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**An Interpretative Phenomenological Analysis of Service Users'  
Perspectives and Experiences of Relapse in Psychosis  
& Clinical Research Portfolio**

PART I

(Part II bound separately)

Claire Maclean, M.A. (Hons)

Submitted in partial fulfilment of the requirements for the degree of Doctorate  
in Clinical Psychology.

Section of Psychological Medicine  
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## **Chapter 1: Systematic Literature Review**

Systematic literature review submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology.

**Coping with early symptoms of relapse in schizophrenia, depression and mania: a systematic review.**

Prepared in accordance with requirements for submission to Clinical Psychology Review  
(See Appendix 1.1)

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## **Abstract**

*Background:* This paper explores coping with early symptoms of relapse in schizophrenia, depression and mania. *Methods:* Seventy-seven publications of coping in schizophrenia, depression and mania were identified by computer searches of five electronic databases supplemented by hand searches of key journals. Twelve studies including 897 participants met criteria for inclusion. *Results:* The findings from this review suggest that the majority of individuals use coping strategies with early symptoms of relapse in schizophrenia, depression and mania. These coping strategies can be divided into active and restrictive coping strategies which are designed to regulate affect and arousal. The findings from this review suggest that active coping strategies are more helpful than restrictive coping strategies in reducing the likelihood of relapse in schizophrenia, depression and mania. *Limitations:* Few prospective studies have been reported and there is a lack of reliable and valid measures to assess coping with early symptoms of relapse in schizophrenia. *Conclusions:* Teaching clients cognitive and behavioural techniques designed to regulate their emotional and behavioural early symptoms of relapse in schizophrenia, depression and mania could improve clinical outcome and reduce relapse.

## **Introduction**

Relapse is the medical term used to describe the recurrence of an episode of an illness or the exacerbation of illness symptoms that are partially remitted (Gumley, Karatzias, Power, McNay & O'Grady, 2006). Bebbington et al. (2006), operationalise relapse in psychosis in terms of positive psychotic symptoms. Full relapse involves a progression from an asymptomatic state in terms of positive psychotic symptoms to one characterised by a reappearance of such symptoms. Partial relapse implies significant exacerbation of an incompletely remitted state and both can be clinically catastrophic. Relapse remains a major factor in the development of illness chronicity and the consequences of repeated relapses are damaging for both the client and their family (Wiersma, Nienhuis, Sloff & Giel, 1998).

Complex mental health difficulties including schizophrenia, bipolar disorder and major depression are often recurring in nature, which is likely to be associated with increased emotional distress and impaired social, vocational and interpersonal functioning (Gumley & Schwannauer, 2006; Lam & Wong, 2005). Research suggests that following a first episode of psychosis, approximately 16% experience relapse at 1 year, 54% at 2 years and 82% at five years (Robinson et al., 1999). A review of bipolar relapse rates in six naturalistic follow up studies suggests that 49.8% of individuals relapse at 1 year (ranged 42% - 55%) (Coryell et al., 1989; Harrow, Goldberg, Grossman, & Meltzer, 1990; Keller, Lavori, Coryell, Endicott, & Mueller, 1993; Miklowitz, 1992; O'Connell, Mayo, Flatow, Cuthbertson, & O'Brien, 1991; Tohen, Waternaux, & Tsuang, 1990).

Relapse can reduce an individual's sense of control over their illness which can lead to feelings of disempowerment and hopelessness and a variety of secondary psychological difficulties, including depression (Tarrier, 2005), post traumatic stress disorder (PTSD)

(Morrison, 2003), social anxiety (TARRIER, 2005) and low self-esteem (Barrowclough et al., 2003). Birchwood, Mason, Macmillan & Healy (1993) found that post psychotic depression was associated with an individual's perception of being unable to control their illness (relapse) or the fear of psychosis itself. Iqbal, Birchwood, Chadwick & Trower (2000) found that individuals with post psychotic depression experienced greater loss, humiliation and entrapment arising from their illness and they were more likely to attribute the course of their illness to the self (self-blame). They also had lower self-esteem and were more self-critical than non-depressed individuals. It has been suggested that appraisals such as humiliation, loss and entrapment are embedded in the realities of psychotic experiences that may include loss of employment and social role, residual symptoms and hospital admission (Rooke & Birchwood, 1998).

Research suggests that each relapse that a client experiences increases the probability of future relapse and continual residual symptoms. Two prospective studies of first-episode schizophrenia have specifically explored this issue. Shepherd, Watt, Falloon et al. (1989) found that 35% of individuals showed an increased incidence of drug-resistant symptoms following each relapse. Wiersma et al. (1998) found that after each relapse, one in six clients were left with residual symptoms that they had not previously experienced.

#### *'Early signs' or 'Prodromes'*

The term "prodrome" originates from the Greek "prodromos" which means "running before" (Keitner et al., 1996). In medical terms 'prodromes' are defined as the early signs and symptoms that herald a full episode (Molnar, Feeney, & Fava, 1988). Exploration of the literature reveals that although qualitatively different the terms 'early signs' and 'prodromes' are often used interchangeably as 'early signs' were originally conceptualised as 'prodromes'.

'Early signs' or 'prodromes' have been described as cognitive, affective and behavioural early symptoms of a disorder that appear before an episode of schizophrenia, depression or mania (Lam & Wong, 1997). Similarly, 'early warning signs' have been defined as subjective experiences, thoughts and behaviours of the patient that occur in the period before a relapse (Herz & Melville, 1980). The duration of a 'prodrome' is defined as the time interval between the recognition of the first symptom and the moment when the symptoms of an episode are at their most intense (Molnar et al., 1988).

There continues to be a considerable amount of interest and research focused on the recognition of early warning signs. Systematic investigation of the research literature in the areas of schizophrenia, depression and mania has revealed a number of important findings. Jackson, Cavanagh and Scott (2003) and more recently Sierra, Livianos, Argues, Castello and Rojo (2007) have carried out systematic reviews in the area of depression and mania, whereas Norman and Malla (1995) and Van Mijel, Van der Gaag, Sylvain & Grypdonck (2004) have carried out reviews in the area of schizophrenia.

Sierra et al's. (2007) review corroborated the earlier findings by Jackson et al. (2003). Their literature search revealed that patients do identify and detect early warning signs of relapse, although they do find the depressive symptoms harder to identify. They found that 97% identified early warning signs of mania whereas 82% identified early warning signs of depression. The most common depression 'prodromes' appear to be low mood, psychomotor symptoms and increased anxiety, whereas the most frequent manic 'prodromes' are sleep disturbances, psychotic symptoms and low mood.

The systematic review carried out by Norman and Malla (1995) revealed that individuals with schizophrenia and their families do identify and detect 'early warning signs' of relapse. Although there was considerable variation among individuals' early symptoms the

most commonly reported ‘prodromes’ are mood changes (specifically increased dysphoria as reflected in increased tension, depression or anxiety), withdrawal and/or irritability, and vegetative changes such as sleep disturbance and loss of appetite.

Van Meijel et al’s. (2004) review revealed similar findings and they suggested that alongside the more general ‘early warning signs’, the idiosyncratic behaviours of each individual patient are also of importance for the early recognition of relapse.

### *Sensitivity and Specificity*

Given the consistency of the early signs that have been reported by patients and families it is important to investigate the sensitivity and specificity of these ‘early signs’ or ‘prodromes’ as an indicator of emerging relapse. When exploring the predictive power of ‘early signs’, sensitivity refers to the ability of the monitoring system to correctly identify a forthcoming relapse. Specificity refers to the power of these early signs to correctly identify those individuals or times when a relapse will not occur (Norman & Malla, 1995). According to Hewitt & Birchwood (2002), “the clinical implications of retrospective research will largely depend on the degree of specificity which information on early signs affords” (p.397). They suggested that the true predictive efficacy of ‘prodromal’ signs can only be clearly established using a clear a priori definition of ‘prodrome’ as the independent variable.

There are currently ten prospective studies in the area of schizophrenia which explore the predictive power of ‘early signs’ and taken together these articles reveal an overall ‘prodrome’ sensitivity value of 72% and a specificity value of 38% (Gaebel & Riesbeck, 2007). In contrast to the traditional conceptualisation of the ‘prodrome’ these findings suggest that although early signs are possible indicators of relapse they should not be viewed as inevitable signals of recurrence (Gumley et al., 2006). These findings therefore

question the validity of the ‘prodrome’ model. Birchwood (1995) proposed that the ‘prodrome’ should be conceptualised as a personalised relapse signature which includes common symptoms together with features unique to each patient. If an individual’s relapse signature can be identified and recognised, then one might expect that the overall predictive power of early symptoms will be increased (Birchwood & Spencer, 2001).

#### *Validity of the prodrome model*

Herz & Lamberti (1995) suggest that the medical concept of the ‘prodrome’ carries with it the assumption that once the process of relapse has started the progression to full relapse is irreversible, suggesting that the individual is a passive passenger in the process of relapse. The literature however does not necessarily support this medical concept as there is research which suggests that patients do actively regulate their own symptoms as they believe they can prevent a relapse by utilising various coping strategies (Birchwood & Spencer, 2001). Thurm and Haefner (1987) describes the individual as an active agent, using coping strategies to decelerate or forestall the process of relapse.

These findings are consistent with the stress-vulnerability model of psychosis (Neuchterlein & Dawson, 1984) which argues that relapse occurs as an interaction of vulnerability, psychosocial stress, and protective factors (such as personal coping). The vulnerability-stress-coping model suggests that patients do not typically submit to their situation but rather develop coping strategies to deal with the difficult circumstances. It is thought that they also do this in the period preceding the illness in which they perceive ‘early warning signs’. Within this model it is possible that their combined effect could be to self-limit the process of relapse. The presence of ‘early signs’ could therefore be thought of as placing the individual “at risk” for relapse, not as a guarantee of it, and other risk and coping factors may interact to influence the emergence of symptoms (Birchwood & Spencer, 2001).

### *Psychological conceptualisations of relapse*

The current literature reveals a number of psychological conceptualisations of relapse which support the concept of an ‘at risk mental state’. Taken together these models all emphasise the importance of the individual’s idiosyncratic appraisal of ‘early warning signs’ and they suggest that the individual’s response to this evidence of relapse is informed by their specific autobiographical memories of psychosis. Gumley and Macbeth (2006) have proposed a trauma-based psychological model of relapse. This model suggests that low-level psychotic experiences or cognitive perceptual events that share similarities with previous episodes of psychosis (for example, unusual thoughts, headaches, paranoid thoughts and sensory experiences) create a sense of reliving for the individual and that this experience of reliving is reinforced by intrusive autobiographical memories of previous experiences of psychosis. It is proposed that this leads to the activation of negative, catastrophic threat beliefs resulting in emotional distress and affect dysregulation.

### *What does this all mean?*

The literature reviewed so far suggests that the perception of ‘early warning signs’ as leading inevitably to relapse has changed over time and that rather than being “passive passengers” in the process of relapse many individuals may actively regulate their early symptoms in order to try and reduce the likelihood of a further episode. . To help explore this further we need to turn our attention to the literature to investigate how individuals actually do cope with symptoms of relapse to find out if this is an active process. If relapse is an active process that people respond to then we should expect to see different styles of coping.

Over the years coping has acquired a number of conceptual meanings. Coping was originally conceptualised in terms of unconscious ego processes and personality traits

(Folkman & Lazarus, 1980). Coping style theorists postulate that coping is fundamentally consistent across all situations as individuals have specific coping styles and ways of dealing with stress. In other words coping is likened to a stable personality trait (Weiner, Freedheim, Schanks & Velicer, 2003).

More recently however, Lazarus and Folkman (1984) have proposed the transactional stress and coping paradigm and this is currently the most widely accepted definition of coping (Weiner et al, 2003). According to Folkman, Lazarus, Gruen and Delongis (1986) coping is defined as “the person’s cognitive and behavioural efforts to manage the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the persons’ resources” (p. 572). This theory proposes that stressful emotions and coping responses develop in response to cognitions associated with the way in which an individual appraises his or her relationship with the environment (Krohne, 2001). Appraisals of harm and loss, the controllability of the stressor, evaluation of coping efforts and future success are all thought to be important determinants in the deployment of specific coping strategies (Weiner et al, 2003).

When coping with stressful events individuals usually employ one of two main coping strategies: problem-focused coping or emotion-focused coping. Individuals who use problem focused coping try to reduce their emotional distress by doing something to modify or minimise the threatening situation. Individuals’ who use emotion focused coping try and deal with their unpleasant emotions directly (Krohne, 2001). Another distinction that is often made in the coping literature is between active and passive coping strategies (Billings & Moos, 1984). Active coping strategies involve cognitive and behavioural responses which are designed to change the stressor itself or the way the individual thinks about it. Passive or avoidant coping strategies involve responses that stop

the individual from directly addressing the stressful event (Carver, Scheier & Weintrauma, 1989).

Within the coping literature authors often refer to coping strategies as being helpful and unhelpful or adaptive and maladaptive. Whilst the functions of coping are essentially the same in all situations, it is important to note that individuals alter their coping response in order to meet the specific demands of different situations (Folkman et al., 1986). Taking this into consideration and the nature of this review it is important to highlight a potential issue regarding the use of negative and positive terminology when discussing different coping strategies. Due to the nature of the symptomatology within schizophrenia, depression and mania this may be a false dichotomy as helpful and unhelpful strategies may be different within the three diagnoses. Staying in bed for example could be considered to be a negative strategy for depression whereas a positive strategy for mania. It is important therefore to be mindful of this potential limitation when reflecting on the findings of this review.

In this paper a systematic literature review was conducted to explore the following:

1. What strategies for coping with symptoms of relapse have been identified in depression, mania and schizophrenia?
2. What strategies have been found to be helpful and unhelpful?
3. Do certain coping strategies improve clinical outcome?
4. What are the identified coping strategies aiming to regulate?

## **Method**

A systematic literature search was conducted.

### *Data extraction and selection criteria of studies*

An extraction proforma (see Appendix 1.2) recorded eligibility and relevant data such as diagnosis, coping measure, identified coping strategies for early symptoms of relapse and reliability and validity data.

The following inclusion criteria were followed: (1) All articles published in a peer reviewed journal investigating coping with symptoms of relapse in schizophrenia, depression and mania. (2) All articles published between 1980- 2008 (Feb). The following exclusion criteria were followed: (1) All articles investigating coping strategies which didn't focus on coping with the early symptoms of relapse. (2) Case reports. (3) Dissertations. (4) Articles written in a book chapter. (4) Articles written in a language other than English. (5) Qualitative research.

Several approaches were used to search for relevant studies:

### *Electronic Search*

Initially a computerised search was carried out using the following databases: Medline (1950- Feb 2008); All EBM reviews (Cochrane DSR, ACP Journal Club, DARE & CCTR), CINAHL (1982- Feb 2008), EMBASE (1980- Feb 2008) and PsycINFO (1967- Feb 2008). The terms [psychosis] or [schizophrenia] or [unipolar depression or bipolar depression] or [depressive disorders] or [mania] were combined with the terms [prodromal] or [prodromes] or [prodrome] or [early signs] or [early sign] or [early symptoms] or [relapse or recurrence] and the term [coping]. Key journals were also

electronically searched including The Journal of Affective Disorders, Schizophrenia Bulletin and Schizophrenia Research.

### *Hand Searching*

To check the sensitivity of the search criteria the reference section of each identified article was also searched and the 'cited by' function in Ovid was used.

## **Results**

The electronic search produced 432 studies. At this stage 355 studies were excluded on the basis of their title alone. Abstracts were read for the remaining 77 articles and a further 57 were excluded. The remaining 20 articles were read in full and 12 articles were excluded. Eleven studies were excluded because they did not specifically explore participants coping strategies with early symptoms of relapse (Billings & Moos, 1984; Boschi et al, 2000; Carr, 1988; Dittman & Schuttler, 1988; Macdonald, Pica, Mcdonald, Hayes & Baglioni, 1998; Mueser, Valentiner & Agresta, 1997; Roe, Yanos & Lysaker, 2006; Strous, Ratner, Gibel, Ponizovsky & Ritsner, 2005; Singh, Sharan & Kulhara, 2003; Singh, Sharan, Kulhara, 2002; Wiedl & Schottner, 1991) and 1 study was excluded because it reported qualitative data alone (Williams & Collins, 2000).

The remaining 8 articles were included in the review. Hand searching the reference section of the identified articles revealed an additional 4 studies. Therefore in total 12 studies were identified and reviewed.

(Insert Figure 1 and Table 1 here)

### *General characteristics of the studies*

Seven studies investigated coping with early symptoms of relapse in schizophrenia (Boker et al., 1984; Brenner, Boker, Muller, Spichtig & Wurgler, 1987; Cohen & Berk, 1985; Hultman, Wieselgren & Ohman, 1997; Kumar & Rajkumar, 1989; McCandless-Glimcher et al., 1986; Thurm & Haefner, 1987). One study investigated coping with early symptoms of relapse in schizophrenia and depression (Bechdolf, Schultze-Lutter & Klosterkötter, 2002). Two studies investigated coping with early symptoms of relapse in bipolar disorder (Lam & Wong, 1997; Lam & Wong, 2001) and two studies investigated coping with early symptoms of relapse in mania only (Parikh et al., 2007; Wong & Lam, 1999).

Taken together these 12 articles represented 12 studies with the following demographic characteristics: 897 participants, with a mean age of 37 and a 49% (n = 392) male and 51% (n = 403) female split (2 of the studies did not provide the male to female ratio (n = 102): Boker et al., 1984 & McCandless-Glimcher et al., 1986). Forty-one per cent of the overall sample had a diagnosis of schizophrenia, 56% Bipolar Disorder and 3% depression.

### *Methodological Summary*

A methodological evaluation of the literature was necessary prior to a synthesis of the research findings. This summarised the most pertinent information gained from the extraction proforma, in particular design and sampling characteristics, the measures used to assess coping strategies and reliability and validity data.

As a note of caution to the reader, a methodological critique of this literature was challenging for a number of important reasons. A lack of clarity in the presentation of data and the use of vaguely defined terms that were not clearly operationalised made the synthesis of the research findings difficult. Small sample sizes and the use of unstandardised, unpublished measures also contributed to the complexity of this review.

Although the literature described a set of strategies under the umbrella “passive” coping strategies it was decided that this terminology was inappropriate as it did not adequately describe the identified coping responses. The use of the term “passive” is also potentially problematic as it indicates a lack of reaction or active response without fully understanding the underlying psychological processes or goals of the individual. For the purposes of this review the term “restrictive” was thought to be more appropriate.

Of the twelve studies, eight followed a retrospective design, two were cross-sectional studies (Lam & Wong, 1997; Parikh et al., 2007) and two followed a prospective design (Hultman et al., 1997; Lam & Wong, 2001). All of the studies recruited from a convenience sample, only one study recruited a random sample (Wong & Lam, 1999) and only one study had a control group (Brenner et al., 1987).

Of the twelve studies, only five used pre-existing measures to explore coping strategies with early symptoms of relapse. These included the Chronic Mental Illness Symptom Interview, The Coping with Prodromal Symptoms Interview (Lam & Wong, 1997), The Coping Inventory for Prodromes of Mania (Wong & Lam, 1999) and The Bonn Scale for the Assessment of Basic Symptoms (Gross, Huber, Klosterkotter & Linz, 1987). Six of the remaining seven studies used a range of open-ended and semi-structured interviews designed specifically for the research (Boker et al., 1984; Brenner et al., 1987; Cohen & Berk, 1985; Hultman et al., 1997; Kumar & Rajkumar, Thurm & Haefner, 1987). The final study was a pilot study for the Coping Inventory for Prodromes of Mania (Wong & Lam, 1999).

Five of the studies discussed inter-rater reliability of their data (Bechdolf et al., 2002; Boker et al., 1984; Brenner et al., 1987; Lam & Wong, 1997 & Lam et al., 2001) one study

discussed test-retest reliability of their data (Wong & Lam, 1999), two studies discussed the internal consistency of their data (Parikh et al., 2007 & Wong & Lam, 1999) and two studies discussed the construct validity of their data (Parikh et al., 2007 & Wong & Lam, 1999).

As the research in this area is still in the early stages of development limitations are understandable, in particular the limited generalisability of the studies and the diverse methods used for assessing coping. Whilst it is still important to take note of the methodological shortcomings and to be cautious when interpreting the results of the included papers, there are still a range of interesting findings which need to be discussed and explored further.

#### ***Coping strategies with symptoms of relapse in schizophrenia***

Seven studies reported coping strategies with symptoms of relapse in schizophrenia (Bechdolf et al., 2002; Boker et al., 1984; Brenner et al., 1987; Cohen & Berk, 1985; Kumar & Rajkumar, 1989; McCandless-Glimcher et al., 1986; Thurm & Haefner, 1987) and one study explored the predictive value of these coping strategies on relapse (Hultman et al., 1997).

Before exploring the findings in more detail it is important to recognise the limitations of the literature in this area, in particular the lack of clarity of the presented findings and the use of vaguely defined terms to describe coping in response to early symptoms of schizophrenia. Although there were a number of different coping strategies found in all seven studies the challenge of this review has been to synthesise the vaguely defined coping responses (such as 'fighting back', 'behavioural change', 'habituation and adaptation') into coherent domains of coping.

The majority of individuals in the included studies reported using coping strategies with early symptoms of relapse in schizophrenia. These coping strategies could be divided into “active” and “restrictive” coping strategies. Active coping strategies included coping responses that described cognitive and behavioural approach oriented efforts whereas “restrictive” coping strategies included coping responses characterised by avoidance and withdrawal.

There were a number of different active coping strategies found in all seven studies but taken together they can be integrated under the following coping headings: cognitive and behavioural strategies.

#### *Cognitive coping strategies*

Cognitive coping strategies included the following techniques: fighting back (self-suggestion to try and overpower unwanted thoughts) (Cohen & Berk, 1985); internal dialogue (self-reassurance that everything will be okay) (Kumar and Rajkumar, 1989; Thurm & Haefner, 1987); habituation and adaptation to illness (acceptance and learning to live with their illness); (Bechdolf et al., 2002 & Cohen & Berk, 1985) and reality testing (distancing oneself from symptoms and rationalising or reinterpreting symptoms) (Boker et al., 1984; Brenner et al., 1987; Thurm & Haefner, 1987).

#### *Behavioural coping strategies*

Behavioural coping strategies included the following techniques: increasing social contact (Cohen & Berk, 1985; Thurm & Haefner, 1987), talking to a close friend or relative (Kumar & Rajkumar, 1989), distraction techniques (for example, listening to music; engaging in work) (Cohen & Berk, 1985), spiritual activities such as prayer (Cohen & Berk, 1985) and meditation (Thurm & Haefner, 1987), extended will power and behavioural change (for example, doing things at a slower pace and taking some time out)

(Bechdolf et al., 2002; Kumar & Rajkumar, 1989). Behavioural coping strategies also included adjusting medication (Cohen & Berk, 1985; Kumar & Rajkumar, 1989; McCandless-Glimcher, 1986 & Thurm & Haefner, 1987) and seeking assistance from a mental health professional or agency (McCandless-Glimcher et al, 1986 & Thurm & Haefner, 1987).

#### *Restrictive coping strategies*

The more restrictive coping strategies can be integrated under the following coping heading: avoidance and withdrawal. Avoidance and withdrawal included, attempting to ignore the symptoms, avoiding conflicts and emotional strain, a strictly regulated life rhythm (Bechdolf et al., 2002; Thurm & Haefner, 1987) and using drugs or alcohol (Bechdolf et al., 2002; Cohen & Berk, 1985).

Overall, the most frequently reported strategies in dealing with early symptoms of relapse in schizophrenia were active cognitive and behavioural coping strategies and the least reported strategies were restrictive coping strategies. After analysing the 4 studies (Bechdolf et al., 2002; Cohen & Berk, 1985; Kumar & Rajkumar, 1989 & Thurm & Haefner, 1987) that recorded the percentage of coping strategies reported by participants, the mean number of coping strategies was: cognitive (28%), behavioural (62%), avoidance/withdrawal (19%). These findings suggested that patients diagnosed with schizophrenia are more likely to develop active coping strategies to try and reduce the emotional distress provoked by early symptoms of relapse.

#### *Individual variability*

Cohen and Berk (1985) found that participants coping strategies varied with demographic, social, and psychological functioning characteristics. In particular, they found that participants in employment tended to use more cognitive and behavioural coping strategies

whereas unemployed participants often felt helpless in controlling their symptoms. They also found that participants who lived alone were more likely to use behavioural medical strategies (e.g. seeking medical assistance) than those who lived with others. Thurm and Haefner (1987) found that the more experience participants had with illness (duration), the more coping strategies were reported to prevent relapse. These findings suggest that coping strategies vary depending on individual characteristics and circumstances.

#### *Helpful and unhelpful strategies*

McCandless-Glimcher et al., (1986) found that 82% (n = 40) of their participants reported that using coping strategies, specifically behavioural strategies helped them to deal with early symptoms of relapse. They also found that participants engaging in self-treatment were no more likely to have a greater number of hospitalisations than participants seeking professional help (both behavioural strategies).

#### *Clinical outcome*

Although none of the studies investigated whether certain coping strategies were more effective than others in alleviating symptoms, Hultman et al. (1997) found that fewer participants who employed active, social-oriented coping strategies relapsed as compared to participants who employed avoidant, withdrawn coping strategies.

#### ***Coping strategies with symptoms of relapse in depression***

Three studies reported coping strategies with symptoms of relapse in depression (Bechdolf et al., 2002; Lam & Wong, 1997 & Lam et al., 2001).

Before exploring the findings in more detail it is important to highlight that two of the studies in this area have clearly operationalised their own domains of coping and therefore these will be followed in the review (Lam & Wong, 1997; Lam et al, 2001).

Using the Coping with Prodromes Interview, Lam & Wong (1997) investigated how participants cope with early symptoms of relapse in depression and whether or not helpful coping strategies are related to good social functioning. Lam et al's (2001) follow up study investigated which coping strategies were related to good outcome and whether or not different coping strategies predicted future episodes of depression.

Using a cognitive-behavioural model and the stress-diathesis model Lam & Wong (1997) split their sample into a good coping group (n =17) and a poor coping group (n = 12). There were no significant differences between the two groups in terms of participant's age, length of illness or the number of past hospitalisations due to depression.

#### *Helpful coping strategies*

The most common coping strategies reported in the good coping group (n=17) for prodromes of depression were divided into cognitive and behavioural active coping strategies. The behavioural coping strategies included 'get myself organized and keep busy' (n = 9, 52.9%), 'get social support and meet people' (n = 5, 29.4%). The cognitive coping strategies included 'distract myself from negative thoughts by doing things' (n = 4, 23.5%) and 'recognise unrealistic thoughts and evaluate if things are worth worrying about' (n = 4, 23.5%).

#### *Unhelpful coping strategies*

The most common strategies reported in the poor coping group (n=12) were restrictive coping strategies characterised by themes of avoidance and withdrawal. These included 'stay in bed and hope it will go away' (n = 7, 58.3%), 'do nothing' (n = 2, 16.7%) and 'take extra medication such as anti-depressants or sleeping pills' (n = 2, 16.7%).

### *Coping strategies and clinical outcome*

Using the MRC Social Performance Scale (Hurry et al., 1983), Lam & Wong (1997) divided their sample into high and low social functioning groups. They found that 63.6% (n = 7) of individuals in the poor coping group and 27.78% (n = 5) of individuals in the good coping group fell into the low functioning group. The difference was statistically non-significant suggesting that how well participants coped with early symptoms of depression did not have a significant impact on their social functioning

In their follow up study Lam et al., (2001) grouped participants coping strategies with prodromes of depression under the following headings: Behavioural Coping Strategies, Cognitive Coping Strategies and Passive (maladaptive) coping strategies. A total of 73.1% (49/67) of the depression prodrome coping responses were classified under these three categories. The inter-rater reliability was: Behavioural Coping (0.81), Cognitive Coping strategies (0.92) and Passive Coping Strategies (0.65).

With regard to coping with depression prodromes, fewer participants (n = 3, 8.3%) who employed behavioural coping strategies relapsed compared to participants who didn't use these strategies (n = 14, 46.2%). On the other hand, more participants who drank or used other restrictive strategies in the prodromal phase relapsed (n = 21, 66.7%) compared to participants who didn't use these strategies (n = 7, 24.1%). Although the result of using cognitive coping strategies was in the right direction it was not statistically significant.

Using the Bonn Scale for the Assessment of Basic Symptoms (BSABS), Bechdolf et al., (2002) also investigated participants coping strategies with prodromes of depression. The most common coping strategies reported by their sample of participants (n =24) could be divided into cognitive and behavioural active coping strategies and restrictive strategies characterised by themes of avoidance and withdrawal. The cognitive coping strategy

identified was habituation and adaptation to their illness (acceptance and learning to live with their illness) (n = 12, 50%) whereas the most common behavioural coping strategies included behavioural change (n = 13, 54.2%) and extended will power (n = 16, 66.7%). The restrictive coping strategies included avoidance (n = 13, 54.2%) and self treatment with drugs or alcohol (n = 4, 16.7%).

### *Coping strategies with symptoms of mania*

Four studies reported coping strategies with symptoms of relapse in mania (Lam and Wong, 1997; Lam et al., 2001; Parikh et al., 2007 & Wong & Lam, 1999).

Using the Coping with Prodromes Interview, Lam & Wong (1997) also investigated how participants cope with early symptoms of relapse in mania and whether or not helpful coping strategies are related to good social functioning. Lam et al's., (2001) follow up study investigated which coping strategies were related to good outcome and whether or not different coping strategies predicted future episodes of mania.

Using a cognitive-behavioural model and the stress-diathesis model Lam & Wong (1997) split their sample into a good coping group (n = 21) and a poor coping group (n = 15). There were no significant differences between the two groups in terms of participant's age, length of illness or the number of past hospitalisations due to mania.

### *Helpful coping strategies*

The most common coping strategies reported in the good coping group (n = 21) for prodromes of mania were all behavioural active coping strategies. These included 'modifying high activities and restraining oneself' (n = 13, 61.9%), 'engaging in calming activities' (n = 10, 47.6%), 'take extra time to rest' (n = 9, 42.9%) and 'see a doctor' (n = 6, 28.6%).

### *Unhelpful coping strategies*

The most common strategies reported in the poor coping group (n = 15) were restrictive coping strategies characterised by themes of avoidance and denial. These included ‘continue to move about and take on more tasks’ (n = 4, 26.7%), ‘enjoy the feeling of high’ (n = 3, 20%), ‘go out and spend more money’ (n = 3, 20%), ‘find more to fill out the extra minutes of the day’ (n = 3, 20%) and ‘do nothing’ (n = 4, 26.7%).

### *Coping strategies and clinical outcome*

Using the MRC Social Performance Scale (Hurry et al., 1983), Lam & Wong (1997) divided their sample into high and low social functioning groups. They found that 73.3% (n = 11) of individuals in the poor coping group and 19% (n = 4) of individuals in the good coping group fell into the low functioning group. The difference was highly significant suggesting that how well participants coped with early symptoms of mania had a significant impact on their social functioning.

In their follow up study Lam et al., (2001) grouped participants coping strategies with prodromes of mania under the following three headings: Modifying Excessive Behaviour coping strategies, Early Medical Intervention strategies and Stimulating coping strategies. A total of 86.5% (77/89) of participants coping responses for mania prodromes were classified under these three categories. The inter-rater reliabilities of the coping strategies for mania prodromes were significantly better than chance: Modifying Excessive Behaviour (0.73), Early Medical Intervention (0.71) and Stimulating Coping Strategies (0.81).

With regard to coping with early symptoms of mania, fewer participants (n = 4, 12.5%) who employed behavioural coping strategies relapsed compared to participants who did

not use these strategies (n = 16, 45.5%). On the other hand, more participants (n = 18, 50%) who followed the temptation to take on more and engage in arousing activities relapsed compared to those who did not report these strategies (n = 8, 23.1%). Although the result of using early medical interventions was in the right direction it was not statistically significant.

Wong and Lam's (1999) study aimed to develop a specific instrument for the assessment of a broad range of coping strategies used by bipolar patients during the prodromal phase of their manic episodes. Following classical scale development procedures, a scale of 23 items was created. Using principal components analysis, the scale demonstrated four factors: 'stimulus reduction' (SR), 'problem-directed coping' (PR), 'seeking professional help' (SPH), and 'denial or blame' (DB).

Stimulus reduction contains five items describing the efforts to avoid over stimulation or cut down the tasks at hand, e.g. "avoid situations where I might talk too much or inappropriately", "prioritised things and did the minimal essential activities only". Problem directed coping consists of seven items outlining active steps trying to remove or reduce the prodromal signals or to ameliorate their effects, e.g. "tried to monitor and restrain my behaviour", "distract myself or actively switched off from racing thoughts". Seeking professional help includes three items and they are "seeking professional help", "started my medication again" and "reminded myself of the time I was in hospital because of manic depression". Denial or blame has eight items and these include the refusal to believe that the symptoms exist or trying to take it out on others, e.g. "went on as if nothing had happened and hoping that the symptoms would go away", "being irritable and ignored what others said".

Overall, stimulation reduction strategies were used less frequently than all the others. Both stimulus reduction and seeking professional help were positively related to improved social functioning whereas denial or blame was negatively related to social functioning.

#### *Individual variability*

Using the Coping Inventory for Prodromes of Mania, one of the main aims of Parikh et al's. (2007) study was to determine whether demographic and/or clinical variables influenced the use of coping strategies for prodromes of mania. Of all the clinical variables examined, including age of onset, duration of illness, number of previous mood episodes and bipolar subtype, multivariate analysis found only bipolar subtype predicted differential coping response to prodromes of mania. They found that bipolar I participants tended to rely more on seeking professional help and stimulus reduction, whereas bipolar II participants relied more on denial and blame.

### **Discussion**

There are three key issues that arise from this systematic review: the limitations of the current research on coping strategies with early symptoms of relapse, the findings on the nature of these identified coping strategies in schizophrenia, depression and mania, and the implications for clinical practice and future research.

#### *Limitations of current research*

Although the total sample of included studies exceeded 800 participants, the data on coping strategies with early symptoms of relapse in schizophrenia, depression and mania were inadequate. Findings from these studies were limited by the heterogeneity of the samples, the lack of standardised measures to assess coping strategies and the lack of operationalised terminology used to describe coping responses. The retrospective design

of the majority of studies may have also biased or distorted the individuals recall (Fava & Kellner, 1991). Many of the included studies had small sample sizes which also limited the generalisability of the findings.

Whilst the included studies were subject to methodological evaluation, the author did not exclude studies on the basis of methodological weakness. It could be argued that a more definite conclusion regarding the quality of each study would have enhanced the review. This was thought to be inappropriate however due to the small number of studies and the heterogeneity of the included samples and methodologies. Despite these limitations there are a number of consistent themes across the literature on coping with early symptoms of relapse in schizophrenia, depression and mania.

### *The findings*

The findings from this review suggest that the majority of individuals use coping strategies with early symptoms of relapse in schizophrenia, depression and mania. These coping strategies can be divided into active and restrictive coping strategies which are designed to regulate affect and arousal. Active coping strategies included coping responses that described cognitive and behavioural approach oriented efforts whereas restrictive coping strategies included coping responses characterised by avoidance, denial and withdrawal.

The findings from this review suggest that active coping strategies are more helpful than restrictive coping strategies in reducing the likelihood of relapse in schizophrenia, depression and mania. Both Hultman et al. (1997) and Lam et al. (2001) found that individuals with schizophrenia and depression respectively were less likely to have a relapse if they employed more active, social-oriented coping strategies as compared to those utilising avoidant and withdrawal oriented coping strategies. Lam et al. (2001) also found that individuals were less likely to have a manic episode if they employed

behavioural strategies, such as stimulus reduction techniques or medical intervention strategies as compared to restrictive strategies such as denial.

The findings from this review introduce ideas around resilience and how we might begin to formulate individual resilience in the face of relapse. For a number of individuals relapse can be conceptualised as a dangerous and threatening life event that is often associated with painful memories involving trauma, for example involuntary hospital admissions, loss of employment, shame and humiliation, friends not visiting, stigmatising mental illness labels and entrapment. Relapse and the threat of relapse brings with it a number of crucial challenges for the individual in terms of it triggering catastrophic or demoralising appraisals (threat, loss, danger) which can generate significant negative affect (Gumley, 2007). Focusing on an individual's naturally occurring cognitive and behavioural coping strategies in the face of relapse provides an opportunity to have a better insight into individual resilience and recovery.

This review suggests that restrictive coping strategies such as avoidance and withdrawal are more active than previously conceptualised in the literature. Without a comprehensive understanding of how these strategies are organised or the goals of these strategies it is premature to judge the level of passivity or otherwise of the individual as they are faced with the same challenges of difficult emotions and threatening appraisals.

Tait, Birchwood & Trower (2004) found that individuals utilising avoidance coping strategies (e.g. sealing over) were less likely to engage with mental health services, seek help and adhere to treatment than individuals using approach oriented coping responses. They found a clear link between sealing-over and a perception that others see the individual as worthless. These individuals reported interpersonal histories characterised by harsh parental care, lower self-esteem, rejection and abandonment by others. Therefore we

need to carefully consider the developmental and interpersonal origins of a style of coping which appears to restrict affect and may ultimately prevent the individual from responding productively to the threat of relapse. However it is not easy to determine this from the literature reviewed.

#### *Implications for clinical practice and future research*

This review has found that individuals with schizophrenia, depression and mania do frequently use a variety of cognitive and behavioural coping strategies to deal with early symptoms of relapse. This suggests that rather than being “passive passengers” in the process of relapse many individuals do actively regulate their early symptoms in order to try and reduce the likelihood of a further episode. This suggests that contrary to ‘prodromal’ models of relapse it would make more sense to have a model of ‘early signs’ which uses the term ‘at risk mental state’ (Gumley & Macbeth, 2006; Birchwood & Spencer, 2001). This would provide a context to understand individuals’ cognitive and behavioural responses to ‘early signs’ and it would provide professionals with a cognitive-behavioural framework to explore and reinforce helpful and unhelpful coping strategies.

A number of models of relapse prevention focus on reducing positive psychotic symptoms. The findings from this review however suggest that rather than targeting positive psychotic symptoms, the key targets for relapse prevention should be the regulation of affect and arousal. Teaching clients cognitive and behavioural techniques designed to regulate their emotional and behavioural early symptoms of relapse in schizophrenia, depression and mania could improve clinical outcome and reduce relapse. These coping strategies would need to be tailored to the individual’s idiosyncratic symptoms to ensure the most appropriate coping responses were identified and reinforced.

The findings from this review support the recent development of a cognitive interpersonal psychotherapeutic approach which focuses on affect and affect regulation. In collaboration with the client the therapist works with the individual to identify and explore barriers to emotional recovery, relapse detection and relapse prevention. Self-soothing and helpful affect regulation strategies are then identified, developed and strengthened to promote productive coping (Gumley, 2007).

Future research should involve more studies with a prospective design and the development of reliable and valid measures to assess coping strategies is also important, particularly in the area of schizophrenia. A number of the studies in this review lacked clarity in the presentation of their findings and they used vaguely defined coping responses. Future research should therefore be transparent with clearly operationalised terms and definitions. Larger sample sizes and control groups would also improve the generalisability of the findings in this literature.

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Figure 1: Flowchart of article selection process.

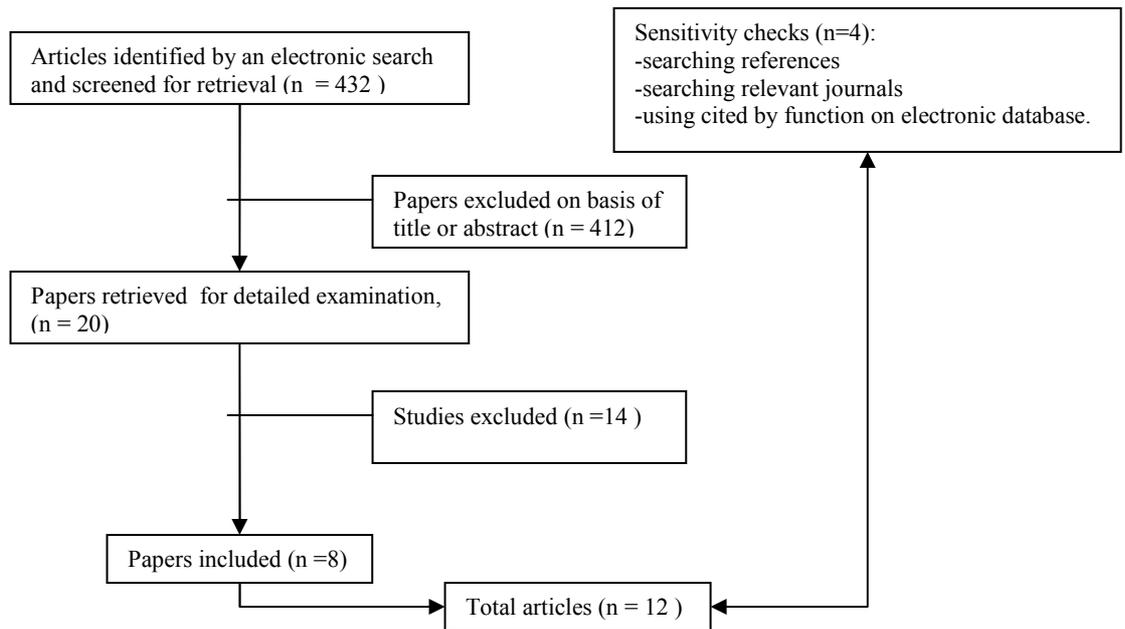


Table 1: Summary of studies included in the review

| Study                   | Design        | Aims  | Sample   | Coping Measure       | Findings   | Strengths  | Weaknesses   |
|-------------------------|---------------|---|--|----------------------|--|--|--|
| Bechdolf et al., (2002) | Retrospective | They investigated prodromal symptoms and coping strategies preceding relapse in schizophrenia and depression. | N = 51<br>27 had a diagnosis of schizophrenia and 24 had a diagnosis of depression.<br>There were 25 males and 26 females with a mean age of 39 years. | BSABS                | Schizophrenia and depression: Participants reported more behavioural coping strategies than restrictive coping strategies. | They used a published coping measure and there were an equal proportion of men and women in their sample.<br>Good inter-rater reliability. | Retrospective design and small sample size. Poorly operationalised coping terms.                       |
| Boker et al., (1984)    | Retrospective | They explored consciously undertaken problem-solving oriented coping strategies with prodromal symptoms in    | N = 40<br>There was no male/female split. Mean age-29.5 years.   | Open ended interview | Participants reported more cognitive and behavioural problem solving coping  | They had clear aims and objectives.<br>Good inter-rater reliability.   | Retrospective design and poorly operationalised coping terms. They used an unpublished coping measure. |

|                        | schizophrenia. |  |  |                      |  |  |   |
|------------------------|----------------|--|--|----------------------|--|--|---|
| Study                  | Design         | Aims   | Sample   | Coping Measure       | Findings   | Strengths  | Weaknesses  |
| Brenner et al., (1987) | Retrospective  | They explored consciously undertaken problem-solving oriented coping strategies with prodromal symptoms in schizophrenia | N = 60<br>There was 21 females and 39 males. Mean age- 31.1 years. | Open ended interview | Participants reported more cognitive and behavioural problem solving coping strategies than non problem solving coping strategies. | They had clear aims and objectives. Good inter-rater reliability. They included a healthy control group. | Retrospective design and poorly operationalised coping terms. They used an unpublished measure. |
| Cohen & Berk (1985)    | Retrospective  | They explored the techniques that patients with schizophrenia have developed to cope with their prodromal                | N = 86<br>There was a 52% male/47% female split.                   | Open ended interview | A variety of active and restrictive coping strategies were identified.   | They had clear aims and objectives and there were an equal proportion of                                 | Retrospective design and poorly operationalised coping terms. They used an                      |

|   |               |   |   |                                  |   |
|---|---------------|---|---|----------------------------------|---|
| symptoms.   |               |   |   | men and women in their sample.   | unpublished measure.  |
| Coping strategies varied with demographic and social variables. |               |   |   |                                  |   |
|   |               |   |   |                                  |   |
| <b>Study</b>  | <b>Design</b> | <b>Aims</b>   | <b>Sample</b>                                 | <b>Coping Measure</b>            | <b>Findings</b>   |
| Hultman et al., (1997)  | Prospective   | They examined the predictive value of social support and coping style for relapse in schizophrenia. | N = 42<br>There were 17 males and 23 females. | They used an interview schedule. | They found that fewer participants who used active, social oriented coping strategies relapsed as compared to those who used avoidant, withdrawn coping strategies. |
|   | Retrospective | They assessed   | N = 30<br>There were 20                       | Semi-structured                  | They had a small same size and their exclusion criteria was unclear. Reliability and validity data was not discussed.   |
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|   |               |   |   |                                  |   |
| Kumar & Rajkumar  |               |   |   |                                  | Clear aims and  |

(1989)

participants perception of prodromal symptoms and they explored coping strategies with early symptoms in schizophrenia.

males and 10 females with a median age of 29.6 years.

interview.

Participants reported the following coping strategies: 'internal dialogue', 'talking to close friend/relative', 'seeking medical help' and 'engaging in work'.

objectives and clearly stated inclusion and exclusion criteria

Retrospective design and poorly operationalised coping terms. No reliability or validity data and they used an unpublished coping measure.

Study

Lam & Wong (1997)

Design

Cross-sectional

Aims

They investigated participants' prodromal symptoms and coping strategies. They also explored whether recognising prodromal symptoms and

Sample

N = 40  
There were 17 males and 23 females with a mean age of 43.7 years.

Coping Measure

Coping with Prodromes Interview.

Findings

Divided sample into good coping group and poor coping group. They divided coping responses into active cognitive and behavioural coping strategies (helpful) and passive coping

Strengths

Clear aims and objectives. Good inter-rater reliability. Clearly operationalised coping responses.

Weaknesses

Cross-sectional design.

|                    |             |  |   |                                  |   |   |                             |
|--------------------|-------------|--|---|----------------------------------|---|---|-----------------------------|
| Lam et al., (2001) | Prospective | adaptive coping are related to good social functioning.<br><br>They investigated which types of coping strategies at prodromal stages are linked with good clinical outcome. | N = 40 (bipolar)<br>There were 17 males and 23 females. | Coping with Prodromes Interview. | They found that fewer participants who employed behavioural coping strategies for mania and depression relapsed compared to those who used passive(restrictive) strategies. | Prospective design. Clear aims and objectives. Previously published measure and good inter-rater reliability. | Exclusion criteria unclear. |
|--------------------|-------------|--|---|----------------------------------|---|---|-----------------------------|

|                                   |        |               |   |   |   |  |   |   |
|-----------------------------------|--------|---------------|---|---|---|--|---|---|
| McCanless-Glimcher et al., (1986) | Design | Retrospective | Aims  | Sample  | Coping Measure                                      | Findings   | Strengths   | Weaknesses  |
|                                   |        |               | They explored symptoms that are recognised as indicators of relapse in schizophrenia and investigated | N = 62<br>There was no male/female split. Mean age- 38.7 years. | They adapted the Chronic Illness Symptom Interview. | They divided coping responses into three categories:<br>1) Behaviours related to self- | Clearly stated inclusion and exclusion criteria. Clear aims and objectives and they adapted | Retrospective design and poorly operationalised coping terms.<br>No reliability or validity data. |

|                       |                 |   |  |  |   |  |  |
|-----------------------|-----------------|---|--|--|---|--|--|
| Parikh et al., (2007) | Cross-sectional | coping strategies when these symptoms are present.  | N = 203<br>There was no male/female split. Mean age- 40.8 years. | Coping Inventory for Prodromes of Mania. | treatment. 2) Behaviours involving help seeking. 3) Behaviour involving both.                       | a previously published measure.  | Cross-sectional design and the coping measure was designed for bipolar I participants. |
|                       |                 | They investigated coping with early warning signs of mania in bipolar disorder. They investigated whether demographic and clinical characteristics impact coping preferences. |  |  | They found that only bipolar subtype predicted differential coping responses to prodromes of mania. | Clearly stated inclusion and exclusion criteria They used a previously published. Acceptable internal consistency and good construct validity. |  |

|                        |               |   |   |                            |  |  |   |
|------------------------|---------------|---|---|----------------------------|--|--|---|
| Study                  | Design        | Aims  | Sample  | Coping Measure             | Findings                                 | Strengths  | Weaknesses                                      |
| Thurm & Haefner (1987) | Retrospective | They explored how participants with schizophrenia | N = 37<br>There were 23 males and 14 females with a | Semi-structured interview. | They divided coping responses into three | Clear aims and objectives and they discussed reliability and | Retrospective design and poorly operationalised |

Wong & Lam  
(1999)

Retrospective

cope with prodromal symptoms of relapse.  
To develop an instrument for the assessment of a broad range of coping strategies used by manic depressive patients during their prodromal phase of mania.

mean age of 33 years.  
N = 206  
There was a 40% male/60% female split with a mean age of 44 years.

Pilot scale for CIPM

categories:  
1) Various behavioural strategies. 2) Seeking reliable social contacts. 3) Intrapsychic coping.  
Four empirically derived subscales: Stimulus Reduction, Problem Oriented Coping, Seeking Professional Help and Denial and blame.

validity data.  
Random sample. Clear aims and objectives. Clearly presented results. High internal consistency and construct validity.

copng terms.  
Retrospective design. The study relied on self-reported diagnosis of manic depression.

## **Chapter 2: Major Research Paper**

Major Research Paper submitted in partial fulfilment of the requirements for the degree of  
Doctorate in Clinical Psychology.

### **An interpretative phenomenological analysis of service users' perspectives and experiences of relapse in psychosis.**

Prepared in accordance with requirements for submission to Journal of Mental Health (See  
Appendix 2.1)

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## **Abstract**

*Background:* Whilst quantitative research has provided a valuable understanding of the social and emotional impact of relapse of psychosis, it is also important to consider the complexity of individuals' experiences in relation to emotional, psychological and interpersonal adaptation following psychosis. *Aims:* In order to get closer to individuals' experiences of psychosis and relapse we need to develop an experiential based account. This qualitative research study set out to develop an in-depth understanding of service users' perspectives and experiences of relapse in psychosis and the meanings they attach to these experiences. *Method:* Using a semi-structured interview seven participants were interviewed - 4 females and 3 males. The interviews were analysed using Interpretative Phenomenological Analysis. *Results:* Four emergent themes were identified and were labelled using participants' words: "You have no control over your life", "You come out running", "Its heart wrenching", and "Coming to terms with my experiences". *Conclusions:* For this group of participants the opportunity to come along and participate in a study about relapse became an opportunity to explore important experiences and meanings that have arisen in their recovery from psychosis. The findings suggest that in order to support recovery it is important to identify how individuals construct and understand their experience of psychosis.

*Declaration of interest:* None

*Keywords:* Relapse, psychosis, qualitative research, Interpretative Phenomenological Analysis.

## **Introduction**

‘Psychosis is an integrative and collective term used to describe a range of human experiences such as hearing voices or suffering from persecutory paranoid beliefs’ (Gumley & Schwannauer, 2006, p.xi).

Relapse is the medical term used to describe the recurrence of an episode of an illness or the exacerbation of illness symptoms that are partially remitted (Gumley, Karatzias, Power, McNay & O’Grady, 2006). Bebbington et al. (2006), operationalise relapse in psychosis in terms of positive psychotic symptoms. Full relapse involves a progression from a state asymptomatic in terms of positive psychotic symptoms to one characterised by a reappearance of such symptoms. Partial relapse implies significant exacerbation of an incompletely remitted state and both can be clinically catastrophic. Research suggests that following a first episode of psychosis, approximately 16% experience relapse at 1 year, 54% at 2 years and 82% at five years (Robinson et al., 1999).

Relapse is potentially a devastating and disorientating critical life event that is often associated with increased emotional and psychological distress and impaired social, vocational and interpersonal functioning (Gumley & Schwannauer, 2006). Living with psychosis and the prospect of relapse can reduce an individual’s sense of control over their illness which can lead to feelings of disempowerment and hopelessness and a variety of secondary psychological difficulties. These include depression (Tarrrier, 2005), social anxiety (Tarrrier, 2005), PTSD (Morrison, 2003) and low self-esteem (Barrowclough et al., 2003). Relapse remains a major factor in the development of illness chronicity. Research suggests that each relapse that a client experiences increases the probability of future relapse and continual residual symptoms (Shepard, Watt, Falloon & Smeeton, 1989; Wiersma, Nienhuis, Sloof & Giel, 1998).

For a number of individuals relapse can be conceptualised as a dangerous and threatening life event that is often associated with painful memories involving trauma, for example involuntary hospital admissions, loss of employment, shame and humiliation, friends not visiting, stigmatising mental illness labels and entrapment (inability to control or escape from psychosis) (Gumley et al., 2006; Gumley, 2007; Knight, Wykes & Hayward, 2003). Relapse and the threat of relapse brings with it a number of crucial challenges for the individual in terms of it triggering catastrophic or demoralising appraisals (threat, loss, danger) which can generate significant negative affect (Gumley, 2007). Birchwood, Mason, Macmillan & Healy (1993) found that post psychotic depression was associated with an individual's perception of being unable to control their illness (relapse) or the fear of psychosis itself. Rooke and Birchwood (1998) found that levels of depression were enduring over time, as were appraisals of entrapment, loss of social role and autonomy, and self-blame. Birchwood (1995) proposed a two-process model of relapse. He suggested that anxiety and depression are responses to the fear of an impending relapse or a failure to explain symptoms and experiences.

Iqbal, Birchwood, Chadwick & Trower (2000) found that individuals with post psychotic depression experienced greater loss, humiliation and entrapment arising from their psychosis and they were more likely to attribute the cause of their illness to the self (self-blame). They also had lower self-esteem and were more self-critical than non-depressed individuals. Gumley (2007) conceptualised psychosis as a life event that triggers depression through awareness of its social, interpersonal and affiliative implications.

The current literature reveals a number of psychological conceptualisations of relapse. Taken together these experientially focused models all emphasise the importance of the individual's idiosyncratic appraisal of 'early warning signs'. They suggest that the individual's response to this evidence of relapse is informed by their specific

autobiographical memories of psychosis. Gumley & Macbeth (2006) have proposed a trauma-based psychological model of relapse. This model suggests that low-level psychotic experiences or cognitive perceptual events that share similarities with previous episodes of psychosis (for example, unusual thoughts, headaches, paranoid thoughts and sensory experiences) create a sense of reliving for the individual and that this experience of reliving is reinforced by intrusive autobiographical memories of previous experiences of psychosis. It is proposed that this leads to the activation of negative, catastrophic threat beliefs resulting in emotional distress and affect dysregulation.

These findings demonstrate the important link between individual appraisals and the development of secondary psychological difficulties following a psychotic episode. Whilst quantitative research has provided a valuable understanding of the social and emotional impact of relapse, it is also important to consider the complexity of individuals' experiences in relation to emotional, psychological and interpersonal adaptations following psychosis. In order to be able to get closer to individuals' experiences of psychosis and relapse one needs to develop an experiential based account. A qualitative, specifically phenomenological exploration of individuals' experiences of psychosis may provide a deeper understanding of how these individuals make sense of their experiences and what meanings they attach to relapse. Therefore, Interpretative Phenomenological Analysis (IPA) was the chosen approach as it aims to capture the lived experiences of the individual without testing hypotheses or making prior assumptions about the meaning of the topic being explored (Reid, Flowers, Larkin, 2005).

Rather than looking for commonalities between different individuals IPA focuses on the in-depth exploration of participants' individual experiences and meanings. The goal is to construct a rich and detailed picture of the phenomenon under investigation using a case by case or idiographic approach (Lyons, 2007). In this respect IPA differs from other

qualitative methods such as grounded theory which usually involves the sampling of large numbers of participants in order to generate a theory from the data (Payne, 2007). Drawing upon its phenomenological roots, IPA is based on the assumption that language reflects the reality of the individuals experience and it makes direct links between language and real life behaviour and thought (Smith, Jarman & Osborn, 1999). This is in contrast to discourse analysis which views language 'as constructing categories and events rather than reflecting reality' (Lyons, 2007, p.161). Although narrative analysis shares a number of similarities with IPA it primarily focuses on lived experiences and identity construction rather than the meanings individuals' attach to experiences (Crossley, 2007).

IPA's experiential focus on the in-depth exploration of specific phenomena means that it is especially well suited to investigating novel and complex areas (Smith, Michie, Stephenson & Quarrell, 2002). Research using IPA usually explores important, life-threatening or life-transforming events, decisions or conditions (Smith, 2006). Living with psychosis and the prospect of relapse is an emotive experience which makes this topic highly suitable for an IPA study. IPA enables individuals to describe their experiences in a way which ensures that they do not lose their essential quality. Their lived experiences can be reported in such a way as to provide new knowledge and a new view to meeting the needs of this vulnerable client group (Reid et al., 2005). Finally and perhaps most importantly IPA provides a voice to a group of people who do not typically have a strong voice (Larkin, Watts & Clifton, 2006).

### *Aims*

This research study set out to develop an in-depth understanding of service users' perspectives and experiences of relapse in psychosis and the meaning they attach to these experiences. Specifically what meanings do service users attach to relapse and what are the implications of these meanings for service users' adaptations to psychosis?

## **Method**

### *Design*

This study was qualitative and employed IPA. IPA has its theoretical foundations in phenomenology, hermeneutics and idiography (Smith & Eatough, 2007). The main aim of IPA is to explore how individuals make sense of their personal and social world in order to understand what meanings they attach to specific experiences or phenomenon (Smith & Osborn, 2003). It is interpretative in the sense that it acknowledges the active role of the researchers' own ideas and understandings in the process of making sense of participants' experiences. Therefore a two stage interpretation process or a double hermeneutic is involved (Smith & Eatough, 2007). Smith and Osborn (2003) describe this as a dual process where “the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world” (p.51).

As a qualitative approach IPA is different from other qualitative approaches by virtue of its acknowledgement of the role of the researcher, its focus on homogeneous sampling and its lack of emphasis on theory generation (Jordan, Eccleston & Osborn, 2007).

### *Participants and recruitment method*

In contrast to the random or representative sampling strategies of quantitative research, IPA studies focus on the detailed analysis of the experiences of small samples most suited to the research question (Smith & Osborn, 2003). Participants are recruited because they are experts in the phenomenon being explored and IPA allows participants' subjective thoughts and experiences of the topic to be investigated (Reid et al., 2005). Smith and Osborn (2003) suggest that sample size is dependent on a number of factors, including the richness of individual accounts, commitment to the level of analysis and the constraints one is

operating under. Smith et al. (1999) suggest that 10 participants is at the higher end of the recommended sample size for IPA.

Participants were eligible to participate in the study if they were aged over 16 years old and had an ICD-10 diagnosis of an affective or non-affective psychosis. Participants were excluded if they were a non-English speaker, had an organic brain disorder or presence of significant learning disabilities. As recommended by Smith and Osborn (2003), the participants in this study represented a reasonably homogenous, purposive sample. All of the participants had experienced psychosis, lived in the same geographical area and considered themselves to be white British. Seven participants, 4 females and 3 males volunteered to take part in the study. Although homogeneity is an aspiration of IPA it is important to consider the practicalities of this in real life research, taking into consideration potential recruitment difficulties and the reality that individuals often experience the same event (for example, psychosis) in completely different ways. While complete homogeneity may be difficult to achieve it is still important to try and recruit 'a closely defined group for whom the research question will be significant' (Smith & Eatough, 2007, p.40)

(Insert Table 1 here)

Participants were aged between 27- 44 years of age, with a mean age of 37.3. All of the participants were receiving care from a Community Mental Health Team (CMHT) within NHS Ayrshire and Arran. Of the 7 participants, 5 had experienced relapse and 2 had only experienced their first episode of psychosis. Although 2 of the participants had not experienced relapse it was decided that this would not affect the homogeneity of the sample as these individuals had both experienced psychosis and they were still living with the possibility of relapse. The research question was therefore still important for these participants and it was decided that their inclusion would enrich the research findings.

Key workers were asked to inform potential participants of the study and to provide individuals with an information sheet (See Appendix 2.2). Participants interested in taking part in the study were asked to contact the researcher directly by telephone.

### *Procedure*

#### *Ethics*

The study was carried out in accordance with the British Psychological Society's ethical guidelines (BPS, 2006). Full ethical approval for the study was obtained by the local research ethics committee and relevant clinical governance bodies within NHS Ayrshire and Arran (07/S0201/28). Participants were fully informed about the research procedure and gave their consent to participate before data collection took place. They were informed about the full aims of the study prior to data collection and complete confidentiality was maintained throughout the research process. Written consent for participation, recording and transcribing of interviews and publishing anonymised quotations was sought from all participants (see appendix 2.3). To ensure anonymity each participant was given a gender appropriate pseudonym.

#### *Data collection*

Data were collected through semi-structured interviews. The interviews lasted for a maximum of 60 minutes and were recorded for later transcription. This resulted in approximately 7 hours of interview material rich in information. Consent for the interviews and tape recording was sought at the beginning of each interview. It was made clear to participants that they had the right to withdraw at any time.

The participants were asked to talk as widely as possible about their feelings and experiences of psychosis, relapse and recovery. It was the responsibility of the researcher

to build a safe and supportive environment in which the individuals could explore their experiences openly. The interviews were semi-structured in that the researcher was informed by the schedule but participants were encouraged to talk in depth about their own experiences and important personal topics. Verbatim transcripts of the semi-structured interviews served as the raw data for the study. Following each individual interview the principal investigator (CMac) recorded her thoughts and reflections on the interaction between herself and the participant. This was an important process as these interactions had the potential to influence her interpretation of the interview data.

### *Interview schedule*

In order to address the aims of the study, the principal investigator constructed a semi-structured interview schedule drawing on her own clinical experience and a review of some papers from the existing quantitative and qualitative literature on psychosis (Brown & Kandirikirira, 2007; Gumley, 2007; Iqbal et al., 2000; Knight et al, 2003; Morrison, 2003; Perry, Taylor & Shaw, 2007). The interview schedule was developed to enable participants to reflect on a number of aspects of their experiences and the interview questions were developed using guidelines outlined by Smith and Eatough (2007). A series of open-ended and non-directive questions were developed to encourage participants to talk about their experiences of psychosis, relapse and recovery.

Areas to be explored in the interviews, which were identified in the interview schedule, formed the basis for the open-ended questions used to initiate discussion. The areas explored in the interviews with the participants were: How do participants appraise their own experience of psychosis?, how do they describe relapse and how do they view it? and how do these meanings impact on subsequent adjustment and recovery? Additional prompts (e.g. Can you tell me more about that?) and questions (e.g. What does relapse mean to you?) were identified under each general area and these were used when required

to ensure that the issues of interest were addressed (A complete list of questions and prompts are outlined in the interview schedule in appendix 2.4).

Comfort levels were assessed before and after each interview to monitor any changes in participants' distress levels. This was monitored using a 10-point likert scale with 1 being "not at all comfortable" and 10 being "extremely comfortable" (See Appendix 2.5). Participant's verbal and non-verbal communications were also observed to monitor any possible signs of tiredness or anxiety.

(Insert Table 2)

Table 2 reveals that talking about their experiences of psychosis and relapse did not appear to affect participant's level of comfort. In fact a number of the participants reported that they had actually found the interview to be a positive experience.

### *Analysis*

The Semi-structured interviews were analysed using IPA. IPA is not considered to be a prescriptive approach but rather it provides a set of flexible guidelines which can be adapted in light of individual research aims (Smith & Eatough, 2007). The transcripts were analysed according to the method outlined by Smith and Osborn (2003). The first stage of analysis involved reading and re-reading transcripts. This ensured that the researcher was familiar with the content of each interview. The left-hand margin was then used to make notes of anything that appeared important and interesting. With each reading of the transcript the researcher became more immersed in the data, becoming more sensitive and responsive to what was being said. This uncovered new insights and preliminary interpretations.

The second stage involved returning to the transcript afresh and using the right-hand margin to change initial notes and ideas into more specific themes or phrases. During this process the principal investigator used her own theoretical knowledge ‘to make maximum psychological sense of the data’ (Storey, 2007, p.55). Taking into consideration the methodological tension between the phenomenological and interpretative aspects of IPA, it was important at this stage to stay grounded in the original transcripts to ensure there was a clear connection between the themes and the data. This enabled the researcher to remain committed to IPA’s phenomenological focus without over-emphasising the interpretative aspect of IPA.

The third stage involved compiling a master list of themes and connections between the themes were explored (clustering of themes). Clustered themes were grouped into overarching themes and given a descriptive label (super-ordinate theme list). Although the detailed case by case analysis of individual transcripts was time consuming it enabled the researcher to engage with the richness of the individual accounts and do justice to each case. A comparison of themes across transcripts was then carried out. This allowed the researcher to identify recurrent themes that were fairly consistent across the participants but it also revealed diversity in the transcripts. Tables of quotes from across all interviews were then constructed for each theme to ensure that the themes were supported verbatim within the transcripts.

#### *Reliability and Validity*

All of the transcripts were read by another researcher familiar with the topic area to check for content validity of the themes. Another strategy which may be used to confirm the quality of the analysis is respondent validation (Payne, 2007). This involves returning the emergent themes to the participants in order to obtain feedback about their credibility (Yardley, 2000). A tension however currently exists in the literature about whether or not

this actually is a valuable strategy. Some argue that respondent validation enhances the validity of the research findings (Yardley, 2000), whereas others argue that rather than establishing the validity of the themes this strategy might generate more data from differing perspectives (Payne, 2007) and may put unnecessary demands on the participants (Barbour, 2001). After careful consideration the principal investigator decided not to employ this strategy, as she felt that it could make considerable demands on the participants' time and emotional well being.

The main researcher also made use of peer supervision and advice from experts in the field of IPA. According to Polkinghorne (2005), "the validity and trustworthiness of qualitative research is related to the selection of viable sources that promote a deepening of the understanding of the experiences inquired about" (p.141). The purpose of a qualitative study and also of this study is to elicit in-depth knowledge about the phenomenon under investigation, not knowledge that can be generalised (Smith & Eatough, 2007).

### *Reflexivity*

This section is written in the first person in order to make it more meaningful. As discussed by Willig (2001), "personal reflexivity involves reflecting upon the ways in which our own values, experiences, interests, beliefs, political commitments, wider aims in life and social identities have shaped the research" (p.10).

Before embarking on the study I reflected on my own personal and professional values, beliefs and experiences. I am a 27 year old, white, middle class, Christian, Scottish woman. I have worked as a shop assistant, waitress, support worker, assistant psychologist and a researcher. I am now a third year clinical psychology trainee. A number of my close friends have experienced mental health difficulties and at times I have struggled with my own thoughts and emotions. Although I have no personal experience of psychosis I

have worked with a number of individuals who have experienced psychosis in in-patient and out-patient settings. I have worked in a community mental health team for the last six months and I have been fascinated by the complexity of individuals' psychotic experiences. My clinical practice has been influenced by the work of Max Birchwood and colleagues, Andrew Gumley, Nick Tarrier, Anthony Morrison and Christine Barrowclough. Their work has helped to increase my psychological understanding of psychosis and they have facilitated my confidence working in this area. These experiences have influenced my thinking as a therapist, clinical psychologist and a researcher and they have motivated me to carry out qualitative research in this area. Carrying out this study has helped me to appreciate the importance of involving service users in research and the development of future services. It was hoped that my psychological knowledge and therapeutic skills would enrich the study and enhance the research process.

## **Results**

### *Reflections upon interviews*

Drawing on my own clinical experience helped to prepare me for the interviews. The foundations of my therapeutic style are the skills of empathy and active listening and I feel these enabled me to feel more confident in my role as an interviewer. All of the participants were eager to share their life changing experiences with me. Any initial anxiety they may have had about talking to me seemed to disappear almost immediately as they began to talk about their complex and emotive experiences. Although I set out to explore individuals' experiences of relapse it quickly became apparent that they wanted to explore important experiences and meanings that have arisen in the context of their recovery from psychosis. I found this change in the agenda rather unsettling and I remember feeling overwhelmed with information that didn't seem to answer my research

question. In order to try and explore this further I decided that it was important to try and think psychologically about the situation and reflect on how I was feeling. I found this process to be cathartic and I started to understand why I was struggling. I realised I had become preoccupied with answering my original research question and as a researcher I felt as though my own agenda was not being satisfied. Reflecting on this in supervision was extremely useful as it gave me an opportunity to openly discuss my concerns with a more experienced qualitative researcher. It also helped to remind me that it is the individual who is the expert and not the researcher and that it is my responsibility to ensure the research agenda is open to new insights from the participants. Taking notes after each interview helped me to reflect on my interviewing style and it enabled me to adapt my interviewing approach to ensure that I was being participant led at all times. I believe this helped to facilitate the richness of the individual accounts.

The themes that emerged from the analysis of each transcript were compared in order to present the dominant stories of the participants' experiences. This revealed both shared and contrasting experiences. Four super-ordinate themes encapsulating the participants' lived experiences of psychosis were identified. These themes were labelled: "*You just have no control over your life*", "*You come out running*", "*It's heart wrenching*" and "*Coming to terms with my experiences*". As a result of participants desire to explore important experiences and meanings that have arisen in the context of their recovery from psychosis, much of the content of these four super-ordinate themes is not related to relapse but a career of being ill and wider experiences related to recovery. Labels were chosen because they were felt to represent the essence of the theme and participants' words were used in order to stay close to the original transcripts.

Although these will be discussed as separate themes, a full appreciation of each individual theme can only be achieved through an understanding of the others and their inter

connections. Each of the themes are presented in detail and clear illustrations from each transcript are provided (page and line numbers for the quotes are given in parentheses). Whilst the principal investigator has strived to provide quotes that epitomise the single theme under consideration, the intertwining nature of the themes means that individual quotes may illustrate more than one theme. This is considered to be important as it helps the reader to understand the participants' wider network of experiences.

The complexity of participants' accounts was striking and this was reflected in the range of experiences that participants recounted, usually in relation to their first episode of psychosis. Participants gave rich and detailed descriptions of their experiences, providing vivid and emotive memories. Fiona provides an illustrative quote:

*“One particular thing that I do remember was being in bed late at night and this presence at the end of the bed sort of came across me and then this voice came into my head saying what do you live for and I said people” (Pg 2, Ln 4).*

***Theme 1: “You just have no control over your life” (Kim, Pg 4, Ln 82)***

Despite variation in individual accounts, all of the participants described experiences that underpinned a disruption to their sense of control:

*Kim: “You just want it to stop, leave you alone. It’s as if it’s somebody else that is doing it to you cause you have no control. Somebody else is making you like that” (P8, Ln 193).*

Participants' loss of control was reflected in a number of experiences, including the psychosis itself, involuntary hospitalisations, medication and enforced treatment regimes. These experiences all represented a significant shift in the participants' balance of control.

For example, Kim talked about her early fears of being sectioned and her language conveyed a sense of vulnerability. This vulnerability seemed to reflect her own experiences of psychosis but also her experiences of being “picked on” and feeling “unsafe” in hospital:

*“I used to be frightened in the hospital years ago, used to get people that picked on you, other patients, some of them picked on you, picked on me. It doesn’t help you any, it makes you feel vulnerable again, feeling vulnerable doesn’t help you” (Pg 12, Ln 290).*

Campbell reflected on his initial experiences of medication and the uncontrollability of his emotions. The use of the word “barrage” illuminates his experience and it creates powerful imagery of him being trapped and in the ‘firing line’ of his medication:

*“They tested me on a barrage of different medications and some of it was pretty bad you know, like I was sat down and I couldn’t move, I was sorta stupefied and then from that it went to the extreme opposite where you know I was hyperactive” (Pg 6, Ln 60).*

Campbell also shared his initial experiences of ECT and he described being so disorientated and confused that he didn’t know what was happening to him. The following extract reflects how disempowered and angry he felt by his early experiences:

*“One of the things they did with me the first time round was that they gave me ECT and that was pretty heavy going... I had that six times you know and eh I was really angry with my mother at the time cause she made me sign the consent form you know, and I didn’t even know what it was” (Pg 23, Ln 560).*

When describing their experiences of losing control all of the participants articulated a sense of feeling trapped and powerless. Kim reflected on being “trapped” in a different world and being unable to tell the difference between her dreams and reality. The following quote conveys her sense of helplessness:

*“You’re trapped in a different world. You lose all sense of reality and your dreams become nightmares and you don’t know whether they are true or not. You can’t tell the difference between dreams and reality if you know what I mean” (Pg 3, Ln 73).*

Fiona reflected on her childhood and how she was brought up to believe that having a mental illness was “on a par with Cancer or any other terminal illness”. The extract below seems to illustrate the powerlessness and hopelessness attached to her experiences:

*“My grandmother had a diagnosis of schizophrenia, I was brought up, I was brought up thinking that mental health problems, mental illness was the worst thing that could ever happen to your health, on a par with cancer or any terminal illness and it was a terminal illness you know” (Pg 11, Ln 249).*

Campbell recounted his experience of being “forcibly injected” with medication. The use of the phrase “fighting people off” provides a powerful and emotive image that illuminates the distressing and disempowering nature of his experiences:

*“I mean there were times when I was forcibly injected with a drug to knock me out and you know I mean I was fighting people off” (Pg 7, Ln 173).*

When describing the emergence of psychosis and their experiences of losing control, all of the participants reflected on their experiences of loss; loss of the dreams they had

envisioned for themselves, loss of hopes and aspirations, loss of a social network and loss of the person that they used to be. For example, Campbell shared his early ambitions to be an artist and the devastation he felt when his dreams were suddenly shattered by his unexpected stay in a psychiatric unit. The following extract illuminates this distressing change in the direction of his life course:

*“Well, when I was doing my art course the previous year it was I think it was the best years of my life, the best year of my life. I loved it I really did and I was sort of, I had really high ambitions you know to become a really serious artist and when I found myself in the psychiatric unit you know everything had changed. I thought I am never going to be that artist anymore and that really got to me” (Pg 12, Ln 295).*

Fiona described her loss of autonomy and the lack of control she felt she had over her life. The following quote illuminates a sense of injustice as though she feels she is being denied her basic human rights. Her use of the phrase “dictated to” provides a compelling statement which seems to reflect the disempowering nature of her experiences:

*“I often feel that my whole life is dictated to by my medication, by my doctor and that’s not fair... A loss of autonomy, everybody should be able to, should be the author of their own existence if you like, they shouldn’t, their lives shouldn’t be in the hands of another person” (Pg 24, Ln 580).*

Stephen reflected on the loss of his social network and the negative impact this has had on his confidence and his ability to engage in social situations:

*“I have become really withdrawn because of it all, I don’t have the same connection of friends, I don’t have the same social life and ehm I don’t have the confidence I used to have” (Pg 13, Ln 308).*

Tom described how he had changed as a person and how he had lost the ability to laugh or even do the things he used to enjoy. There was a sense of loss of identity and melancholy attached to his experiences and this seems to be conveyed in the quote below:

*“I am not the same guy I used to be. I don’t feel I am the same person I used to be. As I say I don’t have the ability to laugh, do the things I used to” (Pg 51, Ln 373).*

***Theme 2: “You come out running” (Jill, Pg 28, Ln 698)***

All of the participants shared their initial shock at the emergence of their psychosis and their immediate desire to “escape” from the awfulness of what had happened to them. They talked about how they tried to “forget” about these early experiences as though they were just too painful for them to process at this stage in their recovery. Jill reflected on how she wanted to “run away” from her experiences:

*“The first few you come out, you kinda come out running cause you want to get away from it and you don’t want to think about it...I just couldn’t bring myself to talk about it because it was so frightening” (Pg 9, Ln 220).*

Within this superordinate theme, two sub-themes emerged: *Struggle to accept illness as part of self* and *Struggle to regain control*. Before reflecting on these sub-themes in more detail it is important to note that for a number of participants the term “illness” was used to describe their experiences.

### *Struggle to accept illness as part of self*

All of the participants reflected on how “terrifying” and “frightening” their initial experiences had been and the majority of them shared how painful it was to acknowledge their illness as being a part of them. For example, Jill reflected on how she saw herself as having two selves, a “well me” and an “ill me”. This response seemed to be protective in some way as it allowed her to separate and segregate herself from the devastating impact of her experiences. Her initial experiences appeared to have been so traumatic that she wanted to get as far away from them as possible. The following extract provides a powerful illustration of her struggle:

*“The first time I was really, really bad. Ehrm, it was horrendous you know, just screaming, sedated for about a week, it was just a real nightmare... There was me ill and me well and that the two didn’t, it was like two different sides, it was like a different life and when I was well I just didn’t want to think about it or talk about it” (Pg 9, Ln 213).*

Stephen talked about his initial reluctance to take any medication as he believed that his illness was drug induced and that it wasn’t something that he had to worry about. His initial experiences seemed to be so distressing that he couldn’t cope with the idea that his psychosis was a part of him:

*“At first when I was first unwell, the initial beginning of it, I was kinda withdrawn about it and I didn’t want to acknowledge it as being part of me. I just wanted to make it though it wasn’t there at all” (Pg 4, Ln 103).*

### *Struggle to regain control*

Following the emergence of their psychosis and the loss of control they had experienced, all of the participants described strategies that they used to try and regain control of their lives. These strategies seemed to develop in response to the painful nature of their experiences and their desire to “escape” and “run away” from what had happened to them. For example, Tom shared the distressing nature of his experiences and the devastating impact they have had on himself and his family. This devastation and pain made Tom want to “withdraw” from his experiences and “forget” all about them:

*“That’s just part of my life, one year of my life I just want to put behind me and forget”*  
(Pg 14, Ln342).

In order to try and cope with feeling trapped and disempowered a number of participants articulated coping strategies to try and escape from their experiences. For example, Kim shared her experiences of self harm:

*“I felt as though I couldn’t live the life I was in. I just wanted to escape, from my illness that is. Taking tablets. Another thing that I do to ease frustration is I hit my head of the wall and that helps me sometimes”* (Pg 3, Ln 58).

and later when reflecting on why this was helpful:

*“It’s part of the release. It diverts my mind from being closed in and it’s like a sensation I get, as though, right I can get through this and I do that. It’s as if it eases me”* (Pg 3, Ln 66).

Another strategy that a number of participants used to try and cope with their psychosis was to reassure themselves that their initial episode was a “one off” and that they were “cured”. This coping strategy seemed to be protective in some way as it allowed them to believe that they would never have to deal with such painful experiences again. This is illuminated by a quote from Campbell:

*“I also didn’t ever think it would happen again so I couldn’t understand it, I thought why has all this come back, I thought I was cured you know” (Pg 13, Ln308).*

***Theme 3: “It’s a bit heart wrenching” (Stephen, Pg 11, Ln 269)***

Although there was variation between individual accounts, all of the participants shared the emotional impact of their psychotic experiences. Their affect was predominantly painful and it appeared to develop as the individuals struggled to process and make sense of their difficult experiences. In their personal struggle participants described a range of emotions, including “sadness”, “shame”, “humiliation”, “embarrassment”, “guilt” and “fear”.

Campbell reflected on having depression and this seemed to develop as he became more aware of the magnitude and complexity of his experiences. In the following quote he describes the devastating moment when he realised that he wasn’t going to achieve his dream of becoming an artist and the powerful sadness that this then evoked:

*“I got depressed you know, I got quite depressed at one point. I think it was a lot to do with the medication but it was also, I suppose it was after four or five months of being in a psychiatric unit. What’s happened to my life? You know why has this happened to me and how am I going to get out of here and all that kind of things” (P12, Ln 284).*

Tom seemed to struggle to understand his experiences and he appeared overwhelmed at what had happened to him. The following quote illustrates his ongoing struggle and his continued search for answers:

*“Why me? What did I ever do? I never did anything to anybody, I never went out of my way to cause harm to anybody. I never asked for any of this to happen. I just wanted to have a quiet life, that’s all I want and I couldn’t get it” (Pg 8, Ln 192).*

Tom also shared the impact his experiences have had on his wife and the guilt he has been left to deal with:

*“You know as I say my wife had a baby in amongst it all as well and I feel guilty for not being there for her, I just feel really guilty for that” (Pg 13, Ln 310).*

Stephen reflected on experiences he has had when his family have told him about his “out of character” behaviour when he has been unwell. He has found these experiences very difficult to come to terms with and he continued to struggle with feelings of “embarrassment” and “shame”:

*“I have said and done things that I shouldn’t have really, that are out of character and just I suppose it is things you wish you didn’t do but then I didn’t know at the time so, I just think it is learning things that I have done which might have kinda upset someone...I think it’s kinda like a regret and embarrassment you know. Why did I do it? Did I really do that?...I suppose there is a lot of shame in that as well” (Pg 12, Ln 284).*

Within this superordinate theme the following sub theme emerged: *“Normal people think that schizophrenics are knife wielding maniacs”* (Campbell, Pg 14, Ln 333). This sub theme captures participants’ accounts of feeling stigmatised.

Stigma was a serious concern for all of the participants as it appeared to add to the distress and disorientation of their experiences, thereby complicating their individual recovery and adaptation. Participants’ feelings of stigma were related to their psychiatric diagnosis and the negative representation of mental illness in society. Mary reflected on how she has struggled to come terms with her diagnosis and the persistent fear she has of being negatively evaluated by others. The following quote seems to reflect her ongoing struggle and her reluctance to accept the “label” that evokes so many negative connotations:

*“Cause I don’t like to be, I hate the label, I hate the stigma attached to it...You feel people are judging you... so you feel people make judgements pretty quickly, maybe thinking you are boring or a looney”* (Pg 9, Ln 220).

Fiona described a lack of mental health awareness and understanding in society and she reflected on how this is reinforced by the negative portrayal of mental illness by the media:

*“People aren’t educated with mental health ...I think a lot of it is because there is an association in the, by the media that people with mental health problems are dangerous, there has been so much publicity around psychosis, especially schizophrenia and murders and assaults”* (Participant 9, P14, Ln 320 ).

***Theme 4: “Coming to terms with my experiences” (Stephen, Pg 3, Ln 60)***

This theme captures participants' accounts of how they have come to terms with their experiences. Although the data presented for this theme is larger than the first three themes it was felt that this was important as it clearly represents the developmental complexity of the participants' emotional, psychological and interpersonal adaptations to psychosis.

Reflecting on the ways in which participants came to terms with their experiences revealed that these were embedded in experiences of support seeking and reciprocity in relation to services. Although these experiences are important it was decided that to disaggregate experiences of help seeking from the overarching theme of “coming to terms with my experiences” would be inappropriate, as it would misrepresent the accounts and experiences of the participants. These experiences have therefore been interpreted as being essential to the illumination of the two main sub themes.

Within this superordinate theme, two sub-themes emerged: *“Making sense of my experiences”* and *“You are learning throughout your life”*.

*“Making sense of my experiences”*

After the initial confusion and disorientation, all of the participants described a process of adaptation in which they tried to make sense of their experiences. For all of the participants developing an understanding of their experiences was extremely important. This understanding was facilitated by a number of experiences, including input from mental health professionals, support from family and friends and normalisation processes.

Kim reflected on the input she has received from her CPN and her best friend and how important it has been for her to feel listened to and understood. This understanding has played a significant role in helping her to make sense of her experiences. The following quote seems to reflect how enlightening and empowering these experiences have been for her:

*“Cause it helps when people understand you and sometimes it helps you understand yourself and what you are going through and people listening and feeding back things helps you make sense of what is going on in your own head” (Pg 20, Ln 487).*

All of the participants reflected on sharing their mental health experiences with other service users and this seemed to help them to make sense of their experiences as it enabled them to feel less isolated and alone. Tom reflected on the cathartic and therapeutic nature of this information sharing process:

*Tom: “Well at the start you just feel like you are a nutter or something, you’re the only one going through this and then you realise that other people have got mental health problems as well and you are not alone” (Pg 25, Ln 611).*

Making sense of their experiences allowed a number of participants to feel more in control of their lives and this appeared to facilitate their ability to cope and adapt to their experiences. Kim reflected on her developing resilience:

*“I think it makes it a wee bit more controllable...sometimes if somebody says something that is significant that lifts you up a wee bit and your dreams stop swirling the same as if you have worked it out, take a look at this, this is what it means and it helps you” (Pg 10, Ln 239).*

*“You are learning throughout your life”*

For all of the participants, making sense of their experiences appeared to develop and change over time and this was illustrated in the diversity between the transcripts of those who had experienced relapse as compared to those who had not. All of the participants who had experienced relapse seemed to reflect on their journey and they articulated a change over time in their own knowledge and understanding of their experiences. Kim talked about this developmental process:

*“You are learning throughout your whole life, still learning and eventually one day you are going to learn enough about yourself to realise things” (Pg 21, Ln 512).*

For the five participants who had experienced relapse there seemed to be a powerful change in the meaning that they attached to their experiences. This change over time was reflected in participants coming to terms with the recurring nature of their experiences, feeling less afraid of their experiences and beginning to process undesirable feelings.

Although there was variation between individual transcripts, a number of the participants shared their experiences of relapse and how they have managed to come to terms with the recurring nature of their experiences. These participants talked about how they came to the realisation that they can no longer “escape” or “run away” from what has happened to them:

*Stephen: “So I think I understand that it is a long term thing now because I have relapsed that many times, it cannae just be pushed aside as being a one off thing” (Pg 6, Ln 142).*

The majority of participants described feeling “less afraid” of their experiences and this seemed to develop in response to their positive experiences of recovery. For example, Campbell shared his experiences of relapse and how he came to realise that his psychosis is “temporary” and that after treatment he will get better. This seems to be articulated in the quote below:

*“I think I am now less afraid cause every time I have recovered I have got back, got back to normal and so I think well if it happens again there is no reason why you know, some point I will get released after I get the treatment and I will be okay again...So there is always that positive aspect of it that you can recover and it is not something that is going to be detrimental to your life” (Pg 24, Ln 583).*

Fiona reflected on attending a hearing voices group and how this has helped her to feel “less ashamed” of her experiences. Receiving support from other service users and mental health professionals seems to have helped her to process and come to terms with her difficult experiences:

*“I always felt really ashamed of it but through knowing that other people went through very similar things and there are lots of people out there, I realised that maybe I wasn’t that there wasn’t really anything wrong with me, it’s just the way I am really, lots of people do have these experiences” (Pg 29, Ln 710).*

Whilst these experiences are still painful all of the participants articulated a developing sense of hope and optimism:

*Stephen: “Just because I know it is something that happens to quite a lot of people and I know now that people have actually recovered and gone on to lead normal lives” (Pg 4 , Ln 88).*

For the five participants who had experienced relapse there was also a change over time in the strategies they used to try and regain control of their lives. These strategies developed from a desire to “escape” and “run away” from their experiences to more approach oriented coping strategies. This highlighted the importance of taking responsibility for their own recovery and it provided a better insight into individual resilience. For example, Jill reflected on the integration of her two selves (“well me” and “ill me”) and how she was now able to accept her illness as being part of her self. This change seems to have developed as she has been able to process and integrate the painful aspects of her experiences:

*“I would have said that the two things have become more merged, it’s not like there is a well me and an ill me, it’s not so dramatic, I want to talk about it now, I want to sort it out and not just run from it and forget about it and push it away” (Pg 12, Ln 293).*

Kim reflected on how she is now more accepting of the input she receives from mental health professionals. This change seems to have developed as she has come to realise that she no longer needs to “escape” from her experiences:

*“...you get peace but you can get that way with outside help now, I know that now, I used to not know that, if I go into hospital it helps me because you have got the input of all the nurses sorting your medication and actually they are no going to judge you” (Pg 11, Ln 275).*

Campbell shared his experiences of mountaineering and rock climbing and he reflected on the importance of these activities in helping him to feel less withdrawn and more in control of his experiences:

*“But what helped me was ehm I went rock climbing and I met this guy who was into it and he introduced me to a mountaineering club...and that helped a lot cause that focuses your mind...so it kinda suppressed all these strange behaviours and strange thoughts and it got pushed to one side and it did help me” (Pg 7, Ln 157).*

For the two participants who had not experienced a relapse they understandably appeared to be at a different stage in this process of adaptation. Although they were beginning to develop an understanding of their illness there was a clear sense that they were still struggling to process and come to terms with their distressing and disorientating experiences. Tom reflected on his ongoing struggle:

*“I mean you can spend the rest of your life thinking about this and it would just eat you up, easily. But I can’t do that, I won’t let it do that. I am just not going to think about, I just want, that’s part of my life, one year of my life I just want to put behind me. And forget about cause it’s just too hard.” (Pg 14, Ln 342).*

The emotional impact of their experiences was still extremely raw and both Mary and Tom articulated a powerful and enduring fear of relapse:

*Mary: “Just the thought of ever going back there it’s just horrible, absolutely horrible, I mean I spent most of my time crying, feeling very, very depressed” (Pg 8, Ln 200).*

In contrast to the participants who had experienced relapse Mary and Tom shared their ongoing desire to “escape” and “forget” about their experiences. It seemed as though they both wanted to get as far away from their experiences as possible as though the pain and trauma was still too difficult for them to cope with. Mary talked about her ongoing struggle to accept her experiences:

*“I have this label just now as having mental health troubles and I am desperate to off load it, I am desperate to feel 100% and no have to use the resource centre, have to have people out visiting me or have to be taking medication” ( Pg 14, Ln 328).*

## **Discussion**

Participants’ lived experiences of psychosis and relapse were explored in this study. This was achieved through the interviewing of seven participants who had experienced psychosis and analysis of their transcripts using Interpretative Phenomenological Analysis. The participants were aged between 27-44 years of age and they were recruited from a Community Mental Health Team within NHS Ayrshire and Arran.

This research study set out to develop an in-depth understanding of service users’ perspectives and experiences of relapse in psychosis and the meaning they attach to these experiences. Although participants talked about their feelings and experiences of relapse this was not the dominant story that emerged from the analysis as participants were more interested on reflecting on the course and development of their illness. For this group of participants the opportunity to come along and participate in a study about relapse became an opportunity to explore important experiences and meanings that have arisen in the context of their recovery from psychosis. Much of the content of the themes therefore is not related to relapse but a career of being ill and wider experiences related to recovery.

All of the participants had their own individual story to share and they used the interview process to actively construct and make sense of their experiences.

Four emergent themes were identified and were labelled using participants' words: "*You just have no control over your life*", "*You come out running*", "*It's heart wrenching*" and "*Coming to terms with my experiences*". Although the themes were presented separately a full appreciation of each individual theme is best understood within the context they provide each other. It is important therefore to explore the interconnections within and between the themes.

Taken together the four emergent themes illuminate the complexity of individuals' experiences and they reveal the developmental process of their emotional, psychological and interpersonal adaptations to psychosis. Participants described a painful and difficult process of how they respond to and make sense of their very frightening and stigmatising experiences. Participants reflected on the emergence of their psychosis and the associated disruption to their lives. They talked about a loss of control which was reflected in a number of experiences, including the psychosis itself, involuntary hospitalisations and enforced treatment regimes. They all reflected on their experiences of loss; loss of the dreams they had envisioned for themselves, loss of hopes and aspirations, loss of valued friendships and a loss of identity. The emotional and interpersonal impact of these experiences were devastating as they described feelings of isolation, anger, shame and depression.

In order to cope with the awfulness of these experiences participants reflected on their initial immediate responses to the emergence of their psychosis. At this stage in their recovery they all articulated a desire to escape and runaway from the devastation of what had happened to them. They reflected on how terrifying their initial experiences had been

and a number of participants shared how painful it was to acknowledge their illness as being a part of them. This response seemed to be protective in some way as it allowed them to separate themselves from the devastating impact of what had happened. Although they tried to get as far from their experiences as possible they appeared to be caught up in a struggle to process and find meaning in their experiences and this resulted in predominantly painful affect. This personal struggle was further complicated by their fear of being negatively evaluated and stigmatised by other people.

After the initial confusion and disorientation the participants described a process of adaptation in which they tried to make sense of their experiences and this appeared to develop and change over time. This developmental process was reflected in the diversity between the transcripts of those who had experienced relapse as compared to those who had not. For the five participants who had experienced relapse they described a process in which they worked through their painful experiences, developing a sense of hope and optimism. This was reflected in participants coming to terms with the recurring nature of their experiences, feeling less afraid of their experiences and beginning to process undesirable feelings (painful affect). Participants articulated a desire talk about their experiences, an acceptance of outside help and taking responsibility for their own recovery. Participants described feeling less isolated and withdrawn and more in control of their lives. For the two participants who had not experienced a relapse there was a sense that they were still struggling to process their distressing experiences and they understandably appeared to be at a different stage in this process of adaptation.

All of the participants' experiences and meanings were embedded in the context of their recovery from psychosis and taken together the themes mirror a developmental process that you might expect in the course of a relapsing illness. For this group of participants the opportunity to come along and participate in a study about relapse became an opportunity

to reflect on important experiences in their wider story. This change to the agenda uncovered important and unexpected insights into the individuals' lived experiences, highlighting the importance of staying open to new insights from participants. Remaining participant led at all times enabled the principal investigator to explore enlightening areas that had not been predicted by the interview schedule. This illustrates the importance of the interview being guided by the schedule rather than dictated by it. The participant is considered to be the experiential expert and should therefore be 'allowed maximum opportunity to tell his or her own story' (Smith & Eatough, 2007, p.42). Whilst the principal investigator remained mindful of the aims of the study she allowed the interview schedule to evolve in line with participants' own stories. All of the participants were asked the same initial question ("As a person can you tell me a little bit about your interests?") and the rest of the interview became informed by the participants' responses. They immediately talked about their experiences of psychosis and this enabled the principal investigator to follow up and explore (using prompts) important topics brought by the participants. During each interview the majority of the questions on the interview schedule were explored at some point, however the order of the questions changed depending on the individual participant.

This study provided rich qualitative data that contributes to the growing body of literature on adaptation and recovery in psychosis and it highlights the therapeutic importance of developing coherent stories and narratives. The findings from the study also contribute to the growing body of literature on the emotional and interpersonal impact of psychosis. Participants' narratives shared similar findings with literature that has found evidence of a loss of control attached to psychotic experiences (Rooke & Birchwood, 1998), trauma (Morrison, 2003), disempowerment (Rooke & Birchwood, 1998; Birchwood et al., 1993) and stigma (Knight et al., 2003). The findings of the study are consistent with research that suggests that psychosis and relapse are critical life events that are often characterised

by feelings of entrapment, loss and a sense of danger (Gumley & Schwannauer, 2006; Iqbal et al. 2000).

Participants' accounts provided support for the growing literature that suggests that recovery is a dynamic process that does not simply mean the absence of symptoms or a return to the former self (Brown & Kandirikirira, 2007). Participants' recovery narratives shared similar themes with the existing qualitative literature which highlights the importance of acceptance, understanding of the self, empowerment, making sense of experiences and hope (Andresen, Oades & Caputi, 2003; Pitt, Kilbride, Nothard, Welford & Morrison, 2007; Perry, Taylor & Shaw, 2007; Smith, 2000).

The current study suggests that how individuals talk about and make sense of their experiences is an important part of recovery. Reconstructing a coherent, meaningful story of their experiences allowed participants to work through their painful experiences developing a sense of hope and optimism. This supports research which suggests that narratives can provide a unique insight into psychotic experiences and the individual process of recovery (France & Uhlin, 2006). The findings from the study introduce ideas around resilience and how we might begin to formulate individual resilience in the context of recovery from psychosis.

The study findings suggest that recovery involves a number of stages and this is consistent with other qualitative research that highlights recovery as a developmental process (Andresen et al., 2003). Five studies have identified phases or stages in the recovery process (Baxter & Diehl, 1998; Davidson & Strauss, 1992; Pettie & Triolo, 1999; Spaniol, Wewiorski, Gagne & Anthony, 2002 & Young & Ensing, 1999) and although there is no consensus on the exact delineation of the stages, an emerging pattern of themes have been identified. Andresen et al. (2003) conceptualised the findings of these studies into a five

stage model of recovery. These five sequential stages move from moratorium, a time characterised by denial, confusion, hopelessness, identity confusion and self-protective withdrawal through to awareness, preparation and rebuilding to growth. Growth is characterised by hope, resilience and a positive sense of self.

The study findings highlight that an individual's recovery style can develop and change over time and this was illustrated in the developmental change in some of the participants' coping strategies. In response to their first episode of psychosis all of the participants described a recovery style that involved running away and escaping from their experiences. This seemed to have a protective function as it allowed participants to separate and segregate themselves from the devastating impact of their experiences. Jackson et al. (1998) suggests that this recovery style may reduce difficult emotional states and maintain psychological equilibrium at these early stages.

For the five participants who had experienced relapse there seemed to be a powerful change in the meanings that they attached to their experiences and this seemed to develop in response to the realisation that they could no longer run away or escape from what had happened to them. As this realisation and self-awareness started to develop they spoke about an acceptance of their illness, a need to be more open about their experiences, the importance of taking responsibility for their own recovery and a sense of hope. This change in their recovery style seemed to develop as they began to process and integrate the painful aspects of their experiences. This theme provides support for the growing literature which suggests that recovery style is not a stable personality trait (Thompson, McGorry & Harrigan, 2003).

### *Clinical implications*

The findings from this study help us to think about how we can best promote and support individuals emotional and interpersonal recovery from psychosis. Recovery is a developmental process that needs to be nurtured and services need to adopt an optimistic and hopeful recovery oriented model that communicates the message that recovery from psychosis is possible. This message needs to be shared with service users, their families and friends and the wider community as a whole. Services need to adopt a person centred, individualised approach that encourages individuals to actively participate in their recovery, allowing them to regain a sense of empowerment, autonomy and control. Services should encourage individuals to share their experiences with other service users as this can promote recovery by engendering hope, self-awareness and reducing stigma and isolation. Stigma is a barrier to recovery and should be challenged at every opportunity and mental health awareness needs to be encouraged at all levels (Brown & Kandirikirira, 2007).

The findings from this study support the recent development of an integrative cognitive interpersonal approach to recovery and relapse prevention. This formulation based psychological therapy incorporates a number of treatment strategies which are designed to facilitate emotional recovery from psychosis, the prevention of psychosis recurrence and optimal interpersonal and social development (Gumley & Schwannauer, 2006). This psychological approach suggests that in order to support recovery it is important to identify how individuals construct and understand their experience of psychosis. This information allows the therapist to tailor the intervention to the current recovery style of the individual client. The therapist then helps the client to construct a narrative account that enables them to explore new meanings and resolutions, alternative helpful beliefs and appraisals and the development of adaptive coping and interpersonal behaviours. Coherent narratives are

encouraged as a way of capturing and exploring important meanings and overcoming paranoid states of mind or an avoidant and sealing over recovery style (Gumley, 2007).

### *Limitations*

There are some limitations with this study which are important to acknowledge. Firstly, the findings from this study can not be generalised due to the small sample size. The purpose of this study however was not to obtain knowledge that can be generalised but rather an in-depth knowledge about the phenomenon under investigation. This study aimed to provide a voice to a group of people who do not typically have a strong voice. Secondly, it is important to recognise that the four main themes identified in this study are only one interpretation of the data. It is possible that another researcher with different interests, personal characteristics and theoretical beliefs could have interpreted the transcripts in a different way. Jordan (2007) reflected on this contentious issue concluding that multiple coherent interpretations of the same data are possible as it illustrates a unique interaction between the individual researcher and the participants.

### *Conclusions*

In conclusion, the emergent themes illuminated the complexity of individuals' experiences and the developmental process of their emotional, psychological and interpersonal adaptations to psychosis. The findings from this study, together with previous research, suggest that in order to support recovery it is important to identify how individuals construct and understand their experiences of psychosis. Examination of our themes may provide a valuable foundation from which to conduct further empirical and qualitative research.

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Table 1: Participant characteristics at time of interview

| Participant | Gender | Age | Relationship Status | Living status       | Employment status | Diagnosis              | Number of relapses |
|-------------|--------|-----|---------------------|---------------------|-------------------|------------------------|--------------------|
| Campbell    | Male   | 41  | Single              | Living with parents | Unemployed        | Paranoid Schizophrenia | 5 +                |
| Tom         | Male   | 35  | Married             | Independent         | Unemployed        | Psychosis              | First episode      |
| Mary        | Female | 39  | Single              | Independent         | Volunteer         | Psychosis              | First episode      |
| Fiona       | Female | 41  | Boyfriend           | Living with parents | Unemployed        | Affective psychosis    | 5 +                |
| Stephen     | Male   | 27  | Single              | Independent         | Unemployed        | Schizophrenia          | 4                  |
| Kim         | Female | 44  | Single              | Independent         | Unemployed        | Affective psychosis    | 6                  |
| Jill        | Female | 32  | Separated           | Independent         | Volunteer         | Paranoid schizophrenia | 6 +                |

Table 2: Level of comfort before and after the interview

| Participant Name. | Comfort level before interview. | Comfort level after interview. |
|-------------------|---------------------------------|--------------------------------|
| Campbell          | 7                               | 8                              |
| Stephen           | 6                               | 7                              |
| Fiona             | 7                               | 9                              |
| Mary              | 7                               | 7                              |
| Tom               | 8                               | 8                              |
| Jill              | 7                               | 7                              |
| Kim               | 8                               | 8                              |

## Appendix 1.1: Manuscript Submission Guidelines



CLINICAL PSYCHOLOGY REVIEW: **Guide for Authors**

**SUBMISSION REQUIREMENTS:** Authors should submit their articles electronically via the Elsevier Editorial System (EES) page of this journal (<http://ees.elsevier.com/cpr>). The system automatically converts source files to a single Adobe Acrobat PDF version of the article, which is used in the peer-review process. Please note that even though manuscript source files are converted to PDF at submission for the review process, these source files are needed for further processing after acceptance. All correspondence, including notification of the Editor's decision and requests for revision, takes place by e-mail and via the Author's homepage, removing the need for a hard-copy paper trail. Questions about the appropriateness of a manuscript should be directed (prior to submission) to the Editorial Office, details at URL above. Papers should not exceed 50 pages (including references).

Submission of an article implies that the work described has not been published previously (except in the form of an abstract or as part of a published lecture or academic thesis), that it is not under consideration for publication elsewhere, that its publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out, and that, if accepted, it will not be published elsewhere in the same form, in English or in any other language, without the written consent of the Publisher.

**FORMAT:** We accept most word processing formats, but Word, WordPerfect or LaTeX are preferred. Always keep a backup copy of the electronic file for reference and safety. Save your files using the default extension of the program used.

Please provide the following data on the title page (in the order given).

*Title.* Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.

*Author names and affiliations.* Where the family name may be ambiguous (e.g., a double name), please indicate this clearly. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name, and, if available, the e-mail address of each author.

*Corresponding author.* Clearly indicate who is willing to handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that telephone and fax numbers (with country and area code) are provided in addition to the e-mail address and the complete postal address.**

*Present/permanent address.* If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

*Abstract.* A concise and factual abstract is required (not exceeding 200 words). This should be typed on a separate page following the title page. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separate from the article, so it must be able to stand alone. References should therefore be avoided, but if essential, they must be cited in full, without reference to the reference list.

**STYLE AND REFERENCES:** Manuscripts should be carefully prepared using the Publication Manual of the American Psychological Association, 5th ed., 1994, for style. The reference section must be double spaced, and all works cited must be listed. Please note that journal names are not to be abbreviated.

Reference Style for Journals: Cook, J. M., Orvaschel, H., Simco, E., Hersen, M., and Joiner, Jr., T. E. (2004). A test of the tripartite model of depression and anxiety in older adult psychiatric outpatients, *Psychology and Aging*, 19, 444-45.

For Books: Hersen, M. (Ed.). (2005). Comprehensive handbook of behavioral assessment (2 Volumes). New York: Academic Press (Elsevier Scientific).

**TABLES AND FIGURES:** Present these, in order, at the end of the article. High-resolution graphics files must always be provided separate from the main text file (see <http://ees.elsevier.com/cpr> for full instructions, including other supplementary files such as high-resolution images, movies, animation sequences, background datasets, sound clips and more).

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## Appendix 1.2: Extraction Proforma

First author and date:

Diagnosis:

### Section 1: Methodology

1. Are the aim(s) of the study explicitly stated?
2. Is appropriate demographic information about the sample provided?
3. Large sample size?
4. Was it a prospective, retrospective or cross-sectional study?
5. Were inclusion and exclusion criteria defined?

### Section 2: Measures

6. Is there a pre-existing coping measure used to investigate coping strategies? (If so what is it?)
7. Is reliability and validity data presented for the measure?

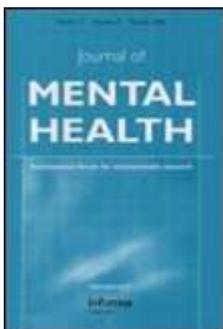
### Section 3: Results

8. Are the results presented clearly?
9. What are the identified coping strategies for early symptoms of relapse?
10. Are the coping responses clearly operationalised?

### Section 4: Discussion

10. Are clinical implications discussed?
11. Are the limitations of studies clearly expressed?

## Appendix 2.1: Manuscript Submission Guidelines



### Journal of Mental Health

### Instructions for Authors

Further information about the journal including links to the online sample copy and contents pages can be found on the [journal homepage](#).

*Journal of Mental Health* is an international journal adhering to the highest standards of anonymous, double-blind peer-review. The journal welcomes original contributions with relevance to mental health research from all parts of the world. Papers are accepted on the understanding that their contents have not previously been published or submitted elsewhere for publication in print or electronic form. See the [Evaluation Criteria of Qualitative Research Papers](#) and the [editorial policy document](#) for more details.

**Submissions.** All submissions, including book reviews, should be made online at Journal of Mental Health's [Manuscript Central site](#). New users should first create an account. Once a user is logged onto the site submissions should be made via the Author Centre. **Please note that submissions missing reviewer suggestions are likely to be un-submitted and authors asked to add this information before resubmitting.** Authors will be asked to add this information in section 4 of the on-line submission process.

The total word count for review articles should be no more than 6000 words. Original articles should be no more than a total of 4000 words. We do include the abstract, tables and references in this word count.

Manuscripts will be dealt with by the Executive Editor, Professor Til Wykes, Department of Psychology, Institute of Psychiatry, De Crespigny Park, London, SE5 8AF, United Kingdom. It is essential that authors pay attention to the guidelines to avoid unnecessary delays in the evaluation process. The names of authors should not be displayed on figures, tables or footnotes to facilitate blind reviewing.

**Book Reviews.** All books for reviewing should be sent directly to [Martin Guha](#), Book Reviews Editor, Information Services & Systems, Institute of Psychiatry, KCL, De Crespigny Park, PO Box 18, London, SE5 8AF.

**Manuscripts** should be typed double-spaced (including references), with margins of at least 2.5cm (1 inch). The cover page (uploaded separately from the main manuscript) should show the full title of the paper, a short title not exceeding 45 characters (to be used as a running title at the head of each page), the full names, the exact word length of the paper and affiliations of authors and the address where the work was

carried out. The corresponding author should be identified, giving full postal address, telephone, fax number and email address if available. To expedite blind reviewing, no other pages in the manuscript should identify the authors. All pages should be numbered.

**Abstracts.** The first page of the main manuscript should also show the title, together with a structured abstract of no more than 200 words, using the following headings: Background, Aims, Method, Results, Conclusions, Declaration of interest. The declaration of interest should acknowledge all financial support and any financial relationship that may pose a conflict of interest. Acknowledgement of individuals should be confined to those who contributed to the article's intellectual or technical content.

**Keywords.** Authors will be asked to submit key words with their article, one taken from the picklist provided to specify subject of study, and at least one other of their own choice.

**Text.** Follow this order when typing manuscripts: Title, Authors, Affiliations, Abstract, Key Words, Main text, Appendix, References, Figures, Tables. Footnotes should be avoided where possible. The total word count for review articles should be no more than 6000 words. Original articles should be no more than a total of 4000 words. We do include the abstract, tables and references in this word count. Language should be in the style of the APA (see *Publication Manual of the American Psychological Association*, Fifth Edition, 2001).

**Style and References.** Manuscripts should be carefully prepared using the aforementioned *Publication Manual of the American Psychological Association*, and all references listed must be mentioned in the text. Within the text references should be indicated by the author's name and year of publication in parentheses, e.g. (Hodgson, 1992) or (Grey & Mathews 2000), or if there are more than two authors (Wykes *et al.*, 1997). Where several references are quoted consecutively, or within a single year, the order should be alphabetical within the text, e.g. (Craig, 1999; Mawson, 1992; Parry & Watts, 1989; Rachman, 1998). If more than one paper from the same author(s) a year are listed, the date should be followed by (a), (b), etc., e.g. (Marks, 1991a).

The reference list should begin on a separate page, in alphabetical order by author (showing the names of *all* authors), in the following standard forms, capitalisation and punctuation:

a) For journal articles (titles of journals should *not* be abbreviated):

Grey, S.J., Price, G. & Mathews, A. (2000). Reduction of anxiety during MR imaging: A controlled trial. *Magnetic Resonance Imaging*, 18, 351-355.

b) For books:

Powell, T.J. & Enright, S.J. (1990) *Anxiety and Stress management*. London: Routledge

c) For chapters within multi-authored books:

Hodgson, R.J. & Rollnick, S. (1989) More fun less stress: How to survive in research. In G.Parry & F. Watts (Eds.), *A Handbook of Skills and Methods in Mental Health Research* (pp. 75-89). London:Lawrence Erlbaum.

**Illustrations** should *not* be inserted in the text. All photographs, graphs and diagrams should be referred to as 'Figures' and should be numbered consecutively in the text in Arabic numerals (e.g. Figure 3). The appropriate position of each illustration should be indicated in the text. A list of captions for the figures

should be submitted on a separate page, or caption should be entered where prompted on submission, and should make interpretation possible without reference to the text. Captions should include keys to symbols. It would help ensure greater accuracy in the reproduction of figures if the values used to generate them were supplied.

**Tables** should be typed on separate pages and their approximate position in the text should be indicated. Units should appear in parentheses in the column heading but not in the body of the table. Words and numerals should be repeated on successive lines; 'ditto' or 'do' should *not* be used.

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## Appendix 2.2: Participant Information Sheet



### Service User's experience of psychosis and relapse, Version 2, 10/09/07

#### Participant Information Sheet

I would like to invite you to take part in a research study. My name is Claire Maclean and I am a Trainee Clinical Psychologist. I am interested in learning about people's experience of psychosis and relapse. It was suggested you may be able to help me in this study. Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask me any questions that you might have.

#### **What is the research about?**

This research is about psychosis and relapse. Psychosis involves having unusual experiences which may include hearing voices when there is no-one there or 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 number of people will go on to have a relapse. A relapse means having a return of unusual experiences.

In this study I would like to understand people's individual experiences of psychosis and relapse. I am interested in how people feel about relapse. I am interested in what it is like to experience a relapse and how people cope with it. I also want to find out about people's experiences of getting better.

If we learn more about your experiences of psychosis and relapse, it may help us make changes and develop services.

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

We are asking people who have experienced psychosis to take part in this study.

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

No you do not have to take part in this study. It is completely up to you to decide whether or not you want to take part. If you decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. The consent form is a way of making sure you know what you have agreed to. If you decide to take part you are still free to withdraw at any time and you do not have to give a reason.

### **What will happen next?**

If you decide to take part you can contact me and we can arrange to meet up for an initial chat. You are welcome to bring a friend, family member or your keyworker with you. If you still want to take part you and I can meet and have a discussion that is likely to last approximately an hour, although this can be flexible, depending on how you find the experience. It may be useful to meet on a second or third occasion, but we can decide about that after our first meeting.

### **What do I have to do?**

If you would like to take part please contact me directly on the number above.

At our first meeting I will answer any questions or concerns you may have. I will be asking if the meeting(s) can be recorded on a digital recorder. I will show you the equipment and demonstrate how it works before starting recording. You are free to stop the recording at any time during the interview(s). I will then ask about your experience of psychosis and relapse.

There are no right or wrong answers. It is your own experiences that I would like to hear.

### **Why are the interviews being recorded?**

I need to record the interviews to carefully understand your experiences and our conversation. All information will be kept strictly confidential. During our conversation I will check with you that I have understood correctly, and later I will provide you with written feedback to further check I have understood your perspective. I will write up every interview removing all identifiable information and will destroy the tapes afterwards. Quotations from the interview may be used in my report at the end.

### **What is the down side of taking part?**

It is possible that our meeting(s) may cover topics that are difficult or distressing for you to talk about. However if this is the case you can end the interview at anytime or just take a break.

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

There are no direct benefits to you of taking part. The information we learn from this study will help to plan future research and develop new psychological therapies for people who experience psychosis. This study will provide new knowledge and a new view to meeting the needs of this client group.

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

Yes.

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

I will provide you with a summary of the results of the study. The final results and conclusions of the study will be published in a scientific journal and will form part of my qualification in Clinical Psychology. Your name or any identifiable information unique to you will not be included in any publication.

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

The University of Glasgow.

**Who has reviewed the study?**

The study has been reviewed by the Department of Psychological Medicine at Glasgow University to ensure that it meets important standards of scientific conduct and has been reviewed by Ayrshire and Arran's Research Ethics Committee to ensure that it meets important standards of ethical conduct.

Thank you very much for reading this and for any further involvement with this study.

## Appendix 2.3: Participant Consent Form



### **CONSENT FORM**

Title of Project: Service User's experience of psychosis and relapse.  
Version number 2, 25/09/07.



Please Initial

Box

I confirm that I have read and understood the information sheet for the above study and have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason, without my medical care or legal rights being affected.

I give consent for the researcher, Claire Maclean, to access my case notes in order to obtain information regarding my diagnosis.

I understand that the interview will be tape recorded solely for the purposes of the research study as described in the Participant Information Sheet.

I understand that the researcher may publish direct quotations, after the interview has been transcribed, and all names, places and identifiers have been removed.

I give consent for the researcher to contact my GP and Consultant Psychiatrist to let them know of my participation in this study.

I agree to take part in the above study.



Name of participant:

Researcher:

Date

Date:

Signature:

Signature:

## Appendix 2.4: Interview Schedule

### Rough Guide-Not verbatim/Follow the lead of the individual participant.

"Before we start I would like to thank you for agreeing to meet with me. As you are aware my name is Claire Maclean and I am a Trainee Clinical Psychologist working in Ayrshire and Arran. Today I would like to spend some time talking to you about your experiences of psychosis and relapse and how you feel about these experiences. There are no right or wrong answers and if you would rather not answer a question please just let me know".

I will explain that the interview will last no longer than an hour but that we may need to meet up again in order to get a good understanding of their experiences. I will also explain that I would like to meet up with them when I have finished the research in order to tell them about my findings. I will then explain the Likert Scale and reiterate the fact that they can stop the interview at any time (In order to monitor any changes in participants comfort, this will be monitored before and after each interview using a subjective 10 point likert scale with 1 being "not at all comfortable" and 10 being "extremely comfortable").

"During our interview it is important that I listen to you very carefully so I am planning on recording the interview (show the equipment and give the participant the opportunity to examine the digital recorder). Only I will listen to the tapes and I will keep them safely locked in a filing cabinet in my office. Are you happy for me to record our interview? (If participant consents I will start recording). Any questions? "

Reiterate that it is their individual experiences that I am interested in understanding!!!

"Now that you know a little bit more about me and what I am interested in I would like to begin by finding out some more about you".

### **Topic Guides (not rigid):**

#### **Getting to know them:**

As a person could you tell me a little bit about your interests?

#### **1. Experiences of mental health services (interested in their experiences of psychosis to help set the scene):**

Could you describe the experiences that led to you becoming involved with mental health services? (CMHT).

#### **2. Relapse:**

- What does the word relapse mean to you?
- Could you describe any experiences you have had where your problems have come back?
- How would you describe this experience?

\*\*How do you think these experiences that we have been talking about today might have affected your life/or not?

**“Now we are going to move on and talk about other areas in your life, in particular your recovery from psychosis. We might have covered some of this earlier but to begin”....**

### **3. Recovery:**

- Can you tell me about some things that have helped your recovery?
- Can you tell me about some things that have made your recovery difficult?
- How do you think about your future?

Prompt:

- Relationship with family
- Relationship with friends
- Specific experiences

- Finally, is there anything I haven't asked you that you wished I had?

Example Probes for all of the above questions:

Can you tell me more about that?

Can you give me an example of that?

What did you think about that?

How did you feel about that?

What did that mean for you?

Can you tell me a little bit more about that?

In order to access specific autobiographical memories, participants will be asked questions such as “can you give me a specific example of what you mean?” “Can you remember a specific memory to describe what you are saying?”

## HOW DO YOU FEEL?

Place a circle around the number from the scale below to show how comfortable you feel just at the moment.

Not at all

Moderately

Completely

0 1 2 3 4 5 6 7 8 9 10

Appendix 3: Major Research Proposal

Major Research Proposal:

An Interpretative Phenomenological Analysis of service user's perspectives on relapse in psychosis.

Name of trainee- Claire Maclean  
Research Supervisor-Dr Andrew Gumley  
Field Supervisor- Dr Janice Harper  
Date- 30/03/07

### Structured abstract of project

The proposed research aims to explore adults' experiences of psychosis and relapse and the meaning they attach to these experiences. Specifically what meanings do service users attach to relapse and what are the implications of these meanings for service users' adaptations to psychosis? There are currently a number of psychological models in this area which suggest that fear of recurrence may play a role in individuals' experiences of psychosis and relapse. It has been suggested by some researchers that fear of recurrence may even be a precursor to relapse (Gumley, White & Power, 1999). Although we cannot rule this out we are as yet unable to confirm these claims for two reasons. Firstly, the evidence supporting these findings was generated predominantly from psychological models and secondly, there is an obvious lack of qualitative and phenomenological literature in this area. Empirical evidence to support fear of recurrence as an important clinical construct is therefore not yet well established. In order to investigate this further we need to explore a phenomenological account based on meanings attached to relapse as constructed by individuals who have experienced psychosis.

In-depth interviews will be employed to explore adults' experiences of psychosis and relapse and the meaning they attach to these experiences. The interviews will be analysed using Interpretative Phenomenological Analysis (IPA). A deeper understanding of individuals' experiences will offer insights into ways in which clinicians may best support this group of vulnerable adults.

## Introduction

### **Background:**

Relapse is the medical term used to describe the recurrence of an episode of an illness or the exacerbation of illness symptoms that are partially remitted (Gumley, Karatzias, Power, McNay & O'Grady, 2006). Relapse is potentially a devastating and disorientating life event that is often associated with increased emotional and psychological distress and impaired social, vocational and interpersonal functioning (Gumley & Schwannauer, 2006).

It has been proposed by Herz & Melville (1980) that fear of relapse is a precursor to actual relapse. In their study they completed detailed interviews with 145 patients and families and found that the majority of both groups detected non-psychotic changes preceding relapse. The early signs most commonly reported were the non-specific signs of nervousness, increased tension and an alteration of sleep and appetite. According to Hirsch & Jolley (1989), experiences associated with early signs of relapse include fear of losing control, puzzlement and perplexity and fear of going crazy. From a cognitive perspective these appraisals represent an individual's response to signals towards the possible (but not inevitable) recurrence of psychosis (Gumley et al., 1999).

A model of relapse proposed by Thurm and Haefner (1987) describes the individual as an active agent, using coping strategies to decelerate or forestall the process of relapse. Birchwood (1995) proposed a two-process model of relapse. He suggested that anxiety and depression are responses to the fear of an impending relapse or a failure to explain symptoms and experiences. Birchwood (1998) proposed that depression following psychosis may be linked to appraisals of psychosis and perceived implications of psychosis for the self. Iqbal, Birchwood, Chadwick & Trower (2000) found that individuals with

post psychotic depression experienced greater loss, humiliation and entrapment arising from their psychosis and they were more likely to attribute the cause of their illness to the self (self-blame). They also had lower self-esteem and were more self-critical than non-depressed individuals.

Gumley et al. (1999) suggest that relapse is the result of a psychological process involving individuals' appraisal of their own experiences. The focus of this model is the idea that individuals have extremely negative and catastrophic appraisals of relapse and ultimately the consequences of relapse. These appraisals are understandable given the highly disorientating and distressing nature of psychosis. They suggest that some appraisals may produce a fear of relapse and that this may generate a state of elevated vigilance and threat monitoring. Gumley et al. (under review) found that individuals' appraisals of fear of relapse were as sensitive to relapse as dysphoric and low-level psychotic symptoms.

More recently Gumley & Macbeth (2006) have proposed a trauma-based psychological model of relapse. This model suggests that low-level psychotic experiences or cognitive perceptual events that share similarities with previous episodes of psychosis (for example, unusual thoughts, headaches, paranoid thoughts and sensory experiences) create a sense of reliving for the individual. This experience of reliving is reinforced by intrusive autobiographical memories of previous experiences of psychosis. It is proposed that this leads to the activation of negative, catastrophic threat beliefs resulting in emotional distress and affect dysregulation. Individuals' attempts to manage this experience may lead to the acceleration of relapse.

Although limited there has been some qualitative research, which has investigated individuals' experiences of psychosis and relapse. Baker (1995) investigated whether individuals who suffer from schizophrenia are able to detect early signs and symptoms of

relapse. Among other things she found that individuals begin to fear relapse and they try to limit the negative impact of their illness by monitoring for signs of early relapse.

The above empirical findings are undoubtedly fascinating and they have clearly made a significant contribution to the psychosis evidence base. The current literature appears to suggest that fear of recurrence may play a role in individual's experience of psychosis and although we cannot rule this out we are as yet unable to confirm these claims for two reasons. Firstly, the evidence supporting these findings was generated predominantly from psychological models and secondly, there is an obvious lack of qualitative and phenomenological literature in this area. Empirical evidence to support fear of recurrence as an important clinical construct is therefore not yet well established.

At this stage we cannot presume that the construct (fear of recurrence) is actually present and we do not have enough evidence to predetermine hypotheses. In order to be able to get closer to individuals' experiences of psychosis and relapse we need to develop an experiential based account. A qualitative, specifically phenomenological exploration of individuals' experiences of psychosis may provide a deeper understanding of how these individuals make sense of their experiences and what meanings they attach to relapse.

Interpretative Phenomenological Analysis (IPA) was the chosen approach as it aims to capture and explore the experiences of the individual without testing hypotheses or making prior assumptions about the meaning of the topic being investigated (Reid, Flowers & Larkin, 2005).

IPA enables individuals to describe their experiences in a way which ensures that they do not lose their essential quality. Their lived experiences can be reported in such a way as to provide new knowledge and a new view to meeting the needs of this vulnerable client

group (Reid et al., 2005). Finally and perhaps most importantly IPA provides a voice to a group of people who do not typically have a strong voice (Larkin, Watts & Clifton, 2006).

### **Aims:**

This study aims to use qualitative methods to investigate clients' experiences of psychosis and relapse and the meaning they attach to these experiences. Specifically what meanings do service users attach to relapse and what are the implications of these meanings for service user's adaptations to psychosis? In-depth interviews eliciting memories and experiences of psychosis and relapse and subsequent IPA will be used to achieve these aims.

### **Plan of investigation:**

#### **Participants and Recruitment**

A purposive selection of adults will be undertaken whereby specific individuals will be recruited due to their potential for adding to the understanding of psychosis and relapse. All participants will be aged 16 years and above with a diagnosis of schizophrenia or similar. Participants will be recruited from Community Mental Health Teams (CMHT) within Ayrshire and Arran. Participants interested in taking part in the study will be referred by their CMHT keyworker, individual therapist or Consultant Psychiatrist with agreement from their multi-disciplinary team.

The researcher is currently engaged in establishing relationships with possible referrers.

#### **Inclusion and Exclusion criteria**

All participants will be asked to give informed written consent. Individuals will be excluded if they are a non-English speaker, have organic brain disorder or presence of

significant learning disabilities. Where an individual's ability to give informed consent is compromised by acute psychosis they will be excluded until their recovery and mental state is stable.

### **Design and Procedures**

An in-depth interview will be constructed based on the aims of the study. A series of questions, which will be open-ended and non-directive, will be set up to explore the following areas:

- How do participants appraise their own experience of psychosis? Elicit episodic memories.
- How do participants describe relapse and how do they view it (what does it mean to them?).
- How do these meanings impact on subsequent adjustment and recovery?
  - Explore impact on affect and emotion.
  - Explore impact on behaviour (help seeking, safety seeking, coping).
  - Explore impact on interpersonal relationships.

The questions should function as triggers that will encourage participants to talk about their experiences. Focused and/or specific questions should be used to encourage participants to elaborate.

Each interview will last no more than an hour and further interviews may be undertaken in order to build rapport and gain a full understanding of their perspective. Initial interviews will inform recruitment. In order to monitor any changes in participants comfort levels, this will be monitored before and after each interview using a subjective 10 point likert scale with 1 being "not at all comfortable" and 10 being "extremely comfortable. Before

taking part in the study participants will be informed that they can withdraw their participation at any time.

Individuals approached to participate in the study will be provided with an information sheet and all participants will be asked to sign a consent form. Written informed consent will be obtained before each interview. All interview data will be transcribed. To ensure confidentiality the data will be anonymised.

### **Settings and Equipment**

Participants will be met and interviewed at Ayrshire Central Hospital or at an agreed health clinic local to the individual. A Sony digital voice recorder (ICD-V60 512mb) will be required for each interview. In addition, a computer with qualitative software (N-Vivo) will be needed for transcription purposes.

### **Sample Size Justification**

None required due to qualitative nature of this piece of work. In contrast to the random or representative sampling strategies of quantitative research, IPA studies focus on the detailed analysis of the experiences of small samples most suited to the research question (Smith & Osborn, 2003). Participants are recruited because they are experts in the phenomenon being explored and IPA allows participants' subjective thoughts and experiences of the topic to be investigated (Reid et al., 2005). Smith, Jarman and Osborn (1999) suggest that 10 participants is at the higher end of the recommended sample size for IPA.

### **Data Analysis**

The purpose of data gathering in qualitative research is to provide evidence for the experience it is investigating. The evidence is in the form of accounts people have given of the experience.

IPA has been selected to best answer the research question. IPA is "an attempt to unravel the meanings contained in accounts through a process of interpretative engagement with the texts and transcripts" (Smith, 1996, p.189). This results in a greater understanding of the phenomenon under investigation as based upon individuals' experiences (Willig, 2001). While having the aim of gaining an understanding of the world as it is perceived by participants IPA also acknowledges the active role of the researchers' own ideas and understandings in the process of making sense of the participants' experiences (Smith & Osborn, 2003).

IPA requires that subordinate and overarching themes are identified within and across transcripts through a process of reading and re-reading texts. Links are forged between the identified themes and these can then be viewed alongside information drawn from existing theories to gain an understanding of how psychosis and relapse is perceived and experienced by the individuals in the study (Smith, 1996). Interviews will be transcribed as soon as they have been completed and analysis will begin soon thereafter.

A proportion of the transcripts will be analysed by another researcher who uses IPA to ensure that similar themes are being uncovered and to allow for discussion of emerging themes.

***Personal reflexivity:*** This involves "reflecting upon the ways in which our own values, experiences, interests, beliefs, political commitments, wider aims in life and social identities have shaped the research. It also involves thinking about how the research may have affected and possibly changed us, as people and as researchers". (Willig, 2001, p.10)

Being aware of personal reflexivity is paramount to effective qualitative research and I will therefore undoubtedly need to reflect upon the interaction between myself and the participants involved in this study. This would need to be acknowledged during the analysis of the interview material as my interactions with the participants would have the potential to bias my interpretation of the interview data. To allow for the use of this additional data comprehensive notes will be taken following each interview. As discussed by Reid et al. (2005), participant-researcher interaction is a particular strength of IPA as this method explicitly acknowledges its influence in the analytic process.

### **Validity and Reliability**

According to Polkinghorne (2005), the validity and trustworthiness of qualitative research is related to “the selection of viable sources that promote a deepening of the understanding of the experiences inquired about” (p. 141). The purpose of a qualitative study and also of this study is to elicit in-depth knowledge about the phenomenon under investigation, not knowledge that can be generalized (Hallett, 1995).

This study aims to produce a rich and in-depth understanding of service users’ perspectives and experiences of relapse. It will provide a voice to service users who are not normally given the opportunity to tell their story and the findings will provide a foundation upon which further qualitative research can be carried out in the future.

### **Health and Safety Issues**

Taking into account the principal researcher’s experience (Trainee Clinical Psychologist) and the client group interviews will only take place at Ayrshire Central Hospital or within clinic space in the local area. Local health and safety protocols will apply and local supervision arrangements will support monitoring of these protocols. Interviews will be

carried out during working hours to ensure that there will always be another clinician in the building.

Participants' comfort levels will be assessed before and after the interviews to monitor any changes in their distress levels. There will be a four step protocol put in place if this happens:

1. Suspend interview.
2. Stay with them until their distress decreases.
3. If they remain distressed seek assistance from another member of clinical staff.
4. Contact their Keyworker or Consultant Psychiatrist.

Participants' non-verbal and verbal communications will also be observed to monitor any possible signs of tiredness or anxiety.

### **Financial Issues**

Travel expenses within Ayrshire and Arran will be covered by the health board. A Sony digital recorder will need to be purchased at the cost of approximately £99.99.

### **Timescale**

- Major Research Proposal- 30<sup>th</sup> March 2007.
- Systematic Review Outline- 30<sup>th</sup> March 2007.
- Ethical approval to be obtained by September 2007.
- Recruitment to commence in October 2007.
- Data collection to be completed by the end of April 2008.
- Draft of thesis to be completed by the end of June 2008.
- Submit research portfolio at the end of July 2008.

### **Practical Applications**

1. Develop a measure based on individual's experience of relapse.
2. Use individuals' experiences to develop and communicate an understanding with other users.
3. Use individuals' experiences and views of psychosis and relapse to help design a relapse prevention recovery programme.
4. This study will explore the utility of this methodology for future studies and provide hypotheses for quantitative investigation.

### **Ethical Approval**

Ethical guidelines are particularly important when the participants are vulnerable people, such as individuals recovering from psychosis (Koivisto, Janhonen & Vaisanen, 2003). According to Willig (2001), the same basic ethical considerations apply to the treatment of participants in both qualitative and quantitative research. Ethical approval will be sought from the Local Research Ethics Committee and the Ayrshire and Arran Clinical Governance Group. This study will follow the ethical considerations described by Elmes, Kantowitz & Roediger (1995), i.e. participants will be fully informed about the research procedure and give their consent to participate before data collection takes place; there will be no deception of participants in the study; they will be informed about the full aims of the study prior to data collection and complete confidentiality will be maintained throughout the research process. Written consent for participation and recording and transcribing of interviews will be sought from all participants. Consent to use and publish anonymised quotations will also be sought. If there is disclosure of risk to a participant or

their intention to harm others the researcher will inform their key worker or Consultant Psychiatrist.

There could be ethical issues viewed with asking keyworkers to refer their clients into the study. The nature of the therapeutic relationship for example could lead to individuals feeling coerced into taking part in the research. In order to avoid this we would need to have a very clear referral pathway which would indicate the exact role and responsibility of the individual keyworker.

In this study it will be very clear that the keyworker is there to inform potential participants of the study but not to coerce them into taking part. They will be asked to provide information sheets which will allow the individual to make an informed decision about taking part in the study. After reading the information sheet it would then be the responsibility of the individual client to contact the researcher for further information.

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