within the literature as to how a critique of qualitative research should be considered. It has been argued that an all-encompassing critical appraisal checklist for qualitative research may be neither appropriate nor possible (Greenhalgh, 1997). Within this review an appraisal of methodology was undertaken to inform an understanding of each study in its own terms and to enable the researcher to consider ways in which the methodologies used shaped the emergent research findings. Studies using two types of qualitative methodology were included in the review; grounded theory (Glaser & Strauss, 1967; Glaser 1978, 1992; Strauss, 1987; Strauss & Corbin, 1990, 1998) and interpretative phenomenological analysis (IPA) (Smith, 1996; Smith et al., 1997, 1999).

Grounded theory studies

A tool for reviewing grounded theory studies (Appendix 2.1) was developed in a previous study (Boyd & Gumley, 2005). This is a flexible guide developed on the basis of the qualitative criteria proposed by Yardley (2000) and has assimilated controversies discussed by several grounded theorists. Eighteen grounded theory studies were reviewed.

Sensitivity to Context

A debate in grounded theory is that the literature review should be delayed until after the analysis is formed (Charmaz, 2003). All studies conducted a literature review prior to analysis and only two studies highlighted their awareness of the debate. One study in particular justified their approach by stating: "the author viewed literature reviewing as sensitising the researcher to gaps in knowledge" (Boyd & Gumley, 2007; p3). This is consistent with Blumer's (1969) depiction of sensitising concepts. In terms of initial sampling, most studies mentioned their use of "open-ended" questions and several papers evidenced how sampling and interview questions were adapted to emergent theory. Two studies incorporated the views of service users into their initial sampling design, for example: "two pilot interviews were conducted on the basis of which modifications to the interview structure and phrasing were made" (Barker et al., 2001; p201). Most studies evidenced how initial decisions made were not made based on

preconceived frameworks and two studies specifically discussed this (McCann & Clark, 2003; Boyd & Gumley, 2007). Several studies evidenced attempts to be sensitive to the sociocultural setting of the research and to incorporate participant's perspectives into the study design. In addition to inclusion in pilot studies, there were attempts to form rapport and engage service users prior to commencing interview and some studies provided evidence of continued sensitivity during the interview. Williams & Collins (1999) stated: "during the interviews there was less emphasis on addressing all content areas than adhering to topics that resonated with respondents….and using their chosen language to explore the subjective experience" (p 65).

Commitment and rigour

The majority of the studies discussed the application of analysis consistent with grounded theory methodology, however, few studies gave examples to demonstrate how grounded theory strategies were applied. Therefore, despite the suggestion of relevant strategies, one could not always be sure that there was an absence of "technical fixes" (Barbour, 2001; p1115). Descriptions of coding ranged from no detailing of coding techniques to general statements such as: "data were coded into main themes and subthemes throughout the interview period" (Robertson & Lyons, 2003; p418), to a substantial number of studies that provided detailed descriptions of the process. For example, Humberstone (2002) discussed initial "open coding" which was followed by the process of "axial coding" and "diagramming" and the final stage of "selective coding" (p368). Many of the studies that detailed analysis strategies discussed the use of constant comparative analysis. However only two studies gave examples of how this was used: "comparing statements of patients who rejected hospitalisation with those accepting help" (Sayre, 2000; p74). Only two studies stated that the data were not transcribed and many studies evidenced their use of memos in the analysis process. Methods such as triangulation and multiple coding were used to improve internal validity. The study by Boyd & Gumley (2007) evidenced how the data were open to scrutiny by others in various ways, including analysis by "two independent researchers", "discussion in research supervision" and at a "grounded theory group" and "a preliminary synthesis was produced for a conference presentation" (p5).

Transparency and coherence

In line with the study's sensitisation to criteria for qualitative research, Boyd & Gumley (2007) provide a specific discussion to evidence their consideration of transparency and coherence (p6). Other studies showed similar strengths by demonstrating a clear and powerful narrative, being transparent in use of methods and data presentation, evidencing reflexivity and showing fit between theory and method adopted. However, few studies were transparent in their rules for coding data, consistent with the suggestion by Barbour (2001) the reader was left to "take it on trust" that the themes emerged from the data (p1116). However, there were some examples of coding in practice. For example, Sayre (2000) presented excerpts of data and stated that they were "initially understood as a rejection of hospital treatment" and discussed how this changed "as the analysis progressed" (p74). The researchers use of reflexivity within the studies was variable, some researchers provided no reflection where it appeared acknowledgement was required and others demonstrated substantial insight. For example there was no reflection in a study where the researcher acknowledged they had a therapeutic relationship with two of the participants (Gee et al., 2003) or in a study where the findings were taken from a larger unpublished thesis (McCann, 2002). However, Robertson and Lyons (2002) reflected upon the "context in which the interviews occurred" the researcher's personal characteristics, "female", "similar age", "status as a psychologist" and her "knowledge of puerperal psychosis" (p428). All studies justified the use of a qualitative approach and most discussed grounded theory specifically. However, few studies, presented a position on the debate of actively finding what is there (i.e. social constructivist), vs. the emergence of discovery (positivistic) approach.

Impact and importance of the research

In a number of studies, descriptive themes were presented as opposed to a grounded theory. For example, Leiphart & Barnes (2005) presented a description of five short themes. Other studies, however, presented a substantive grounded theory including a diagrammatic presentation of their findings (Boyd & Gumley, 2007; Robertson & Lyons, 2002; Williams & Collins, 1999). Several studies discussed how their research provided directions for future research, and one study provided a specific focus in the form of listing future research questions (Ware et al., 2004).

Interpretative phenomenological analysis (IPA) studies

The criteria for IPA evaluation were generated from a paper that critically evaluates the use of IPA in health psychology (Brocki & Wearden, 2006). The researcher and research supervisor independently developed a list of quality criteria based upon this paper and then reviewed and collated their results to create an IPA guide (Appendix 2.2). Three IPA studies were reviewed.

All three studies used semi-structured interviews as their method of data collection. This is described as the exemplary method of data collection for IPA (Smith & Osborn, 2003). The studies evidenced how the interview was used to facilitate the participants' ability to tell their own story in their own words; this is defined as a central premise of IPA (Smith et al., 1997). One study stated: "questions were kept deliberately open, providing cues for the participants to talk with a minimum amount of interruption or constraint by the interviewer" (Knight et al., 2003; p213). Brocki and Wearden (2006) suggest the importance of conveying an understanding of how the interview was constructed or including a copy of the interview so that the reader may judge the quality of the interview and the impact this may have had on the data obtained. They note that in their review rarely did papers detail this information. Similarly the three papers gave little information on interview construction. However, one paper did provide a copy of their interview (Campbell and Morrison, 2007), another gave information on the four principal focus areas (Knight et al., 2003) and the third paper presented the opening question (Macdonald et al., 2005).

Sample sizes were small, reflecting the emerging consensus of the use of smaller sample sizes in IPA (Smith, 2004). Furthermore, in accordance to IPA methodology, sampling tended to be purposive. For example to illuminate their exploration of young people's experiences of social relationships during the recovery phase of first-episode psychosis, Macdonald et al, (2005) interviewed young people with first episode psychosis participating in a group treatment program specifically tailored to their social/recreation and vocational needs. None of the studies discussed how sampling developed throughout data collection or how the role of saturation was considered.

In the analysis stage, the use of the IPA approach was explicitly stated in two papers. One paper referred to Smith et al's (1999) detailed account of analysis. The third paper stated that: "data were analyzed drawing from Colaizzi (1978) and Moustakas' (1994)

accounts of phenomenological analysis" and described steps in analysis consistent with the approaches outlined in the other two studies (Macdonald et al., 2005; p133). This suggests support for previous arguments that IPA has been wrongly labelled as phenomenological analysis (Fade, 2004). Two papers highlighted how themes were selected, one of these papers evidenced how themes were not chosen purely for their prevalence, stating: "other factors, including the richness of particular passages which highlight the themes and how the themes helps illuminate other aspects of the account are also taken into account" (Knight et al., 2003; p213). All papers discussed how researcher bias was minimised in selecting themes, this included "constant reflection and re-examination of the verbatim transcripts" (Knight et al., 2003; p213) and "the emerging themes were then cross checked with the text to ensure that the analysis was firmly grounded in the accounts" (Campbell & Morrison, 2007; p66). Specific validation strategies were also employed, one study described how follow-up interviews were conducted "to further clarify details from the initial interview and for participants to provide additional information or to rectify any discrepancies in the researchers understanding of the content" (MacDonald et al., 2005; p133).

It is recognised that in IPA, the researcher has an interpretative role in analysis (Smith, 1996), therefore Brocki and Wearden (2006) argue that this process should be acknowledged prior to and during the analysis stage. All of the papers engaged in this reflection to varying degrees. The paper by Campbell and Morrison (2007) discussed the role of the researcher from the outset in their recognition that IPA "research is a dynamic process in which the researcher also has a role to play" (p65). Later on they reflected "it is inevitable that the researchers own conceptions are inherent in these findings" (p66)

This review has used two purposely-developed guides to consider the methodological strengths and weakness of all 20 qualitative studies. The scope of its review does not enable a more detailed discussion and reflection on the potential impact of each paper. It is argued that all studies present a positive movement towards enabling the subjective experiences of individuals who experience psychosis to be better understood.

Metasynthesis

In their *Handbook for synthesising qualitative research*, Sandelowski and Barroso (2007) conceptualise metasynthesis as "an interpretive integration of qualitative findings that are themselves interpretive syntheses of data" (p151). This synthesis draws upon Noblit & Hare's (1988) method of meta-ethnography, which is analogous to the comparative analysis method favoured by grounded theory. This involved listing concepts and themes from each individual study, which were then organised and related to one another using constant comparative techniques to form an overall synthesis. For purposes of clarity, quotes from participants are presented in italics and quotes from authors are not.

Synthesis Findings

Five interacting themes are presented.

I. The interpersonal impact of living with psychosis.

All studies discussed the interpersonal impact of living with psychosis. Participants described many qualitative changes in their experience of interpersonal relationships following their experiences of psychosis.

Changes in Interpersonal Relationships

Fourteen studies suggested that the experience of psychosis resulted in the deterioration and sometimes breakdown of relationships with spouses, family and friends. Participants often attributed this change to their own difficulties. One participant stated *"I didn't really have a relationship with them* (family) *at the time because of the problems I was having. It put a lot of strain on my mum. She was very worried about me, she didn't know what to do about me. She didn't know how to help me"* (Gee et al., 2003; p6). Studies suggested that even within relationships that continued there was evidence of substantial strain and stress. Women who experienced puerperal psychosis talked about the impact upon their husbands: *"he was so scared, I was being really weird and telling him I wanted to kill myself. He was trying to be supportive but he just looked so scared. I put a lot of pressure on him"* (Robertson & Lyons, 2003; p 421).

There was evidence within participants' narratives that interactions with others became difficult and impoverished. Relating and communicating with others presented a challenge: *"It's difficult because conversation is always two way and you don't really know when to take the information in and when to take it out"* (Barker et al., 2001; p207). Participants again felt that this experience was due to their own difficulties: *"can't have a conversation with me because I don't add to the flow, like the words spoken by the next person. I haven't got that gift, that flair"* (Macdonald et al., 2005; p136). This participant engaged in a comparison of himself with others, this was often seen in narratives that described interpersonal relationships. Individuals experiencing psychosis often understood their interpersonal interactions as confirmation that they were different: *"I'm not like everybody else am I"* (Knight et al, 2003; p217).

Given these interpersonal changes, it is not surprising that a significant proportion of participants described a degree of loneliness, isolation and feelings of being distant from others. Humberstone (2001) hypothesised that the sense of alienation reflected in her participants' narratives was a direct result of the intrapsychic experience of psychosis and its consequent treatment. An important component of this was the physical alienation of being treated in hospital or living in residential facilities. One participant in this study stated: *"that's the thing about schizophrenia, it leaves you alone emotionally and alone physically. . . I got really lonely. People my own age left me alone. . . the trouble with schizophrenia was loneliness"* (Humberstone, 2001; p369). Barker et al (2001) discussed in their study how the relatives of individuals experiencing psychosis also noted that their family member was "separate from society" (p206). Isolation could also add to an individual's experience of symptoms: *"When you're really alone you get nervous and things, you get paranoid"* (Browne & Courtney, 2005; p321). Whilst the distress of isolation was frequently evident within the narratives, there was also evidence of participants behaving in a manner that maintained distance within interpersonal relationships. One study commented that the process of maintaining distance was necessary to the "perseverance" of relationships (Beal, 1999; p181). Participants in this study discussed how they sought distance from significant others to manage strong feelings such as anger, so as not put further strain on relationships. A young man in the study by Hirschfield et al (2005) described a different form of a distancing whereby he felt he needed friends but held back in his expression of this need. *"When I am with people, I don't say what I feel. I go round to Ken's right, cos I really want to see someone and cos I don't want to be on my own. Cos I can*

handle being on my own but I don't really like it, and then I am waiting, see I ring his buzzer and I am thinking 'god I hope he is in' cos I really want to see him… then I hear he is in I suddenly act as if 'oh hi Ken, how are you doing?' … like normally, when what I mean is 'oh Ken you are in, wicked, wicked, I thought you might have been out' and like you are in and it is really good you are sort of thing" (p259). Frequently, it was the individual's psychotic experiences that led them to keep a distance from others. Boyd and Gumley (2007) found that participants experiencing paranoia felt that they were "under attack" and that "paranoia was often a fear of what others will do" (p13) and this led them to maintain distance from others.

The impact of how others react

Eighteen studies suggested that the reactions of others and how the surrounding system or community responded to the individual experiencing psychosis were important. These feelings were often articulated by participants in an expression of not feeling understood by others: *"they don't understand, people don't understand things that happen to me"* (Knight et al., 2003; p214) or believing that others now saw them differently *"It's just that they* (former friends) *view me differently now you know, because I've become psychotic they think that you are now a waste of life or something"* (MacDonald et al., 2005; p137). Consistent with the changes in interpersonal relationships, participants attributed the reactions of others as the consequence of their own difficulties. However, other participants were able to consider the lack understanding and education about psychosis: *"I don't know if it's just that they don't understand much about it and they just… maybe they're scared that its going to affect them maybe… They aren't aware about mental illness themselves and they want to keep as far away as possible from that kind of thing because they themselves will become…"* (Gee et al., 2003; p6). The reactions of others were important in developing trust and providing people that participants could turn to. One participant described how they could not confide in others about feeling down as this would cause worry and upset: *"I want to be able to say I feel terrible and have people acknowledge that and not go oh my god it's happening again"* (Robertson & Lyons, 2003; p421).

It is suggested within the narratives that participants expected negative reactions from others and thus their experiences included a sensitivity or an element of self stigma: "a reaction to themselves in light of their experiences of mental illness and/or public stigma" (Knight et al., 2003; p210) but there was also an element of public stigma

articulated by participants: *"Part of society sees schizophrenics as dangerous and unacceptable. I have had it from my parents, my family and my friends, my close encounters"* (Knight et al., 2003; p214), another participant in this study reflected upon this experience from his interactions with professionals: *"even by doctors. They don't see you as a person thats O, not OK, but acceptable"* (p214). The impact of stigma led to changes in the way participants and significant others around them behaved. One relative commented on their son's experience of stigma and suggested that they kept their son away from other people: *"I haven't encouraged him to come here very much because of what happens when he comes here the neighbours usually open the door just to question him"* (Barker et al., 2001; p207).

Optimism for building new relationships.

Interpersonal experiences for individuals with psychosis have thus far been presented as somewhat challenging and negative. However, many participants described how they remained keen to be close to others and build new relationships. Humberstone (2001) stated that every participant in her study "spontaneously discussed their family and their desire to be closer to them"(p370). Several studies discussed the contexts in which relationship building occurred and conferred that they often developed through individual's participation in events and routines facilitated through health services. Angell (2003) and Beal (1999) concurred that relationships for such individuals appeared to develop through "various contexts of opportunity" (p18). Beal (1999) stated that individuals "used routines to generate safe interaction opportunities, taking advantage of situations that were highly predictable" (p177). A friend of a client stated: *"she takes a lot of joy just sitting out there. For us it might seem insane, the noise and the pollution of the cars. But just to see life going by – I think that satisfies that need for contact and it helps with her isolation"* (Beal, 1999; p178). Studies suggested participants' place of residence facilitated the development of relationships. Often the residence provided a sense of connectedness and a routine in which interaction was almost a certainty: *"I talked to them every day. . . I don't share my personal stuff. . . we cooked together"* (Beal et al., 2005; p205). Studies suggested that friendships were more frequently formed with other service users with whom they had shared experiences, one participant stated: *"I think that with* (friends from the programme), *because they are going through the same thing, or nearly the same thing, we just get along better'* (Macdonald et al., 2005; p134). Whilst the research suggests that individuals would try to engage with others in various ways, eight studies suggested that

efforts to enrich social opportunities were sometimes not well received by others. One man gave the following example: *"one suggestion that came up in several* (self help) *books was, when trying to meet people, that one would walk into a room and exude a certain aura or self confidence… well, I tried that, and I was approached by a campus police officer, and he said "are you following a student here?" and I didn't know what he was talking about… I wasn't following anybody. I was trying really hard to meet people"* (Angell, 2003; p20). These studies suggested that individuals found it difficult to build new relationships but that most individuals were not precluded from wanting to engage with others and the formation of relationships remained important. This may be explained by the role of interpersonal support and the potential value of this experience within relationships.

II. The importance of interpersonal support

All the studies supported the notion that interpersonal support plays an important role for individuals' experiencing psychosis. Whilst it has been suggested that familial interactions could be difficult, it was also evident that individuals valued the support of their families. One participant stated: *"you know my family stuck with me and they have got confidence in me, more now than what they did"* (Macdonald et al., 2005; p135). However, narratives sometimes suggested an absence of family support. In those cases, what was important was the availability of support within the immediate environment. Fifteen studies recognised the importance of this, one participant stated: *"It's very important, one of the most important things is…. a home where everyone supports you if you need to be supported… so that's the main thing"* (Browne & Courtney, 2005; p320). However, several studies suggested that relationships with friends and other service users were subject to stress and strain, one participant stated: *"I trust most of the professionals I know more than I would trust the so-called friends I have"* (Williams & Collins, 1999; p70). Support from services and mental health professionals was an important theme across studies.

Sixteen studies discussed the role of interpersonal support from services and professionals. Frequently, service users viewed the experience of receiving support from services positively, one individual linked the experience with decreased symptoms: *"since I got here, the voices stopped. I'm not sick anymore"* (Sayre, 2000; p77) and another patient described a sense of relief that others were taking care of their

difficulties: *"I think the most positive thing is that my life is managed better than I was managing it on my own"* (Leiphart & Barnes, 2005: p396).

Engaging service users in a supporting relationship

Four studies discussed the difficulties of engaging service users in team input. Leiphart and Barnes (2005) stated that for their participants, initially "it was difficult to adjust to working with new treatment providers and unsettling to adjust to the intensive nature of the program" (p396), one participant stated, *"I just didn't trust them"* (p396) . The issue of trust is further supported by Watts and Priebe (2002) who described the difficulties faced by individuals when they sought help from services. They reported that participants felt that "many initial attempts at obtaining help for the psychological distress were met with rejection" (p445). One participant in this study stated: "*It took two years before anyone listened to me and admitted me. So two years I was trying to be admitted but nobody would have me because they kept telling me I was fine, but two years without no treatment, no medication, nothing. . . after two years I was so far gone that they had to admit me. It didn't have to come this far"* (p446). McCann and Clark (2003) also outlined the importance of promoting access and being available for services users. These narratives highlight the importance of accessibility and the way that health services respond to early help seeking behaviour.

In terms of subsequent treatment, McCann (2002) described two main strategies for uncovering hope with services users, including "enhancing motivation" and "developing pathways to wellness". He stated that "developing pathways represents nurses working together with clients to plan for the future" (p87) and that the overall process of enabling clients to uncover hope "comprises finding out what their hopes and dreams are and attempting to weave these within strategies that seek to enable transition" (p90). McCann and Clark (2004) suggested strategies for advancing self-determinism including "educating, which necessitates informing and equipping clients to facilitate recovery to wellness" and "fostering self-control" (p15). These strategies were primarily generated from the perspective of the authors and health care providers. It is important, to understand the support processes that are valued by service users.

Developing a user-based understanding of effective support

Nine papers presented a position on service users' views of the support that they receive from professionals and health services. These studies suggested the importance of

developing a user based understanding of effective support. Several studies described how service users were overwhelmed by the experience of hospitalisation, in particular Sayre (2000) stated: "respondents perceived their hospitalisation as a bewildering attack and imprisonment" (p78) and Humberstone (2001) stated: "Hospitals, medication and both inpatient and outpatient staff were perceived as things to be survived rather than services that facilitated survival" (p370). One service user described the importance of being listened to regarding their treatment: *"Just trying to work out how I can stop them seeing me now. I don't have a choice, they just come. They don't listen sometimes"* (Watts & Priebe, 2002; p449). Another service user described how explanations were communicated to them: *"I thought what's caused this? So they said the damaged area of the head, this bit round here, that's all I was told really. It was quite evasive"* (Barker et al., 2001; p205). Ware et al (2004) provided a summary of important aspects of support for services users; this appeared to encompass user's views from other studies. Ware stated "feeling known by practitioners was very highly valued", this included conveying an understanding of the clients difficulties, personality, preferences for care and accepting their point of view. Participants spoke about the "importance of talking" and "offered clear advice for practitioners on how to listen" (p557), including making eye contact and not answering the phone during appointments. Participants also felt it was important to be made to feel like "somebody" and they disliked being treated *"like a baby"*, *"being told what to do"* and *"being dismissed as incompetent"* (p557). Ware et al (2004) argued that service users' values support a theme of "connectedness" and that "we may read the importance of "connectedness as a bid for social inclusion"(p558). This suggests that interpersonal support from health services and professionals may be of greater importance to service users in the context of impoverished interpersonal relationships and experiences.

III. Gaining control over experiences

Seventeen studies described themes of control. The narratives suggested feelings of lacking in control were inherent within the individual's experience of psychosis: *"I think it's part of the sickness that gives me no control"* (Williams & Collins, 1999; p66). This was supported by narratives that suggested psychotic experiences often evoked feelings of being out of control: *"well it is feeling that you are not really in control of your life when people are plotting against you, or that sort of thing. You don't really have any control. . . over your life"* (Campbell & Morrison, 2007, p69). Studies suggested that individuals experienced a fluctuating sense of control. Williams and

Collins (1999) stated "a reoccurring focus for all respondents was the struggle to maintain and regain control as they experienced increasing symptoms, psychosis and recovery" (p66). The experience of hospital admission was described as "the surrender of control to other people" (Williams & Collins, 1999; p71). Control was also an important factor in subsequent treatment and within the experience of interpersonal support. Participants valued the opportunity to exercise a measure of control over their treatment: *"he consults me on the dose of medication I want. . . treats me as the best person to know how I'm feeling"* (Ware et al., 1999; p557). On other occasions, narratives suggested that participants were relieved when others stepped in to make decisions for them (Williams & Collins, 1999; Leiphart & Barnes 2005). Control appeared to be important part of the individual's perception of their ability to make a recovery. When asked if there was anything that helped him to stay well, one participant stated: *"when I am in control, in control of myself, in control of the things I do. I would like to be in control of anything that I do"* (McCann & Clark, 2004).

Narratives suggested that participants felt a lack of control over the choices they could make within their environment. Gee et al (2003) described "practical limitations such as not being able to go on holiday, pursue activities, feeling of reduced choices and sense of financial uncertainty" (p7). Participants felt lacking in control with respect to their housing arrangements and interactions with others. One participant stated: *"see if you haven't got a stable home environment, every time you move you lose those friends"*. This influenced individuals experience of affect and affect regulation, a participant reflected on their unmanageable rent: *"I can't even begin to think how much that effects my feelings and that . . . I just find its extremely stressful to have to pay that sort of rent"* (Browne & Courtney, 2005; p318).

Studies suggested that participants adopted various coping strategies in order to gain control over their experiences. Boyd & Gumley (2007) described how participants experiencing paranoia were repeatedly placed in situations of confusion and uncertainty, feeling they were under attack and thus feeling fearful. Their coping response was to "activate the safety systems" (p15), they would do this by worrying, ruminating on the threat, imagining further possible threats, blaming someone else, being suspicious and vigilant, inflating their perceived strength or denying they were frightened. Boyd & Gumley (2007) stated this "was adaptive in the short term, but also became self-perpetuating for prolonged periods" (p15). Similar coping responses were described in

other studies. Hirschfield et al (2005) stated that participants described two kinds of immediate coping responses; avoidance of experience and expression of experience. This included preventing or blocking out the experience and expressing anger at the presence of unwanted experiences. The men in this study also mentioned painting and drawing as ways of expressing what they were experiencing. Knight et al (2003) found that participants used similar coping to manage stigma, for example avoidance, withdrawal and secrecy: *"I especially try to keep it a secret about my mental illness when I am in the outside world"* (p218). Other ways of taking control included upholding religious beliefs and this provided a sense of hope: *"You know as well as I do that God can intervene in any situation if you give him time. Why worry about anything? God can stop it. No matter how matter how many fires, no matter how many"* (Humberstone, 2001; p370). The importance of participants taking an active role in applying coping strategies that enabled them to feel in control was evident. One participant stated: *"I've been to a lot of different professionals. And some have been good, some have helped, some have not been so good. But the whole thing was, I had to be ready for what was to happen before it actually happened. You know they all had the best of all possible intentions, and the sole responsibility was mine"* (Williams & Collins, 1999; p72). This individual's growing awareness that changes came about in his life only when he was ready to make them happen enabled a more active coping response and fostered a sense of control over his experience. Many participants also described the importance of external resources to cope such as medication and mental health resources. However, even with the application of techniques to gain control, participant narratives suggested that they continued to experience a sense of hopelessness over their ability to maintain a sense of control. One participant stated *"in essence life is a sort of struggle for survival"* (Knight et al., 2003; p217).

IV. Affect: a reaction to the impact of the experiences associated with psychosis

The studies suggested that the impact of the experiences encountered during psychosis resulted in intense feelings of affect. Participants in the studies described different emotions and adhered to difficulties regulating these emotional experiences. Eight studies described how participants experienced anger and this functioned as a way of expressing the internal distress associated with psychotic experiences or hospital admissions: *"I heard voices telling me to kill people. . . I didn't want to hurt nobody though, just stabbed the wall. . . to get my anger out"* (Hirschfield et al 2005; p256).

Anger can also be understood as the participants reaction to uncontrollable changes in their life circumstances, one participant commented on the change in their interpersonal relationships: *"I am angry about it, because I thought they were good friends"* (Macdonald et al., 2005; p136).

The experience of anxiety and fear was described by six studies, this experience was particularly prevalent in the two studies that explored participants' experience of paranoia. Campbell & Morrison (2007) and Boyd & Gumley (2007) suggested that fear and anxiety are consequences of the experience of paranoia. This is illustrated by Boyd's question to a research participant: *"The first thing I have been asking people and I was wondering is what the word paranoia means to you?"* the participant responded: *"it means fear"* (p9). Other studies suggested fear and anxiety were a result of the new and frightening situations that participants found themselves in, for example the experience of hospitalisation, meeting health professionals and lack of control over experiences.

Narratives from several studies suggested participants experienced feelings of uselessness, helplessness and worthlessness, one participant stated: *"it was awful. . . I felt useless and helpless. . . I couldn't talk to anyone about it, I stayed in bed nearly every day"* (Gee et al., 2003; p8). Nine studies suggested that participants experienced a feeling of loss, suggesting that loss was a significant emotion in the reaction to the impact of psychosis. Participants appeared to feel that their lives had undergone a qualitative shift and narratives suggested that they longed for a return of their former self: *"If I could just get back to who I was before this illness started I'd be very happy but I can't"* (Knight et al., 2003; p 216). Robertson and Lyons (2003) stated: "women felt they had lost their minds, identity or indeed their personality" (p424). A participant in Watts and Priebe's (2002) study also commented on the change in their sense of self: *"I can't keep fighting against it and trying to be someone else. As a young boy, growing up, a lot of people used to come to me for protection. I had people that could depend on me. I liked independence, I like to do my own thing, you know: To lead, and I am not in a position to lead anymore"* (p446). Other studies suggested themes of loss, whereby participants described remorse for the life that that they had envisaged living, one participant stated: *"I wanted a family, I wanted a wife, I wanted jobs, I wanted a car, I wanted to have my own business, my own car lot. Things didn't go my way, they, they changed"* (Williams & Collins, 1999; p69). Studies suggested that participants were

aware of the things that they had lost within their lives. Humberstone (2001) stated, "participants were aware of the losses associated with being extruded from society into a marginal position" (p370).

The experience of affect in response to the impact of psychosis not only led to led to anger, fear and anxiety, feelings of worthlessness, deep unhappiness and loss but also thoughts of dying and attempting suicide: *"I just thought it was a waste of time and all these people hated me, and all that business. . . I was feeling really stressed angry and unhappy . . . I tried to take an overdose once. . . of sleeping tablets. . . I vomited back up but that's how bad it was really"* (Hirschfield et al., 2005; p256).

V. Putting it all together: Making meaning from experiences

The findings thus far illustrate the complexity and interacting nature of the experiences and affect states encountered by individuals with psychosis. Given this, it is not surprising that participants' narratives often included extracts where individuals attempted to conceptualise or form an understanding of these experiences. Williams & Collins (1999) described this process as "putting it in perspective". Participants engaged in this process using various methods of exploration. Several participants attempted to understand the cause of their difficulties by attributing the onset to personal qualities and behaviours: *"I have a mental illness because I don't work. It started about 7 years ago when I was a senior in college and didn't get into an honors class"* (Sayre, 2000; p75) or as due to a punishment: *"I thought I was being punished and in a way I thought yeah that is what you deserve"* (Hirschfield et al., 2005; p262). In Robertson and Lyons (2003) study, women understood the cause of puerperal psychosis as a result of childbirth which led them to view themselves as experiencing "a separate form of mental illness", as such they felt they needed separate and specialised forms of treatment: *"you're classed as a mental patient, rather than someone with an illness following childbirth, I think there's a difference you need specialist help"* (p419).

When participants reflected upon their experiences of psychosis, they often conceptualised them in the context of an understanding about themselves. Often individuals reflected how the experience had resulted in a changed sense of self: *"since I've become psychotic and that, all my views have changed. I view the world differently now. I look at things differently than I used to. . . I don't want to go back into that*

lifestyle that I lived before" (Macdonald et al., 2005). Several participants suggested that this was a positive outcome and that their experiences had enabled them to be "more themselves" (Barker et al., 2001) and led to an improvement in their relationships, *"they've* (relationships with family) *improved a lot now. I can talk much more to them now, we're closer than we were"* (Gee et al., 2003). Often participants were able to form an understanding of their difficulties that enabled them to form a sense of resolution and left them with a sense of hopefulness for the future: *"I've done a lot of things, I've been a lot of, not places, but things. . . uh. . . I've been confused by images and people and the whole thing. It wasn't till recently that my whole act came together and I'm far more on top of things now than I ever have been"* (Williams & Collins, 1999).

Discussion

This systematic review aimed to appraise and assimilate studies in the following three domains: i) the impact of psychosis, ii) quality of life experiences, iii) experiences of interpersonal relationships and supports. It was proposed that this synthesis would provide an enriched account of interpersonal experiences, quality of life and the intersubjective dimensions of meaning and adaptation to psychosis. A methodological critique of the studies suggested that most of the studies adhered to criteria for qualitative research and all of the studies supported a positive movement towards enabling the subjective experiences of individuals with psychosis to be better understood. Five themes were generated from the synthesis of twenty-one studies; i) the interpersonal impact of living with psychosis, ii) the importance of interpersonal support, iii) gaining control over experiences, iv) affect: the psychological reaction to the impact of psychosis and v) putting it all together: making meaning from experiences. These themes interacted in a dynamic manner and reflected the impact of psychosis and quality of life factors. The themes also illuminated the contexts of intersubjective meaning making. This interaction is conceptualised below, together with theoretical and clinical implications of the findings.

Insert figure 1 here

The literature synthesis suggested that the impact of the experience of psychosis could be understood within a dynamic framework of interaction between five key domains of

an individual's life, as illustrated in Figure 1. All themes interacted dynamically with each other and this provided insight into the process of intersubjective dimensions of meaning making. The synthesis observed that the development of appraisals appeared to be grounded within contexts of interpersonal and environmental experiences.

The findings suggest that psychosis has a significant impact upon the individual's interpersonal relationships. The studies found that relationships, communication and interaction with others can deteriorate and breakdown. These experiences can result in isolation and disconnection from others. This sense of distance is exaceberated by the reactions of others and experiences and perceptions of stigma. Despite these difficulties, studies suggested that many individuals remained keen to have close interpersonal relationships and were optimistic about building new relationships. This may be explained by the role of interpersonal experiences in facilitating interpersonal support. Participants placed value in forming relationships that facilitated the availability of interpersonal support.

The studies suggested that participants felt a lack of control as a result of psychotic experiences, interpersonal experiences, events in their environment and their emotional response and ability to make sense of these experiences. Control and strategies for gaining control therefore interacted reciprocally with all themes. The studies suggested that participants experienced diverse emotional reactions in response to their experiences. These emotional experiences can be understood as the psychological reaction and manifestation of the impact of the experiences associated with psychosis. It was evident that affect was mediated by interpersonal experiences and support, sense of control over experiences, coping strategies and the individual's ability to form a conceptualisation of their experiences. Affect therefore interacted with all other themes in a reciprocal manner. The fifth theme represented participants attempt to form an understanding or conceptualisation of their experiences, there was also a reciprocal interaction relationship between this theme and all the other themes. All themes had an impact upon the individual's ability to make sense of their experiences and their ability to make sense of experience penetrated all other themes.

The synthesis findings contribute to the body of literature that discusses the interpersonal changes faced by individual with psychosis (DeNiro, 2005; Tolsdorf, 1976; Westermeyer & Pattison, 1981; Bellack et al (1990). This includes the importance

of the reactions of others and the experience of stigma (Lysaker et al., 2007), which is known to cause emotional discomfort and is associated with fewer social relationships as supported by the synthesis findings. The synthesis findings were also synchronous with literature that suggests the importance of the appraisal of loss (Rooke & Birchwood, 1998; Brown et al., 1995) and this synthesis suggested participants had an awareness of this feeling.

Furthermore, this synthesis contributes to an understanding of the importance of considering interpersonal experiences such as EE, within a familial (Barrowclough et al., 2003) and systemic (Lobban et al., 2005) framework. The findings suggest perceptions of experiences can be explained by interplay between how the individual appraises and responds to their experiences but also how others within the environment and surrounding system appraise and react. Thus, the process of meaning making is grounded within appraisals that may be influenced by experiences within interpersonal, environmental and systemic contexts. This suggests the importance of understanding intersubjective dimensions of meaning making within individuals' experience. This is particularly important because the corroboration of meanings from significant others and the environment may influence recovery style. This is supported by research by Tait et al, (2004) who found that individuals who perceived that others saw them as worthless and also had an insecure sense of their own identity adopted a sealing over recovery style (McGlashan et al., 1977). Thus, intersubjective dimensions of meaning may be important in mediating the process of adaptation and this includes the experience of adaptation from the perspective of individual, family and wider interpersonal contexts.

Clinical Implications

If as suggested, intersubjective meanings have a mediating role within the process of recovery this suggests the importance of developing interpersonal formulations with service users and their families. This may include forming goals for change within a framework of individuals' interpersonal experiences and contexts. This may highlight areas for change within the context of recovery. The role of intersubjective meanings within the adaptation process furthermore supports the use systemic models of working with individuals with psychosis and the carers including family therapy, which has found to be successful in reducing risk of relapse and has been associated with fewer hospital admissions (Pitschel-Walz et al., 2001; Pilling et al., 2002).

Several studies within the synthesis reported the difficulties of engaging service users with support. This may also be explained by the process of adaptation, which may be mediated by service users' appraisals that are influenced by intersubjective dimensions of meaning. Tait et al, (2003) have demonstrated that adaptation style is important in considering service users engagement with services. In this study sealing over adaptation or recovery style was related to poorer engagement in services. This suggests the importance of supporting individuals' to conceptualise their experiences, which may involve processing experiences within interpersonal and environmental contexts in order to develop an integrating coping strategy in their recovery from psychosis.

Limitations

The synthesis utilised a method of triangulation in order to improve the validity and reliability of the findings. Further the synthesis was discussed with the research supervisor in order to expose the process of interpretative integration to further validation. However, it is suggested that checking the emergent themes and interactive model of the impact of psychosis against first-person accounts of psychosis may have facilitated a form of respondent validation. Secondly, whilst the included studies were subject to methodological evaluation, the author did not exclude studies on the basis of methodological evidence of weakness; rather the evaluation was used to consider ways in which the study methodology shaped the emergent findings. It could be argued that a more definite conclusion regarding the quality of each study would have enhanced the review. However, the author was aware of the continuing contention of quality appraisal in qualitative research and the view that it is not possible to exclude all studies that are deemed methodologically flawed because standards change over time and researchers' judgments as to what is flawed vary accordingly to their own disciplines, training and preferences (Paterson et al., 2001).

Conclusions

The synthesis elucidated five key themes that interacted dynamically and reflected the experiences associated with the impact of psychosis and the intersubjective dimensions of meaning making. The findings suggest perceptions of experiences can be explained by the interplay between how the individual appraises and responds to their experiences but also how others within the environment and surrounding system appraise and react. This suggests the importance of working systemically with individuals with psychosis and their families and considering the role of interpersonal and environmental contexts within the process of meaning making.

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Table 1. Final Search Strategy.

	SEARCH TERMS
1	Schizophrenia or psychosis. ab,ti.
2	Grounded theor$ or grounded stud$ or grounded research or interpretative phenomenological analysis or phenomenology or IPA. ab,md,ti.
3	1 and 2
4	impact$ or experience$ or experiential or perspective$ or meaning$ or self report$. ab, ti
5	3 and 4
6	quality or quality of life. ab, ti
7	3 and 6
8	relationship$ or social$ or support$ or interpersonal. ab, ti.
9	3 and 8
10	5 or 7 or 9
11	limit 10 to all journals
12	limit 11 to English
13	limit 12 to humans
14	limit 13 to year 1990 – 2007
15	Remove duplicates

Table 2. Summary of Included Studies

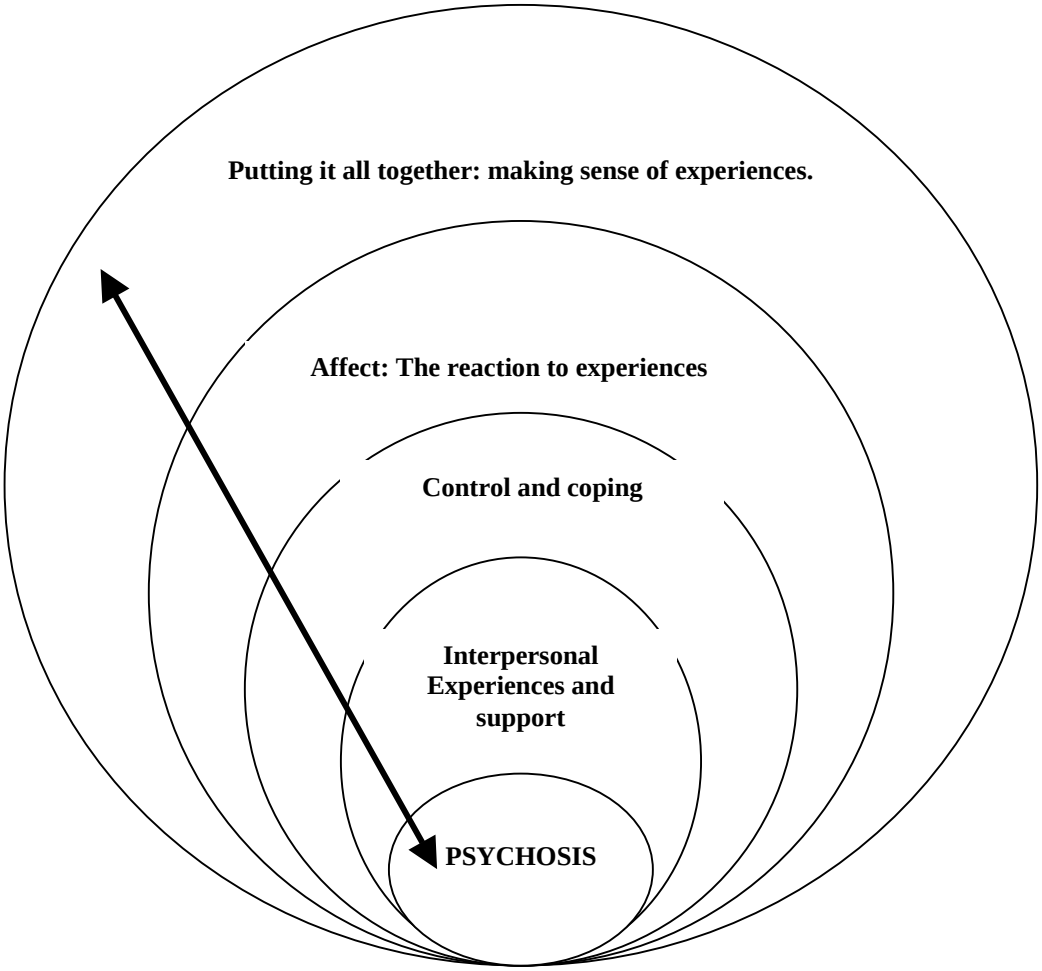
First Author & Year	Sample	Focus of Study	Method	Summary of Findings	Strengths	Weaknesses
Angell, B 2003	20 service users 2 staff	Social Relationship Development amongst assertive community treatment clients.	GT	3 themes within contexts of social relationship development. 'socially organized relationship development', 'professional facilitation of social relationships', 'client initiated social strategies'.	Descriptions suggest commitment and rigour in use of GT. Explanations of coding and theoretical sampling	Highlights potential for blurring of researcher-participant relationship.
Barker, S. 2001	8 service users 8 relatives	Client and family narratives on schizophrenia.	GT	4 stages model included events at the following times 'preceding first psychotic episode', 'time of first psychotic episode', 'first hospital admission' and 'current experiences'. Family and client narratives were compared and analysed individually at each stage.	Sensitive in approach to representing patient group, considerate of complexities of experiences.	States that 'some' strategies of GT were used. Quantitative analysis of inter-rater reliability.
Beal, G. 1999	9 service users 22 friends	Community Integration.	GT	3 key aspects of relationships. 'Importance of routines in producing interaction opportunities', 'Rules of relevance involved in creating friendships', 'processes of maintaining relationships'.	Sensitivity to sociocultural setting. Active involvement of research participants in study design.	How GT techniques used not described, particularly in terms of coding and subsequent analysis. Little reflexivity.
Beal, G. 2005	7 service users	Community Integration.	GT	2 themes: 'venturing forth and connecting' interacted with 'facilitators' to interaction.	Sensitivity to sociocultural setting of research participants.	Commitment and rigour to grounded theory analysis not demonstrated.
Browne, G. 2005	13 service users	Relationship between housing, social support and mental health.	GT	A strong desire among all participants to live in their own home. 2 core-categories – 'qualities of the housing' with 6 subcategories and 'relationships' with 3 subcategories.	Demonstration of rigour and transparency in coding and analysis.	No use of scrutiny through either multiple coding or validation. Location of some interviews.
Boyd, T. 2007	10 service users	Experiential perspective on persecutory paranoia	GT	Core process of fear and vulnerability was constructed. Subcategories of confusion and uncertainty, and self under attack contributed to the core process.	Service users views incorporated into study design and sampling decisions. Openness of data to scrutiny from others.	Lack or respondent validation of the theory.

Campbell, M. 2007	12 service users	Subjective experience of paranoia.	IPA	4 themes: 'the phenomena', 'beliefs about paranoia', 'factors that influence paranoia', 'consequences of paranoia'.	Researchers interpretative role on data discussed prior to and throughout analysis	Lack of argument for sampling non-patient group.
Gee, L. 2003	6 service users	Quality of life.	GT	10 themes: 'barriers on relationships', 'reduced control of behaviours', 'loss of opportunity to fulfil occ roles', 'financial constraints', 'psychotic symptoms', side effects and medication', 'psychological responses', 'labelling and attitudes of others', 'concerns for future', 'positive outcomes'	Novel approach to developing HRQoL tool. Good use of respondent validation and attempt to engage participants.	Little reflexivity. Researcher had therapeutic relationship with 2 participants prior to their involvement.
Hirschfield, J. 2005	6 service users	Meaning of psychotic experiences mean for young men.	GT	4 themes: 'experience of psychosis', 'immediate expression of psychotic experiences', 'personal and interpersonal changes', 'personal explanations'.	Commitment and rigour, good demonstration of how coding, theoretical sampling and saturation completed.	Possible researcher bias highlighted.
Humberstone, V. 2002	13 service users	The experience of supported accommodation.	GT	Central concept 'A way to survive' generated 7 major categories: 'surviving psychosis', 'surviving alienation', 'survival and basic life stuff', 'surviving health services', 'religion/god', 'family', 'identity'.	Commitment and rigour in terms of how coding was completed. Participant's perspectives incorporated.	Lack of reflexivity. No cross-checking/ multiple coding.
Knight, M.T.D. 2003	6 service users	Investigation of stigma.	IPA	Superordinate themes of 'judgement', 'comparison', and 'personal understanding of the (mental health) issue'.	Positive consideration of adapting IPA interview design for individuals with psychosis.	Limited discussion of the researchers' interpretative role in analysis.
Leiphart, L. 2005	5 service users	Experience of Assertive Community Treatment	GT	5 themes: 'in the beginning: anxiety and anger', 'meeting pragmatic needs and listening fostered trust', 'early symptom recognition', 'accepted, cared about, and a sense of belonging', 'open to encouragement and motivated to improve'.	Use of participant validation.	Commitment and rigour in GT not well demonstrated. Small literature review does not acknowledge Watts (2002) study.
McCann, T 2002	9 service users 8 family 24 nurses	How community mental health nurses help uncover hope for the future	GT	2 core categories: 'Strategies for uncovering hope' with 2 subcategories: 'enhancing motivation' and 'delivering pathways to wellness and core category of 'the context of uncovering hope'.	Triangulation	Lack of transparency – data is taken from a larger study, not presented. No reflexivity in relation to this.

McCann, T 2003	9 service users 8 family 24 nurses	Nurses' role in increasing clients' willingness to access mental health services.	GT	Overarching phase of 'engaging' from larger study. This took place within 'the context of being accessible' and 'strategies for enhancing accessibility to services' are presented.	Findings of the larger study are at least presented in this study.	Data taken from larger unpublished thesis.
McCann, T 2004	9 service users 24 nurses	How community mental health nurses promote self-determination with clients	GT	2 categories: 'Educating' and ' 'fostering self-control' are discussed.	Greater transparency in this paper – open about data analysis occurring within context of larger study.	Data taken from larger unpublished thesis.
Macdonald, E. 2005	6 service users	Social relationships in early psychosis	IPA	5 themes: 'hanging out with people I like and who understand me', 'valuing families and other supports', 'spending less time with old friends' 'something happened to me –being different now', 'building new relationships'.	Acknowledgement of researchers interpretative role throughout and steps taken to reduce bias.	Lack of clarity of IPA method utilised.
Robertson, E. 2003	10 service users	Living with puerperal psychosis: a qualitative analysis.	GT	3 main categories: 'puerperal psychosis as a separate form of mental illness', 'loss' and 'relationships and social roles'	Reciprocal style of interviewing enabled by the time taken to build rapport with participants. Good reflexivity.	Theoretical saturation not attempted.
Sayer, J. 2000	35 service users	Patient's perception of being a psychiatric patient	GT	6 attribution styles: 'problem', 'disease', 'crisis', 'punishment', 'ordination' and 'violation' produced a grounded theory of 'self worth'	Transparency in coding and comparative and negative case analysis. Method sensitive to users interaction difficulties.	Data not transcribed. No evidence of analysis and results being open to scrutiny.
Ware, N. 2004	51 service users	Relationships with practitioners and quality of care.	GT	8 categories: 'getting extra things', 'looking for common good', 'feeling unknown', 'the importance of talk', 'feeling like somebody', 'practitioner availability', 'practitioner flexibility', 'input into treatment'.	Clarity of theme presentation, focused specifically on service user priorities.	No transcription. Not clear on how data was analysed.
Watts, J. 2002	12 service users	Experience of Assertive Community Treatment	GT	4 themes: 'early help-seeking behaviour', 'identity', 'the therapeutic relationship', 'provider perspectives'.	Embedded within relevant literature and empirical data. Impact and importance of research strongly argued	Rigour of data collection and analysis not shown. No participant validation.

Williams, C. 1999	15 service users	Impact of psychosis on understanding of self.	GT	Presented a subjective theory of illness and recovery that included 3 themes: 'the control crisis', 'putting it in perspective', 'coping with relapse'	Sensitive to sociocultural experiences and perspectives of participants.	Concern that initial sampling decisions and subsequent coding and analysis were based on a preconceived theoretical framework.

Figure 1. The Interactive Model of The Impact of Psychosis and the Intersubjective Contexts of Meaning Making.



Chapter Three

Major Research Proposal

An exploration of service users' experience of relapse in psychosis: A grounded theory approach.

Hayley Veitch

Summary of Project

Aim: To explore service users' experiences of relapse and to construct a psychological understanding of relapse based upon user-defined meanings.

Design: An interview based study using grounded theory principles to analyse qualitative data.

Method: Semi-structured interviews will be devised using a social constructionist version (Charmaz, 1990, 2003, 2005, 2006) of the original Grounded Theory (Glaser & Strauss, 1967). The interview will focus on individual's experience and understanding of relapse. Individuals who have experienced psychosis or similar as defined by ICD-10 criteria will be invited to consent to participate in the study.

Analysis:

Analysis will be conducted in line with Charmaz (2006) and will emphasis reciprocity between emerging micro-codes and themes and subsequent data sampling. The sampling process will continue until no new categories emerge from the analysis. Pragmatically, it is expected that this study will not recruit less than eight participants.

Practical Applications:

It is proposed that in developing a user-based understanding of relapse, the study will encourage improved user engagement within services and enable the development of measures and interventions derived from constructs identified as meaningful and important to service users.

Introduction

Background

Psychosis is a major life-event (Birchwood et al, 1993; 2004) that affects 1% of the U.K population (Davies & Drummond, 1994), however, it is anticipated that up to 25% of the population encounter a psychotic experience at some point in their lifetime. Recurrence of psychosis, whilst not inevitable can be a common component of an individual's experience of psychosis. The literature suggests that following a first episode, 20-35% experience relapse at 1 year, 50-65% at 2 years and 80% at 5 years (Robinson et al, 1999 & Tarrier et al, 2004). Relapse remains a major factor in the development of illness chronicity and is known to be associated with decreased social and vocational functioning. Although much is known about the personal and environmental factors that increase the risk of recurrence (biological vulnerability, stressful relationships, life events, substance abuse (Bentall, 2004)), there has been relatively little qualitative exploration of individuals' experiences of relapse.

Despite the scarcity of autobiographical accounts exploring service users experience of relapse, there are several studies that explore Depression and Post-traumatic stress disorder (PTSD) within the experience of psychosis. These studies suggest the process of recurrence is likely to be a distressing event for service users.

Birchwood et al (2000) conducted a study to investigate the course of depression in schizophrenia and found that post-psychotic depression was common in 36% of patients at at least moderate intensity during the 12 months following an acute psychotic episode. They argue that post-psychotic depression is embedded in the realities of a psychotic experience. Thus, suggesting that the service user experiencing a recurrence of psychosis may be vulnerable to psychotic depression. Birchwood et al (2000) also highlight that the beliefs or appraisals about psychosis made by those who experience it are important. The present author argues that this importance arises from the fact that the beliefs and appraisals made by service users are grounded in real experiences and may be a reflection of the traumatic experiential affect encountered.

In their companion paper (Iqbal et al 2000) they identify the specific appraisals made by individuals who developed post-psychotic depression and report that they felt greater

loss, humiliation and entrapment arising from their psychosis and were more likely to attribute the cause of psychosis to the self. They also had lower self-esteem and were more self-critical than non-depressed individuals. These findings further support the role of traumatic events in the development of negative appraisals and affect during psychotic experience. Furthermore, for the service user who has experienced relapse and thus endured a re-experience of such negative appraisals, it is likely that there will be further impacts on self esteem and perceived sense of controllability and consequently there may be further vulnerability to the development of co-psychotic depression. In support of this Birchwood and Jackson (2001) found that relapse can be a precursor to depression and also suicide.

Rooke and Birchwood (1998) also identified that appraisals of loss, humiliation and entrapment were common and associated with life events reported by depressed psychotic patients. Appraisals of life events occurring throughout their experience of psychosis, such as unemployment and compulsory admission, were related to their subsequent experience of negative affect. This study highlights specific autobiographical experiences that underpin negative appraisals. It also provides insight into the possible life events that an individual experiencing relapse may re-encounter. The evidence from the literature also suggests that this re-experience of distressing life events may lead to further experiences of negative appraisals and affect, many of which the service user may have encountered in a previous episode of psychosis. Many service users will experience several episodes of relapse and we may at this stage speculate that without successful intervention the strength of their belief in re-occurring negative appraisals and the magnitude of affect experienced may be intensified. Thus, creating an understanding of recurrence as a distressing cyclical process, where distress continues to accumulate with each experience of relapse.

Similarly, there are a number of studies that explore specifically, the association between psychotic experience and the subsequent development of posttraumatic stress disorder (PTSD) (Shaw et al 1997; Morrison et al 2003; Shaw et al 2002; Meyer et al 1999; Harrison et al 2004 & Jackson et al 2004). These studies suggest that the development of PTSD phenomenology is associated with the psychological distress of the experience of psychosis. For example, in the same way that traumatic events cause intrusive and distressing memories, clinical observation suggests that the experience of psychosis has a similar capacity to confront the individual with horror, fear and

helplessness and thereby create the same pattern of symptoms as follows real events (American Psychiatric Association [APA], 1994). The treatment experience as well as the distress of psychotic symptoms has been associated with traumatic reactions (Shaw et al 2002). This includes specific events such as seclusion (Fisher, 1994; Hammill et al, 1989; Wadeson & Carpenter, 1976) and being under involuntary treatment (Adams & Hafner, 1991; Kane et al., 1983). Furthermore, autobiographical accounts (Glenn, 1974; Jefferson, 1964; Rogers et al, 1993 & Susko, 1991) identified stressors in the hospital environment such as enforced medication, restrictions on every day living and ECT with some writers alluding to intrusive memories and nightmares years later.

Shaw et al (1997) also found that individuals recovering from hospitalisation for a psychotic episode reported traumatic and intrusive recollections of their experience of psychosis. Specifically aspects of treatment such as closed ward care, seclusion and medication side effects generated high levels of distress. In terms of developing an understanding of the experience of relapse, the literature exploring PTSD and psychosis suggests that service users experiencing relapse may face a subsequent recurrence of previously experienced traumatic events.

However, whilst we might infer from the discussed literature that much like the acute stages of psychosis, relapse is a process that involves distressing life events that induce a re-experience of negative affect such as depression and trauma, there are currently no studies designed to specifically explore how service users experience and evaluate relapse. Hence, many of the claims made thus far are not built upon specific experiences of relapse. Consequently, the present author advocates that further exploration and an understanding of individuals' specific experiential narratives is required to comprehend fully the meanings and appraisals associated with the experience of relapse.

The author argues that an exploration of service users' experience of relapse must be sensitive to users' reports of their subjective experience and accounts of their adaptation to recurrence. Consequently, the concepts and meanings derived from their individual reports may not necessarily be predefined within the existent literature. There may be a number of complex mediators which influence the report provided by individual service users. Firstly, the term "relapse" may not be an accepted construct for certain individuals and the prospect of recurrence may have different meanings for service users and hence relapse may be defined in different ways.

Secondly, in contrast to the suggestions from the literature, the service users' experience of relapse may not always be negative. For example, studies by Morrison et al (2002) and Morrison et al (2005) indicate that service users can have positive beliefs about voices and paranoia. Thirdly, work by Chapman and McGhie (1963) suggests that individuals with psychosis have an awareness of their unusual experiences and become aware of subtle changes in their presentation. Thus, suggesting that there is role of awareness and understanding associated with the individual's experience. Finally, the individual may not readily seek help during the early stages of relapse. This may be due to fears about the meaning and consequences associated with relapse or more simply because they had not been advised by a health professional to do so.

Collectively, the above points emphasise, that whilst the existent literature might suggest that the experience of relapse is associated with trauma, it is difficult to form assumptions about users' experiences. Thus, in order to develop a user-based understanding of relapse, a method of exploration that is not based on preconceived assumptions and enables the development of new and unbiased theoretical meaning needs to be developed. One solution to this empirical problem is grounded theory methodology.

Grounded theory

There has been a growing interest in the use of qualitative methods to study experiences of individuals with psychosis and grounded theory is one of the most widely used qualitative research methodologies (Benoliel, 1996; Rennie et al. 2002). Grounded theory methods emerged from sociologists Glaser and Strauss (1965, 1967) in their attempt to articulate how qualitative research could be used not just to provide rich descriptions but also to generate "theory from data".

A grounded theory approach to service users' experience of relapse in psychosis is proposed. Literature pertaining to relapse in psychosis has been reviewed, however as it has been identified that we cannot always infer that users experiences are negative, an approach needs to be developed that suspends our assumptions.

Aims

The overall aim of the study is to construct a qualitative investigation into service users' experience of relapse in psychosis. The researcher aims to develop an interview that will facilitate a free flowing self-reflective narrative that is grounded in specific autobiographical memories, from which a user-based psychological understanding of relapse can be constructed. The construction of meanings throughout the interview may enable a richer understanding about the importance of relapse to service users and may further enable the development of meaningful assessment measures and points for intervention. Furthermore, staff may use these understandings to improve communications with service users.

Plan of investigation

(i)Participants

Service users eligible to participate in the study will include inpatients and out patients who meet or have met criteria for Schizophrenia or similar or Bipolar Disorder in accordance to ICD-10 classification. Individuals under the age of 16 years, people with a learning disability or individuals who do not speak English as a first language will be excluded from the study. Patients who have are currently experiencing acute symptoms will not be recruited. Individuals who have experienced relapse within the past month or confirmed early signs of relapse, will also be excluded from the study. With the patient's consent, the researcher will liaise with the patient's keyworker or doctor to confirm that the patient has a diagnosis of schizophrenia or similar and check that involvement in the research study will not affect the patient's treatment and that there are no pertinent clinical risk factors. If the keyworker or doctor feels participation in the study would be detrimental to the patient's treatment stage, the patient will be excluded from the study. The participants will not be involved in other research at the time of interview.

In line with grounded theory methodology it is necessary to gain data from participants with a range of relapse experience, this will mean interviewing participants who have no experience of relapse and interviewing those who have experienced several episodes of relapse. Therefore, recruited participants will provide an account of their understanding

of relapse based upon no experience of relapse or a retrospective account based upon previous experience(s) of relapse.

As a guide, it has been suggested that a sample of between eight and twenty participants is desirable for good qualitative research submitted in DClin Psy theses (Turpin et al. 1997). However, Grounded theory logic invokes theoretical saturation as the criterion to apply to sampling completion. This means that data will continue to be collected until gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of the emerged core theoretical categories (Charmaz, 2006). The pragmatics of this issue are discussed further when Power Calculations are addressed.

(ii) Recruitment

Following careful consideration of the risk issues associated with recruitment with individuals who have had experiences of psychosis, it has been decided to involve a local lead investigator to support the running of the project. Dr Vicki Coletta, Consultant Clinical Psychologist has agreed to act as local lead investigator and it has been agreed that her main roles will be to:

1. Provide a link between the researcher and the local resource centres.
2. Facilitate the meeting of the researcher with the Community Mental Health Team from the resource centres.
3. Help establish clear health and safety protocols for the interviews and for supporting individuals in the event of any distress.

The involvement of Dr Coletta will mean that recruitment will be conducted in the context of established local health and safety protocols.

Participant recruitment will follow a two-stage process. The study will be advertised via an advert (Appendix 3.1) that will be displayed in Arndale and Riverside Resource centres in Glasgow. The advert will include a tear-off slip which the patient can either place in a secure box within the reception area, hand to their keyworker or send to the researcher. The first stage of recruitment will be when the potential participant makes an expression of interest by returning the completed slip. By returning the tear-off slip, the participant will be made aware that they consenting for the researcher to contact their keyworker or doctor to ensure that participation in the study does not interfere with any

treatment that they may be receiving or that there are not any other pertinent clinical risk factors that would prevent the participant from taking part.

Once the keyworker or doctor has confirmed that it is appropriate for the patient to participate in the research, the second stage of the recruitment process will involve the patient formally consenting to participation. This will involve providing the participant with a full information sheet (Appendix 3.2) and answering any questions that the participant may have. If the participant still wishes to take part they will be asked to sign the consent form (Appendix 3.3). The participant will be informed that the researcher will check again prior to commencing the interview that their involvement in the study will not be detrimental to any treatment they may be receiving.

The researcher will aim to schedule interviews during the participants' routine visits to the resource centre. Where this is not possible and the participant has to engage in additional travelling for the purpose of the interview, travel expenses will be paid to the value of receipt.

(iii) Measures

Data will be collected by semi-structured interview (Appendix 3.4) with each participant. Prior to commencing interviews it is proposed that meetings are planned with service users or a user organisation to enable consultation regarding the suitability of the proposed patient information, interview format and measures. This may sensitise the researcher to the suitability and appropriateness of the material and sampling methods and enable participant perspectives to be incorporated into the study design.

The researcher is aware that consistent with Blumer's (1969) depiction of 'sensitizing concepts', researchers begin their studies with certain research interests which provide ideas to pursue and sensitize the researcher to ask particular questions. However, the researcher is mindful that these guiding interests should provide points of departure for developing rather than limiting ideas. Thus, sensitizing concepts provide a place to start within data collection and the researcher will aim to be as open as possible to new views throughout the research process.

(iv) Design and procedures

It is proposed that a social constructionist version (Charmaz, 1990; 2003; 2005; 2006) of the original Grounded theory (Glaser & Strauss, 1967) shall be used in devising the structure of the semi-structured interview and subsequent data analysis. Taking this perspective necessitates looking at meaning making as an iterative process (Charmaz, 1990). Thus, the process of Grounded Theory is dialectical and active 'construction' rather than based on an objective reality, as suggested by Glaser's version of Grounded Theory. Within the semi-structured interview, questions will be open ended, flexible and adapted to emergent theory as it evolves in order to develop theoretical sampling (Dey, 1999).

A single researcher will interview participants. Every attempt will be made to ensure participants are comfortable and a visual analogue scale will be used to monitor levels of discomfort and distress before and after the interview. Participants will be informed that they can end the interview at any time and the researcher will enquire if the participant is happy to continue upon noticing any signs of distress.

During the first part of the interview the researcher will take socio-demographic information from all participants, this will enable the reader to assess the relevance and applicability of the findings (Elliott et al. 1999). The following information will be taken: name, date of birth, gender, duration and onset of psychosis. The participants will not be asked about their experience of relapse at this time, since their understanding and experience of this concept will form the foundations for exploration throughout the semi-structured interview. The second part of the interview will be based on the semi-structured interview contained within Appendix 3.4.

The researcher will receive ongoing supervision and guidelines devised by Madill et al (2005), which provide recommendations for the supervision of qualitative projects, will be followed. In order to monitor clinical competence, the researcher will also be expected to discuss clinical issues arising from the conduct of the interviews during the process of supervision, which will be conducted for a minimum of one hour per week.

(v) Settings and Equipment

The interviews will be conducted within hospitals and clinics in Greater Glasgow. The researcher will aim to arrange for interviews to take place in which the service user is

familiarised and comfortable. All interviews will be digitally recorded and transcribed by the researcher for subsequent coding.

(vi) Power Calculation

Power within grounded theory studies are deemed by theoretical saturation, whereby the process of data collection and data analysis continue until no new categories can be identified and until new instances of variation for existing categories have ceased to emerge. However, the researcher acknowledges the pragmatic tensions that this method of data collection poses. Indeed within grounded theory there has long been an unresolved tension between and within data collection strategies (Charmaz, 2006). What is important within grounded theory studies is that the methodology employed allows the researcher to capture rich, substantial and relevant data that stands out. As such grounded theorists (Glaser, 1992, 1998, 2001; Stern, 2001) argue that the logic process of obtaining saturation supersedes sample size. In reference to theoretical saturation Charmaz (2006) suggests that researchers should use the concept not as a machine that provides the rules but as a guideline in order to be open to what is happening in our field of research and be receptive to the need to sample further and recode earlier data. Thus, the researcher will use the process of theoretical saturation as a process that ensures the construction of a rich understanding of relapse. To construct this understanding the researcher will aim to interview participants with a range of relapse experience; this may include users who have no experience of relapse following psychosis and those who have experienced numerous episodes of relapse.

(vii) Proposed Data Analysis

Analysis shall consist of initial transcribing and subsequent coding and categorisation of the data. In grounded theory analysis there is a simultaneous involvement in data collection and analysis, which means that emerging analysis shapes data collection decisions (Charmaz, 2003, 2006).

Throughout the process of data collection and analysis the researcher will write memos of personal reflections and theoretical insights. Memo-writing is the pivotal immediate step between data collection and writing drafts of papers (Charmaz, 2006). These can be used from the outset to construct themes, inform of bias, and sensitise to areas of exploration. As categories emerge, constant comparative analysis will be conducted and the researcher shall look for negative cases (those that do not fit within categories) in

order to elaborate upon the emerging theory and capture the full depth of the initial data. Theoretical sampling will be conducted whereby further data is collected in order to challenge and elaborate upon the existent categories that have emerged from the earlier stages of analysis. Participant validation will also be used whereby later interviews with participants will be arranged to verify how the researchers development of emergent categories relates to the participants experience.

The ideal end point for completion of the study will be when the researcher feels that theoretical saturation has been achieved.

Practical Applications

Relapse prevention and management of future symptoms are critical in the two years following first episode in terms of determining long-term outcome (Birchwood et al 1998; Harrison et al 2001) and relapse prevention has become a focus for individual psychological intervention. Thus, it is important that we gain an understanding of individuals' experience of relapse and the meanings that they attribute to their experience in order offer an intervention that is user focused and derived from constructs identified as important to service users. Furthermore, while most studies indicate that the experience of psychotic symptoms themselves are primarily responsible for patients' trauma (Kennedy et al, 2002; Meyer et al, 1999; Shaw et al, 2002), some studies suggest that the methods used to treat psychosis may be partially responsible (McGorry et al 1991; Frame & Morrison, 2001). This further supports the requirement to develop a user-defined understanding of relapse that can be integrated into the construction of treatment.

Furthermore, Gumley et al (2003) report a trial of 144 individuals who were operationally defined as "relapse prone". They found that Cognitive Behavioural Therapy (CBT) delivered during the early stages of relapse was associated with a significant reduction in relapse rate at 12 months. However, other studies such as the application of cognitively orientated psychotherapy for early psychosis ("COPE"), (Jackson et al 1998; Jackson et al 2001) have not been successful preventing relapse in individuals experiencing psychosis. Furthermore, there is an increasing realisation that antipsychotic drugs alone are rarely sufficient to achieve the best clinical outcome (Pilling et al., 2002). Thus, although there is some evidence to suggest that CBT and antipsychotic medication are effective interventions for managing relapse, there is a

growing body of evidence that suggests a need to develop new approaches in order to meet the many needs of these individuals. The present authors argue that the current study will aid a greater understanding of both relapse and the required interventions for service users.

The current study focuses on user involvement in defining and understanding relapse and hence the outcome will be the construction of user-based understandings of the meaning of relapse. These user-based definitions may differ from those of clinicians and may lead to a greater understanding of what relapse means to the service user, this in turn may shape and develop our understanding and the services and interventions offered to services users.

Timescale

January 2006	Draft proposal submitted
March 2006:	Final draft proposal submitted.
April 2006:	Submit ethics form.
May/June 2006:	Consultation with service users regarding interview process.
July 2006:	Recruitment meetings with clinicians.
August 2006:	Begin Recruitment.
August- Sept 2006	Commence first interviews. Ongoing data analysis and creation of new questions.
Sept – Nov 2006	Further interviews. Data analysis, create new questions and search for differences.
Dec – February 2007	Final interviews and later participant validation interviews.
February – March 2007	Further data analysis.
March 2007- April:	Write up.
April 2007:	Penultimate draft to supervisor.
May 2007:	Revisions to Penultimate draft.
June 2007:	Final Copy to Supervisor and revisions to Final Copy
July 2007:	Submission for Doctorate in Clinical Psychology

Ethical Approval

Ethical approval will be sought from the research ethics committee, permission to gain access to participant case notes will also be requested. In line with ethical considerations, the following procedures will be put in place. The researcher is trained in handling distress and care will be taken to ensure that high emotional arousal is not induced. A visual analogue scale to assess level of discomfort and distress will be used at the beginning and end of the interview. The interviews will be tape recorded and anonymised to conceal identity. During transcription, the transcripts will be anonymised using the find and replace function on Word XP.

A local lead investigator will oversee health and safety issues associated with the running of the project. Service users will be invited to participate via an advertised placed in community mental health centres. This will ensure that keyworkers are not directly involved in participant recruitment and hence their therapeutic relationship with the service user will not be utilised for the purpose of recruitment. With the participants' consent, the researcher will check with keyworkers prior to commencing the interview that the individual's involvement will not interfere with any treatment they may be receiving.

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Chapter Four

Major Research Project

Service Users' Construction of Relapse Experiences in Psychosis: A Grounded Theory Approach.

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Abstract

Quantitative research has led to an understanding of the multifaceted impact of psychosis and of the debilitating nature and profound psychological and emotional consequences associated with the experience of relapse. However, there have been no studies that have collaborated with service users in order to form an experiential perspective of relapse. The aim of this study was to explore service users' experiences of relapse in order to construct a psychological understanding of relapse based upon user-defined meanings. Eleven service users who had a diagnosis of Schizophrenia or Bipolar Disorder were interviewed. The interviews were transcribed verbatim and the transcripts were analysed using a social constructionist version of the original grounded theory method. Two core concepts emerged. *The Content of Construction* reflected the magnitude and trauma of the personal, environmental and interpersonal experiences that were embedded within the meaning of relapse. These experiences illuminated *A Central Process of Adaptation* whereby relapse necessitated an individualised process of adaptation. The process of adaptation was embedded both within the content of experiences but also within the narrative form, or the way that participants talked about their experiences. Two styles of narrative were observed and it was suggested that they mirrored styles of recovery known as integration and sealing over. The importance of how service users define and talk about their experiences is emphasised. Psychotherapeutic implications of the synchrony between narrative form and adaptation are discussed.

Introduction

Psychosis is a term referring to experiences such as hearing voices that other people do not hear, seeing or sensing things that other people do not see or sense and holding unusual beliefs (delusions) or beliefs about the malevolent intention of others which seem unwarranted (paranoia) (Thornhill et al., 2004). Relapse is a medical term used in this context to describe the recurrence or exacerbation of psychotic experiences. Whilst not inevitable, relapse can be a common component of an individual's experience. Studies suggest that following a first episode of psychosis, 20-35% of individuals experience relapse at 1 year, 50-65% at 2 years and 80% at 5 years (Robinson et al, 1999; Tarrier et al, 2004). Relapse is often associated with increased emotional distress, impaired social, vocational and interpersonal functioning and the combination of these experiences may lead to voluntary or involuntary hospital admission. The experience of psychosis and relapse has also been associated with secondary psychological difficulties including depression, post-traumatic stress disorder, social anxiety (Tarrier et al., 2005) and low self-esteem (Bentall & Kaney, 1996; Barrowclough et al., 2003).

In a study investigating the course of depression in psychosis, Birchwood et al (2000) found that post-psychotic depression was common in 36% of patients at at least moderate intensity during the 12 months following an acute psychotic episode. They found that post-psychotic depression is embedded in the realities of a psychotic experience and that the individual's beliefs or appraisals about psychosis are important (Birchwood et al., 2000; Birchwood & Iqbal, 1998; Rooke & Birchwood, 1998). In support of this Iqbal et al (2000) found that post psychotic depression was predicted by cognitive appraisals of psychosis, particularly loss, shame and entrapment, which occurred independently of the severity of psychosis. The authors proposed that the individuals' awareness of their psychosis and their subsequent appraisal of this experience resulted in depression. It has also been argued that appraisals such as loss, entrapment and humiliation are grounded in the realities of psychotic experiences that may include hospital admission, loss of employment and social role and residual symptoms. (Rooke & Birchwood, 1998). Gumley et al (2006) found that the experience of relapse was associated with increased negative appraisals such as entrapment and self-blame. They stated that relapse may be conceptualised as a critical life event that signifies the uncontrollability of psychosis.

Several studies have found the experience of psychosis is related to the subsequent development of posttraumatic stress disorder (PTSD) (Shaw et al., 1997; Morrison et al 2003; Shaw et al., 2002; Meyer et al., 1999; Harrison et al., 2004 & Jackson et al., 2004). Shaw et al, (1997) found that the individuals in their sample reported intrusive and distressing recollections of the experience of psychosis and described symptoms of avoidance characteristic of PTSD. It was found that PTSD was not just associated with the experience of psychosis, but the individual's perception of treatment and systemic factors such as how others react were also important (Shaw et al., 1997; Shaw et al., 2002).

A substantial body of research highlights the interpersonal difficulties and qualitative relationship changes experienced by individuals with psychosis (see Chapter Two for a review). Barrowclough et al (2003) suggested that the individual's perception of experiences within their interpersonal environment is also important. They found that the immediate interpersonal environment, specifically criticism from relatives, was associated with increased negative self-evaluations and that such evaluations in turn led to positive psychotic symptoms. A significant finding was that the impact of criticism was mediated by its association with negative self-evaluations made by individuals diagnosed with schizophrenia.

The body of literature reviewed thus far highlights the importance of individuals' appraisals and evaluative thinking style in the development of secondary psychological difficulties following the experience of psychosis (Chadwick et al, 1996; Drayton, 1995; Rooke & Birchwood, 1998 & Birchwood et al., 2000). Whilst quantitative research has led to an understanding of the multifaceted impact of psychosis (Tarrier, 2005) and of the debilitating nature and profound psychological and emotional consequences of relapse, it is evident that service users' interpretation and appraisals of their experiences are instrumental in the determination and course of secondary difficulties. Therefore further exploration of individuals' specific experiential narratives may enable a greater understanding of the meanings and appraisals associated with the experience of relapse.

There are several reasons for engaging in a qualitative exploration of this kind. Firstly, the concepts and meanings embedded within individual experiential narratives of relapse may not necessarily be predefined within the existing quantitative literature. A number of factors may influence the narrative of service users. The term relapse is a

medically constructed term and may not be a construct accepted by all individuals experiencing psychosis. The prospect of recurrence may have different meanings for service users and hence relapse may be defined in different ways. Secondly, in contrast to the conclusions drawn thus far, service users' experiences of relapse may not always be negative. For example, studies by Morrison et al (2002) and Morrison et al (2005) indicate that service users can have positive beliefs about voices and paranoia. Thirdly, work by Chapman and McGhie (1963) suggests that individuals with psychosis have an awareness of their unusual experiences and become aware of subtle changes in their presentation. These factors suggest the importance of engaging in an exploration of relapse that is sensitive to users' reports of their subjective experience and accounts of their adaptation to recurrence.

Qualitative research methodology was chosen as it recognises that the social world is complex and dynamic and is constructed from multiple realities (Banister et al., 1994) There is now a growing body of qualitative research exploring the impact of psychosis (see Chapter two for a review), however no qualitative studies have specifically explored service users' experiential perspective on relapse. This study was conducted using a grounded theory methodology as it enables the participant to be the expert in an exploration of their experiences in order to develop a theory that is grounded in the data.

In summary, the aim of the research study was to explore service users' experiences of relapse in order to construct a psychological understanding of relapse based upon user-defined meanings. It was proposed that developing a user-based understanding of relapse would enable the development of measures and interventions derived from constructs identified as meaningful and important to service users and this may foster improved user engagement within services.

Methodology

Grounded Theory

In essence, grounded theory serves as a way to learn about the "worlds we study and a method for developing theories to understand them" (Charmaz, 2006). A social construction version (Charmaz, 1990; 2003; 2005; 2006) of the original grounded theory (Glaser & Strauss, 1965, 1967) was used. The process of grounded theory is dialectical and active 'construction' rather than based on an objective reality, as

suggested by Glaser's version of grounded theory. In the process of active construction, themes and research observations emerge from a dialogue that has been jointly constructed through a process of meaning making (Charmaz, 2000). Therefore, constructivism fosters researchers' reflexivity about their own interpretations as well as those of their research participants. In order to consider methodological rigour this research was sensitised to criteria for qualitative research presented by Yardley (2000).

Participants

A total of eleven adult service users participated in the study. Ten participants were recruited from two community mental health teams and one participant was recruited from an inpatient unit. Participant characteristics are displayed in Table 1. The participants were three women and eight men aged between twenty-six and sixty years old (mean age: forty-three). Of these participants, ten had a diagnosis of Schizophrenia and two individuals had a diagnosis of Bipolar Disorder according to ICD-10 classification. Three service users who responded to the advertisement did not attend for the first meeting with the researcher. Two service users who attended for the initial meeting decided not to participate. One man described anxieties about being able to talk about his experiences in a manner that would flow and make sense to the researcher. He also described concerns that talking about his experiences might unearth issues that he thought he had resolved. Another service user was worried that she might not be able to remember her experiences and decided not to participate.

Insert Table 1 here

Procedures

Recruitment followed a two-stage process that was supported by a local lead investigator who ensured that established health and safety protocols were followed. Stage one included individuals making an expression of interest. The advertisement (Appendix 3.1) was displayed in three community mental health centres and one inpatient unit and included a tear-off slip that enabled individuals to express interest by completing the information and placing their slip in the secure box within the reception area, handing it to their keyworker or sending it to the researcher. The advert made potential participants explicitly aware that by returning the tear-off slip they gave their consent for the researcher to contact their keyworker or Consultant Psychiatrist in order to ensure that their participation in the study would not interfere with any treatment that they were receiving. No service users were advised not to participate in the study.

Stage two included obtaining formal consent from the service users. Each service user was invited to meet with the researcher to discuss further what the study entailed. During this meeting the researcher discussed the details in the information sheet (Appendix 3.2) and answered any questions that the participant had. Participants were given a week to consider their involvement in the study. Following this time if they wished to participate they were asked to sign a consent form (Appendix 3.3). The participant was informed that the researcher would check again, prior to commencing the interview that their involvement in the study would not be detrimental to any treatment they may be receiving.

Sensitivity to context

The researcher was aware of the debate presented by Charmaz (2003) that the literature review should be delayed until after forming the analysis. However, it was not possible to completely delay the review, as a research proposal was required for submission to the Clinical Psychology Doctorate course and the Greater Glasgow and Clyde Ethics Committee (Reference No: 06/SO701/69, Appendix 4.1). Therefore, the researcher commenced the study informed by knowledge derived from some of the previous studies within the field of psychosis. However, this enabled the researcher to be sensitised to an initial understanding of psychosis and was consistent with Blumer's (1969) depiction of sensitising concepts that grounded theorists often begin their studies with certain research interests and a set of general concepts. These concepts were used as points of departure that formed a place to start. Therefore, initial sampling decisions were not based on a preconceived theoretical framework but rather initial sampling was open and interview questions were flexible and adapted to emergent theory as it evolved (Dey, 1999).

The research study was presented to several community health teams, an inpatient unit and a group of clinical psychologists and feedback was requested on how to make participation in the study accessible to service users. The initial meeting with the research participants to discuss the study functioned as an engagement session. Several participants were keen to begin to talk about their experiences of psychosis at this stage. This was not a recorded session but enabled the researcher to be sensitised to an understanding of their experiences and facilitated the development of rapport prior to

commencing the interview. Participants used their own terminology for discussing their experiences. For example one participant began to talk about her experience of "schizophrenia" and she was keen to refer to this as "s". This was then incorporated into the in-depth interview with this participant. In this way, the study was sensitive to the language, social interaction and culture of the participants as described by Yardley (2000).

The in-depth interview was also conducted in a manner that was sensitive to the context of research. Participants were interviewed in familiar locations such as the community mental health centre that they regularly attended or the inpatient unit in which the participant was currently a patient. Whilst an interview guide was developed (Appendix 3.4) the interview was not formerly structured, the priority was to enable participants to talk about the experiences that they felt were important. The researcher opened the interview with an initial orientating question: "I wonder if we could start by looking at that word relapse, is that a term that you are familiar with?" Further prompts aimed to facilitate exploration such as: "I'm interested in what you're saying, can you tell me more about that?" "Can you tell me what you mean by that?" The researcher was aware that discussing experiences of relapse had the potential to be upsetting for participants. Therefore a formal measure was used to monitor their level of comfort before and after the interview. This included presenting participants with a ten point Likert scale and asking them to rate how they felt before and after the interview. Talking about experiences of relapse did not affect level of comfort and indeed, in most cases participants reported feeling more positive following the interview, see Graph 1.

Insert Graph 1 here

Commitment and rigour

Eleven participants were interviewed following an initial engagement session. Five of the participants were interviewed on two occasions. The length of the interview was flexible dependent on participant engagement and preference. The total interview length ranged from 30 to 109 minutes (average length 63 minutes).

The author transcribed each interview and simultaneously made initial memos of personal reflections and initial coding ideas, prior to commencing the subsequent interview. This enabled the researcher to be simultaneously involved in data collection

and analysis so that emerging analysis could shape data collection decisions (Charmaz, 2003; 2006). Each transcript was then coded line by line and the researcher used this process to enrich the memos and record an initial understanding of codes relevant to emergent tentative categories. Each transcript was then subjected to focused coding and advanced memos including the researchers reflections of the emerging conceptual categories were elaborated upon.

It is argued that the grounded theory method depends on using constant comparative methods (Charmaz 2006). The researcher constantly compared similarities and differences at each analytic level. For example, initial interview statements and incidents were compared within and across all interviews. Subsequently, coding was also compared within and across interviews. Coding was open to scrutiny in various ways to validate the emerging codes and process of comparative analysis. Codes were discussed with the researcher's supervisor at bi-weekly meetings and within a grounded theory group that met frequently for peer supervision. Three transcripts were also given to a Social Worker within a multidisciplinary team and his thoughts on the narratives were considered in the analysis.

Theoretical sampling was used following interview with participant 7 to enrich the emerging categories. This involved seeking statements and events from participants that would elaborate and illuminate the emerging conceptualisations. During the early stages of analysis the interview formed the focus for theoretical development. At a later stage in the analysis, theoretical sampling was used to advance analytic thinking. This included the researcher using qualitative software ($NVIVO_7$ QSR, 2005) to explore and analyse an emerging theme within the narratives. It has been argued that the use of computer software for qualitative analysis contributes to a more rigorous analysis (Bazeley, 2007). This process refined an emerging core concept within the data; the way in which participants speak about their experiences. Theoretical sampling continued until the continuous analysis suggested that the categories were saturated or when it was felt that gathering fresh data no longer generated new theoretical insights (Charmaz, 2006). The researcher was aware of the proposition by Dey (1999) that the term saturation is 'another unfortunate metaphor' and that the process may lead researchers to force data into categories. The researcher therefore tried to avoid this process by remaining open to the data and returning to recode earlier data whenever questions about emerging categories arose.

Transparency and coherence

The context in which the interviews occurred was considered throughout the research process. Participants were interviewed by a female researcher as part of her Doctorate in clinical psychology. The researcher had some experience of working with individuals with psychosis throughout her 3-year training programme. The interest to complete this study developed from a growing awareness of the complexities of the experience of relapse for service users. What followed was a desire to a build a theory that articulated an understanding from service users' perspectives that was derived from constructs identified as meaningful to these individuals.

Findings

For purposes of clarity, the researcher's dialogue is presented in **bold** type. Brief remarks adding to the speech of the primary speaker are inserted into the paragraph in parentheses e.g. *(is that right, okay)*. Non-verbal behaviour or gestures are presented in { } style brackets. Pauses are indicated by dots, whereby one dot is equal to a one second pause. Interruptions in speech are indicated by slashes / assigned to the person being interrupted. Times when the speaker is unable to finish their sentence are indicated by a dash – .

Participants' familiarity with the term 'relapse'.

The researcher commenced the interview with an exploratory question that invited participants to talk about their familiarity and understanding of the term 'relapse'. This led participants to reflect upon the construct of relapse. Of the eleven participants interviewed, six stated that they were familiar with the term. The remaining five participants also went on to talk about what the term meant to them. Collectively they described it as 'a fancy name for becoming unwell again', 'a setback', 'a recurrence', 'going back the way' or 'going into hospital again'. They often reflected how the 'doctor' had used the term, suggesting that they understood it to be a medical term used by professionals. Two participants stated that the information they received about the research led to an understanding of the term, suggesting the role of the research in initiating a familiarity with the term 'relapse'.

Is that a term that you were familiar with before we met?
P10: Not really no.
When was the first time you heard that word?

P10: Oh, well, when I got the leaflet *(mmm hmm)*, the information, is the first time I really, you know, like. . . . you know like, realised I am part of that you know kind of thing. That's like the first time really.
So it sounds quite new to you? *(yeah aha)*. So, I'm guessing it's not really a word you would use then, that word relapse?
P10: Not really, no aha.
What do you understand the word to mean, what does it mean to you?
P10: I don't know, I suppose it's just getting really bad symptoms *(aha)* you know, illness *(yeah)* that's what it means, getting it again.

Overall, most participants gave an explanation of relapse that suggested they had an understanding that this term meant a return of experiences that they associated with psychosis. However their narratives conveyed that 'relapse' was not a term within their vocabulary that they would ordinarily use to describe their experiences.

The interview initiated a process of construction

After talking about their familiarity with the term relapse, participants were invited to explore 'what experiences come to mind when you think about the term?' For most participants this question triggered memories that they associated with the experience of relapse and led to an exploratory construction of memories and the meanings of experiences. In the following example the participant had recently come to the attention of services and it was thought he had lived in isolation with the experience of psychosis since late adolescence. It appeared as though engaging in the interview initiated a novel process of making meanings and understanding his experiences.

What comes to mind when you think about the term relapse?
P2: Erm going forward as such but as I say building something and then it gets destroyed you know, that's what I'm thinking about *(aha aha)*. Yeah aha, yeah you build something and its just, it gets destroyed for no apparent reason, its just something on my mind *(mmm hmm)* you know, I mean its like, I felt like that when I was quite young and err whenever there was anything like I'd perfect, somehow it would always end up. . . . trashed.

Most participants were keen to engage in a construction of their experiences. This was evident in the following narrative, where the researcher commenced the interview process and was interrupted by the participant who was already absorbed in a process of active construction where memories and affect are recalled and pieced together.

As you know the study is about forming an understanding of what relapse means to you *(mmm hmm)* and understanding more about individuals experiences of relapse/
P4: Yeah, I feel that is the important thing that you've just touched on there, the individual. Err, there's not enough, in my opinion within the psychiatric system that look towards the individual *(mmm hmm)*. It seems to be, err as far as the medication is concerned, you felt if

> you had a problem, it wasn't being listened to and you were pasteurised to a certain extent and medicated *(mmm hmm)*, er to somehow keep you under control.

For some participants considering experiences of relapse evoked difficult memories that they appeared reluctant to explore. This had an impact on the participants' ability to engage in a free flowing narrative and consider the meaning of their experiences.

> P11: I just, I can remember I was cutting myself, that's all, round about that time.

The following participant was affected by the impact of recalling his memories. He understood his experiences as 'madness' and 'bizarre'. His interpretation of the meaning of his experiences made it difficult for him to continue to construct an active dialogue. This was evident in his narrative as he paused and conveyed that he felt unable to develop his narrative further.

> P2: Err. . . I think when I got a relapse I was just hearing voices and you know imagining stuff and. . . you know and err. . . . just, och its all madness, you know but err I don't really know what to say -

The research interview aimed to provide participants with a safe and open environment in which they could engage in a discussion about the experiences that they associated with their understanding of relapse. This experience evoked powerful memories, aroused strong feelings and intense meanings. Some participants welcomed this experience and were keen to construct and make meanings within their narrative. For other participants the experience of construction was too difficult and they did not readily engage in an exploration of experiences. Thus, there were varying degrees to which participants were able to talk about their experiences.

THE CONTENT OF CONSTRUCTION

Replaying Psychotic Experiences

In the construction of experiences and meanings of relapse, all participants described their psychotic experiences. This included telling the researcher about their auditory hallucinations, delusional beliefs and experiences of paranoia. Participants' relayed psychotic experiences in an in-depth manner, describing vivid traumatic memories that contained powerful imagery and exuded a freshness to their recall. For most participants a decade had past since the occurrence of such acute experiences. However, describing

the content of psychotic experiences appeared to evoke a sense of reliving and re-experiencing the event, as though the experiences were being replayed in the participants' minds.

> P2: So I was walking along the motorway and I thought, I was thumbing it, and could hear everybody else's voice but they couldn't hear my voice, I thought I was psychic you know and I wondered why they wouldn't stop and help me. . -
> **How did that experience feel to you?**
> P2: I was really sad Hayley *(you felt sad)* I was sad yeah I remember, errr-
> **What about it made you feel sad?**
> P2: Because. . . . I thought I was a Zoran Warrior and they were, so they should be helping me, but I just kept walking. Sometimes I used to get phantom smells you know *(aha)* I used to smell like, sweat like, and err. . . . strong aftershave, strong aftershave, stuff like that and even, even excrement, you know stuff like that *(yeah yeah)* you know.

Many participants recalled their first psychotic experience, which reflected how the process of constructing an understanding of relapse involved participants talking about their experiences from the beginning, as though they were keen to tell the researcher how their journey began. The following participant recalled his first experience of psychosis that occurred some forty years ago, despite the passage of time there was an inherent traumatic quality to his narrative that suggested the difficulty he had encountered processing his experiences. This lack of processing reflected the complexity of adapting and forming a sense of resolution from such traumatic experiences.

> P1: My first experience of this place (inpatient unit) was at seventeen and a half, I got up out my bed one time thinking my Dad was God. He came in once or twice and I thought Dad your God to me and I'm Jesus, this night I got up and attacked staff and I got an injection in the sciatic nerve unfortunately, was put to X Hospital and they operated on me for a dropped foot in the left side because I was attacking nurses trying to break out the ward. . . I didn't know where I was *(mmm mmm)*. One minute I was in X, X, X, or X {names various towns in Scotland} next minute I was in here, going to the toilet at midnight with my gownies on and I thought I was in hell and I didn't deserve to be there, I was Jesus, my Dad was God and attacked the staff and got a jag in the sciatic nerve.

A number of participants became preoccupied with replaying the content of psychotic experience, for example describing the voices that they heard and the images within their hallucinations and they were reluctant to explore the meaning of these experiences. This again highlighted the complexity of processing such traumatic experiences. The preoccupation with narrating the content of psychotic experience also appeared to have a protective function, whereby talking only about the content enabled participants to somewhat disengage from powerful meanings and emotional

involvement, which may have felt overwhelming. The following participant articulated the protective function of psychotic experiences when he defined his paranoia as his 'personal safety net'.

> P4: Somehow I was this, err ultimate power *(mmm hmm)* that had this control and had err. . . it's absolutely mind blowing nonsense.
> **It feels that way now?**
> P4: It feels that way because I was never brought up that way, never in that way totally detached from things *(mmm hmm)* but at times I've got to be honest with you, at times, I revert back into it *(mmm hmm)* because its my one safety net, its my personal safety net *(yeah)* nothing can touch me, nothing can effect me *(mmm hmm)* errr -

Narrating the Control Balance

Participants described how recurrence of psychosis disrupted their sense of control. Relapse experiences made it challenging for participants to maintain a level of control and participants' narratives suggested that the balance of control could shift unexpectedly. In this narrative the following participant explained how relapse 'attacks' his balance of control.

> **Tell me what you mean by that, how is relapse like something attacking you?**
> P5: Well its something chiselling away *(mmm hmm)* trying to do away with my confidence and trying to do away with. . . I'm feeling err, alright at this time *(mmm hmm)* you know I feel err, happy *(okay)*, contented and this attacks me, it comes like err, a paralysation at one half of the brain, as if the wires went like, poof, haywire *(mmm hmm)*.

Participants described a fluctuating sense of control as the balance was continually disrupted. Experiences such as going into hospital and taking medication were important factors that all participants talked about that contributed to shifts in the balance of control. On some occasions shifts in the balance of control could contribute to participants sense of feeling 'powerless' (P9), whilst on other occasions positive experiences could shift the balance favourably and empower participants. Feeling more in control appeared to facilitate their ability to cope and adapt to experiences.

Hospital memories and current service support

All participants described their experiences of being in hospital. Memories of being in hospital were again vivid and there was a freshness to the recall of such memories. One participant reflected upon his first admission twenty years ago and stated:

> P4: the memory of it is so acute. I could probably give you a breakdown of the top ten songs that were in the charts. How could I have been so wrong, how could I possibly be so wrong and yet the memories of that are more acute than memories of two or three weeks ago.

Hospital experiences often represented a significant shift in the balance of control, whereby participants felt that they had lost all control and indeed that others were controlling them. A participant recalled her experience of being in hospital twenty-seven years ago. There was powerful imagery and adjectives within her narrative as she discussed how she felt controlled. A sense of reliving this traumatic experience was conveyed as she talked, this suggested she had been unable to adjust to the impact of this experience despite the passage of time. Her powerful recall of these memories also communicated to the researcher how such experiences were important within the process of adaptation and recovery.

> **It sounds like you feel that there wasn't any collaboration?**
> P9: There's no, we were just, you're rights were totally taken away, your freedom was taken away, your rights were taken away, you're dignity was taken away and the treatment was erm, exacerbated the illness really *(mmm hmm)* rather than, apart from the drugs, when they eventually hit on the right drug, you have to go through a gammit of all these terrible drugs with terrible side effects *(yeah)*, it's just like trial and error *(mmm hmm)*, but they don't tell you, no "we're having this program, we'll trial it and error, we'll try on all these different drugs, they might be distressing" blah blah blah, they don't involve you at all *(yeah yeah)* they just treat you like a cow, in a cattle shed or something, you know *(yeah)* totally unfeeling, un, un, insensate, well its not insensate but, you know but its got no rational *(mmm hmm)* powers at all *(aha aha)*.

Some participants were positive about their current experience of service support. Positive perception of service support had an impact on participants' ability to cope and adjust to the experiences of psychosis. In the following narrative the participant described his positive relationship with his CPN.

> **How does it feel to have that level of support?**
> P8: Oh it's fantastic. Even the X Centre {names CMHT} as well they've been great *(mmm hmm)* when I was really ill as I said to you 2 years ago *(mmm hmm)* oh they were great, fantastic *(mmm)*.
> **What are the most important things about the support that you have? What helps?**
> P8: Well its like X (names CPN) she says phone her any time *(yeah)* err she always says oh right, you know she's on the same level as me as well, its like I can talk to her and stuff, erm and she understands and it was strange too but when I was really ill 2 years ago she was the one that I felt I had to see first and she was great and she was really good.

An important part of the helpfulness of this relationship appeared to be the openness and availability of support but also the fact that the CPN fostered his sense of control over his experiences.

Participants who had a greater number of admissions and relapses, appeared unable to adapt to the experience of being in hospital and receiving support from professionals. The following participant related current experiences of support to previous negative experiences and had a rigid perception of support as controlling, penalising and causing him harm. His narrative suggested that being admitted to hospital continued to evoke trauma and fear and he appeared to feel that obtaining control of his experiences within a hospital environment was unobtainable.

> P1: They're taking away my life and my freedom *(mmm hmm, mmm)* and castrating me and making me paranoid and sluggish and memory. . . all the things. . . heart trouble. Its as though they're trying to bump me off if I don't do it myself, they'll do it. . . with the jag, get a heart attack or something. I want to know what their reasons are, I'm entitled to know.
> **How do you feel about them, when you say them?**
> P1: I don't like them at all. . . I've got. . I want away from psychiatry you know. . . I've had a hell of a life with this, indoctrinated schizophrenia.

Taking medication

All participants talked about their experience of taking medication, suggesting that this was an integral component of the experience of recurrence. Despite the frequent negative perceptions of service support, medication was often viewed as something that 'helps' was 'great' or 'excellent' and 'cured them' (voices). Medication appeared to shift the balance of control favourably.

> P3: But I think on the medication that I'm taking it seems to be easing a lot of the pain *(mmm hmm)* you know and its helping me sleep *(mmm hmm)* you know I feel as if my brain's slowing down.

Most participants valued their medication and spoke about its importance and how it helped them stay well.

> P8: If you're really unwell all you're thinking is right I wanna get a medicine that helps *(mmm hmm)* that's what I think.
> **So medicine would be important/**
> P8: Yeah, if you're really unwell you want that to work first of all *(yeah)* yeah progress you know *(yeah)* when you are unwell all you think is oh right medicine, I need a medicine that works you know, forget everything else *(okay)* if you're that unwell *(okay)*.
> **Medicine is very important at that time.**
> P8: Yeah and and if you don't take your medicine you can get a relapse you know so for me I take it every night at the same time just in case you know.

However, for small number of participants, particularly those whose narrative reflected an embedded negativity, medication was another way that they were controlled, 'manipulated' or 'experimented upon' (P1).

> **Right. OK. Aha, and what are your thoughts about the medication, generally?**
> P1: Uh, it's a downer. I could get depressed thinking about it.
> **Hmmm, this sounds very important to you.**
> P1: Yeah, it manipulates your mind, it's a, it's a medical straight jacket *(right aha).* A chemical straight jacket you know.
> **What makes you think/**
> P1: These drugs are powerful they manipulate your thoughts.

Another participant described how medication was a 'minefield, it's a jungle, you never what you're going to get but the thing is its up to them, they take care of all these things' (P5). Thus, medication was not always perceived as facilitating the control balance.

Describing the Interpersonal Atmosphere

Talking about experiences of relapse led all participants to reflect and discuss their memories of relationships and interactions with others. Memories of interpersonal experiences appeared to be embedded within the construction of relapse experiences. Participants would talk about these experiences on a continuum from early life relationships to current interactions and support from others, through to their hopes for future relationships.

Early life experiences

Many participants reflected on early life relationships. This appeared to represent their attempts to construct an understanding of how early experiences had contributed to their difficulties. This was a difficult process for most participants, however, talking about their early experiences enabled them to convey to the researcher that these experiences were important in forming an understanding of themselves and their difficulties.

> **It sounds like there have been a number of difficult relationships even before you became unwell?**
> P7: Oh yes, oh yes and I know right it is psychosis and relapse I'm doing, but as a child I've been in every hospital, I've had every illness *(mmm),* I've had everything *(mmm)* you know *(mmm)* and my mother she say some really hurtful things *(mmm)* and erm when I started to write about my life and things like that *(mmm mmm)* and I wrote it down saying that I didn't choose to come into the world with physical mental illnesses *(mmm hmm mmm hmm)* and I've been very very highly strung and wet the bed till I was a teenager you know *(mmm hmm)* so my psychiatrist said to me maybe if I didn't have experiences like that then I might

be different *(mmm hmm)* but that's another thing that upsets me, I, oh I find it very hard to accept things.

For many participants early difficulties were another experience towards which they had to form a sense of resolution.

Familial Support

The availability of family support was an important factor for participants. Most participants conveyed feeling a lack of support from their family. In the following narrative the participant talked about how his family would not talk about his experience of being unwell, this led him to form a painful conclusion that they 'weren't very loving'.

So the family that you keep in touch with, how have those relationships been over the years?
P6: Could you repeat the question?
The family that you keep in touch with, your mum and your sister, how have those relationships been over the years that you have been unwell? How have you found those relationships?
P6: . . . . I don't know *(you're not sure)*
Do you feel that your experience of relapse has affected them at all?
P6: Don't talk about it.
That's useful that you can tell me that, you don't talk about being unwell?
P6: They don't talk about it.
They don't talk about it, mmm hmm.
P6: I don't know just not a very loving family I suppose.
Is that the way you feel? {{Participant nods}}.

As a result of the difficult meaning that this exploration evoked, the participant conveyed a sense that he did not wish to explore this issue in any greater depth. His disengagement from a more in-depth exploration ensured that difficult and overwhelming emotions were not evoked further and reflected the complexity of adapting to this experience.

Only a minority of participants described positive familial supports, whereby they felt their family 'understand' and they could go to them when they experienced a problem.

P8: I think, if I'm in the house and I've got something, something's troubling me, I'll just say to mum or dad *(aha)* err and they'll just say okay what do you want to do, you're okay, just go out for a twenty minute run and then come back again, you know what, or I'll go and run like a 10K. I think its good to feel like its, its normal life but its the way other people look at it and the way they deal with it.

This participants' perception of the way his family reacted to him was important because it made him feel that they were supporting him and this made coping and adapting to his experiences less of a challenge.

The reactions of others

Participants' often talked about how others reacted towards them, they described these experiences vividly and it was evident that these experiences were important. A participant whose last hospital admission was twenty-seven years ago illustrated how the reactions of others could evoke trauma and a sense of stigmatisation. She recalled the reaction of a janitor whilst she was in hospital.

> P9: I suppose it was quite funny but to me I was so ill, I was sitting in a lotus position *(right)* not because I was Hindu or anything but I was just, things that go through your mind, things occur to you *(yeah)* and it affects your behaviour, *(aha)* your thoughts effect your behaviour, I don't know why I was doing that, but this man, there was a wee peep hole in the door and he looked through and he went something like "oh her ladyship contemplating her naval in there" and I was very, very hurt by that *(yeah)* you know it was mockery, you know he was laughing, they were all having a laugh, you know which was very hurtful.

Family reactions were also very important to participants.

> P7: Over the years they've {family} said, "nip it in the bud" you know, erm and "ooh you can't think like that" and "I don't know how you've got time to be depressed", there's just, there's still a stigma, it's happened to me once that I'm not to mention "mental health, don't mention that".
> **Who said that to you?**
> P7: My mum's sister, they've all be that way no supportive
> **So there's that kind of stigma?**
> P7: Yes and I get angry at them *(mmm hmm)* you know I get angry at them when they say that because I've came a long long way and I feel it's just like you know, but I've been taken down all my life and they always use a term like "X {P7} is not right in the head."

The reactions of others contributed to participants' beliefs about being misunderstood and unaccepted. The reaction of others made it difficult to feel supported by people within their environment and this lack of support complicated the process of recovery and adaptation.

An awareness of changing relationships

As well as the importance of how others reacted, participants had an awareness and sensitivity towards changes in their relationships with others. When they talked about

these experiences, participants reflected how their role within the family or within their friendships had changed.

> P4: I feel that over the past, err, the past twenty years of having this illness *(mmm hmm),* I'm not the type of person that they can turn to with a problem *(mmm)* so therefore everything seems to be nice and errr, its very much light-hearted when I meet my family, nothing is, errr, there's no real problems *(mmm hmm)* that I have to deal with, they're not coming on the phone to me saying, could you do this or do that or whatever *(mmm)* its very much don't pressure me because of what I've been through *(you feel that/)* at the same time. . . . It's not right and it's not normal and sometimes I can pick up the frustrations and the hurt and the anger *(mmm hmm)* errr, from my family members.

The awareness of changing relationships appeared to add to participants' sense of isolation and separation from others. This in turn impacted on how supported participants felt in their journey of recovery.

Comparing self to others

Participants were also prone to comparing themselves with others. This is evident in the following narrative in which the participant concluded from comparing herself to an old friend that things 'hadn't worked out' for her.

> P10: I've had a couple of experiences like that you know how you see people that you've not seen for years *(mmm hmm)* and then you don't know if to say anything. . . in fact it was 10 years ago I was at a friends wedding and erm. . . there was a girl, she'd been in my sixth year studies chemistry class and we got quite friendly and but then when she went to uni that was it, you know I never really contacted her again and she was at the wedding *(right)* and so I only went to the night thing I never went to the full wedding. Anyway I never went to see her and she never went to see me kinda thing you know *(mmmm)* I don't know, I felt kinda embarrassed about things not working out for me *(okay)* ken what I mean *(aha)* she's a doctor you know, she's qualified as a doctor and everything *(aha)* and I just kinda felt. . . she probably felt awkward as well you know just the way things had worked out for her and they hadn't worked out for me kinda thing.

Participants' comparisons of themselves with others often conveyed a sense of loss, as they reflected that they had not done as well as others or had 'missed out' (p5).

A sense of isolation

Often when participants talked about their interactions and relationships with others their narratives eluded to a sense of isolation. Participant 10 went onto describe how 'my last concert was about three years ago and that was with a befriender' and the people in the 'rehab unit' had taken her to the cinema 'at least two years ago anyway'. Often participants felt that they relied upon services to facilitate social opportunities

with others. If social opportunities were not facilitated, there was a sense of isolation and loneliness to participant's lives, particularly if they lived alone.

> P3: For the best part of when I'm not sitting here, actually sitting in this room, there isn't anybody like, like as far as having a friend goes. You know these are things that I would like to share with somebody to, to get it out my system you know, to get *(yeah aha)* I think these kinda places do help quite a bit you know *(mmm hmm)* to thingme that.

This participant made jokes of his experience of isolation and loneliness in order to diffuse the negative consequences of being alone, such as 'anger', 'frustration' and 'things getting broken' that were occasionally alluded to. Many narratives alluded to an embedded sense of isolation.

Expressing Affect

Participants' construction of experiences associated with their understanding of relapse led to a diversity of emotional expression. Participants would laugh when they reflected upon how their experiences were 'bizarre' and 'all madness' (P2). Contrastingly when they talked about psychotic experiences they conveyed fear and helplessness. Describing previous experiences of hospital treatment often led participants to feel angry (see P9). When participants considered what they had 'lost' they acknowledged deep sadness. Many of these emotions are evident in the above narratives.

This participant conveyed the sense of fear and helplessness that could be instilled by psychotic experiences.

> P11: Sometimes its scary do you know what I mean *(yeah)* sometimes its dead scary *(yeah)* you what I mean, when the voices tell me, I could do anything, you know what I mean, they're repeating themselves all the time, do you know what I mean *(yeah yeah)*.
> **That sounds really bad, aha.**
> P11: What can you do about it, you know what I mean, aye.
> **Do you feel that way, that you can't do anything about it?**
> P11: What you gonna do man, the voices tell me to cut myself I'll do it, just to get them off my back you know what I mean.

The construction of experiences associated with their understanding of relapse, frequently led participants to reflect on what they had lost during the course of experiencing psychosis.

> P4: If I go back to my very first break down, I've gone on about this point over and over again, but err I felt as if when I took the first break down, it was how much do you want

> to lose here pal, how much would you prefer to lose and I felt as if I was to lose too much, I was to lose respect, I was to lose love *(mmm hmm)*, I was to lose everything that mattered to me and over the years I've lost a hell of a lot, I've still got a bit of it still in place but I don't want to lose anymore *(of course yeah)* I definitely don't want to lose anymore.

The construct of loss was extremely relevant to participants; the experience of relapse often embodied what they had lost. In addition to 'love' and 'respect' this included, relationships, jobs, housing and possessions that were important to him. One participant remorsefully reflected on the loss of his 'sports car' (P5). The narratives reflecting loss suggested that participants felt they had lost a proportion of who they used to be and that they were grieving for their former life and what they perceived could have been their future.

Bringing the narrative back to the present and thinking about the future

Towards the end of the interview, participants' construction narrative, similar to a story telling process, became focussed on the present. They talked about their current situations and they began to think and talk about the future. All participants conveyed that they hoped never again to experience a recurrence of psychosis and there was a sense of fear about this prospect.

> P7: Well it's one of these things right I know they've happened *(mmm hmm)* but at the back I've got these wee doubts like phew. . . you know, phew, I don't really want to go down as far as to have to be taken in again {to hospital} *(mmm hmm mmm hmm)* and that's what I've got at the back of my mind *(yeah yeah)* aha.
> **It's a worry in the back of your mind.**
> P7: In the back of my mind, the amount of my life time that's past, its sits there and if I take on with all that {family stress} it surfaces *(mmm hmm)* and then I start doubting myself and you know, it frightens me.

Thinking about the future, another participant described the magnitude of the impact of relapse.

> P9: Hopefully he {God} gives me something else like arthritis or something next time {{laughs for 2 seconds}} which I have got, but its no bother compared to schizophrenia, no bother, no bother.

Several participants spoke about 'having that hope for the future' (P6) within these narratives several participants talked about a 'cure' and this thought appeared to provide participants with a sense of hopefulness.

P2: Maybe there'll be a cure you know, maybe there'll come up with a cure, if they could cure it *(aha)* that would be brilliant, to come up with maybe one day a cure maybe, maybe a tablet that you can take that kicks, just starts the chemicals flowing normally *(yeah)* you know that would be amazing you know.
Is that something you would hope for in the future?
P2: Aye I would love it, I would love that to happen you know, I've got friends who suffer from mental illnesses *(mmm hmm)* you know that would be amazing.
Yeah. . . if that doesn't happen how do you feel the future will be?
P2: Just, just keep coping and taking medication and just plodding on Hayley aye.

However often participants conveyed a sense of hopelessness and worry about 'getting left behind' as time continued to move on. The following participant described this feeling within her narrative as she thought about the future.

P10: I just, I just worry about the future you know *(mmm hmm)* I mean just now I'm quite reliant on my parents you know for taking me to appointments things like that. I've started to feel time is going by you know so quickly you know *(mmmm)* I mean I left school, its nearly twenty years since I left school *(right)* I've never had a proper job and I'm like what is going on you know and kind of like time is going by I'll have to do something you know *(mmm mmm)* I can't just sit in the house for the rest of my life, you know everybody's, everybody else is getting on you know, jobs or whatever *(mmm mmm)* you know, but I feel like I'm getting left behind.

Therefore, thoughts about the future often contained a mixture of hopefulness versus hopelessness and fears of relapse and the consequences of this experience.

Valuing a space for making meanings

All participants reported benefit from talking about the experiences that they associated with relapse. This was evident within their comments at the end of the interview and also within the subjective reports of comfort before and after the interview (see Graph 1).

Participant 3 whose experiences suggested an embedded sense of loneliness, reported the following at the end of the interview.

P3: It's been interesting, I like to get a good gab you know, yeah, I don't usually get the opportunity *(aha)* you know I'm usually sitting in the house and maybe I'm stuck for words, you know what I mean, it was good to, good to, it's good to actually speak to people you know. There's nothing like talking to another human being as such you know {{laughs for 3 seconds}} rather than talking to the wall {{laughs for 2 second}}, I found it kinda educating. You know what I mean, I do sense the way I feel when you're getting a buzz out of it you know, its good, its really interesting {{laughs for 2 seconds}}.

Often the final interactions between the researcher and participant suggested that a therapeutic relationship had been built over a short time period.

> **It's been really useful to speak today X, you've really enriched my understanding *(aha)*, its been really helpful *(aha)* thank you.**
> P9: Well its quite good to talk about it you know put it into words.
> **Oh that's good, you certainly put it into words very well, you have a very nice way of expressing yourself.**
> P9: Thank you, so its been very therapeutic you know *(I'm glad)* very therapeutic.
> **How do you feel just now?**
> P9: It's good to know that somebody cares, you know what you went through *(yeah)* you know I don't know if I've ever really told anybody before, you know, how bad it was *(mmm mmm)* its been helpful, you're a good listener.

It is difficult to speculate upon the impact of the experience of participating in the research interview. However, there was certainly evidence of the benefit in providing an opportunity for constructing an understanding of experience or for allowing 'a space to put it into words' (p5).

THE CENTRAL PROCESS OF ADAPTATION

Participants' construction of relapse experiences illustrated the challenges inherent within recurrence of psychosis. Participant 9 summarised the challenges that relapse presented for her at the end of the interview.

> P9: Time of coping, competence, confidence, helping others, strength, power, control, gives way to sensitivity, vulnerability, dependence, brokenness, fragility, confusion, being helped, lack of control, powerlessness, being at the mercy of others and your thoughts and feelings.

A central theme emerging from *The Content of Construction* was that relapse evoked a complex coping response and necessitated an individualised process of adaptation. The complexity of coping and adapting to the challenges of relapse was embedded within the narratives as participants constructed an understanding of their experiences. Participants described how relapse presented 'something different every time' (P7) and how coping with the experience of relapse was 'a learning curve' (P5). Participant 4 reconstructed an understanding of relapse that further illuminated the central process of coping and adaptation.

> P4: I think relapses I've had over the years, I've been aware that I'm not quite there yet *(mmm hmm)* err. . . . its difficult to say *(yeah)*. I think basically what relapse means to me is, you're coming up with different ways of looking at it *(mmm hmm)* and err, trying to

come to terms with your own problem and you're suddenly made aware that you're not quite there yet.

Narrative form and adaptation

The complexity of adaptation was further illuminated by the narrative form; the way that participants talked about their experiences. It was apparent from *The Content of Construction* that talking about experiences of relapse was sometimes a difficult process. As is evident in the narratives, the process of construction led to an interaction between the recall of powerful memories, emotional reactions and the process of meaning making. Participants were resilient in the way that they regulated this experience. The following narrative provided insight into this regulatory experience.

So thinking about the ways that you've coped, it seems quite difficult for you to fully tell me about that, is/
P5: See that's another thing, I'm passable today.
What do you mean?
P5: I'm neither good nor bad, I'm sort of in limbo *(mmm hmm, mmm)* as they say , so I can tell you some things, other days I might no be able to tell anything, other days I might be able to tell you everything *(mmm hmm mmm hmm)*, it's a lucky bowl you know.

It was apparent that sometimes participants would engage in an in depth exploration of their experiences and at other times their narrative would become fragmented and disengaged from exploration. The researcher found that it was possible to code narrative form. Two styles of narrating experiences emerged from this stage of analysis that appeared to reflect participants approach to adaptation.

Firstly, narrative style often conveyed participants' level of engagement and depth of processing. For example, participant 1's narratives reflected the difficulty that he experienced processing, reflecting upon and forming meaning from his experiences. As illustrated in the quotations, there was an embedded negativity within his narratives and he lacked curiosity in exploring his own thoughts and the views and positions of others. Often his narrative reflected his feelings of confusion about his experiences and his accounts were limited in depth of expression. Other participant narratives also reflected this style of engaging with experiences. For example, participants 5, 6, 10 and 11 would leave the researcher with the impression that they were limited in the level of processing that they could engage in. This appeared to function as a strategy to limit painful memories and to avoid the overwhelming affect that an exploration of experiences might evoke.

How does it make you feel?
P11: . . . I dunno *(aha)* I don't think about it much, you know what I mean.
Do you try to not think about it?
P11: Aye, that's why I go to X (names recreation facility for people with mental health problems), play pool, snooker and that *(those are things you can do there)* aye *(mmm hmm)* passes the days for you, you know what I mean.

These styles of narrative reflected the difficulty of talking about such experiences and engaging in an exploratory search for meaning. The sense of powerlessness conveyed in their dialogue also reflected that participants were sometimes passively involved in the management of their experiences.

In contrast, participant narratives at times suggested they perceived a value in the process of making meaning from experiences. For example, as illustrated in the narratives, participants 2, 3, 4, 7 and 9 often engaged in a productive search for meaning. Throughout their discourse, they presented a balanced perspective whereby they would consider alternative accounts. They recalled memories that exuded a freshness and vividness to their recall and yet the participants retained some focus on developing an understanding of their experiences. The narratives of Participant 3 exuded a curiosity as he actively searched for meaning from his experiences. This is conveyed in the following narrative as he explored an understanding of his experiences in order to let the researcher know how he felt.

P3: But I think on the medication that I'm taking, it seems to be easing a lot of the pain *(mmm hmm)* you know and its helping me sleep *(mmm hmm)* you know I feel as if my brain's slowing down.
Okay, things feel slower *(yeah, aha, yeah)*. What is the pain that is easing?
P3: The pain of the whole mumbo and jumbo about everything and anything you know, I just feel as if my mind's working over time, I've got all these different scenario's and all different problems *(mmm hmm)*, you know what I mean. If you can imagine rolling the world up in a wee ball and somehow its implanted in my mind you know and its in my mind and its left for me to fix everything, I'm lying there and this is the way that I am feeling, you know.

The Central Process of Adaptation was illuminated by both the content and form of narrative construction and this process appeared to be embedded within the narratives. Analysis suggested that the way that participants spoke about their experiences may reflect styles of coping and adaptation from the experience of relapse.

Discussion

This study used an in-depth interview to engage service users who had experienced psychosis in a discussion about their experiences of relapse. Whilst participants accepted the term relapse, it was not a term that they ordinarily used to describe their experiences. It was observed that presenting participants with an open question that invited them to consider relapse experiences triggered powerful meanings and led to a process of construction, where memories were recalled and explored to varying degrees. Five themes were evident within *The Content of Construction.* Participants' replayed traumatic psychotic experiences such as auditory and visual hallucinations, delusional beliefs and paranoia, in doing so they recalled vivid memories, powerful imagery and the emotional intensity of their experiences. They talked about the balance of control and how their fluctuating sense of control shifted during experiences associated with relapse such as hospitalisation, service support and taking medication. Participants described their interpersonal atmosphere and it was apparent that memories of relationships and interactions with others were embedded within their construction of relapse. Participants recalled their early life experiences, familial support, and the reactions of others, engaged in comparison of themselves to others and described their sense of isolation within the context of relapse. Participants conveyed a diversity of emotional experiences throughout their construction of relapse, including laughter, sadness, fear, loss, helplessness and anger. Finally participants' narratives became focused on thinking about the future, including thoughts of hopefulness versus fear of future relapse. The content and form of narrative construction conveyed the complexity of adapting to experiences of relapse and illuminated a central process of adaptation. A theoretical conceptualisation of participants' experience of relapse is illustrated in Figure 1.

Insert Figure 1 here.

This study provided rich qualitative data that contributes to the growing body of literature on the impact of psychosis. Service users' accounts were synchronous with literature that has found evidence of the traumatic experience of psychosis (Shaw et al., 1997; Morrison et al., 2003; Shaw et al., 2002; Meyer et al., 1999; Harrison et al., 2004 & Jackson et al., 2004), experience of interpersonal difficulties and change (Arieti, 1974 ; Butzlaff & Hooley, 1998; Leff & Vaughn, 1985) feelings of lack of control, hopelessness, loss (Rooke & Birchwood, 1998; Birchwood et al, 1993), anger (Haddock

et al, 2004; Robertson & Lyons, 2003) and fear (Boyd & Gumley, 2007). However, this study observed that these experiences were particularly embedded within an understanding of the meaning of relapse and that such experiences illuminated the complexity of adaptation.

For the services users in this study, relapse included a magnitude of personal, environmental and interpersonal experiences that necessitated adept coping and adaptation resources. The narrative style and form further illuminated the complexity of adaptation. Two styles of narrative were evident; one conveyed engagement and curiosity as participants became absorbed in the recall of experiences and construction of meaning. The other style of narrative reflected a disengaged, fragmented and somewhat avoidant style of constructing meanings from experiences of relapse. It is proposed that these two narrative styles might reflect adaptation experiences such as sealing over and integration (McGlashan et al., 1977). McGlashan's definition of these recovery styles suggests that integration reflects the extent to which a person shows interest and curiosity with respect to understanding their experiences and incorporating them into wider meaning and structure. In contrast sealing over reflects an avoidant style deployed to distance and dissociate experiences away from the self. These recovery styles mirrored participants' narrative styles in the construction of meaning from experiences.

The findings suggest that the way service users talk about their experience of relapse is important. It was evident in the narrative style that for some participants engaging in a discussion about their experiences of relapse was too difficult because it triggered powerful and traumatic memories that had the potential to evoke overwhelming emotions and understandings. Hence sealing over functioned as a way of regulating the complex interaction between memories, meanings and affect.

There are several clinical implications that arise from the findings of this study. The study observed that service users did not ordinarily use the term relapse when they talked about their experiences and that generally this was viewed as a medical definition. It is important therefore to consider how we communicate with service users. Participants valued the researcher adopting their terminology and this helped to build an alliance. These findings suggest that clinicians should be mindful of using medical terminology and should adopt the language of their clients where possible. Sometimes

clinicians may feel that it is necessary to use medical terms such as relapse, for example within relapse prevention work, on these occasions it is important that the clinician collaborates with the service user in order to develop a joint understanding of the construct of relapse prior to commencing therapeutic work.

The study has highlighted that it is not just the content of what service users' talk about that is important, but also the way that they talk about their experiences may elucidate complex adaptation processes. If as suggested, styles of narratives are analogous to processes such as sealing over and integration, narrative style may reflect vulnerabilities to secondary psychological difficulties. For example Drayton et al (1998) have found that individuals who tended to seal over experienced greater levels of depression and made more negative self evaluations than those who presented with an integration recovery style. Furthermore, in a study exploring the relationship between recovery style and service engagement, Tait et al (2003) found that sealing over was associated with considerably lower service engagement than integration recovery styles. It is therefore important to assess and understand narrative styles in order to support service users appropriately in their recovery and facilitate engagement with services. This study has observed that it may be possible to code narrative style in a way that reflects recovery or adaptation styles such as sealing over and integration. This may enable clinicians to tailor intervention according to the current recovery style reflected in the narratives of their clients.

The study also has important psychotherapeutic implications in the area of relapse prevention, which is arguably one of the most important aspects of an individual's recovery. An approach to relapse prevention is the identification and monitoring of early warning signs (Birchwood et al., 2000b). Early warning signs can be defined as subjective experiences, thoughts and behaviours that occur in the phase preceding psychotic relapse (Heinrichs & Carpenter, 1985; Herz & Merville, 1980). The researcher suggests that engaging in a process of identifying early warning signs might be difficult for some service users. As observed within the findings of this study, service users might find it challenging to engage in a process of recall and reflection of memories, feelings and thoughts associated with their experience of relapse. The challenging nature of this process may lead some service users to disengage from an exploration of their early warning signs. A similar process may also occur in other forms of psychotherapy. For example within other cognitive behavioural approaches,

service users may be invited to engage in a process of conceptualisation, this may involve reflecting on the contribution of their early experiences to their current difficulties. Some individuals may not be ready to engage in this reflective process and their narrative style may convey a reluctance to explore such an understanding. It is therefore important within psychotherapeutic interventions with individuals in recovery from psychosis to consider the individuals' narrative style and how this reflects their readiness to engage in the proposed therapeutic process. At times service users may be keen to explore and understand (integration) and at other times they wish to disengage from a process that is challenging (seal over). Clinicians should be mindful of these adaptation styles as they may reflect the complexity of the individual's recovery and provide insight into how the process of adaptation may be facilitated.

If narrative style conveys important information about adaptation processes, it may be possible to facilitate narrative development in order to foster an integrative style of recovery and adaptation to experiences of relapse. This proposition has been somewhat supported by Lysaker and colleagues (Lysaker & Lysaker, 2001; Lysaker & Lysaker, 2002; Lysaker et al., 2003; Lysaker & Buck, 2006) who found that individuals diagnosed with schizophrenia may have difficulties making sense of events in a narrative fashion and may have stopped evolving a story of their lives. Lysaker & Buck (2006) suggest that engaging in a process of narrative enrichment may enable clients to continue to evolve a story of their lives. Reflecting on these findings and the suggested importance of narrative within the process of adaptation and further the benefit reported by service users of engaging in a research interview that encouraged narrative construction, the researcher suggests that a psychotherapeutic process of narrative enrichment may facilitate a process adaptation. The process of engaging service users in an in-depth interview that activated construction, suggests that important components of such a psychotherapeutic process may be the development of a therapeutic and non-hierarchical relationship between the client and therapist. Secondly, it would be important within a process of narrative enrichment that the therapist did not attempt to provide the client with content. Therefore within therapy if it becomes evident that the client has a limited story, the therapist should not offer the client stories, but rather reflect the difficulty of their experience. A third component may be that the therapist engages in a process of guiding the client to recall material that is temporarily unavailable to them. Thus, the therapist may actively help the client to overcome barriers by encouraging them to remember and expand upon material and by seeking

clarification when it appears that the dialogue has become fragmented. The researcher proposes that psychotherapy that focuses on narrative enrichment in which the therapist facilitates a process of meaning making through assisting participants to weave together and integrate memories, feelings and thoughts associated with their experience of psychosis and relapse, may enable individuals to develop a richer sense of their story and thereby promote adaptation and recovery

Limitations

The findings presented here were based on eleven participants' perspectives and were analysed by the researcher. The current findings are one possible presentation of the data and it may be argued that findings are bound to the context and conditions of this study (Hutchinson, 1993). It is accepted that there are infinite interpretations possible of any given text and lengthy quotations are presented in order that the reader may make their own interpretations. Strategies such as triangulation and respondent validation may have been a beneficial. However, given the relativist perspective adopted, these approaches were not deemed pertinent and the researcher was keen to avoid reducing the research to a list of technical procedures (Barbour, 2001). Furthermore, it is noted that the data collected in respondent validation are subject to the same process of interpretation as the primary data (Bloor, 1997). What remained paramount throughout the conduct of this research was the researcher's focus on reflexivity.

Conclusions

In summary, this study conducted the first qualitative exploration of service users' construction of relapse experiences in psychosis using a grounded theory approach. This study found that *The Content of Construction* elucidated *A Central Process of adaptation*. It is suggested that relapse includes a magnitude of personal, environmental and interpersonal experiences that necessitate adept coping and adaptation resources. The process of adaptation was evident in the content and form of the participants' narratives. It was observed that service users' narrative styles may mirror styles of recovery such as sealing over and integration and that it may be possible to understand the process of adaptation by an examination of these narratives. Based upon this observation the study proposed that a psychotherapeutic approach of narrative enrichment might facilitate narrative development and thereby promote adaptation and recovery. This study invites further exploration of the empirical questions regarding narrative form and adaptation that have been generated from this study.

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Table 1. Participant characteristics at time of interview.

Participant	*Gender*	*Age (Years)*	*Education*	*Relationship Status*	*Living Situation*	*Diagnosis*	*Subjective report of number of times experienced recurrence*
P1	M	57	16 years	Single	Hospital	Schizophrenia	6
P2	M	38	College	Single	Independent	Schizophrenia	2
P3	M	36	16 years	Single	Independent	Schizophrenia	Unknown – new to services
P4	M	42	Degree	Divorced	Independent	Schizophrenia	6
P5	M	60	16 years	Single	Independent	Schizophrenia	At least once a year
P6	M	26	College	Single	Independent	Schizophrenia	3
P7	F	57	16 years	Married	Independent	Bipolar Disorder	6
P8	M	28	16 years	Single	Living with parents	Schizophrenia	2
P9	F	52	Degree	Married	Independent	Schizophrenia and Bipolar Disorder	4
P10	F	30	College	Single	Living with parents	Schizophrenia	3
P11	M	47	16 years	Girlfriend	Independent	Schizophrenia	6

Graph 1. Level of comfort before and after the interview.

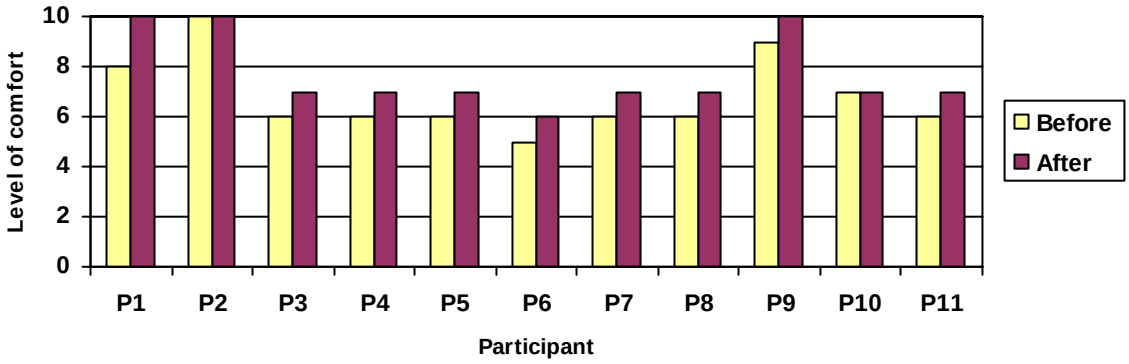
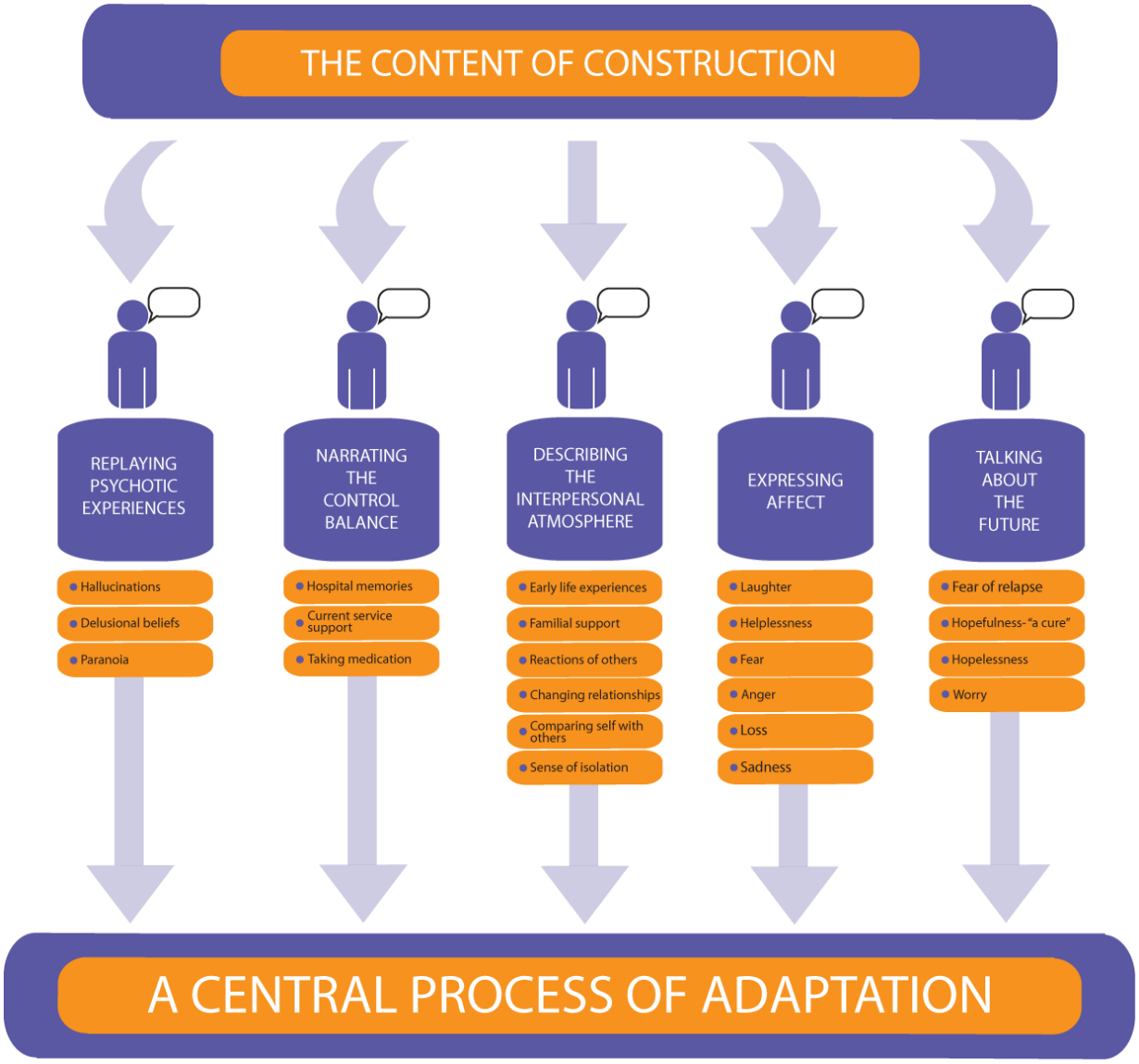


Figure 1. Service users' construction of relapse



Chapter Five

Single N Design Proposal

Staff emotions, coping style and perceived self-efficacy. The effect of a staff training approach for staff working with a client with a learning disability and longstanding challenging behaviour: A Single N Experimental Design.

(Bound in Part two)

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Prepared in accordance to requirements for submission to *Journal of Intellectual Disability Research* (Appendix 5)

Abstract

From a behavioural perspective the role of staff behaviour in the development and maintenance of challenging behaviour displayed by people with learning disabilities has been described as a cycle of reinforcement. Research suggests that staff responses to challenging behaviour may be influenced by psychological factors such as their emotional reactions, belief systems, attributions, self-efficacy and coping style. Using a single case methodology this study proposed to further understand the nature of staff's responses to challenging behaviour. WB was a 57-year-old man with a moderate learning disability who presented with a longstanding history of challenging behaviour. The staff team at his residence described difficulties managing his behaviour and they reported a lack of confidence in their approach and intense states of affect in response to WB's behaviour. The proposed ABC experimental case design will include professional development sessions and support staff to implement guidelines to enable more effective management of WB's challenging behaviour. The outcome of this intervention upon staff variables and the challenging behaviour of WB will be examined. It is proposed that this experimental case design will add to the development of cognitive models of staff responses to challenging behaviour and will elucidate important components of effective support for staff working with individuals with challenging behaviour.

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Appendix 1.1

Data Collection Sheet for Service Based Evaluation

Case No:	
Therapist Discipline:	
	Rate inclusion of items
Presenting Problems (1) Onset (1) Duration (1) Frequency & Severity (1) Reason for seeking assistance (1)	
Personal Background (1) Family Relationships (1) Childhood (1) Education (1) Occupation (1) Social Relationships (1) Psychiatric & Medical History (1)	
Formulation (1) Primary Problem (1) Predisposing Factors (1) Precipitating Factors (1) Maintaining Factors (1)	
Treatment Recommendations Required Intervention (1) Estimated length of treatment (1)	

1 point will be allocated for inclusion of the 4 general areas. Addition points will be allocated for inclusion of specific details related to that general area.

Appendix 1.2

GUIDELINES FOR SUBMISSION TO *SCOTTISH MEDICAL JOURNAL*

The Scottish Medical Journal is published four times per year - in February, May, August and November - and is devoted to the publication of original investigations in all branches of medicine, review articles, historical subjects of medical interest, and clinical memoranda. Papers are accepted for publication on condition that they are offered to this journal alone and that they become the property of the Scottish Medical Journal.

MANUSCRIPTS SHOULD BE SUBMITTED AS FOLLOWS.

One copy on paper sent to:

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An email attachment in Word or Text to smjsubmit@yahoo.co.uk

Papers

Papers should be written in clear concise English. Manuscripts should be typed, double spaced including title page, abstract, text, acknowledgements, references, figures, tables and legends. Number pages consecutively beginning with the title page. Total word count should not exceed 2500 words.

The title page should include the name(s) and address(es) of all author(s) and a word count. The corresponding author's email address should be included. Authors should include any declaration of any financial or commercial interest. Proofs will be sent to the corresponding author's address unless otherwise stated.

The second page should carry an abstract of not more than 200 words (Background and Aims, Methods and Results and Conclusion). Below the abstract include three to five key words or short phrases for indexing.

The description of methods and results should be in sufficient detail to allow repetition by others. Data should not be repeated unnecessarily in text, tables and figures. The discussion should simply repeat the results, but should present their interpretation against the background of existing knowledge.

References

References should be numbered consecutively in the order in which they appear in the text. Identify references in text, tables and legends by arabic numerals in superscript e.g. 3 or 2-4. Use the style of references adopted by Index Medicus. The titles of journals should be abbreviated and when there are more than six authors, it should be

abbreviated to three authors followed by et al. The title of article, abbreviated name of journal, year, volume, first and last page numbers. ‘Personal communications’ and ‘unpublished observations’ (including information from manuscripts submitted but not yet accepted) should be so identified in parenthesis in the text and not included as references. Reference to books should include surname and initials of author(s), title of chapter, editor(s), title of book, place of publication, name of publisher, year, volume and page numbers.

Tables

Tables numbered in roman numerals should be submitted on separate sheets and should be designed to appear in either one column or across the whole page. Omit internal horizontal and vertical rules and do not submit tables as photographs.

Illustrations

Images should be supplied seperately to the manuscript as high resolution JPEG at 300dpi. Please indicate clearly in the copy where figures should be inserted. Illustrations both half tone and line, should be referred to as ‘Figures’ and should be numbered in arabic numerals. They should be technically excellent. Each figure and table should be accompanied on a separate sheet by a short legend as a heading with explanatory matter in footnotes. The name(s) of the author(s) should be written on the reverse side of the paper copy.

Case Reports

These will be summarised in the Journal and full text will be available on the Journal website. The authors should not include names, initials or hospital numbers of patients, which might lead to their recognition. A patient must not be recognisable in any photograph unless written consent has been obtained.

Appendix 2.1

Grounded Theory Guide (GTG)

This checklist is intended to be a flexible methodological guideline for the review of grounded theory studies. A demonstration of 'how' a study applied a methodological technique is of greater quality than a cursory mention of a technique i.e. a "technical fix". Importantly there is no absolute agreement on the methodological procedures of grounded theory (Dey 1999, p 23) and there should be an inter-play between the criterion below and the data in the studies. The review should be creative and enable the emergence of quality methodology or approaches that are not be covered by this guideline. This is of particular relevance as it is unknown how researchers have adapted grounded theory for use in studies of psychosis. Please reference any comments to relevant paragraphs in studies where possible.

Title of paper reviewed: …….

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1. How was the study *sensitive to context* in the following?

Relevant literature and empirical data:

- How were the understandings created by previous investigations, using similar methods and topics considered? (Yardley 2000, p.219)
- How did the work link to the work of others, including quantitative/empirical research?
- **GT DEBATE:** OR 'delaying the literature review until after forming the analysis' (Charmaz, 2003, p.83).

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Initial Sampling:

- How was the original sample selected at the ‘point of departure’? (Charmaz, 2003, p.85)
- **GT AGREED TENET:** Did sampling follow that, “initial decisions are not based on preconceived theoretical framework” (Glaser & Strauss, 1967, p.45)
- **GT AGREED TENET:** How were sampling and interview questions flexible and adapted to emergent theory as it evolved i.e. theoretical sampling? (Dey, 1999, p.5)

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Sensitivity to Sociocultural setting:

- How was the study sensitive to the language, social interaction and culture of participants? (Yardley, 2000, p 220)
- How was the social context of the interaction between researcher and participant considered (e.g. gender, status as mental health professional) and how was this incorporated into the study design? (Yardley, 2000, p 220)

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Participants' perspectives:

- To ensure sensitivity to different perspectives how were procedures for eliciting and incorporating the opinions of the population being studied or other relevant groups considered?

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Ethical issues:

- How did the researcher address ethical issues raised by the study e.g. informed consent or confidentiality or how they have handled the effects of the study on participants during and after the study? (CASP, 2002)

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2. How was ***commitment*** and ***rigour*** demonstrated?

Commitment through an in depth engagement with the topic:

- A clear immersion in the relevant literature.
- Competency and skill in method shown (Yardley, 2000, p221).

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Constant Comparative Analysis:

- **GT AGREED TENET:** How did the researcher constantly compare similarities and differences between instances, cases and concepts, to ensure that the full diversity of the data is explored? (Hayes, 1997, p.261)

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Negative case analysis:

- How was a case or instance used to challenge an emergent theme? (Hayes 1997, p270)
- Were cases presented which did not fit an emerging conceptual system?

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Coding:

- **GT DEBATE:** How did the research progress from open coding, i.e. "coding the data in every way possible…for as many categories that might fit", toward selective coding i.e. delimiting coding to the only variables that relate closely to the "core" variable of the emergent theory (Glaser, 1978, p.56)?
- **OR** using a preconceived coding paradigm e.g. axial coding as described by Strauss & Corbin (1990, p.96)?
- Were examples of theoretical codes provided?
- **GT AGREED TENET:** How were memos used in the allocation of codes (Dey, 1999, p.11)?

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Data collection and depth/breadth of analysis:

- **GT AGREED TENET:** Did analysis start with the data? (Charmaz, 2003, p.87).
- How were efforts made to collect data from a variety of sources i.e. triangulation (Barbour, 2001, p.1117)?
- How was multiple coding used i.e. cross checking of coding strategies and interpretation of data by independent researchers (Barbour 2001, p.1116)?
- How was variation built into the theory e.g. not based on a single example (Corbin & Strauss, 1990 p.10)?
- **GT AGREED TENET:** How did the synthesis provide "readily apparent connections between data and lower and higher level abstractions of categories and properties" (Glaser & Strauss, 1967, p.37)?
- **GT DEBATE:** Were interviews transcribed? (Charmaz, 2003, p.87 para 3).

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Theoretical saturation:

- **GT AGREED TENET:** How was theoretical saturation i.e. the non-emergence of new properties categories or relationships demonstrated? (Dey, 1999, p.8) Consider a proclamation vs. proof.

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Validation:

- **GT DEBATE:** How were views of participants validated or emergent themes/theory feedback to participants, i.e. respondent validation?
- OR How was the unsuitability of this technique explained?
- How was analysis/themes/theory opened to the scrutiny of others?

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3. How *transparent* and *coherent* was the research?

Clarity and power of description/argument:

- How clear was the narrative of the research?

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Transparent methods and data presentation:

- Detailing aspects of data collection process.
- Rules for coding data e.g. by presenting excerpts of textual data.

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Reflexivity:

- Transparent through open reflection on how experiences or motivations or constraints of researcher may have influenced process, in both interactions with participants and with data at a theoretical coding level.

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Coherence by showing a fit between theory and method adopted:

- A justification of choice for grounded theory including an understanding of its philosophical basis. In particular did they present a position on the debate of ‘actively finding what is there’ (i.e. social constructivist), vs. the ‘emergence or discovery’ (positivistic) of theory?

- How did the study demonstrate a grounding in the philosophy of the method and a discussion on the selection of method?

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4. Was the *impact* and *importance* of the research shown?

Theoretical (enriching and understanding):

- **GT DEBATE:** Was a 'grounded description' or a 'grounded theory' produced? (Charmaz, 2003, p.101).
- Likelihood of stimulating further studies or explaining a phenomenon.
- A novel insight on a phenomenon under study and *not* a replication of previous findings.
- Directions for future research.

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Sociocultural:

- Highlight the impact of wider socio-cultural processes on a phenomenon e.g. analyses of socio-political function of individualistic health promotion rhetoric can help to explain why the ideal that it is possible to maintain health through personal endeavour remains popular despite evidence that individual behaviour has much less impact on health than other factors such as socio-economic status.

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Practical (for community, policy makers; health workers):

- Meeting objectives of analysis
- Importance for intended community.
- New practical applications from research.

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How has the study adapted the method to the study of participants suffering from psychosis?

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Please note below if the papers reviewed was of particularly high quality in any of the areas above or in other additional areas.

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References:

Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? *BMJ, Vol.322*, 1115-1117.

Barbour, R. S. & Barbour, M. (2003). Evaluating and synthesizing qualitative research: the need to develop a distinctive approach. *Journal of evaluation in Clinical Practice, Vol.9,* 179-186.

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Elliot, R., Fischer, C.T., & Rennie, D.L., (1999). Evolving guidelines for publication on qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology, 38 (3)* 217-229.

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Glaser, B. (1978). *Theoretical sensitivity.* Mill Valley, CA: Sociology Press.

Hayes, N. (1997). *Doing qualitative analysis in psychology.* Psychology Press: UK.

Strauss, A. & Corbin, J. (1998). *Basics of qualitative research: techniques and procedures for developing grounded theory.* 2nd Edition: SAGE publications.

Yardley , L. (2000). Dilemmas in qualitative health research. *Psychology and Health, Vol. 15,* 215-228.

Appendix 2.2

IPA Guide

Developed from criteria generated from *A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology* (Brocki & Wearden, 2006).

Title of paper reviewed: ……
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1. DATA COLLECTION

What were the methods of data collection?

- Use of exemplary method for IPA (Smith & Osborn, 2003), semi-structured interviews using open-ended questions and non-directive style.
- OR Alternative methods and justification e.g. focus groups, written narratives, email interviews.
- Use of participant diaries? 'An excellent alternative to providing a narrative account for analysis' (Brocki & Wearden, 2006).

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How was the design of the interview presented?

- Were examples of prompt questions given or 'minimal probes' presented?
- OR copy of the interview.
- How was the interview constructed? E.g. on basis of theory or existent writings?
- How was the approach to data collection described?

- Did the design ensure that the approach to analysis was flexible in-depth exploration ‘without an attempt to test a pre-determined hypothesis of the researcher’ OR without ‘preconceived ideas?’ (Smith & Osborn, 2003).

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How was the researcher’s interpretative role in analysis discussed at this stage? (Smith, 1996)

- E.g. role of preconceptions, beliefs and aims

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2. SAMPLING

Was sample size in accordance with the aims of IPA analysis?

- E.g. large data sets mat result in the loss of potentially subtle inflections of meaning (Collins & Nicolson, 2002).

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How was purposive sampling conducted?

- E.g. ‘The aim is to select participants in order to illuminate a particular research question.’
- How did sampling support the analysis? Do the authors present a position on the consideration of generalisability?

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How was saturation presented?

- How was the potential problematic nature of saturation in IPA discussed?

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3. ANALYSIS

How was the IPA approach defined?

- E.g. use of IPA specifically stated? OR ‘inductive interpretations using phenomenological framework’. Was Smith’s (1966) paper described as a way to define the approach?

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Themes:

- Evidence of theme representation in transcripts
- How was theme selection discussed e.g. ‘the eloquence with which one participant summarises the point others sought to say in more words and less precisely’ (Brocki & Wearden, 2006) Or ‘manner in which theme assists in the explanation of other aspects of the account’
- How was researcher biased minimised in selecting themes e.g ‘a final rereading of the original transcripts to ensure that interpretations were grounded in participants’ accounts’ (Collins & Nicolson, 2002)
- Were excerpts from transcripts presented to provide a ‘grounding in examples’ and as ‘central to IPA?’

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How was the analysis process described?

- Detailing aspects of analysis.
- Was the absence of a detailed formulaic procedure for IPA acknowledged?
- How did the researcher evidence moving from the ‘descriptive to the interpretative?’
- How were theoretical preconceptions brought by researchers discussed?

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Validation:

- How were analyses checked and interpretations validated by others? How was this open to discussion if validation was not completed?

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Reflexivity: The interpretative role of the researcher:

- How is the explicit recognition of the interpretative role of the researcher in IPA (Smith et al, 1999) acknowledged? N.B. even if it is not mentioned outright.

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Fit between theory and method adopted:

- How did researcher reflect on the usefulness and appropriateness of utilising IPA with their data set?

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How has the study adapted the method to the study of participants suffering from psychosis?

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Please note below if the papers reviewed was of particularly high quality in any of the areas above or in other additional areas.

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Appendix 2.3

Guidelines for submission to *Qualitative Research in Psychology*

Article presentation
Manuscripts should be double-spaced throughout, especially the references. Pages should be numbered in order.

The following items must be provided in the order given:

1) Title Page
Authors and affiliations
Authors should include their full name and the establishment where the work was carried out (if the author has left this establishment his/her present address should be given as a footnote).
For papers with several contributors, the order of authorship should be made clear and the corresponding author (to whom proofs and offprints will be sent) named with their telephone/fax/email contact information listed.

Abstract
Please provide an abstract of approximately 150 words. This should be readable without reference to the article and should indicate the scope of the contribution, including the main conclusions and essential original content. This is not needed for observations or commentaries.

Keywords
Please provide at least 5-10 key words.

About the author
Please provide a brief biography to appear at the end of your paper. Click here for examples.

2) Text
Subheadings should appear on separate lines. The use of more than three levels of heading should be avoided. Format as follows:
1 Heading
1.1 Subheading
1.1.1 Subsubheading
Footnotes should be avoided. If necessary they should be supplied as end notes before the references. Do not use programming to insert these.

3) References
The Harvard style of references should be used. The reference is referred to in the text by the author and date (Smith, 1997) and then listed in alphabetical order at the end of the article applying the following style:
For a book…
Hollway, W. and Jefferson, T. 2000: Doing qualitative research differently: free association, narrative and the interview method. London: Sage.
For an edited book…
Brown, L.M. 2001: Adolescent girls, class, and the cultures of femininity. In Packer, M.J. and Tappan, M.B., editors, Cultural and critical perspectives on human development. Albany, NY: SUNY Press.

For a journal article…
Madill, A., Jordan, A. and Shirley, C. 2000: Objectivity and reliability in qualitative analysis: realist, contextualist and radical constructionist epistemologies. British Journal of Psychology 91, 1-20.

4) Acknowledgements
Authors should acknowledge any financial or practical assistance.

5) Tables
These should be provided on a separate page at the end of the paper and be numbered in sequence. Each table should have a title stating concisely the nature of information given. Units should be in brackets at the head of columns. The same information should not be included in both tables and figures.

6) Figure captions
These should be provided together on a page following the tables.

7) Figures
Figures should ideally be sized to reproduce at the same size. However, the typesetter can manipulate sizing where necessary.
All figures should be numbered consecutively in the order in which they are referred to in the text. Qualifications (A), (B) etc can only be used when the separate illustrations can be grouped together with one caption.
Please provide figures at the end of your paper on a separate page for each figure. Once accepted you will be required to provide a best quality electronic file for each figure, preferably in either TIFF, or EPS format.
For an information sheet about creating electronic versions of your figures please click here.

General
Abbreviations should be spelled out when first used in the text. Full stops should be used in lower case abbreviations (e.g., i.e.,) but not for capitals (SAS, ANOVA).
Spelling can be either UK or US English but must be consistent throughout the paper.

Mathematical
Numbers below 10 should be written out in the text unless used in conjunction with units (e.g., three apples, 4 kg).
Use spaces (not commas) within numbers (e.g., 10 000, 0.125 275).
Full points (not commas) should be used for decimals. For numbers less than one, a nought should be inserted before the decimal point . (e.g., 0.125 275).
SI units must be used. English units may appear in parenthesis following the SI units.

Permissions
It is the responsibility of the author(s) to obtain written consent from the original publisher and author(s) to use the following material published previously elsewhere. 1) All maps, diagrams, figures and photographs (forms are available from the publishers); 2) Single passages of prose exceeding 250 words, or scattered passages totalling more than 400 words from any one work. Please supply the publisher with full information for all work cited, including author, date published, publisher and page references. EU copyright extends to 70 years after the death of the author or 70 years after publication of a scholarly edition. Please forward all correspondence to the Journals Production Department, SAGE Publications Ltd, with your accepted manuscript.

Proofs
Proofs are sent to the corresponding author by pdf in an email to check for typographical errors. Modifications cannot be incorporated at this stage without incurring heavy costs hence the original text cannot be altered.

Offprints
The corresponding author only will be supplied with 25 offprints of his/her article. Additional offprints can be ordered at page proof stage.

What does relapse mean to you?

UNIVERSITY of GLASGOW

NHS Greater Glasgow

I am a Trainee Clinical Psychologist. I am conducting a research study in the field of psychosis and relapse. I am interested in speaking to individuals who have experienced psychosis and I would like to learn more about your experience and understanding of the term relapse.

What is the research study about?

This research is about developing an understanding of individual's experience of relapse or recurrence of psychosis.

What is psychosis and what does relapse mean?

Psychosis involves having unusual experiences which may include hearing voices when there is no-one there and seeing and feeling things that other people do not. Individuals may also hold strong beliefs that are not shared by others. However, everyone's experience is different and unique.

Although many people who experience psychosis recover, a significant number of people will go on to have a relapse. A relapse means having a return of unusual experiences.

Why is this research important?

If we understand more about the experience of relapse it may be possible to improve how we communicate with individuals who have experienced relapse and how we involve these individuals in planning relapse prevention therapies.

What is involved?

I will aim to meet you at your local resource centre and I will ask you about you're understanding and experience of relapse. There are no right or wrong answers. With your consent I will record this session.

What happens next?

If you are interested in taking part please complete the tear-off slip below and hand it to your keyworker or receptionist.

In order to ensure that your participation does not get in the way of any ongoing treatment that you may be receiving, I'd like to contact your keyworker. If your keyworker feels that your involvement in the research will not interfere with your ongoing treatment, I will contact you to arrange a meeting to talk about what is involved in the study and answer any questions that you may have.

Please complete the tear-off slip if you are happy for me to contact your keyworker in the first instance.

Thank you for taking the time to read this advert and I hope to have an opportunity to find out more about your experiences.

Hayley Veitch
Trainee Clinical Psychologist
Stewart Centre, 5 Ardencraig Road, Glasgow, G45 OEP.
Contact Number: 0141 634 5430. Email: h.veitch.1@research.gla.ac.uk

Name ..... Telephone No.....(optional)

Address .....

Email .....

Keyworkers name ..... Keyworkers base / Contact No.....

Signature.....(I agree that you may contact my Keyworker)

For office use: Relapse Study - Please contact Hayley Veitch, Trainee Clinical Psychologist, Stewart Centre, 0141 634 5430.

*** Not actual size**

Participant Information Sheet. Version 2 (24th July 2006)

Study Title: What does relapse mean to you?

Dear X

Thank you for expressing an interest in taking part in my research, I was pleased to hear that you may be interested in taking part. Here is some more information for you to read about my research.

My name is Hayley Veitch and I am a Trainee Clinical Psychologist. I am completing this research as part of my qualification in Clinical Psychology.

Before you decide if you would like to take part in this study it is important for you to understand why the research is being carried out and what it will involve. Please read the following information carefully.

What is the research about?
This research is about developing an understanding of service users' experience of relapse of psychosis.

Why is this research important?
Although there have been many studies of relapse, very few have focused on users experience of relapse.

Therefore, if we understand more about the experience of relapse from your perspective, it may be possible to improve how we communicate with service users and how we involve service users in planning relapse prevention therapies.

What do I mean by psychosis?
Psychosis involves having unusual experiences which may include hearing voices when there is no-one there and seeing and feeling things that other people do not. Individuals may also hold strong beliefs that are not shared by others. However, everyone's experience is different and unique.

To find out more about psychosis, you can access a document written by the British Psychological Society called *Recent Advances in Understanding Mental Illness and Psychotic experiences* by accessing the following internet link:

http://www.bps.org.uk/document-download-area

What do I mean by relapse of psychosis?
Many people who experience psychosis recover. However, a significant group of people will go on to have a relapse. A relapse means having a return of unusual experiences such as hearing voices, seeing and feeling things that others do not or having distressing suspicious or paranoid thoughts. We know that these experiences usually cause distress and often lead to a re-admission into hospital.

Can I take part?
Yes you can if you have experienced an episode of psychosis. It is not necessary for you to have experienced relapse.

Do I have to take part?
No, you do not have to take part. It is entirely up to you do decide whether you wish to take part. If you decide not to take part this will not affect your treatment in any way.

What happens next?
If you decide to take part we can arrange to meet up and have an initial conversation. I will answer any questions or concerns that you may have. You can then take some time following this meeting to decide whether you would like to be involved in the study.

What do I have to do?
If after the short initial meeting you are still happy to take part, we can arrange another time to meet and have a longer discussion. This may last from 45 minutes to an hour but this will be flexible depending on how you feel at the time. In some cases it may be useful meet on a second occasion. With your consent I will record the session(s) using a digital voice recorder. Before I start recording I will show you the equipment and how it works. You may stop the recording at any time during the interview.

I will then ask you about you're understanding and experience of relapse. There are no right or wrong answers. I am very interested in hearing about your personal understanding and your experiences.

Does my interview need to be recorded?
Yes. It is important that I can listen to your interview and type it out into a word processor after we have met. This will help me to develop an accurate understanding of your experiences and our discussion. The recording of your interview will not be listened to by anyone else other myself.

Will my taking part be kept confidential?
All information collected during this study will remain confidential. As you know, with your consent, I have checked with your keyworker that your participation in the study does not interfere with any treatment that you may be receiving. Prior to the interview, I will check again as it is important to ensure that the research is not interfering with any of your treatment needs.

After the interview has been typed out, the audio recordings will be destroyed. Any information such as your name, other people's names or specific places will be removed. In this way no-one can identify you from the information that we collect. The final results of the study will be published in a scientific journal and important quotations of participants will be included. However, all quotations used will be anonymised and no information identifying you will be included in any publication.

It may also be useful for me to view your medical records to obtain information about the types of problems you have experienced and any experiences of relapse or hospital admission you may have had in the past.

All information collected during the study will remain confidential, however if you informed me of a risk that you may harm yourself or another person I would need to discuss this with your keyworker. I would always inform you of my need to do this, I would not do this without your knowledge.

Are there any benefits to taking part?
No. Some people find it helpful to talk about their experiences but there are not any immediate benefits to you taking part. However, this study will help us understand more

about experiences of relapse and we hope that this will allow us to improve services and develop interventions that are tailored to service users' requirements and needs.

Are there any negatives about taking part?
It is possible that during our discussions we may cover topics, which you find emotional to talk about. You do not have to talk about anything that you do not want to talk about and if you feel any discomfort or distress you can stop the interview at any time. You may also end your involvement with the study at anytime; this will have no affect on any treatment that you may be receiving.

Who has reviewed the study?
The University of Glasgow are involved in the organisation and funding of this study. The study has been reviewed by the Department of Psychological Medicine to ensure that it meets standards of scientific research and by Greater Glasgow Mental Health Division Ethics Committee to ensure that it meets important standards of ethical conduct.

What if I have a complaint about the study?
If during or after the study there is anything you are unhappy with you can talk to a member of staff involved in your care. If they cannot resolve the problem for you, they will pass your concerns to a more senior member of staff. If you would prefer not to raise your concerns directly with a member of staff, or are not happy with the action taken you may complain in writing to the Division's Complaints Office, Primary Care Division Headquarters, Gartnaval Royal Hospital, Glasgow, G12 OXH.

Thank you for reading this information. Perhaps if you are still happy to participate we could arrange a further time to meet up at the Stewart Centre and conduct the interview. If you have any questions feel free to contact me at The Stewart Centre on 634 5430.

I look forward to meeting with you to discuss the research further.

Yours sincerely

Hayley Veitch
Trainee Clinical Psychologist
Stewart Centre
0141 634 5430

Appendix 3.3

CONSENT FORM: Version 2, 24th July 2006

Title of Project: What does relapse mean to you?

Name of Researcher: Hayley Veitch

Please Initial Box

1. I confirm that I have read and understood the participant information sheet dated 24th July 2006 (version 2) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without my medical care or legal rights being affected. ☐
3. I understand that the interview will tape recorded solely for the purposes of the research study as described in the Participant Information Sheet (24th July, version 2). ☐
4. I understand that my medical records may be looked at by the chief investigator. ☐
5. After the interview has been typed out, and all names, places and identifiers have been removed I understand that the researcher may publish direct quotations. ☐
6. I agree to take part in the above study. ☐

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of person taking consent (if different from researcher)	Date	Signature
_____	_____	_____
Researcher	Date	Signature

1 for participant, 1 for researcher, 1 to be kept confidential

Appendix 3.4

Interview design.

So we've spend some time today and last week talking about the research. As you know the study is about forming an understanding of what relapse means to you and understanding more about individuals' experiences.

Initial Q's: Understanding of term relapse

I wonder if we could start by looking at the word relapse. Is that a term relapse, you are familiar with?

Is that a term that you would use?

What does the word relapse mean to you?

When was the first time you heard that word?

Intermediate Q's: Understanding of experiences

Where appropriate, questions such as these will be used to explore patients views and experiences further:

What experiences come to mind when you think about the term?

Tell me about what happened…..

Tell me about your thoughts and feelings when….

How, if at all have your thoughts and feelings changed

Are there particular experiences that come to mind?

Looking back on that, are there any particular occasions that stand out for you?

What helped you to manage/ who has been the most helpful?

Prompts: I'm interested…. can you tell me more about that?
- What do you mean by that?
- What is a X like?
- What do you mean really frightened?
- So, what does unwell or X mean to you?
- When did you first experience these feelings?
- How does it feel for you?
- What were your thoughts then?
- What did you do?
- What are you thinking right now?
- How did you feel?
- How did others react?

Primary Care Division

Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH
Tel: 0141 211 3600
www.nhsgg.org.uk

NHS Greater Glasgow

Miss Hayley Veitch Trainee Clinical Psychologist Greater Glasgow Primary Care NHS Division Psychological Medicine Gartnaval Royal Hospital Glasgow G11 7NA	Date	18 September 2006
	Your Ref	
	Our Ref	
	Direct line	0141 211 3824
	Fax	0141 211 3814
	E-mail	Liz.jamieson@ glacomen.scot.nhs.uk

Dear Miss Veitch

Full title of study: **An exploration of service users' experience if relapse in psychosis: A grounded theory approach**

REC reference number: **06/S0701/69**

Thank you for your letter of 25 August 2006, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Committee held on 14 September 2006. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

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

Ethical review of research sites

The favourable opinion applies to the research sites listed on the attached form.

Conditions of approval

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

Approved documents

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

Document	*Version*	*Date*
Application		22 May 2006
Investigator CV		22 May 2006
Investigator CV	One	24 August 2006
Protocol	Twp	25 August 2006

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Protocol		22 May 2006
Covering Letter		22 May 2006
Advertisement		22 May 2006
Advertisement	Two	
Participant Information Sheet	Two	
Participant Information Sheet		22 May 2006
Participant Consent Form		22 May 2006
Participant Consent Form	Two	
Response to Request for Further Information	Letter	25 August 2006
Supervisor CV		22 May 2006

Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

Statement of compliance

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

06/S0701/69 Please quote this number on all correspondence

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

Yours sincerely

W. T. McCartney

Winifred McCartney, Research Ethics Administrative Assistant
For and on behalf of
Dr Paul Fleming, Chair

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

Cc: Mr Brian Rae

SF1 list of approved sites

Primary Care Division

Research & Development Directorate
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow G12 0XH
Tel: 0141 211 3600
www.nhsgg.org.uk

NHS Greater Glasgow

Date 08 November 2006
Your Ref
Our Ref BR/AW/approve

Direct Line 0141 211 3661
Fax 0141 211 3814
Email annette.watt@gartnavel.glacomen.scot.nhs.uk

Miss Hayley Veitch
Trainee Clinical Psychologist
Greater Glasgow Primary Care NHS Division
Department of Psychological Medicine
Gartnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Dear Miss Veitch,

Project Reference Number: **PN06CP014**
Project Title: **An Exploration of Service Users' Experience if Relapse in Psychosis: A Grounded Theory Approach**

Thank you for completing the Research & Development (R&D) Management Approval Application for the above study. I am pleased to inform you that R&D management approval has been granted by NHS Greater Glasgow & Clyde Community and Mental Health Partnership subject to the following requirements:

- You should notify me of any changes to the original submission and send regular, brief, interim reports including recruitment numbers where applicable. You must also notify me of any changes to the original research staff and send CV's of any new researchers.
- Your research must be conducted in accordance with the National Research Governance standards. (see CSO website: www.show.scot.nhs.uk/cso)
  Local Research Governance monitoring requirements are presently being developed. This may involve audit of your research at some time in the future.
- You must comply with any regulations regarding data handling (Data Protection Act).
- If recruitment takes place out with the groups stated in the methodology you must inform the Research and Development Directorate and the ethics committee.
- Brief details of your study will be entered on the National Research Register (NRR). You will be notified prior to the next submission date and asked to check the details being submitted.
- A final report, with an abstract which can be disseminated widely within the NHS, should be submitted when the project has been completed.

Do not hesitate to contact the R & D office if you need any assistance.

Thank you again for your co-operation.
Yours sincerely

pp **Brian Rae**
Research Manager

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Appendix 4.3

Appendix 4.4

Notes for Contributors

Psychology and Psychotherapy: Theory Research and Practice (formerly *The British Journal of Medical Psychology*) is an international scientific journal with a focus on the psychological aspects of mental health difficulties and well-being; and psychological problems and their psychological treatments. We welcome submissions from mental health professionals and researchers from all relevant professional backgrounds. The Journal welcomes submissions of original high quality empirical research and rigorous theoretical papers of any theoretical provenance provided they have a bearing upon vulnerability to, adjustment to, assessment of, and recovery (assisted or otherwise) from psychological disorders. Submission of systematic reviews and other research reports which support evidence-based practice are also welcomed, as are relevant high quality analogue studies. The Journal thus aims to promote theoretical and research developments in the understanding of cognitive and emotional factors in psychological disorders, interpersonal attitudes, behaviour and relationships, and psychological therapies (including both process and outcome research) where mental health is concerned. Clinical or case studies will not normally be considered except where they illustrate particularly unusual forms of psychopathology or innovative forms of therapy and meet scientific criteria through appropriate use of single case experimental designs.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Reviewing

The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be aware of the identity of the author. All information about authorship including personal acknowledgements and institutional affiliations should be confined to the title page (and the text should be free of such clues as identifiable self-citations e.g. 'In our earlier work...').

4. Online submission process

1) All manuscripts must be submitted online at http://paptrap.edmgr.com.

First-time users: Click the REGISTER button from the menu and enter in your details as instructed. On successful registration, an email will be sent informing you of your user name and password. Please keep this email for future reference and proceed to LOGIN. (You do not need to re-register if your status changes e.g. author, reviewer or editor).

Registered users: Click the LOGIN button from the menu and enter your user name and password for immediate access. Click 'Author Login'.

2) Follow the step-by-step instructions to submit your manuscript.

3) The submission must include the following as separate files:

Title page consisting of manuscript title, authors' full names and affiliations, name and address for corresponding author - A title page template is available to download.

Full manuscript omitting authors' names and affiliations. Figures and tables can be attached separately if necessary.

4) If you require further help in submitting your manuscript, please consult the Tutorial for Authors - Editorial Manager - Tutorial for Authors
Authors can log on at any time to check the status of the manuscript.

5. Manuscript requirements
Contributions must be typed in double spacing with wide margins. All sheets must be numbered. Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text. Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate page. The resolution of digital images must be at least 300 dpi. For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions: Psychology and Psychotherapy: Theory, Research and Practice - Structured Abstract Information

For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
SI units must be used for all measurements, rounded off to practical values if appropriate, with the Imperial equivalent in parentheses.
In normal circumstances, effect size should be incorporated.
Authors are requested to avoid the use of sexist language.
Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations etc. for which they do not own copyright.

For guidelines on editorial style, please consult the APA Publication Manual published by the American Psychological Association, Washington DC, USA (http://www.apastyle.org).

6. Brief reports
These should be limited to 1000 words and may include research studies and theoretical, critical or review comments whose essential contribution can be made briefly. A summary of not more than 50 words should be provided.

7. Publication ethics
Code of Conduct - Code of Conduct, Ethical Principles and Guidelines
Principles of Publishing - Principles of Publishing

8. Supplementary data
Supplementary data too extensive for publication may be deposited with the British Library Document Supply Centre. Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

9. Post acceptance
PDF page proofs are sent to authors via email for correction of print but not for rewriting or the introduction of new material. Authors will be provided with a PDF file of their article prior to publication.

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11. Checklist of requirements
Abstract (100-200 words)
Title page (include title, authors' names, affiliations, full contact details)
Full article text (double-spaced with numbered pages and anonymised)
References (APA style). Authors are responsible for bibliographic accuracy and must check every reference in the manuscript and proofread again in the page proofs
Tables, figures, captions placed at the end of the article or attached as separate files