

SWINBURNE UNIVERSITY OF TECHNOLOGY

**Understanding Adaptation to First-Episode Psychosis: Trauma and Growth
Responses**

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ABSTRACT

It is generally accepted that psychosis is a traumatic experience that can lead to a shattering of one's beliefs about the self, others, and the world. First-episode psychosis (FEP) is an especially devastating experience as it usually occurs during adolescence and early adulthood, a crucial period in identity formation. To date, empirical investigations of the traumatic nature of psychosis have been confined largely to the impact of psychotic symptoms and negative treatment experiences as precipitants of a diagnosis of posttraumatic stress disorder (PTSD). However, understanding the traumatic nature of FEP need not be restricted to the experience of the acute episode but can be extended to adaptation to this experience during the recovery phase. Further, a comprehensive understanding of the traumatic nature of psychosis, especially FEP, needs to consider a broader trauma response which goes beyond the diagnosis of PTSD and incorporates potential positive outcomes.

To extend understanding of the traumatic impact of FEP and individuals' reactions to it, this research draws upon ideas of how people integrate and adapt to FEP. In clinical practice, recovery from FEP is predominately focused on restorative outcomes, which include ameliorating symptoms and replacing skill deficits. Yet, research suggests that recovery from psychosis is a dynamic and ongoing process in which people play an active role in. Authors have indicated that recovery from psychosis cannot be considered a return to prior health because the experience of psychosis has changed one's life permanently (e.g., Oades et al., 2005; Davidson, 2003). Instead, it is argued that people can engage in a process of searching for meaning and purpose which can result in fundamental change (e.g., Reeves, 2000). This suggests that constructive as well as restorative processes are relevant to recovery from FEP. Posttraumatic growth is a concept postulated to capture positive outcomes from traumatic experiences that can parallel the pain and anguish trauma can cause. Growth goes beyond a return to prior level of functioning and involves a transformation which exceeds what was present beforehand (Tedeschi & Calhoun, 2004). Five domains of posttraumatic growth have been proposed: a greater appreciation of life and changed sense of priorities; warmer, more intimate relationships with others; a greater sense of personal strength; recognition of new possibilities or paths in life; and spiritual and

existential development. This model is applied in the present research to provide a broader understanding of the traumatic impact of FEP and subsequent recovery.

The current thesis aimed to explore how people understand the experience of FEP and its potentially distressing, restorative, and constructive outcomes. A pilot study was conducted first with two men and one woman who had experienced a first occurrence of psychosis. Results of interpretative phenomenological analysis (IPA) suggested further investigation was warranted of a broader model of the trauma associated with FEP and subsequent recovery. In the subsequent main study ten people with first-episode psychosis (3 women & 7 men) participated and clinicians were also interviewed as well a loved one of eight participants. IPA of data from in-depth interviews supported the proposal that recovery from FEP can be conceptualised within a trauma framework and constructive changes are crucial in understanding the impact of FEP and subsequent recovery and adaptation.

In line with earlier research, the IPA data demonstrated the potentially traumatic nature of psychotic symptoms and negative treatment experiences. However unlike previous studies, this investigation highlighted that the traumatic nature of FEP is not contained to the acute episode and goes beyond the symptoms of PTSD to impact on one's identity, relationships, and world view. The interviews also showed that people engage in managing their experience of FEP in a range of ways which can be both adaptive and maladaptive. Further, FEP can bring about positive transformation and these constructive changes can be perceived as an element of recovery. Comparative analysis of four case studies pointed to the importance of understanding various ways FEP can impact on the person and the nature of constructive changes in the context of individual's explanatory model of FEP. The four case studies showed different levels of constructive processes and outcomes, which included both real and illusory constructive change. Interviews with loved ones showed the significant impact FEP can have on them, corroborating this broader view of the trauma response.

The data were used to develop a temporal model of the recovery process which offers pathways for future research directed at expanding our understanding of the impact of FEP, subsequent recovery and adaptation. Applying this model will also assist to identify further avenues for facilitating clinical practice with FEP clients and their loved ones.

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DECLARATION

I declare that this dissertation is my own account of my research and does not contain any work that has been previously submitted and accepted for the award to the candidate of any other degree or diploma at any institution, except where due reference is made in the text of the examinable outcome. To the best of my knowledge this thesis contains no material published or written by another person, except where due reference has been made in the text of the examinable outcome. The ethical principles for research as stipulated by the Australian Psychological Society, Alfred Hospital, Royal Melbourne Hospital, and Swinburne University of Technology have been adhered to in this research.

A handwritten signature in blue ink that reads "Jane Dunkley". The signature is written in a cursive style with a long, sweeping tail on the letter "y".

Jane Dunkley

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CHAPTER 1: INTRODUCTION AND OVERVIEW

First-episode psychosis (FEP) has been identified as a critical period and psychiatric crisis where early detection and intervention are imperative (Birchwood, 1999; McGorry & Young, 2003). First-episode psychosis can be particularly dramatic because it occurs at a young age and subsequently can significantly hamper developmental processes such as identity formation. The focus of this thesis was the process of recovery from FEP. It considers the trauma of this experience, specifically the distressing nature of psychotic symptoms and acute treatment as well as secondary consequences such as a shattered sense of self. A broader notion of recovery is examined, which includes restorative and constructive processes. Researching the distressing nature of FEP and recovery from this experience will further our understanding of how to implement early intervention and improve treatment adherence and clinical outcomes.

A trauma framework provides the most comprehensive understanding of individuals' experience and adjustment to FEP. Yet, the current application of the trauma framework in understanding the impact of psychosis has been restricted to the diagnosis of PTSD as a result of psychotic symptoms and acute treatment and the broad range of distressing experiences people can encounter both during the acute phase and the recovery process has not been acknowledged. The only study to investigate other secondary outcomes of psychosis in understanding the trauma associated with this experience found a range of significant stressors beyond PTSD symptoms (TARRIER, Khan, Cater, & Picken, 2007). Further, people experiencing a first occurrence of psychosis are likely to have numerous psychological reactions (Jackson & Iqbal, 2000) such as suicidal ideation (TARRIER et al.). A focus on a diagnosis of PTSD disregards the range of responses people can have to this experience and in turn discounts the distress experienced by individuals who do not go on to develop this disorder. Further, it does not consider *how* or *why* the experience of FEP is distressing. It fails to recognise the impact of psychosis on one's sense of self and world view, which is central to the conceptualisation of adjustment and adaptation to FEP (Jackson & Iqbal). Treatment difficulties with FEP patients may stem from inadequately addressing the traumatising nature of this experience, such as its impact on the individual's sense of self (Mueser & Rosenberg, 2003).

The trauma framework can also be applied to recovery and adaptation processes. Recovery models discuss the need for clients to engage in a meaning-making process, integrate their experience, and re-establish identity (e.g., Andresen, Oades, & Caputi, 2003; McGlashan, Dochery, & Siris, 1976). However, research examining recovery from psychosis, including FEP, has focused predominately on functional outcomes. A more comprehensive view of the trauma response should also include constructive processes and outcomes. A recent concept in the trauma literature which informs this study is posttraumatic growth. Posttraumatic growth considers the positive changes that can come about from trauma as well as parallel distress (Tedeschi & Calhoun, 2004). The study of constructive change following the experience of FEP has the capacity to provide greater depth of understanding about adaptation to first occurrence psychosis, as well as foundations for further therapeutic work and more effective clinical interventions. To date, no known study has researched potential constructive outcomes and processes in the context of recovery from FEP.

Understanding the personal meaning, significance, and trauma attached to FEP is critical for treatment aimed at enabling recovery from this experience (Gumley & MacBeth, 2006). Very few studies have investigated the subjective experience of trauma associated with FEP and those that do are not in-depth phenomenological studies (e.g., Shaw, McFarlane, & Bookless, 1997). Therefore, further research is required to better understand the subjective experience of FEP, including its traumatic impact over time (Jackson & Birchwood, 2006) and subsequent adjustment. An ideal study design for exploring the immediate and ongoing traumatic impact of FEP and subsequent recovery process is longitudinal and exploratory in nature. This study adopts an in-depth phenomenological approach to enable a focus on the individual's responses to the trauma and subsequent recovery, including potential transformative processes. A longitudinal method is also applied to allow adaptation to FEP to be tracked over time, enabling a comprehensive portrayal of the trauma, restorative and constructive processes and outcomes following a first occurrence of psychosis.

Thesis Overview

Chapter 2 first discusses the nature of FEP to provide context to the population being researched. Chapters 2 and 3 provide an overview of the literature in understanding the traumatic nature of psychosis and the recovery and adaptation process. Chapter 3 presents the concept of posttraumatic growth as an avenue for understanding the impact of psychosis and subsequent recovery and adaptation.

Initially in chapter 4 the researcher's personal reflection on the thesis topic is discussed to help the reader put the interpretations of the study's findings into perspective. Next a rationale for the methodology chosen is discussed. The qualitative approach Interpretative phenomenological analysis (IPA) was conducted to best meet the needs to this study. Interpretative phenomenological analysis is concerned with the subjective experience and addresses and understands the meaningful experiences of individuals through an interpretative process (e.g., Biggerstaff & Thompson, 2008). The validity of qualitative research is also discussed in this chapter.

Chapter 5 presents the pilot study and outlines the method of data collection and analysis and the research participants. Results from a pilot study are also reported in chapter 5 which includes the methodological changes made. Throughout this chapter findings are discussed in terms of potential clinical and theoretical implications.

Chapter 6 presents the main study and its methodology, which includes the changes implemented from the pilot research, and FEP participant characteristics. Chapter 7 reports the qualitative results of the group following the trajectory of the illness experience. Data from interviews with clinicians and loved ones are reported in order to provide further insight into the experience of FEP and to allow for triangulation of the data. Again, potential clinical and theoretical implications are discussed. Chapter 8 presents four case studies in order to provide a comprehensive understanding of the possible ways constructive changes can manifest during people's recovery from and adaptation to FEP. Qualitative data are integrated with interview data from clinicians and loved ones, as well as FEP participants' quantitative results. Lastly, chapter 9 provides group results on the loved ones' experiences of FEP as this was found to be pertinent in interviews with them and thus was considered important in furthering an understanding of the impact of FEP and

how people manage this experience.

The final chapter, chapter 10, provides a general discussion of the findings of the research according to the aim of the study and specific research questions. A model of understanding adaptation to FEP is presented which incorporates the findings and guides this discussion. Clinical and theoretical implications are addressed, as well as methodological issues and considerations for future research.

CHAPTER 2: PSYCHOSIS AS A TRAUMATIC EVENT

The nature of FEP is discussed to provide context to this illness prior to discussing it as a traumatic experience. The remainder of chapter 2 develops an argument that understanding the traumatic nature of FEP needs to go beyond considering the distress of the acute episode in the context of a PTSD diagnosis. Instead, it is argued that the interpretation of distress associated with FEP should be broadened to include the recovery phase of the illness and an understanding of the threat to one's sense of self, relationships with others, and worldview. It is argued that focusing on PTSD symptomatology restricts our understanding of the range of trauma reactions that can result from experiencing FEP. Detailed examination of the subjective experience permits an understanding how the illness impacts on the person.

Epidemiology of First-Episode Psychosis

According to ORYGEN Youth Health, Melbourne, Australia (2008a), about three out of every 100 young adults will experience a psychotic episode, making psychosis more common than diabetes in young people. Over a period of 4 years (1997-2000) the Early Psychosis Prevention and Intervention Centre (EPPIC) in Melbourne, Australia, completed a study looking at the incidence of treated FEP (Amminger et al., 2006). The service's catchment area has a population of approximately 880,000 and they are mandated to treat all individuals who present with FEP to public mental health services in this geographically defined area. At the time of Amminger et al's research the age range of EPPIC clients was 15 to 29 years. The study included all individuals assessed at EPPIC and identified as eligible to receive treatment for FEP. Over the four year study period, 2,087 individuals were assessed, 1,054 were given a provisional diagnosis of FEP, and 1,019 (687 men & 322 women) met the intake criteria for FEP during the first six weeks of treatment at EPPIC. Schizophrenia spectrum diagnoses accounted for 70-75% of diagnosis in men and 62-67% of diagnoses in women.

Psychosis manifests as a range of symptoms which include disorganised speech, thoughts, behaviour, delusions, and hallucinations. Disorganised speech is evident when the person's statements are not logically connected and the content of the speech usually does not make sense. Examples can include incoherence and loose associations. Disorders of thought, such as thought blocking, are often present and related to the former. Disorganised behaviour includes behaviour that is not goal-directed and can seem random and odd. Delusions are falsely held beliefs that cannot be influenced or corrected and are often characterised as bizarre and non-bizarre. Lastly, hallucinations involve sensory experiences that do not objectively exist such as hearing voices (Fauman, 2002). Psychosis is not a diagnosis itself, but can develop into more long-term and debilitating illnesses such as schizophrenia and schizoaffective disorder.

Rapid intervention for early psychosis is considered imperative with deterioration in symptoms and functioning occurring within 2-5 years after a FEP (Mueser & Rosenberg, 2003). Research indicates a high rate of recovery from FEP (e.g., Lieberman, 2002). For instance, Lieberman discovered that 73% of 118 people with FEP had fully recovered and 16% were partially remitted within 1 year, with a median response rate of 9 weeks. Yet, many individuals experience psychotic relapses within 5 years of an initial episode of psychosis (Birchwood, 2000). Gleeson (2004) reviewed 23 prospective studies examining relapse following FEP. A high relapse rate was identified in the 10 to 15 months following first onset psychosis, with relapse ranging between 60-96%. Similarly, Lieberman found that the cumulative relapse rate for 104 patients who had successfully recovered from their first episode was 81.9% at 5 years. Continuing research on the impact of FEP and subsequent adaptive processes is fundamental to working towards improving early intervention and decreasing relapse rates.

In the course of relapse people may not recover as well as after the initial episode, and are instead left with persistent symptoms and associated functional impairment and reduced responsiveness to treatment (Lieberman, 2002). Subsequently, people with FEP are at risk of developing an enduring mental illness. In Farrelly et al.'s (2007) research, 47% of participants had a psychotic disorder, predominately schizophrenia, 8 years after they were first diagnosed and treated for first onset psychosis. A number of factors have been identified which influence remission and treatment response from FEP. These include

gradual onset (e.g., Lieberman; Röpcke & Eggers, 2005), shorter duration of illness, lower baseline severity of symptoms (e.g., Lieberman), duration of untreated psychosis (e.g., Lieberman; Lincoln & McGorry, 1999; Simonsen et al., 2007), pre-morbid functioning/adjustment, age at onset, sex (e.g., Malla et al., 2006, Simonsen et al.), treatment, and place of origin (e.g., Menezes, Arenovich, & Zipursky, 2006).

First-episode studies suggest that men have a poorer outcome (Simonsen et al. (2007), and the early age of onset is associated with more severe illness (Röpcke & Eggers, 2005). The incidence of FEP in the EPPIC study was about twice as high in men than women and the mean age at hospital admission was 21.9 years (men) and 22 years (women) (Amminger et al., 2006). The preponderance of FEP was highest in men who were aged 20-24 and the risk of developing FEP for men was significantly higher in this age range. Incidence of this illness was significantly higher in the 15-19 and 20-24 age groups for women, with the risk being highest in the 15-19 age range (Amminger et al.).

People who have had a first onset of psychosis often meet the criteria for other Axis I psychiatric disorders, which can influence the course of the co-morbid psychotic disorder (Farrelly et al., 2007). In a sample of 182 people with a current psychotic disorder, Farrelly et al. found that 23.1% also met criteria for substance use disorder, 15.9% for an anxiety disorder, 3.8% for a mood disorder, and 1.6% for another Axis I diagnosis. Farrelly et al. also discovered 50.5% had at least one past co-morbid diagnosis. Co-morbidity was associated with greater severity of general psychopathology (Farrelly et al.). There is also an excess mortality rate in the first few years after contact with mental health services (Lawrence, Jablensky, Holman, & Pinder, 2000). Young people with mental illness are at high risk of suicide with mental illness being present in as many as 90% of suicides and suicide rates being particularly high during the early course of mental illness (ORYGEN Youth Health, 2008b). Homelessness, stigma, substance abuse, and violence and harassment can also occur (Tarrier et al., 2007). Further, the impact of FEP on the “self and development may be potentially cataclysmic, causing derailment, truncation, deflection, or paralysis of the person’s developmental trajectory” (Jackson, Edwards, Hulbert, & McGorry, 1999, p. 271).

Psychosis has the potential to change or alter the person's usual way of construing themselves, the environment, and their future, and the devastation is further potentiated where the person is relatively young and developmentally immature (Jackson et al., 1999, p. 271).

Despite the detrimental impact of FEP, it is only recently that there has been an interest in the early detection of schizophrenia and other psychotic disorders. Predominately, interventions in psychosis have neglected to consider age of onset and phase of illness (Birchwood, 1999). Birchwood suggests that this reflects the dominance of acute crisis and rehabilitation care, which considers psychosis as a long-term and chronic disability and fails to consider first onset psychosis as a time when the trajectory of this illness can be influenced with significant implications for secondary prevention. Other key failures in treatment of people with early psychosis include prolonged delays in accessing treatment, traumatic and alienating treatment strategies, failure to effectively engage individuals in treatment and poor continuity of care (McGorry, 2004). Early intervention for psychosis aims to improve recognition and access; promote and accelerate recovery; minimise secondary morbidity; and reduce widespread damage (McGorry & Yung, 2003). While early intervention has begun to flourish, minimising the deficits of FEP remains a great challenge. If trauma-related issues within the psychosis population are taken into account, psychosis assessment and psychosocial treatments and treatment outcomes could be improved, as well as a reduction in secondary disorders (Mueser & Rosenberg, 2003).

The Trauma of Psychosis

When I got into hospital I was terrified. I could see blood on the walls, especially in the toilets and I saw bodies, pieces of bodies cut up and hanging out of their laundry bags and I was also scared I was going to get stabbed in the back by all the patients... When I first went into the lock-up room I thought they were going to cremate me, that's the fear that I had (Hamlyn & Merson, 1984).

If this was actually happening we would not have to persuade people that this person's experience would be a frightening one. As early as 1977 Jeffries proposed the idea "that going crazy is a traumatic experience" (p.199). He articulated that we are dealing with an "acute psychophysiological disorder which has a most unpleasant effect on the person who experiences it," (p. 199) that is, psychosis is a traumatic event that can lead to "traumatic neurosis" (p. 199). In 1976, Wadeson and Carpenter highlighted distressing aspects of the seclusion room through an examination of art work produced by 62 patients with schizophrenia two to three weeks before and after discharge from hospital and one year later. At no time were participants asked to draw pictures of the seclusion room, yet over one third did. Punishment was a theme presented in the art with many of the patients believing they were in jail, and one person even thinking she was in a gas chamber. Being secluded evoked intense emotional states such as fear, terror, anger, resentment, estrangement, hostility, destructive impulses, retaliation, guilt, and confusion. At one year follow-up negative reactions to the seclusion room were still intense, with many of the participants representing their entire psychiatric illness as the time they spent in isolation.

Psychosis is considered one of the most severe events a person can be subjected to (Lundy, 1992), with psychotic symptoms (e.g., visual and auditory hallucinations) and treatment experiences (e.g., restraint & seclusion) being considered the hallmark of this distress. It is generally accepted that the potentially traumatic nature of psychosis can shatter one's beliefs about the self, others, and the world (Riedesser, 2004) and subsequently have a profound affect on the individual in the short and long-term (Tarrier et al., 2007). Yet, while the potentially terrifying experience of psychosis is markedly clear, it has received little attention from clinicians and researchers (Bendall, McGorry, & Krstev, 2006) since Jeffries articulated the notion of "psychic traumatisation" (p. 60) in 1977 and Wadeson and Carpenter's research highlighted the distressing nature of seclusion in 1976, a treatment still used today. A recent influx of interest in the trauma of psychosis has produced little empirical research.

Posttraumatic Stress Disorder and Psychosis

It is widely acknowledged that people who have experienced a trauma can have a range of traumatic reactions such as repeated experiencing of the event, hyperarousal, emotional numbing, and avoidance of stimuli that could remind the person of the traumatic

event (Ehlers & Clark, 2000). This cluster of symptoms is identified in the *DSM-IV-TR* (American Psychiatric Association [APA], 2000) and The International Classification of Diseases (*ICD-10*; World Health Organization [WHO], 1992) as PTSD. High rates of comorbid PTSD and psychotic disorders have been found. For instance, Frame and Morrison (2001) discovered 67% of 60 adults with a schizophrenia spectrum disorder and who had been admitted to hospital with an acute episode of psychosis had a diagnosis of PTSD and 50% still experienced PTSD at 4 to 6 month follow-up. It has been argued that psychotic experiences and acute treatment can be so terrifying that it can precipitate PTSD (e.g., Morrison, Frame, & Larkin, 2003).

The concept of secondary PTSD in the wake of a psychotic episode (McGorry, 1995) has been demonstrated in case studies. In 1989 Shaner and Eth discussed a 32-year-old man diagnosed with schizophrenia and complicated by PTSD. The person's delusions, hallucinations, and paranoia were experienced as threats of torture, death, and public ridicule. Post psychosis he thought about what he endured, worried that it would recommence, and had nightmares in which the traumatic experiences returned. According to Shaner and Eth he became hypervigilant, avoided stimuli associated with the trauma and appeared numb. Similarly, Lundy (1992) described a case of a 16-year-old boy with schizophrenia who experienced intrusive and recurrent recollections of his psychosis, avoided things that reminded him of his experiences of being unwell, and was hypervigilant and scanned for reminders of the psychosis. For example, he actively avoided showers because this was what he did when the music began playing in his head. Also, he muttered to himself because this prevented the intrusions of thoughts that were frightening, and he refused medication in an attempt to avoid reminders of the symptoms the medication was being used to treat.

The debate as to whether the experience of psychosis can function as a traumatic event and precipitate PTSD is an interesting nosological issue. The definition for trauma in PTSD has changed across the different editions of the *DSM* since being introduced in *DSM-III* (APA, 1980), demonstrating that trauma is difficult to define. For example, when PTSD was introduced in the *DSM-III*, Criterion A was defined as "existence of a recognisable stressor that would evoke significant symptoms of distress in almost everyone" (p. 238). Therefore, how psychosis fits in the DSM definition of trauma depends on the criteria at the

time (Bendall et al., 2006). However, traditionally theories have suggested that stressors leading to PTSD are external rather than internal (Lundy, 1992). In order to fulfil the *DSM-IV-TR* (APA, 2000) criteria for PTSD, an identifiable and objective stressor needs to be defined (Breslau, Chase & Anthony, 2002) regardless of the potential trauma symptoms present:

Criterion A

The person has been exposed to a traumatic event in which both of the following are present: (1) the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others; (2) the person's response involved intense fear, helplessness, or horror (APA, 2000, p. 427-428).

As it stands, Criterion A as a necessary condition and distinct class of traumatic stressors is in doubt (Rosen & Lilienfield, 2008). Criterion A only considers the subjective experiences of those events meeting Criterion A1 (Weathers & Keane, 2007). Also, it fails to acknowledge threat to psychological integrity or perceived threat (Christopher, 2004; (Jackson, Knott, Skeate, & Birchwood, 2004) which studies suggest is central to developing PTSD. A study that looked at rape, an objective traumatic event, found that victims who perceived the assault as life threatening were more likely to develop PTSD than those who did not (Kilpatrick, Saunders & Amick-McMullan, 1989). Similarly, Carlson and Dalenberg (2000) suggest perceived emotional or psychological pain can cause just as much overwhelming fear as apparent physical pain, which is particularly relevant in allowing for the experience of psychosis as a possible trauma, an internally threatening experience. Further to this, McNally et al. (2004) found that merely believing one has been traumatised, in the case of this study that one had been abducted by aliens, can generate emotional response equivalent to that exhibited as a result of an objective trauma. This raises the possibility that PTSD can result from real or imagined events if they are sufficiently stressful (Rosen & Lilienfield), a case in point being the experience of psychotic symptoms.

Given that an event is only ever traumatic with respect to a particular individual, it is arguable that PTSD constitutes the symptoms outlined in Criteria B-F and Criterion A could be omitted without loss of diagnostic accuracy (Maier, 2007). Even so, people who

have psychosis can experience symptoms which would clearly be life-threatening and involve actual or threatened death or injury if they were real, such as nihilistic and persecutory delusions (Bendall et al., 2006). Yet, research on the traumatic nature of relatively common but stressful life events triggering PTSD, such as work-related stress (Ravin & Boal, 1989), has placed uncertainty in the necessity of experiencing life-threatening events for a diagnosis of PTSD. Considering this, events surrounding psychosis such as restraint could precipitate PTSD. Even so, these experiences can involve threat to the physical integrity of the self (e.g., Bendall et al.; Priebe, Broker, & Gunkel, 1998) such as the sudden introduction to a closed environment with other people who are acutely unwell (Morrison et al., 2003). Other like events include involuntary admission, police involvement, duress or coercion, forced sedation, and seclusion (McGorry et al., 1991).

To further support psychosis as a possible precipitator of PTSD, Bendall et al. (2006) point out that post-psychotic PTSD appears to follow the same course as PTSD from other traumatic events. A significant number of people who develop PTSD do so soon after the trauma they have experienced and it abates over time (Bendall et al.), which appears to be the course of post-psychotic PTSD. For instance, in McGorry et al.'s (1991) study 46% of their early psychosis participants had PTSD soon after discharge but this reduced to 35% 11 months later. Likewise, while Centofanti, Smith, & Altieri (2005) found that PTSD was not significantly correlated with months since discharge, there was a general trend towards high post-psychotic trauma rates in more recently discharged participants.

The possibility of the psychotic experience precipitating PTSD can also be considered in examining the relationship between negative symptoms of psychosis and PTSD. In 1990, Stampfer hypothesised that the negative symptoms of psychosis and PTSD are both manifestations of a response to trauma. He posited that negative symptoms are indivisible from avoidance and numbing and other similar characteristics including flat affect, withdrawal, lack of interest in life, and disconnection from others. Further to this, McGorry et al. (1991) hypothesised that the similarities between PTSD and negative symptoms might be related to the extreme stress an individual with these disorders can experience. Thus, negative symptoms present after a psychotic episode could be a reaction to the traumatic nature of psychosis and reflective of co-morbid PTSD (McGorry et al.; Stampfer).

There is little evidence to support Stampfer's (1990) theory. McGorry et al.'s (1991) research provided a small degree of support as participants who were experiencing PTSD symptoms had a rise in negative symptoms between the two follow-up periods of 4 and 11 months, whereas the non-PTSD group did not. However, there was no significant relationship between the level of negative symptoms and the PTSD scale and avoidance subscale on the Impact of Events Scale. Studies by Priebe et al. (1998) and Tarrier et al. (2007) found no correlation between PTSD symptoms and negative symptoms of schizophrenia. Although Meyer, Taiminen, Vuori, Aijala, & Helenius (1999) found a positive correlation between the number of negative symptoms and psychosis-related trauma, this did not remain an independent factor in multivariate analysis. From these studies it appears unlikely that negative symptoms are reflective of a trauma reaction.

One study by Harrison and Fowler (2004) found evidence for a relationship between post-psychotic PTSD and negative symptoms. They focused on avoidance and its relationship with negative symptoms. They also examined the association between negative symptoms and traumatic reactions to psychosis and hospitalisation, and the relationship between trauma and autobiographical memory in thirty-eight people with schizophrenia and few positive symptoms. Results showed that participants who avoided traumatic memories about their psychosis and hospitalisation had more negative symptoms, and those with more negative symptoms retrieved fewer specific autobiographical memories. Further, avoidance of traumatic memories about psychosis and lack of specificity in autobiographical recall significantly predicted negative symptoms. Although the findings are contradictory, Harrison and Fowler's study provides some support for the view that negative symptomatology could be reflective of a posttraumatic response and invites further study. This is particularly important given potential clinical implications such as avoidance of treatment being reflective of trauma rather than negative symptoms (Shaw et al., 1997).

In summary, the potentially highly traumatic nature of psychosis was identified as long ago as the mid 1970s and its treatment experiences (Jeffries, 1977; Wadson & Carpenter, 1976). Case studies (e.g., Shaner & Eth, 1989) also confirm this distress and identify the onset of PTSD as a result. Further, there is some evidence that negative symptoms could be a traumatic response to the impact of the psychotic experience. Yet, as

Criterion A stands, the ability of psychosis to fulfil it depends on the allowance that a stressor may be subjectively as well as objectively experienced (Morrison et al., 2003; Reidesser, 2004). Specifically, that threat to psychological integrity or perceived threat is recognised (e.g., Jackson et al., 2004). Nevertheless, researchers have persisted in examining the relationship between psychosis and acute treatment and PTSD.

The Relationship between PTSD and the Illness Experience

Researchers have examined acute treatment and psychotic symptoms as precipitants of PTSD. However, results have been inconsistent making it difficult to identify specific illness and treatment experience which might generate PTSD. Further, methodological issues and participant characteristics which have been researched have not provided clarification. Nonetheless, it is possible that neglecting to focus on the subjective experience may have contributed to the variable research findings. How people perceive the illness is likely to play a role in the development of PTSD in this clinical population. Still, research examining the relationship between appraisals of psychosis and PTSD are inconclusive. This body of research questions the usefulness of a diagnosis of PTSD in understanding the trauma associated with psychosis.

Treatment Experiences

Research exploring the relationship between trauma symptoms and number of admissions and involuntary hospitalisation has produced inconsistent results. Even though rates of co-morbid PTSD ranging from 25% to 54% have been found amongst people with psychosis with one or more admissions within the last 159 months, a relationship between number of admissions and involuntary hospitalisation and trauma symptoms was not found in a number of studies (Centofanti et al., 2005; Frame & Morrison, 2001; Jackson et al., 2004; Priebe et al., 1998; Shaw, McFarlane, Bookless, & Air, 2002). One study by McGorry et al. (1991) researched distress over time (inpatient treatment and 4 and 11 months post discharge) and still found that PTSD was unrelated to first admission or involuntary status.

Limited support for a relationship between PTSD symptoms and involuntary admission was found in two studies. Meyer et al. (1999) found of 152 PTSD symptoms recorded, 37 (24%) were related to coercive measures, and people who had experienced any type of coercive treatment had higher treatment-related trauma 8 weeks after admission but not at week 1. In their study, involuntary patients were no more traumatised than voluntary patients. However, when treatment-related traumatisation was examined on its own they found that traumatic stress was significantly associated with involuntary admission 8 weeks post admission. Similarly, Tarrrier et al. (2007) reported a significant relationship between PTSD and being detained under the mental health act amongst FEP patients. This was associated with more avoidance symptoms and a trend towards more intrusive symptoms.

Other coercive treatment measures have also been researched with mixed findings. In McGorry et al.'s (1991) study, participants' written responses on the PTSD scale revealed a tendency to link posttraumatic symptomatology to the external or contextual aspects of treatment. For example, some participants reported recurrent nightmares involving seclusion or forced sedation. Likewise, both Centofanti et al. (2005) and Shaw et al. (1997) found that being on a closed ward or in seclusion was rated as the most distressing coercive measures, and in Tarrrier et al.'s (2007) study being forced to take medication was the most distressing treatment experience. However, other studies show only limited evidence for the distress of seclusion (Meyer et al., 1999) and no relationship between trauma and admission to a secure ward (Jackson et al., 2004). Centofanti et al. discovered a significant correlation between post-psychotic PTSD and police involvement in admission, while Jackson et al. did not. In Meyer et al.'s study curfew time was significantly associated with total scores on the Clinician-Administered PTSD Scale and Impact of Events Scale-Revised at week 8 post admission.

One conclusion that can be drawn from these inconsistent findings is that a wider range of treatment that extends beyond coercive measures requires research. No relationship between PTSD and duration of hospitalisation has been reported (Jackson et al., 2004; Tarrrier et al., 2007). Yet, Shaw et al. (1997) found that being physically abused on the ward was rated as the third most distressing experience. Also, Centofanti et al. (2005) showed that being sexually harassed by other patients was in the top four most

distressing hospital experiences. Further still, while focus has been on the trauma associated with hospitalisation, interestingly Jackson et al. did not find place of first treatment (home versus ward) was related to trauma symptoms. This may imply that for some people hospital is no more distressing than outpatient treatment. Neither treatment environment is traumatic, and/or the trauma associated with psychosis could be associated with other illness experiences, such as symptoms.

The Experience of Psychotic Symptoms

Research suggests that psychotic symptoms are more distressing than treatment. While 11% of participants had PTSD in Meyer et al.'s, (1999) study, none met criteria for this diagnosis solely on the basis of traumatic aspects of hospitalisation. Further, when comparing coercive treatment with psychotic symptoms, coercive measures were not associated with trauma. Of the 152 PTSD symptoms recorded, 69% were associated with psychotic symptoms. However, only five participants had a diagnosis of PTSD that was associated with psychotic symptoms alone. Frame and Morrison (2001) also discovered that psychotic symptoms explained 52% of the variance in PTSD symptoms. Yet, Priebe et al. (1998) and Tarrier et al (2007) found no relationship between PTSD and positive symptoms, again attesting to the complex relationship between PTSD and the experience of being unwell

The relationship between the severity of psychotic symptoms and PTSD has also been researched, although findings are inconclusive. The dose-response model suggests the magnitude of the stressor is related to the development of PTSD (Rosen & Lilienfield, 2008). In accordance with this, Meyer et al.'s (1999) results showed that being more psychotic was related to higher levels of traumatisation and the only significant risk factor for developing post-psychotic PTSD was a high total score on the Positive and Negative Syndrome Scale (PANSS). In contrast, other studies have found very limited or no support when examining severity of illness and trauma (Priebe et al., 1998; Shaw et al. 1997; Tarrier et al., 2007). These findings are consistent with Rosen and Lilienfield's review of the PTSD literature, which showed inconsistent support for the dose-response model. Thus, there is little support for severity of psychosis contributing to the trauma of being unwell. However, it is arguably difficult to compare the severity of psychotic symptoms and PTSD due to the fluctuating course of psychosis.

A key issue when studying the relationship between psychosis and PTSD is that psychotic symptoms may not be entirely resolved (Bendall et al., 2006). Even when treatment has started symptoms can take time to cease or may not even abate (Edwards et al., 2002). Yet, PTSD is based on the idea that trauma is discrete (e.g. car accident) and that the disorder develops as a result of the experience (Bendall et al.). Therefore, PTSD is usually diagnosed and studied after the trauma has resolved. However, there are many circumstances in which trauma and PTSD symptoms are less discrete, such as ongoing childhood sexual abuse (Bendall et al.). Bendall et al. suggest that the uncontrollable nature of ongoing psychotic symptoms might be traumatic enough to increase the risk for PTSD. Likewise, Meyer et al. (1999) found that levels of psychotic symptoms were associated with a higher level of traumatisation at both weeks 1 and 8 post-discharge in their study, and this was even clearer at the latter time point. In contrast, Tarrier et al. (2007) found that trauma symptomatology was not related to residual psychotic symptoms. Similarly, untreated psychosis was not associated with PTSD (Tarrier et al.). Given the variability of research findings, measuring severity and duration of psychosis may not be the best way of determining the distress of the illness. Instead, determining which types of symptoms are more traumatic may be more practical.

Research has found that certain psychotic symptoms are more traumatic than others, in particular symptoms implying perceived threat. These include symptoms related to suspiciousness (Myer et al., 1999; Shaw et al., 2002) and persecution (Myer et al.; Shaw et al., 1997; 2002), passivity phenomena (Shaw et al., 1997; 2002), and unusual thought content (Meyer et al.), as well as visual (Shaw et al., 2002) and olfactory hallucinations (Shaw et al., 1997). More consistent results in researching the traumatic nature symptoms suggest that this aspect of psychosis is more distressing for people than severity and duration. Therefore, it is important to develop an understanding of why these symptoms are traumatic for people and move from the objective to the subjective experience.

Predictors of Post-psychotic PTSD

As highlighted, the relationship between PTSD and positive symptoms and treatment experiences remains tenuous and inconsistent. Also, the rates of post-psychotic PTSD vary across studies. Differing results may be due to the nature of the samples used and differing methodologies (Chisholm, Freeman, & Cooke, 2006). Studies differ on a

range of variables including: trauma history, FEP versus multiple episodes, differing diagnoses, co-morbidity, gender, age of onset, time assessed post psychotic episode, mental state/level of recovery, different treatment settings, sample size, and measures used. The only study to look at gender discovered that women tended to have more psychosis-related trauma symptoms (Meyer et al., 1999). Further research is needed on examining gender differences before conclusions can be made.

Morrison, Read, and Turkington (2005) suggest that trauma may predispose people to appraise their psychotic experiences in a particular way which causes more distress. Consistent with this, Chisholm et al. (2006) found that previous traumatic events were associated with post-psychotic PTSD symptomatology. Similarly, Centofanti et al. (2005) discovered that the level of post-psychotic PTSD and number of previous traumatic events were significantly related. However, Shaw et al. (2002) found that a history of PTSD did not predict the development of post-psychotic PTSD. Further, Tarrier et al. (2007) did not find a significant relationship between PTSD and past trauma, and previous trauma was not related to distressing aspects of FEP. Therefore, the relationship between previous trauma and distress associated with psychosis is unclear.

Research has also considered the frequency of psychosis and treatment experiences as predictors of PTSD. Chisholm et al.'s (2006) research showed that previous psychotic episodes were associated with PTSD symptoms rather than FEP. Similarly, McGorry et al. (1991) did not find that first admission was related to PTSD. In contrast Meyer et al., (1999) found that younger subjects, with presumably fewer psychotic episodes and adverse treatment experiences, had higher levels of traumatic stress. Other research has found no association with number of admissions (e.g., Centofanti et al., 2005; Shaw et al., 2002) and duration of hospitalisation (Tarrier et al., 2007) and PTSD. Thus, the number of episodes and hospitalisation do not appear to be consistent predictors of trauma symptomatology.

In 1997, Shaw et al. stressed the importance of researching a more homogenous group according to specific illness and treatment variables because the existence of PTSD symptoms had been found in their heterogenous sample. Meyer et al.'s (1999) exclusion of people with affective psychosis may have impacted on the low frequency of people with PTSD in their study. Indeed, they proposed that people with affective psychosis may be more prone to developing PTSD. Corroborating this, McGorry et al. (1991) found that the

level of depressive symptoms was related to post-psychotic PTSD at follow-up. Understanding how the presence of co-morbidity is likely to impact on the development of trauma symptoms is important both for research and clinical practice. The psychosis population is by nature a heterogeneous group and therefore researchers who exclude people, particularly on the basis of their co-morbidities, do not provide an accurate reflection of the population.

Examination of methodological issues and participant characteristics has not yet provided clarification for the differing results examining the association between trauma symptoms and psychosis. It is argued that the equivocal results support the idea of individual disparity (Jackson & Iqbal, 2000). Bendall et al. (2006) proposed that a more sophisticated understanding of the trauma associated with psychosis and acute treatment needs to include the role of appraisals. Indeed, Shaw et al. (2002) suggested from their finding that people who are more distressed by the experience of hospital and psychotic symptoms had more pronounced PTSD symptoms. Therefore, an understanding of *why* the experiences are distressing is invaluable. At present little is known about the role of appraisals in mediating the trauma response (Jackson et al., 2004).

The Role of Appraisals

Understanding PTSD in psychosis should include the role of cognitive appraisals instead of focusing on the simplistic traumatic event causes PTSD relationship (Jackson & Birchwood, 2006). Current models of PTSD emphasise the role of appraisals of traumatic events to reflect the significant individual differences in response to the same traumas (e.g., Ehlers & Clark, 2000). Ehlers and Clark propose that PTSD becomes an ongoing issue when an individual processes a trauma as a serious and current threat. In part this threat arises from disturbances in personal appraisals. Such appraisals include interpretations of symptoms, other people's reactions, and the consequences of the traumatic event on one's life (Gumley & MacBeth, 2006). Negative self-related cognitions have been found to be more influential in strengthening PTSD symptoms than negative beliefs about the world (O'Donnell, Elliot, Wolfgang, & Creamer, 2007). O'Donnell et al. concluded that internally driven threats were more powerful in determining the development of PTSD than external threats. This is particularly relevant to the experience of psychosis, an internally driven threat. Yet, we have very little understanding of the possible mediating effects of the

appraisals of psychosis on trauma symptoms (Jackson et al., 2004).

Pertinent to the argument for recognising psychosis as a traumatic event has been the importance of the subjective experience, and specifically threat to psychological integrity or perceived threat (e.g., Jackson et al., 2004). However, most studies do not take this into account and have favoured the 'objective' experience. The importance of the subjective experience is inadvertently evident in research, such as Priebe et al.'s (1998) study, where involuntary patients reported more negative aspects of acute treatment than voluntary patients suggesting that they perceive hospital as more distressing. Further, perceived loss of control associated with enforced treatment (Shaw et al., 1997) and confusion (Centofanti et al., 2005; TARRIER et al., 2007) and fear (TARRIER et al.) associated with being hospitalised was more distressing than other more obvious aspects of treatment such as coercive measures. Yet, these investigators did not directly research the relationship of these psychological factors to PTSD. Shaw et al. (1997) and Centofanti et al. believed participants could not clearly differentiate between illness and treatment stressors. Subsequently, the stressor for post-psychotic PTSD was considered to be the combined experiences of hospital and symptoms in these studies. Yet, researchers underscore the need for focusing on the role of appraisal (e.g., McGorry et al., 1991; Meyer et al., 1999; Priebe et al.; Shaw et al., 2002).

A search of the literature found only two studies (Chisholm et al., 2006; Jackson et al., 2004) and one unpublished paper (Brunet & Birchwood, 2008) which explored the role that appraisals of acute psychosis played in mediating the development of a PTSD diagnosis or PTSD symptoms. In Jackson et al.'s study, those who retrospectively perceived their hospital admission as especially stressful were significantly more likely to meet criteria for PTSD and to report higher levels of intrusions. Further, perceived stressfulness of time on the ward was associated with intrusive memories. Both Brunet and Birchwood and Chisholm et al. found high levels of trauma symptoms to be associated with increased ratings of the awfulness of the threat from persecutory delusions, lower perceptions of control over persecution and of the ability to cope, and higher perceptions of the power of the persecutor(s). Brunet and Birchwood also discovered that participants were more distressed if they appraised their persecutors with more conviction, while Chisholm et al. found that thinking the persecution was deserved was associated with

trauma symptoms. When considering a diagnosis of PTSD, many of the appraisals researched by Brunet and Birchwood did not translate to PTSD later on. Only perceived ability to cope with the persecutory threat of symptoms and appraising the illness as out of control at the time of the episode influenced the development of this disorder at 18 months post acute psychosis.

In summary, studies have examined the presence of both trauma symptomatology and a diagnosis PTSD amongst people with psychosis and their relationship with the illness experience. When studies look at diagnosing PTSD as a result of psychotic symptoms and acute treatment it remains unclear whether this disorder is a useful construct in understanding the trauma of psychosis. Instead, research suggests that an individual's *perception* of their illness experience plays an important role in the development of PTSD (Brunet & Birchwood, 2008; Jackson et al., 2004). Therefore, it is argued that the subjective experience should be prioritised in attempting to further our understanding of the distress associated with psychosis (Tarrier et al., 2007). Even still, while PTSD may capture a clinically significant group in the psychosis population, a phenomenologically pure PTSD diagnosis is not evident in large numbers (Jackson et al.). Attesting to this, Tarrier et al. used standardised assessment specifically modified for detection of PTSD amongst psychotic patients and still found it difficult to identify this diagnosis using the full criteria. Although it is recognised that more studies need to be done as findings are based on limited research, it is questionable whether PTSD is a useful construct in understanding the trauma associated with psychosis.

Is PTSD a Useful Concept in Understanding the Traumatic Impact of Psychosis?

The usefulness of PTSD in understanding the trauma associated with the psychotic experience is in doubt. Rosen and Lilienfeld (2008) suggest that an important learning from the range of studies researching trauma and PTSD is that multiple factors and their complex relationships result in variable outcomes that are unlikely to be explained by a single disorder. Researching the relationship between PTSD and psychosis is likely to be complicated by a complex relationship between the two disorders, as well as difficulty in establishing psychosis as an aetiological event which can lead to PTSD.

A Complex Relationship between PTSD and Psychosis

The various results focusing on the relationship between the experience of psychosis and PTSD attest to a complex bi-directional relationship between these disorders (McGorry, 1995). Just as psychosis can trigger PTSD, Morrison et al. (2003) suggest that trauma could cause psychosis and psychosis and PTSD could both be a part of a spectrum of responses to a traumatic event. Considering the first alternative, effects of early trauma on the brain have been documented in schizophrenia (Seedat, Stein, Oosthuizen, Emsley, & Stein, 2003). Further, there are high rates of lifetime trauma in people who have severe mental illness such as psychosis (e.g., Gearon, Kaltman, Brown, & Bellack, 2003; Neria, Bromet, Sievers, Lavelle, & Fochtmann 2002; Resnick, Bond, & Meuser, 2003) and studies have found that past trauma can influence the development of psychosis (e.g., Bechdolf et al., 2008; Kilcommons, Morrison, Knight, & Lobban, 2007; Shevlin, Houston, Dorahy, & Adamson, 2008). Also, transient psychotic symptoms are accepted as part of borderline personality disorder, a disorder which often presents in the context of a trauma history (McGorry, 1995).

In relation to the second hypothesis, Kozarić-Kovačić and Borovečki (2005) found that many patients who had experienced combat related PTSD demonstrated psychotic symptoms which differed from flashbacks and dissociation (e.g., paranoid delusions). They concluded that psychotic symptoms were an integral part of PTSD and had a symbolic relation to the trauma. Similarly, people who have PTSD and are prone to developing psychosis can experience trauma symptoms (e.g., flashbacks) that can take on psychotic proportions (Seedat et al., 2003). It is also argued that psychotic symptoms might be a domain of symptoms of PTSD where individuals re-experience traumatic events in the form of hallucinations (Sareen, Cox, Goodwin, & Asmundson, 2005). In a review, Morrison et al. (2003) provide research evidence which suggests that there are similar developmental and maintenance processes.

Many authors also articulate the phenomenological overlap between PTSD and psychosis (e.g., Bendall et al., 2006) which makes distinguishing these disorders from one another a complex process and open to interpretation (McGorry et al., 1991; Tarrier et al., 2007). Differentiating between positive symptoms and PTSD symptoms such as intrusive memories and hypervigilance and delusions is likely to be difficult (Bendall et al.; Meyer et

al., 1999; Pinto & Gregory, 1995; Shaw et al., 1997; 2002). For instance, intrusive symptoms of PTSD are “sudden sensory memories that seem immediately real” (APA, 1987, p. 250) and delusions are beliefs that are not real, thus an intrusive thought of a delusion would be difficult to distinguish from a delusion (Bendall et al.). There is also diagnostic overlap in PTSD and negative symptoms such as anhedonia and decreased concentration and avoidance and hyperarousal respectively (Shaw et al., 1997; 2002). Tarrier et al. suggest these common characteristics may result in double counting of symptoms falsely inflating rates of co-morbidity. Further, non-specific symptoms of psychosis such as anxiety could be reflective of a trauma reaction as they overlap with the core symptoms of PTSD. For instance, in Priebe et al.’s (1998) research PTSD symptomatology was related to unspecific signs of schizophrenia, such as anxiety, depression, and neurotic syndromes. It may not be easy to differentiate whether these non-specific symptoms are due to the distress of psychotic symptomatology, treatment, or secondary consequences (Jackson & Iqbal, 2000; Mueser & Rosenberg, 2003).

The Role of Aetiology in Diagnosis PTSD as a Consequence of Psychosis

Another issue in diagnosing PTSD as a consequence of psychosis relates to the role of aetiology. Identifying which aspect of the illness experience precipitates PTSD can be very difficult. The negative experiences of hospital can become enmeshed with psychotic symptoms (Bendall et al., 2006) and vice versa. For instance, coercive treatment usually occurs due to acute positive symptoms and the nature of this treatment and subjective experiences of it will vary depending on the symptoms present (Bendall et al.). Indeed, Harrison and Fowler (2004) found that positive symptoms were associated with hyperarousal related to hospitalisation. Moreover, in Wadson and Carpenter’s (1976) study, many of the pictures of the seclusion room were associated with frightening delusions related to this experience. It is argued therefore that the complex and multifaceted experience of psychosis makes it difficult to diagnose PTSD as a result of the trauma of the illness experience.

Due to the focus on psychotic symptoms and acute treatment as precipitators of PTSD, other Criterion A events associated with this experience have not been examined in their own right. For instance, Centofanti et al. (2005) discovered that attempted suicide and thoughts of suicide during most recent hospitalisation were rated as the most distressing

admission experience. They found a positive relationship between the number of adverse events associated with harm to self and others and post-psychotic PTSD. Also, thoughts of harming one's family were rated as the second highest distressing experience in Shaw et al.'s research (1997; 2002). Therefore, a wide range of distressing experiences associated with the acute episode should be considered.

Focusing on PTSD increases the possibility of missing other potential stressors associated with the psychotic experience not accounted for by Criterion A (Jackson et al., 2004) such as the reality of being diagnosed as psychotic, which has been identified as traumatic in many first-person accounts (e.g., Anonymous, 1989). Separation from usual activities and family, and anxiety about losing child custody have also been rated as more upsetting than more obvious traumatic experiences such as seclusion and forced medication (Shaw et al., 2002). In Priebe et al.'s (1998) study, involuntary patients reported more negative aspects of acute treatment such as noise, overcrowding and monotony on wards; unkind, rigid, and informal treatment; and lack of empathy and support from staff members. Additionally, in Tarrier et al.'s (2007) study, police insensitivity, fear of other patients and adverse staff attitudes were rated as more distressing than forced medication. Only two studies have looked at the impact of social support (Brunet & Birchwood, 2008; Chisholm et al., 2006). These studies show that people who perceived their social support to be of lower quality had higher levels of traumatic stress. It is argued that a comprehensive examination of the trauma of psychosis goes beyond a diagnosis of PTSD.

As previously noted, PTSD is a diagnosis that occurs after a traumatic event and views the traumatic experience as discrete (Bendall et al., 2006). Even though Bendall et al. put forward an argument for including the traumatic nature of unresolved psychotic symptoms as a precipitator for PTSD, they also acknowledged that diagnosing PTSD amongst people who are still experiencing trauma is problematic. In the case of psychosis, ongoing trauma could be also be related to future treatment experiences and secondary consequences. Psychosis can be the beginning of a series of unpleasant consequences (Gumley & MacBeth, 2006) such as stigma (Bayley, 1996), loss of social networks, lost vocational opportunities, and increased personal disability (Gumley & MacBeth). It has been suggested that recovery from the consequences of psychosis can sometimes be more difficult than the recovery from distress and confusion associated with the initial psychotic

experience (Anthony, 1993; May, 2004).

The personal and emotional significance of psychosis can remain long after the acute episode has resolved (Fowler, 2000). Yet, due to an over reliance on examining the trauma of the initial illness experience, the traumatic potential associated with secondary consequences is poorly understood. Only one study, by Tarrrier et al., (2007) explored the relationship between secondary consequences of FEP and PTSD. However, of the five consequences identified, only those with PTSD had a significantly greater reduction of hopes and aspirations and participants who reported physical harassment or violence as a result of FEP had significantly higher scores on the Clinician Administered PTSD Scale. It is argued that emphasis of future research needs to be shifted to understanding the ongoing traumatic nature of psychosis (Bendall et al., 2006) and beyond a diagnosis of PTSD.

In conclusion, the complex relationship between PTSD and psychosis, and problems attempting to classify psychosis as an experience that can lead to PTSD has led to a number of shortfalls in research examining the distress associated with psychosis. A comprehensive understanding of the traumatic nature of psychosis needs to consider a broader trauma response which goes beyond the initial experience and diagnosis of PTSD. This is particularly relevant in understanding the distress associated with FEP.

Understanding the Traumatic Nature of FEP: Beyond a PTSD Diagnosis

It remains unclear whether PTSD is a relevant concept in understanding how people recover from FEP (Jackson & Iqbal, 2000). Although Meyer et al. (1999) reported that younger clients had higher levels of traumatic stress, a relationship between psychotic symptoms and acute treatment and PTSD in the FEP cohort has not been established (McGorry et al., 1991; Tarrrier et al., 2007). Similarly, while some appraisals (Brunet & Birchwood, 2008) and secondary consequences (Tarrrier et al.) of FEP have been found to be associated with PTSD, a more comprehensive understanding of the trauma of FEP needs to go beyond a diagnosis of PTSD. In particular, how one views him or herself, the world, and others is considered central to understanding the distress of FEP (Jackson & Iqbal).

First-episode psychosis can be especially dramatic because it usually occurs at a critical age during adolescence and early adulthood when the individual is developing a sense of self and identity, forming relationships with others, and orienting themselves to the world. These processes can occur in the context of the developmental task of separating from parents, establishing a crucial but fragile peer network and pursuing vocational aspirations (McGorry & Yung, 2003; Riedesser, 2004). Thus, the onset of psychosis constitutes an assault on these developmental processes which has a distressing impact on various aspects of the person's life such as future aspirations, social acceptance and identity (Tarrier et al., 2007).

Carlson and Dalenberg (2000) point out that the distress associated with a traumatic event can involve damage or threat to one's sense of self and declare that identity confusion is a symptom of trauma. This is likely to occur when core trauma symptoms interfere with major roles such as work and social functioning. Identity disturbance may also occur as a result of behaving in a way that is inconsistent with one's sense of self (Carlson & Dalenberg). Carlson and Dalenberg assert that the essential emotional experience in trauma involving threat to sense of self is the feeling of not being able to internally protect one's self-image. These experiences are integral to psychosis, with the individual's sense of self being significantly challenged as a result of psychosis (Nelson, Yung, Bechdolf, & McGorry, 2007). For instance, adjusting from the belief that the psychotic symptoms are real to seeing the symptoms as coming from within significantly challenges the concept of the self (Jackson & Iqbal, 2000). This is particularly relevant to the experience of FEP because there are no existing cognitive schema with which FEP can be linked and guide adaptation to this event (McGorry, 1995; McGorry, Henry, Maude, & Phillips, 1998).

Disruption to the self as a result of psychosis is a long-standing topic in psychiatric literature (e.g., Jaspers, 1963; Laing, 1968). Drawing on Ogilvie (1987), the impact of psychosis may affect the individual's concept of him or herself as they are, as they wish to be, and the self they fear they might become. Disruption to the self has been described in a range of ways including disintegration (Williams-Keeler, Milliken, & Jones, 1994), collapse (Lysaker & Lysaker, 2001; 2004), and identity crisis (Lally, 1989). A number of authors describe damage and loss to previous characteristics of the self such as to personal integrity and the belief that the self is invulnerable (Cullberg, 2006); uncontrollability of the

self; loss of trust in capabilities; optimism (Koivisto, Janhonen, & Vaisanen, 2003) and competence (Lally); an absence of the capacity to make reasonable predictions about one's self; difficulties in making oneself understood; and finding oneself in a subordinate role (Lafond, 1998). Absorption of stigma into self-image (Lafond) and engulfment through identification as a mentally ill individual (Lally) can also occur.

Only two known studies (MacDonald, Sauer, Howie, & Albiston, 2005; Tarrier et al., 2007) have researched the impact of FEP in relation to the self and others. Tarrier et al. found that there were marked negative consequences in terms of persistent loss, impediment to achieving aspirations and how participants felt about themselves and others. Specifically, 77% of 35 participants identified persistent loss, change or disruption to their life as a result of their psychotic episode, 38% reported harassment or violence, 53% experienced stigma, and 50% indicated social exclusion. MacDonald et al. found that engagement in activities and relationships with peers was impacted. Participants expressed concern of real or perceived rejection by peers and ceased contact with long-standing friends partly because of this. In essence, MacDonald et al. identified that these young people were struggling to integrate their experience of psychosis with their experience of being young adults. Further in-depth studies examining the subjective experience of FEP and its secondary consequences that are pertinent to the developmental stage of this clinical population are required.

Studies found that participants who did not meet criteria for PTSD were still highly traumatised (e.g., Shaw et al., 1997, 2002; Jackson et al., 2004; Tarrier et al., 2007). Also, research has discovered that the trauma of FEP can produce numerous psychological reactions beyond what would typically be classified as trauma symptomatology (avoidance, hyperarousal and intrusion symptoms). In Tarrier et al.'s study, 40% of participants had experienced suicidal ideation and 26% said this was severe and 31% indicated that they had attempted suicide because of their illness. A further 60% of their sample believed their hopes and aspirations were no longer achievable. Further, feelings of loss, entrapment from the expectation of recurring or residual psychotic symptoms (Jackson & Iqbal, 2000), shame (Jackson & Iqbal; Koivisto et al., 2003), humiliation, defeat, hopelessness, and a sense of danger and anxiety that the psychotic episode may re-occur can be present (Jackson & Iqbal), as well as feeling powerless and emotionally and spiritually void

(Bayley, 1996). Also, the threat of experiencing another psychotic episode and/or the memory of the initial episode can continue to impact on the self-esteem of the individual (Fowler, 2000). This range of distressing responses are considered just as important to focus on clinically than trauma symptomatology and should be considered in a broader application of the trauma framework. Further, considering these variables takes into account both the individual's initial reaction to FEP as well as ongoing emotional responses.

Summary

The variability of results across studies exploring the presence of post-psychotic PTSD does not wholly support the contention that this diagnosis is a useful concept in understanding the trauma of psychosis, particularly FEP. Research indicates that there is no simple cause and effect relationship between trauma and psychosis, instead complex and multiple relationships exist (Morrison et al., 2003). Also, only a small to moderate number of people with psychosis have been found to experience co-morbid PTSD.

Studies examining the role of appraisals and secondary consequences in the development of PTSD have begun to consider the subjective experience. However, in-depth qualitative research has not been conducted and research has mostly been quantitative and focused on diagnosing PTSD as an outcome of the initial illness experience. This has prevented a consideration of the wide range of psychological reactions that can occur as a result of FEP and has failed to recognise those who are highly distressed by FEP but do not meet criteria for PTSD. It has also neglected a thorough examination of the range of secondary consequences that can occur as a result of FEP. Closer examination of research and consideration of first-person accounts reveals a range of distressing experiences in the acute and recovery phase of the illness that cannot be accounted for by a diagnosis of PTSD. Further, empirical research and first-person accounts demonstrate that people's reactions to psychosis are variable.

Despite the current controversies and unanswered questions with respect to the distressing aspects of psychosis and development of PTSD, research clearly places psychosis and adjustment to this experience within a trauma framework. Given the seismic

impact that FEP can have on an individual and the critical developmental period it usually occurs within, it is important to continue to research the traumatic nature of this experience and its effects to inform treatment (Tarrier et al., 2007). To go beyond a PTSD diagnosis and expand on our understanding of the traumatic impact of psychosis and individuals' reactions and adjustment to it, in-depth qualitative research is needed to endeavour to explore how people understand, integrate and adapt to this traumatic experience (Jackson & Birchwood, 2006). Chapter 3 provides a comprehensive examination of the nature of recovery from psychosis.

CHAPTER 3: RECOVERY FROM PSYCHOSIS: A RESTORATIVE AND CONSTRUCTIVE PERSPECTIVE

This chapter reviews the recovery literature on FEP. It is argued that recovery models that restrict themselves to restorative outcomes, such as the medical model, cannot adequately capture the process of recovery and adaptation to FEP. Instead, it is recognised that people engage in a meaning-making process in relation to their illness and are actively involved in their recovery process. Considering this, other ways of viewing recovery from FEP are reviewed and a concept from the trauma literature called posttraumatic growth is put forward as a way of understanding potential transformational changes that can come about from FEP. It is argued that constructive changes are likely to play an important role in recovery from and adaptation to FEP.

The Individual's Role in Recovery

Psychosis has historically incorporated assumptions of pervasive and persistent impairment, resulting in a chronic course and poor outcome. It was assumed that the individual was subsumed by and lost to the illness (Henry, 2004). Kraepelin in particular engineered this pessimistic view (McGorry, 1999). Kraepelin's model for schizophrenia meant that a diagnosis of psychosis, especially schizophrenia, created "profound therapeutic nihilism" (McGorry, 2004, p.2). However, research on recovery from psychosis, particularly schizophrenia, led a small number of authors to seriously question the disease model of schizophrenia. For instance, from the 1920s Sullivan was aware of the potential for prevention and early intervention (Sullivan, 1962). The heterogeneity of outcome in psychosis and the empirical evidence that people can recover from this illness was also highlighted challenging the traditional conceptual model that psychosis is a degenerative disorder (Davidson & Strauss, 1992). Yet, it has taken a significant amount of time to emerge from the 'chronicity paradigm' (Birchwood, 1999; Ramon, Healy, & Renouf, 2007). The pessimistic fog surrounding the diagnosis of psychosis has slowly lifted with early intervention (Lieberman, 2002), improved treatments, better outcomes, deinstitutionalisation (Henry), and the rise of consumerism in mental health care (McGorry,

2004). However, it is only recently that ideas about recovery have moved to the forefront of clinical practice and research and a void remains about the meaning of recovery.

Currently the dominant view in mental health services is clinical recovery. Clinical recovery focuses on the effectiveness of treatment and asserts that recovery is an absence of symptoms either because the person's condition has resolved or treatment is controlling them (Coleman, 1999). This reflects a medical model of the illness, which assumes that mental illness is a physical disease. According to the medical model, recovery depends on the diagnosis, illness duration, the illness stage at which treatment began, and the level of disability (Fitzpatrick, 2002). Treatment relies heavily on pharmacological interventions (Kelly & Gamble, 2005) with efforts focused on compliance (Reeves, 2000) and maintaining the person in a stable condition and avoiding relapse (Coleman). However, a rehabilitation model is increasingly applied alongside the medical model in clinical practice. While the medical model focuses on ameliorating symptoms, the rehabilitation model concentrates on redressing skill deficits. Yet, the medical and rehabilitation models fail to recognise the role of the patient and instead apply a uniform understanding of recovery. In these models the person becomes a passive agent in their recovery and the recipient of professional input. This view of psychosis limits our understanding of people's subjective experience of psychosis and does not recognise the active role patients play in their recovery (McGorry, 1992). As a result there is a significant gap in our understanding of recovery from psychosis (France & Uhlin, 2006).

The rehabilitation and medical models imply that recovery is not dynamic but rather that an individual will have stable levels of impairment or fixed states (Green, 2004; McGorry, 1992) which may be mild to significant, but nonetheless a person will always have an illness that needs ongoing treatment (Fitzpatrick, 2002). In contrast, widespread research on recovery identifies recovery as a dynamic, plastic, and ongoing process (e.g., Anthony, 1993; May, 2004; McGorry). Central to the recovery process is the person with psychosis (Rogan, 2000). When people are exposed to something unpredictable like psychosis they encounter gaps in their beliefs about their life and the world and subsequently try to re-build a sense of meaning and coherence (Antonovsky, 1988; Polkinghorne, 1988). The process of meaning-making (Neimeyer, 1993) appears to be very significant for many people with psychosis and through the course of psychosis the

individual will develop an explanatory model in order to understand their illness (Greenfeld, Strauss, Bowers, & Mandelkern, 1989; Perry, Taylor, & Shaw, 2007). This includes their perception of themselves and their attitude towards the disorder (Jackson et al., 1999). Subsequently, each person's way of coping with the experience of psychosis is considered to be qualitatively different, with the person having different strengths and weaknesses (McGorry). McGorry asserted the importance of nurturing the patient's explanatory model so as to prevent damage to one's sense of self, which occurs when the patient's identity is linked with the role of the psychotic patient. This is more likely amongst FEP clients, whose self-concept is considered especially fragile due to their stage of identity development.

Recovery is a concept that means different things to different people and because of this can encompass a wide range of experiences and characteristics (Kelly & Gamble, 2005). As long ago as 1920, Mayer-Gross (as cited in Jeffries, 1977) proposed a phenomenological classification of the various ways in which a person may react to an acute psychotic experience. He distinguished four modes: denial of the future (despair); denial of the experience itself (exclusion); creation of a 'new life' after the illness; and 'melting' of the illness into a continuous set of 'life values.' He claimed the last of these was the most useful. Later research on recovery has confirmed a similar process of adaptation. Studies have examined a range of influencing factors such as level of insight (Shaw et al., 2002), clients' attitude (e.g., Soskis & Bowers, 1969), cognitive appraisals (Jackson et al., 2004), and recovery styles (McGlashan et al., 1976). All have been found to be important in how people experience psychosis. Although debate still exists over describing the course of recovery, research has identified stages, phases, dimensions, and processes (e.g., Andresen et al., 2003; Carr, 1983; Drury, 1992). These studies also confirm the role of psychological factors the distress of psychosis and subsequent recovery. The range of factors researchers have identified as central to recovery from psychosis are shown in Tables 3.1., 3.2, 3.3, 3.4, and 3.5.

Recovery models recognise the trauma of psychosis and describe processes akin to trauma theories. Three theories have been recommended in understanding how people experience the trauma of psychosis. These include the theory of emotional processing by Rachman (1980), Horowitz's stress-response model (1976), and Janoff-Bulman's (1992)

shattered assumptions theory (Jackson & Iqbal, 2000). In applying these models to psychosis, they indicate that it is the absorption of new material from the trauma of psychosis which is integrated, assimilated or worked through during recovery and allows new models and representations of the self and world to develop and leads to successful adjustment and recovery (Jackson & Iqbal). For instance, Janoff-Bulman emphasises pre-trauma appraisals and assumptions about the self and the world. In particular, Janoff-Bulman claims that the individual holds three types of pre-existing assumptions: the assumptions of personal invulnerability; the perception of the world as meaningful or comprehensible; and the view of the self as worthy and good. Janoff-Bulman suggests that these assumptions about the self and world can become shattered by the impact of a traumatic event and trauma symptoms are the by-products of the rebuilding process (Jackson & Iqbal). Table 3.1 shows terms used in the recovery literature to describe the traumatic experience of psychosis and treatment.

Table 3.1

Terms Used to Describe the Experience of Psychosis

Initial Experience of Psychosis
Overwhelmed by the illness (Spaniol, Wewiorski, Gagne, & Anthony, 2002)
Identity crisis (Pettie & Triolo, 1999)
Loss of control (Williams & Collins, 1999)
Crisis of psychosis (Baxter & Diehl, 1998)

As seen in Table 3.1, recovery models frame psychosis as a period of significant disruption and crisis in which people can feel out of control and overwhelmed, which is consistent with the trauma literature on psychosis. The traumatic experience of psychosis can precipitate a range of responses which are presented in Table 3.2.

Table 3.2

Terms Used to Describe Emotional Reactions to the Experience of Psychosis

Emotional Reactions
Denial (Andresen et al., 2003; Baxter & Diehl, 1998)
Self-protective withdrawal (Andresen et al.)
Avoidance, escaping or breaking free (Thornhill, Clare, & May, 2004)
Sealing-over (McGlashan et al., 1976)
Despair and anger (Baxter & Diehl)
Confusion (Andresen et al.; Baxter & Diehl; Perry et al., 2007)

As seen in Table 3.2, recovery models suggest that people struggle to cope with the illness. Emotional reactions such as denial and withdrawal are most often identified early in the recovery journey. Coping with the impact of psychosis using strategies such as these may initially be protective, but in the long-term they inhibit adaptation and become a source of vulnerability (Jackson & Iqbal, 2000). People may continue to employ strategies identified in Table 3.2 to cope with enduring trauma which can be an outcome of increased insight (Bendall et al., 2006). While Shaw et al. (2002) did not find a relationship between increased insight and higher levels of trauma, distress associated with increased insight may have contributed to Tait, Birchwood and Trower's (2003) finding that the number of people with a sealing-over recovery style amongst 42 young multiple-episode patients rose from 28% during the acute episode to 60% after six months.

As a person gains more insight into their symptoms the psychotic experience may also become less traumatic (Bendall et al., 2006). This can occur in the context of coming to terms with the illness, which recovery models identify (refer to Table 3.3).

Table 3.3

Terms Used to Describe Assimilating the Illness Experience

Assimilation
Living with the disability (Spaniol et al., 2002)
Struggling with the disability (Spaniol et al.)
Struggle for control (Williams & Collins, 1999)
Learning, healing and development (Green, 2004)
Acknowledging and accepting the illness (Young & Ensing, 1999)
Awareness of self beyond the illness (Andresen et al., 2003)
Integration (McGlashan et al., 1976; Williams-Keeler et al, 1994)
Awakening (Baxter & Diehl, 1998)
Self-awareness (Coleman, 1999)
Endurance (Thornhill et al., 2004)

McGlashan et al.'s (1976) recovery styles sealing-over and integration present a useful way of understanding how an individual reacts to and adapts to the trauma of psychosis. A person with an integration recovery style views their psychotic episode as a crucial life-altering event and is curious about the illness and ready to accept it. They are aware of the continuity of themselves before, during and after their psychosis, take responsibility for their psychotic experience, and are aware of both the pleasure and pain of it. Integrators search for the meaning of their psychotic experiences and explore their illness for personal information. They are less fearful and negative about mental health and problems in general and tend to be keen to receive support for their concerns. In contrast, for people with a sealing-over style, the psychotic experience can represent a hole in the context of meaning that needs to be sealed over. They are thought to isolate their psychotic experiences because they view it as incompatible with their life and do not accept responsibility for their illness, assuming they are powerless to influence the outcome of the illness and interpreting it concretely and globally as an external traumatic event. Individuals with a sealing-over style probably will not want to examine their symptoms or work with others in understanding their illness because they are still aware of the negative

aspects their psychosis, which was supported by Tait et al.'s (2003) research. These recovery styles can change over time through the course of recovery from the illness (Thompson, McGorry, & Harrigan, 2003).

One study on McGlashan et al.'s (1976) recovery styles sought to understand how people cope with the trauma of FEP and confirmed their clinical usefulness. In a study with 35 people, Jackson et al. (2004) found no difference between the two recovery styles and PTSD diagnosis. Those who had a sealing-over recovery style had less frequent intrusions about their episode than individuals with an integration recovery style, although this was not significant. Yet, 'sealers' were significantly more likely to use cognitive strategies to avoid the intrusions, which suggested they were they used sealing-over strategies to defend against the painful experience of FEP (Jackson et al.). It is also possible that trauma symptoms such as intrusions and re-experiencing may aid the integration of the episode and facilitate psychological recovery (Jackson & Iqbal, 2000).

Recovery models also point to the active role a person can play in their own recovery and identify a range of specific ways people engage in this process (see Table 3.4).

Table 3.4

The Individuals' Engagement in the Recovery Process

Actions
Living beyond the disability (Spaniol et al., 2002)
Striving to attain an overall sense of well-being (Young & Ensing, 1999)
Achieving competence (Williams & Collins, 1999)
Taking stock of one's strengths and weaknesses (Davidson & Strauss, 1992)
Putting an active self into action (Baxter & Diehl, 1998; Davidson & Strauss)
Using one's enhanced self as a resource (Davidson & Strauss)
Responsibility (Andresen et al., 2003)
Being a responsible agent (Davidson & Strauss)
Active agent (May, 2004)
Agency, control, and autonomy (Green, 2004)

Table 3.4 continued

Risk taking and avoiding risks (Ramon et al., 2007)
Developing interdependence (Baxter & Diehl)
Inter-dependency and self-help (Ramon et al.)
Discovering and fostering self-empowerment (Young & Ensing)
Learning and self-redefinition (Young & Ensing)
Search for one's identity and meaning of the illness (Pettie & Triolo, 1999)
Redefining identity (Andresen et al.)
Developing a new identity and positive sense of self (Pettie & Triolo)
Reorganisation of the self and illness (Williams & Collins)
Developing an integrated self (Baxter & Diehl)
Rebuilding (Andresen et al.; Baxter & Diehl)
Rebuilding self: understanding self and empowerment (Kilbride & Pitt, 2006)
Rebuilding life: active participation in life and rebuilding social support (Kilbride & Pitt)
Building a positive personal and social identity (May, 2004)
Striving to reach new potentials of higher functioning (Young & Ensing)
Reconnections with one's environment (Forchuk, Jewell, Tweedell, & Steinnage, 2003)
Giving to others (Ramon et al.)

As Table 3.4 indicates, a person's recovery is often described as a rebuilding process which can be internally or externally driven. For instance, recovery models discuss individuals taking stock of personal strengths and weaknesses and developing a new identity, as well as developing reconnections with the environment. Central to these recovery processes is both a desire to achieve prior functioning as well as a series of responses that could potentially lead to constructive changes. For instance, Young and Ensing (1999) discussed the potential for new self-growth and potentials in the context of a process of learning and self-redefinition.

Recovery models also discuss factors that influence and motivate people to engage in recovery from the psychotic experience. Table 3.5 reflects the internal and external factors that have been identified as influencing and motivating recovery.

Table 3.5

External and Internal Factors that Influence and Motivate Recovery

Influences and Motivational Factors
Competence and dysfunction are considered for capacity (Green, 2004)
A coherent account of experience (May, 2004)
Self-perceptions of knowledge of mental illness and treatment (Resnick, Fontana, Lehman, & Rosenheck, 2005)
Preparation (Andresen et al., 2003)
Assessing the possibilities for change (Davidson & Strauss, 1992)
A desire and motivation to change (Young & Ensing, 1999)
Empowerment (Resnick et al.)
Hope (Andresen et al, 2003; Baxter & Diehl, 1998; Green, 2004; Resnick et al.)
Hope and inspiration (Young & Ensing)
Hope for a better future: a process of change and desire for change (Kilbride & Pitt, 2006)
Meaning (Green)
Finding meaning in life (Andresen et al.)
Optimism (Green; Resnick et al.)
Satisfaction with quality of life (Resnick et al.)
Discovering the possibility of a more liberated and active sense of self (Davidson & Strauss)
Acceptance of self and others (Baxter & Diehl)
Self-confidence, self-esteem, self-acceptance (Coleman, 1999)
Environment, resources, and strains (Green)
Social support (May; Young & Ensing)
People can be a source of support and confirmation of self-worth (Ramon et al., 2007)
Mentorship (Kelly & Gamble, 2005)
Spiritual beliefs (Kelly & Gamble; May)

As shown in Table 3.5, both environmental and individual characteristics are important in influencing a person's engagement in their recovery from psychosis. In particular, the development of hope was a central factor in a number of recovery models.

Unlike the rehabilitation and medical models, these models show that recovery is not only an outcome whereby functioning is restored and symptoms are resolved, but a dynamic and ongoing process in which the individual plays an active role. They show that engaging in a meaning-making process post psychosis is critical for the person to make sense of the experience and actively move forward and rebuild their life and sense of self, which has been shattered through the experience of psychosis (Williams-Keeler et al., 1994). Andresen et al. (2003) found that a definition referred to as psychological recovery was most compatible with the beliefs of those who had a mental illness. It referred to "the establishment of a fulfilling, meaningful life and a positive sense of identity founded on hopefulness and determination" (p. 588). Researching the role of the individual in recovery from psychosis will further our understanding of what helps a person recover (Thornhill et al., 2004).

It has been argued that a multidimensional approach is most appropriate in understanding recovery from psychosis (Anthony, 1993). Anthony outlined three approaches to recovery which can occur simultaneously: (a) clinical recovery which refers to a reduction in symptoms; (b) social recovery which describes the development of meaningful social relationships and roles, vocational activities, and access to housing; and (c) psychological recovery which is defined as the process of developing new ways to understand and manage psychotic experiences and regaining some sense of structure in one's life. Social recovery is akin to the rehabilitation model, while clinical recovery addresses the medical model. Adding the notion of psychological recovery begins to include the person in the recovery process and recognise the dynamic nature of the recovery journey, viewing it as both a process and outcome.

One treatment model that has incorporated the individual in recovery from psychosis is cognitively-orientated psychotherapy (COPE) for early psychosis practised at ORYGEN Youth Health, Melbourne, Australia. This treatment has moved away from the traditional belief that recovery from psychosis only refers to a reduction in symptomatology and improvement in functioning, and instead has included a phase which focuses on the

subjective experience (Jackson et al., 1999). The treatment focuses on assisting people to adapt post psychosis, as well as to alleviate secondary morbidity and relapses. Specifically, COPE focuses on the client's appraisals of themselves and their illness and how their sense of self has been distorted by the psychotic episode. The goal of therapy is to help the person search for meaning in their psychotic experience, to master the experience, and to protect their self-esteem and positive viewed self. The longer-term aim is to enable the person to make a positive adaptation to the onset of the disorder, to play an active role in the management of their illness, and to maintain quality of life. The phases of this stage of treatment are: discovering the self, taking stock of the self, and putting the self into action (Jackson et al., 1999).

Despite its inclusion of the subjective experience, the overarching focus of the COPE is still on restoring and regaining functioning to the point the person would be in their developmental trajectory if they had not developed psychosis. Yet, the recovery models described in Tables 3.1, 3.2, 3.3, 3.4, and 3.5 demonstrate that recovery can also be seen as an opportunity for growth and development beyond what was present prior to the episode.

Psychosis as Precipitating Constructive Processes and Outcomes

The experience and consequences of psychosis can change the lives of individuals irrevocably (Davidson, 2003) and, because of this, the current thesis argues that recovery from this illness goes beyond restorative outcomes to include constructive changes. While the onset of psychosis can be traumatic and devastating at the same time it also creates an opportunity to take stock, learn lessons, and rebuild (Jackson & Birchwood, 2006). For instance, Reeves (2000) argues that with recovery comes a desire to live life to the best of one's ability and through this process people's perceptions of themselves and the world can change into something more positive. It appears that engaging in a process of searching for meaning and purpose in the psychotic experience (Anthony, 1993) can facilitate this transformative process or fundamental change (Green, 2004; Reeves).

A number of writers on recovery and psychosis refer to the possibility of constructive outcomes and processes from the experience of psychosis. For instance, authors have pointed to a redefinition of the self, increased self-awareness, self-development, and personal growth (e.g., Andresen et al., 2003; Barker, Lavender & Morant, 2001; Davidson, 2003; Kelly & Gamble, 2005; Lipner, 1985; Ramon et al., 2007; Repper & Perkins, 2003). Likewise, some see growth in recovery in terms of discovering new meaning and purpose, the meaning of life, changed world view, and existential and spiritual change (e.g., Coleman, 1999; Davidson & Strauss, 1992; Geekie, 2004; Kelly & Gamble; MacDonald et al., 2005), as well an opportunity to reassess one's values and goals (Andresen et al.) and improve interpersonal relationships (Lipner). Further, Forchuk et al. (2003) proposed that recovery from psychosis can bring new opportunities for connections with family, supportive others, and future relationships. Kilbride and Pitt (2006) discuss a process of personal growth from psychosis where one can emerge as stronger than before.

Qualitative studies have shown psychosis to be an opportunity for constructive change. In MacDonald et al.'s (2005) research showed sufferers of FEP developed self-awareness and a redefinition of personal values, attitudes, and beliefs as a result of their experience. This impacted positively on their decision making in social interactions. MacDonald et al. concluded that people's improved social experiences were associated with acceptance of the illness, hope, and discovering a renewed sense of self:

Since I've become psychotic and that, all my views have changed. I view the world differently now. I look at things differently that I used to...I don't want to get back into that lifestyle that I lived before (MacDonald et al., p. 137).

In a study by Thornhill et al. (2004) narratives of enlightenment were reported by people who viewed the experience of psychosis as having positive and developmental aspects as well as negative and difficult features. These narratives showed the development of sudden or gradual understandings and new perspectives on the self or spirituality. Parts of the self previously unrecognised were brought to the forefront and seen as the start of a journey of self-discovery. The general tone of this narrative was educative and thoughtful, with an emphasis on obtaining control and developing important insights:

Let go of being mad.....it was like serendipity....it was like a moment of, you know....religious language would be kind of 'grace' or something, you know. It would be like....something changed. And I was aware that something changed and I let go of something (Thornhill et al., p. 189).

I feel like I've got the control back. And possibly the psychosis helped me to get that control back...I think it was the psychosis that really sort of made me look at things...and having looked at them I feel a lot more...calmer about myself (Thornhill et al., p. 190).

The idea of psychosis as a potential growth experience as well as a painful struggle is not new (Lipner, 1985). For example, Jackson and Watzlawick (1963) suggested that experiencing a psychotic episode can be growth-promoting and crucial in creating a new beginning. In 1992 McGorry suggested the treatment of people with psychotic disorders is in need of some new ideas and techniques. Yet, only Jackson & Iqbal (2000) have recognised the importance of addressing the potential constructive experiences of psychosis in treatment. They also suggested a way of approaching this with clients by encouraging them to think of psychosis as meaningful event which can have both positive and negative aspects and an important effect on their lives.

In conclusion, this literature review indicates that a re-conceptualisation of research on the traumatic nature of FEP encourages a broader view of impact of the traumatic experience and recovery and addresses both restorative and constructive processes and outcomes. Given that change is unavoidable and could be necessary for optimal adaptation, it is important that the way people make these changes following adversity is explored (O'Leary, Alday, & Ickovics, 1998). To date the recovery literature on psychosis has considered how people engage in a meaning-making process in order to adapt to and integrate the psychotic experience. However, growth has not been researched extensively and further study may provide an improved and broader understanding of how people recovery from FEP.

Applying the Notion of Constructive Change in Understanding the Adaptation and Recovery process of FEP

A comprehensive understanding of the traumatic nature of FEP and recovery from this experience needs to consider a broader trauma response which goes beyond the initial experience and diagnosis of PTSD and incorporates potential constructive changes during the recovery phase. Posttraumatic growth is a contemporary concept in the trauma literature which parallels ideas discussed in understanding the trauma of FEP and recovery from this illness. It recognises the positive experiences that can come out of traumatic events while also the parallel pain and anguish trauma can cause (Tedeschi & Calhoun, 2004).

Tedeschi and Calhoun's classification of trauma allows the experience of FEP to be recognised in terms of an experience of trauma. They consider a wider range of events than the traumas required for a diagnosis of PTSD, focusing on experiences that have severely challenged one's past ways of understanding the world and their place in it (Tedeschi & Calhoun, 1999). Also, the nature of the trauma itself, such as whether it is chronic or acute, does not appear to be significant in the development of growth (Tedeschi, 1999), which has been confirmed by research (e.g., Park, Cohen, & Murch., 1996). Therefore, both the acuity of a psychotic episode and subthreshold and residual psychotic symptoms prior and post the acute episode can be considered traumatic. Further, processes discussed in the development of growth overlap with issues discussed in the literature on the trauma of psychosis and subsequent recovery. Thus, posttraumatic growth provides a useful framework for examining the possibility of constructive change in understanding adaptation and recovery process of FEP.

Posttraumatic Growth

Even though psychology has addressed the ways in which crises have offered the possibility of positive change (Resnick & Rosenheck, 2006) and the purpose of clinical work is to promote positive adaptation (O'Leary et al., 1998), focus has been on the negative impact of trauma. The notion of constructive change is not prevalent in research or clinical settings. It was not until the 1980s that researchers focused on the notion of growth

as a result of the struggle with traumatic experiences with studies supporting the idea that suffering can lead to valuable outcomes (e.g., Joseph, Linley, & Harris, 2005).

Tedeschi and Calhoun coined the term posttraumatic growth in 1995. Many other terms have been used to describe this phenomenon of posttraumatic growth. These include, but are not limited to stress-related growth (Park et al., 1996), positive psychological changes (Yalom & Lieberman, 1991), and thriving (O’Leary, 1998). When growth is described as a coping mechanism, the terms used have included positive reinterpretation (Scheier, Weintraub, & Carver, 1986), drawing strength from adversity (McCrae, 1984), and transformational coping (Aldwin, 1994). Other related concepts are resilience, hardiness, sense of coherence, and optimism. Tedeschi and Calhoun (2004) argue that the term posttraumatic growth is preferable for a number of reasons. In particular, it refers to major crises rather than stress as implied by the notion stress-related growth. Similarly, the terms ‘thriving’ and ‘flourishing’ do not clearly imply a significant threat or shattering of fundamental beliefs which can co-occur with distress. Further, the term posttraumatic growth highlights that constructive experiences are not coping strategies but outcomes or ongoing processes. Posttraumatic growth goes beyond the ability to resist and not be damaged by stressful circumstances and the idea of restoring functioning or maintenance of equilibrium. Instead, it is considered to be a transformation or qualitative change exceeding that which was present before the trauma (Tedeschi & Calhoun, 2004). Finally, posttraumatic growth is different to terms such as optimism as they only describe particular personal attributes that allow people to manage adversity (Tedeschi & Calhoun, 2004).

Evidence of growth as a consequence of a wide range of traumatic events gives supports researching the notion of constructive change as a result of FEP. Reports of positive changes have been found in a variety of populations ranging from college students (e.g., Park et al., 1996), HIV/AIDS caregivers (Cadell, 2007), and wives of former combat veterans (Dekel, 2007), and following a wide range of traumas such as domestic violence (Cobb, Tedeschi, Calhoun, & Cann, 2006), road trauma (Harms & Talbot, 2007), and sexual assault (Frazier, Conlon, & Glaser, 2001). Further, research has found that levels of posttraumatic growth do not differ across type of life events (Milam, Ritt-Olsen, & Unger, 2004), which suggests that positive effects of trauma are not restricted by the content or type of event (Christopher, 2004) but rather are related to subjective experience (Linley &

Joseph, 2004). Still, there is little known about the processes and consequences of the experiences of growth following a trauma (Tedeschi & Calhoun, 2004). Examining constructive change amongst people who have experienced FEP will also provide further understanding of the processes and effects of growth.

The Development of Posttraumatic Growth

Tedeschi and Calhoun (2004) draw on Janoff-Bulman's (1992) shattered assumptions theory to describe the process of posttraumatic growth. They assume that people actively construct an understanding or model of reality based on a set of schemas and assumptions. Schemas construct a model of the world to make it understandable, meaningful, and manageable and provide an understanding of one's place in it (Tedeschi & Calhoun, 1999). They are thought to guide one's actions, provide a framework for understanding the causes and reasons for things happening, and give meaning and purpose (Tedeschi & Calhoun, 2004). Trauma presents major challenges to an individual's assumptions and beliefs (Tedeschi & Calhoun, 1995) as existing beliefs are no longer adaptive due to the impact of the trauma (Tedeschi, 1999). Tedeschi and Calhoun (2004) argue that the process of experiencing trauma and subsequent challenge to fundamental assumptions can not only lead to destructive outcomes but can also be a source for unexpected outcomes, that is, growth.

It is not the trauma itself but rather how it impacts on the individual which facilitates growth (Tedeschi, 1999). Posttraumatic growth comes about as a result of the struggle with the trauma and new reality it has caused (Tedeschi & Calhoun, 2004). Therefore, some degree of continuing distress is needed to develop growth (Tedeschi & Calhoun, 1999). Tedeschi suggests that allowing trauma to have an impact rather than avoiding the associated distressing aspects is critical for posttraumatic growth. Yet, some distance from the direct confrontation of the trauma and extreme distress is also thought to be important in facilitating a reflective process, as well as disengagement from old beliefs and goals to prioritise processing the trauma (Tedeschi). Research has confirmed the process of growth as described by Tedeschi and Calhoun (e.g., Park et al, 1996; Wild & Pavo, 2003; Zoellner, Rabe, Karl, & Maercker, 2008).

The development of posttraumatic growth begins with the unmanageable distress the trauma has caused whereby schemas are challenged and attempts to control the situation are unsuccessful (O’Leary et al., 1998). Specifically, the trauma challenges one’s ability to manage emotional distress, one’s beliefs and goals, and one’s life narrative (Tedeschi & Calhoun, 2006). Persistent cognitive processing is at the heart of Calhoun and Tedeschi’s (2006) model of posttraumatic growth. This includes positive, negative, and neutral cognitions which can involve deliberate, thoughtful reflection about the event (Tedeschi & Calhoun, 1999) and this has been confirmed as important in research (e.g., Park & Fenster, 2004; Phelps, Williams, Raichle, Turner, Ehde, 2008; Taku, Cann, Calhoun, & Tedeschi, 2008; Ullrich & Lutgendorf, 2002). The traumatic event initiates thinking about the event and its consequences (Tedeschi & Calhoun, 1999) and comparisons of before and after the trauma are made (Tedeschi, 1999). In particular, the likelihood of growth increases to the extent that cognitive processing is focused on remembering positive pre-trauma experiences, how one is going to cope, how to make sense or finding meaning in the experience (Tedeschi & Calhoun, 1999). Self-disclosure and supportive others are also thought to play an important role in the development of growth. As aspects of the trauma are accepted, goals amended, and new meaning constructed schemas change to incorporate the trauma and future and are more resistant to being shattered. In the final stage, the positive effects of growth are stabilised and this has an ongoing mutual influence on the development of general wisdom about life and the new life narrative that includes the traumatic event and effective behaviour being manifested (O’Leary et al.; Tedeschi & Calhoun, 2004). Figure 3.1 gives a diagrammatic account of the development of posttraumatic growth.

Calhoun and Tedeschi (1998) suggest that posttraumatic growth occurs gradually. Yet studies have demonstrated mixed results with regard to the temporal course of growth. Research has shown that growth can occur as little as 2 weeks post trauma (Frazier et al., 2001) to as long after the event as 8 years and is stable over time (Affleck, Tennen, Croog, & Levine, 1987; Frazier et al.; McMillen, Smith, & Fisher, 1997). Some research found the more time since the trauma the more growth that is reported (e.g., Park et al., 1996), suggesting a longer period of time is required to develop constructive changes. In contrast, Wild and Pavio (2003) found that recency was associated with increased growth. Frazier et

al.'s research showed that some kinds of growth appeared more sudden (e.g., increased empathy), while others seemed to take more time to emerge (e.g., sense of purpose in life). Further still, researchers have also discovered that growth is unrelated to time (e.g., Milam et al., 2004; Weinrib, Rothrock, Johnsen, & Lutgendorf, 2006).

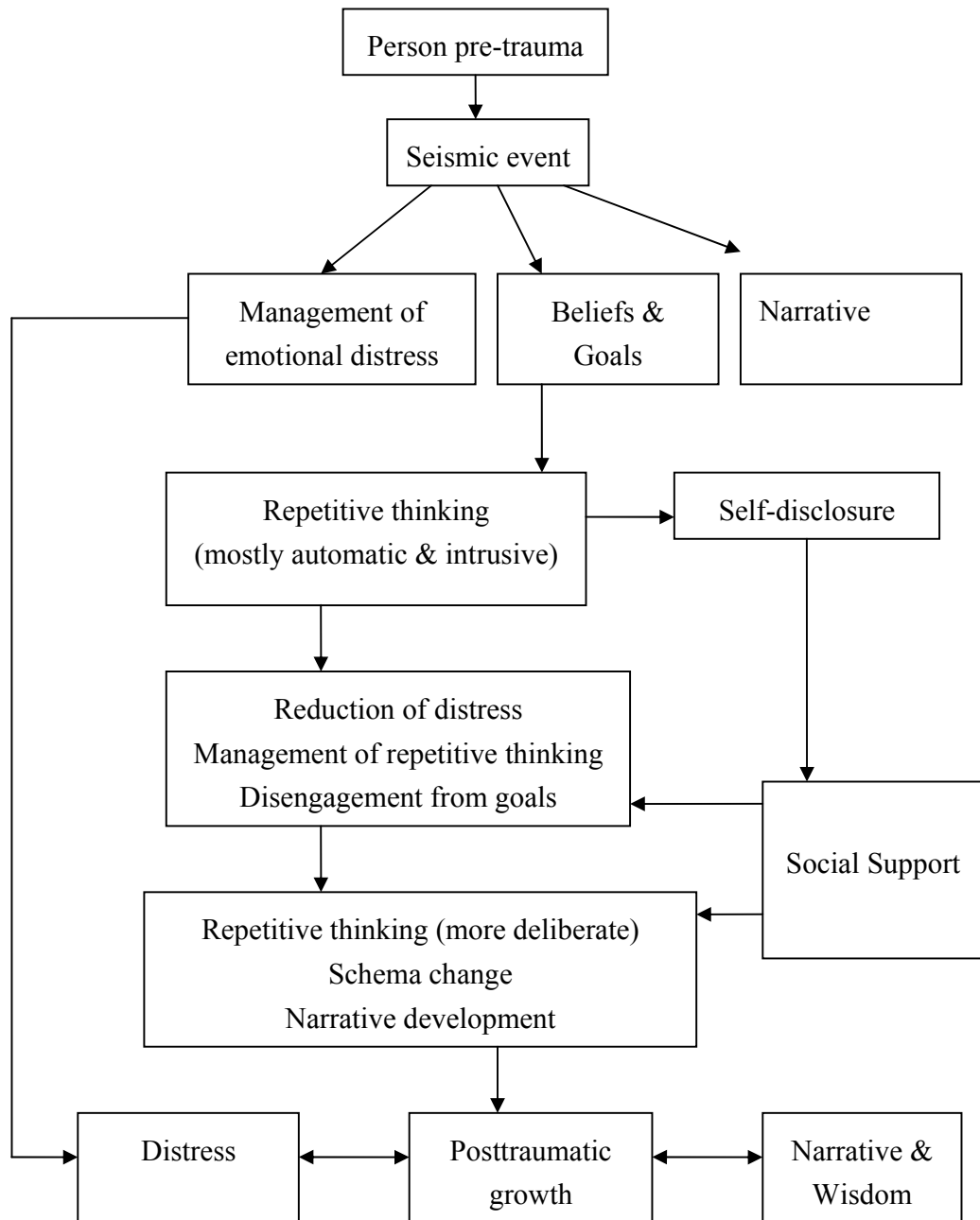


Figure 3.1. The development of posttraumatic growth (Adapted from Calhoun & Tedeschi, 2006, p. 8).

Posttraumatic growth is not considered to be the same as an increase in well-being or a decrease in distress (Tedeschi & Calhoun, 2004) and research has revealed a complex relationship between distress and growth. Some research has shown that high levels of traumatic distress predicts posttraumatic growth (Wild & Pavio, 2003), while other studies have discovered that growth is related to lower levels of distress (Frazier et al., 2001). Also, no relationship between distress and growth has been found (e.g., Powell, Rosner, Butollo, Tedeschi, & Calhoun, 2003). A meta-analysis also showed that reports of growth are associated with greater distress in the first two years of the trauma and less distress after longer periods of time (Helgeson, Reynolds, & Tomich, 2006). Despite the complex relationship between growth and distress, it is clear that the presence of growth does not preclude distress (Weinrib et al., 2006). Moreover, psychological distress can lead to positive change, with many possible patterns of relationships between the two and numerous factors important in bringing this about (Tedeschi & Calhoun, 1999).

The Multidimensional Nature of Posttraumatic Growth

There are five domains of posttraumatic growth (Taku et al., 2008): relating to others, personal strength, new possibilities, appreciation of life, and spiritual change. This model was found to be the best fit when examining the dimensionality of the Posttraumatic Growth Inventory

Relating to others

While trauma can produce significant disruption to one's relationships, coping with the trauma can also lead to positive change in relationships with others. The individual may experience deeper, warmer and more intimate relationship with others. This can be reflected in increased closeness or a strengthening of relationships, as well as greater self-disclosure with their loved ones and a greater sense of connection with others which can produce an increase in empathy and compassion for others (Calhoun & Tedeschi, 2006; Tedeschi, 1999). A greater freedom to be oneself is also discussed which may lead to disclosure of undesirable elements of oneself or one's experience. This may lead to realising who your real friends are, and those that stay produce increased closeness (Calhoun & Tedeschi).

Changed perception of self: Strength and new possibilities

Calhoun and Tedeschi (2006) summarise this theme with the statement “I am more vulnerable than I thought, but much stronger than I ever imagined” (p. 5). They suggest that significant disruption of the assumptive world can produce the belief that one’s world is more dangerous and unpredictable and as such one’s vulnerability becomes more salient. In conjunction with this an increased sense that one has been tested and found to be a person who has survived a significant trauma can produce a sense of strength (Calhoun & Tedeschi), as well as being a survivor rather than a victim and an increase in self-reliance, competence in meeting future life demands, confidence in one’s abilities, and awareness and acceptance of one’s vulnerability (Tedeschi, 1999). Some people report the development of new possibilities in life, developing new interests, new activities, and new paths in life (Calhoun & Tedeschi).

Changes in philosophy of life: Spiritual change and a greater appreciation of life

This domain can present as a shift in life priorities and greater appreciation for life and everyday things (Calhoun & Tedeschi, 2006; Tedeschi, 1999). For instance, what might have been irrelevant or a small thing may become more important, while things that were significant before the trauma no longer are (Calhoun & Tedeschi). A deepening of one’s existential experience can be experienced and expressed as increased questioning about the meaning of life, a greater sense of purpose and satisfaction (Calhoun & Tedeschi). This can include a development or deepening of spirituality (Tedeschi).

Given the multidimensional nature of posttraumatic growth, individuals may report growth in one or in a number of domains, with no growth or continuing difficulty in others (Tedeschi, 1999). For instance, Frazier et al. (2001) found that sexual assault survivors showed negative change in beliefs about the goodness of others and the world as fair and safe. Yet, participants also reported increased empathy, better relationships, and greater appreciation of life. Tedeschi suggests that there might be different processes for each of the domains, or other influential factors may play a role, such as the person’s environment and the nature of the traumatic event. In a study by Zoellner et al. (2008), domains of growth seemed to be differentially important depending on level of PTSD symptoms. Motor vehicle accident survivors without PTSD showed a higher growth in the perception of personal strength than people with PTSD and those with PTSD had more growth in

relation to philosophy of life. This suggests disparity in meaning and significance of the perception of growth at different stages of adaptation to the trauma.

Applying Constructive Changes to Understanding Recovery and Adaptation Processes of FEP

Potential Clinical Implications

Examining potential constructive changes as a consequence of FEP may have important clinical implications, such as the development psychological wellbeing and improved capacity to cope (Tedeschi, 1999). It is not clear whether wellbeing or adjustment is associated with growth (Park & Helgeson, 2006; Tedeschi & Calhoun, 1999) and posttraumatic growth is not considered a coping strategy (Tedeschi & Calhoun, 2004). However, cognitive coping strategies such as focusing on positive aspects of the situation, finding meaning in the trauma, and approaching the crisis as a challenge that can be mastered can facilitate growth and these coping processes are related to adaptation (Schaefer & Moos, 1998). Therefore, the development of constructive changes following FEP could enhance coping resources which are helpful in adapting to this experience and future psychotic episodes. Indeed, recovery models on psychosis emphasise the person playing an active role in their recovery and adjustment.

Social support has been found to be important in the development of posttraumatic growth. Individuals with more social resources are less likely to appraise trauma as a threat and more likely to rely on coping strategies that are linked to constructive changes and positive adaptation (Schaefer & Moos, 1998). Research has also found satisfaction with one's social support is associated with posttraumatic growth (Park et al., 1996). Therefore, exploring constructive changes as a result of FEP could help determine how social supports, including clinicians, could promote adjustment to this experience. This appears particularly relevant to FEP clients given that the experience of being unwell can have a significant impact on relationships (MacDonald et al., 2005).

Facilitating growth amongst FEP clients may improve other secondary difficulties in this population, such as quality of life and post-psychotic depression. For instance, studies have found that growth is associated with positive mood (Park & Fenster, 2004;

Weinrib et al., 2006). Further, Morrill et al., (2008) discovered that posttraumatic growth weakened the damaging relationship between trauma symptoms and depression and quality of life amongst breast cancer survivors. Positive links between growth and physical health such as lower levels of substance use (Milam et al., 2004) have also been identified, which might be particularly relevant in the early psychosis population which has high levels of substance use (Farrelly, 2007).

While FEP can be especially detrimental because it occurs at a young age, Helgeson et al. (2006) suggest that adolescents may be better equipped with the abstract thinking skills needed to experience growth. As well, Tedeschi and Calhoun (2004) suggest that a younger people may report more constructive changes than older individuals because they could be more open to the learning and change of this process while older adults may have more fixed beliefs. However, some maturity may be required in the development of growth. In Milam et al.'s (2004) research the average age of participants was 15.80 years, with the oldest respondents being in Year 12. A positive relationship was found between age and growth suggesting that a certain level of maturity was required. The authors surmised that young adolescents are not as likely to engage in meaning-making in an attempt to perceive benefits due to their developmental stage. Tedeschi & Calhoun also suggest that posttraumatic growth may be more relevant to young adults than children because it requires an established set of beliefs that are shattered by the trauma. However, at this stage there is little research with young adults (Tedeschi & Calhoun). Therefore, researching constructive change amongst people with FEP is opportune.

In clinical practice there is a tendency to favour a decrease in distress and an increase in psychological wellbeing as the most desirable outcomes for people who have experienced a traumatic experience such as FEP. Such a view is confirmed by the medical and rehabilitation models. Although the mixed results in exploring the relationship between wellbeing and distress may indicate growth is not always beneficial, a broader view implies that constructive changes demonstrates a person is living a fuller life in the context of inevitable distress (Calhoun & Tedeschi, 2006). This is consistent with a broader perspective of trauma and recovery from psychosis, with authors articulating that psychosis, while distressing, can bring about deeper constructive change in the context of ongoing symptoms (Andresen et al., 2003; Deegan, 1993; Jackson & Birchwood, 2006).

Considering this, distress associated with FEP does not necessarily preclude the presence and benefit of constructive changes. While people who perceive their psychotic symptoms as particularly threatening are more distressed (e.g., Brunet & Birchwood, 2008; Chisholm et al., 2006; Morrison, Nothard, Bowe, & Wells, 2004), greater levels of perceived threat are associated with increased growth (Armeli, Gunthert, & Cohen, 2001). Therefore, high levels of perceived threat may indicate a greater need to respond to and facilitate the process of constructive change (Park & Fenster, 2004; Tedeschi & Calhoun, 1995) amongst people with FEP.

Constructive Change: Real or Illusory?

In considering the lack of a consistent relationship between growth and psychological adjustment (Zoellner & Maercker, 2006a), people have questioned whether posttraumatic growth represents real change or reflects positive illusion (Park & Helgeson, 2006). The possibility that constructive change may be illusory is important consideration when researching these processes in the psychotic population. For instance, it is common to find people who have positive beliefs about their experience, especially in the earlier stages of their psychotic illness (Morrison, 2001). Further, the positive relationship between intrinsic religiousness (Park et al., 1996) and growth needs to be examined carefully in the FEP population as religious beliefs could be related to delusional content.

According to Taylor's (1983) cognitive adaptation theory, readjustment following trauma includes efforts to identify why the trauma occurred and discovering benefits from it. Framed as positive illusion, this response may help the person to return to or exceed their prior self-perception and world view which may manifest as search for meaning, an effort to regain a sense of mastery, and an attempt to restore a positive sense of self (Maercker & Zoellner, 2004; Taylor). Similarly, temporal comparison theory suggests that people are very keen to maintain a positive self-regard and when it is threatened will construct a negative past sense of self in comparison to their current self to do so (Park & Helgeson, 2006), suggesting that growth may not reflect actual change. Frazier and Kaler (2006) presented three studies to assess the validity of self-reported growth by examining the links between growth and wellbeing using comparison groups and objective measures and found very little evidence for posttraumatic growth. Likewise, McFarland and Alvaro (2000) found that people's reports of improvements were more strongly linked to perceiving the

past as worse than it really was than to actual improvement pre and post trauma.

Research also provides evidence for growth representing actual change. Wild and Pavio (2003) discovered that posttraumatic growth was independent of social desirability. Likewise, there was no association between growth and a tendency towards impression management in Weinrib et al.'s (2006) study suggesting that reports of growth are not necessarily superficial and motivated by self-preservation or self-presentation concerns. Further, Rabe, Zöllner, Maercker, and Karl (2006) found that there were neurological changes in people who had experienced car accidents which correlated with perceived growth. The presence of cognitive processing in reports of growth also suggests that positive changes are authentic (Park & Helgeson, 2006). Weinrib et al. and has found that reports of growth were linked to indicators of cognitive processing from essays that participants wrote about their traumatic experiences, which suggests that posttraumatic growth can come about from a process of trying to understand and make sense of a traumatic event (Park & Helgeson).

There have been a number of suggestions on how to deal with the issue of real versus illusory change. For instance, the need to consider both the benefits and costs of the trauma with the idea that benefit without cost may be less likely to indicate true growth (Cheng, Wong, & Tsang, 2006). Additionally, people who report growth without cognitive processing might be demonstrating illusory growth (Park & Helgeson, 2006). Illusory growth is also thought to be evident when a person cannot give specific examples of how the reported positive outcomes manifest (Maercker & Zoellner, 2004). Therefore, collecting evidence of behavioural change and corroboration from significant others might help distinguish between illusory or actual growth (Linley & Joseph, 2004; Park & Helgeson; Zoellner & Maercker, 2006a). Thus far, research has indicated that third party reports have reliably validated growth (e.g., Park et al., 1996). However, to date comparing self and other reports of growth has been neglected. In contrast, Park and Helgeson suggest people's *beliefs* about growth may be more important in understanding their psychological experience than whether or not their perceptions are supported by objective measures.

Often positive illusions following trauma are claimed to be dysfunctional, yet they may also play a beneficial role in bringing about psychological adaptation (Taylor, 1983). For instance, illusory growth may serve a protective role against trauma both in the initial

stages of threat and as one comes to terms with information that is difficult to accept (Taylor) and integrate, such as the experience of psychosis. Therefore, while aspects of positive beliefs about one's psychotic experience may be akin to illusory growth, they may also play a very important functional and adaptive role. Morrison (2001) explains that psychotic experiences can add meaning to the person's life such as providing excitement, making them special, and defending against self-blame. Thus, positive beliefs about psychotic symptoms could be implicated in their development. A person may take substances to induce symptoms or deliberately allocate attention to them. In turn illusory components of growth following FEP may counterbalance the emotional distress associated with this experience.

Zoellner et al. (2008) contend that inconsistent findings with regard for the relationship between adjustment and constructive change could be related to different cognitive factors being involved in growth at different phases of adaptation. Maercker and Zoellner (2004) put forward a two-component model (the Janus Face Model) which considers both a constructive and a self-deceptive side. The former is linked to functional adjustment or cognitive re-structuring, while the latter may be aligned with factors such as denial, wishful thinking, and avoidance to counterbalance the person's emotional distress, which may represent a short-term adaptive coping strategy but have negative effects on adjustment in the long-term (Zoellner & Maercker, 2006a). Thus, reports of illusory growth may be self-enhancement cognitions to deal with distress and are therefore a coping process, whereas actual growth can be a coping outcome. Accordingly, people who are still emotionally distressed may reflect illusory growth, whereas people who have successfully adapted to the trauma and have overcome psychological distress report true growth (Zoellner et al., 2008). Maercker and Zoellner postulated that illusory growth might not be detrimental if it does not hinder the person from acknowledging the difficult aspects of the trauma and engaging in cognitive processing. Similarly, Park and Helgeson (2006) also suggest that illusory growth could be a pathway to actual change. Overtime, the constructive aspect of posttraumatic growth is thought to grow and be positively related to adjustment and wellbeing, while the illusory component is assumed to decrease (Zoellner & Maercker).

Zoellner et al. (2008) suggest the illusory and veridical sides of growth can be captured by the concepts *optimism* and *openness to new experience*. Optimism might be reflective of illusory growth, whereas openness to change might be indicative of veridical growth. Openness to experience is defined as the tendency to be interested in new situations, new ideas, and new experiences. The person is able consider and tolerate the impact of the trauma, including intense feelings, and to manage uncertainty and the constant nature of change, and has the ability to develop change rather than work against it (Zoellner et al.). Zoellner et al.'s study, which researched the illusory and constructive side of growth in relation to PTSD severity, found that these cognitive processes played different roles in the development of growth dependent on level of trauma. This suggests that both maladaptive and adaptive coping can predict growth and there are important functional differences in the cognitive processes involved in the development of constructive change in relation to trauma severity.

With regard to the FEP population, the nature and function of constructive change could be dependant on level of distress and the recovery and adaptation processes of FEP. For example, openness to change is consistent with subject matter discussed in the recovery literature on psychosis such as the integration recovery style identified by McGlashan et al. (1976). Therefore, it is possible that the recovery styles sealing-over and integration also play different roles in the development of growth. It is concluded that features of growth, illusory and actual, should be considered as pertinent in understanding the impact of FEP and ongoing adaptation to this experience.

Summary

The impact of FEP can be understood within a trauma framework with symptoms and treatment being found to be highly distressing for people, with the potential to develop into PTSD. Yet, the trauma of FEP is broader than a diagnosis of PTSD and should include other secondary consequences and experiences associated with changes to the self as one's previously coherent sense of identity and worldview are shattered in the wake of psychosis. Focusing only on the negative outcomes of a distressing event can lead to biased understanding of posttraumatic reactions and oversimplifies the nature and significance of

the response to trauma (Linley & Joseph, 2004). In fact, only a minority of persons exposed to a traumatic event will develop some sort of pathological disorder and the majority of those who develop PTSD are symptom free in 6-12 months without treatment, while many experience some positive or adaptive effects consistent with posttraumatic growth (Christopher, 2004). Linley and Joseph argue that a comprehensive understanding of trauma reactions needs to consider both positive and negative outcomes.

Recovery has traditionally been assessed with objective measures such as symptomatology, treatment history, and functioning (Andresen et al., 2003), as reflected in the medical and rehabilitation models. Medical and rehabilitation models contribute to effective treatment for psychosis, but the complexities of human experience need to be included in the understanding of psychosis and to enhance the effectiveness of treatment. Although the role of the person as an active agent in their recovery is now recognised and recovery is actively promoted, the predominant aim of services remains to prioritise professional opinion and input to achieve restorative outcomes (Kelly & Gamble, 2005). This is due to an over focus on the pathology of psychosis and the belief that symptom reduction and return to pre-morbid functioning, namely restorative recovery, is a key indication of improvement.

Through researching the impact of psychosis and subsequent adaptation and recovery, a small but influential body of literature on recovery from psychosis has incidentally discovered the possibility of constructive outcomes that occur in parallel to distress. Yet, to date no research has systematically researched constructive processes and outcomes after experiencing psychosis. Exploring the notion of constructive changes in people who have experienced FEP could improve our understanding of how people understand and accommodate to this experience, as well as how they recover from it. Understanding growth fits well with clinicians' desire to emphasise strength and resilience and understand adaptation following adversities such as FEP. Understanding why and how some individuals grow in the aftermath of FEP will broaden our current understanding of the impact of this experience and subsequent recovery and adaptation. Efforts to understand the origins of constructive change, the conditions under which it occurs, and the best ways to assess it may lead to significant clinical implications and more effective clinical interventions for FEP clients.

Aims and Research Questions

The aim of this thesis was to develop a comprehensive understanding of the recovery and adaptation processes of FEP. The current research explored how people understand FEP and considered the traumatic nature of this experience and the presence of restorative and constructive recovery processes. Four research questions guided the research:

- (1) How do people experience a FEP and what is the nature of the ongoing negative impact of FEP?
- (2) How do people engage in managing FEP?
- (3) To explore the presence and nature of restorative and constructive processes of adaptation and recovery from FEP
- (4) What is the process of adaptation and recovery from FEP?

CHAPTER 4: METHODOLOGICAL APPROACH

Rationale for the Methodology

This research was qualitative and longitudinal in nature to track FEP participants' traumatic experience of FEP and adaptive process over time. It adopted an in-depth phenomenological approach, specifically interpretive phenomenological analysis (IPA). By engaging in qualitative research a better understanding of how people comprehend the impact of FEP and adapt to and recover from this experience can be established. Couched within an adaptation and recovery framework, the key focus of this thesis is to develop a greater awareness of the meaning-making process people go through in understanding their experience of FEP and subsequent changes.

Lieberman argued in 1989 that there are many mental states which are not easily understood by objective measures given their subjective nature, psychosis being a case point. However, the subjective experience of psychosis remains little understood. This is partially attributed to the depreciation of qualitative research as well as the perception that the person is lost to the illness (Davidson, 2003). Historically, psychosis has been seen as a deteriorating illness which leaves the person out of touch with reality. While these views are beginning to shift, the meaning-making process people go through in understanding their illness as well as their beliefs and attitudes remains largely neglected (Davidson). Yet, people's accounts of psychosis and recovery demonstrate a willingness and capacity for introspection, self-examination, and integration of internal experiences (Lipner, 1985) and highlight the importance of this meaning-making process (Roe & Davidson, 2005; Geekie, 2004; Werbart & Levander, 2005). Thus, as Roe, Chopra, and Rudnick (2004) argue, an individual with mental illness should be considered a "goal-directed agent, actively coping with the disorder and influencing its course" (p. 123).

While numerous studies focus on the signs, symptoms, and management of psychosis, research that follows clients qualitatively through their experience of psychosis and recovery is limited (Forchuk et al., 2003). Qualitative studies are important in understanding adaptation to psychosis as they can demonstrate the variety of ways people can respond to and understand their psychotic experience (Geekie, 2004). For example,

they can highlight psychological development and change (Davidson, 2003); how people make sense of themselves and their situation (Frances & Uhlin, 2006; Williams & Collins, 1999); and what recovery means, what factors influence and aid recovery, and what individuals see as crucial to their recovery (Kelly & Gamble, 2005), which is pertinent to clinical practice with people with psychosis (Jackson et al., 2004). Thus, it is asserted that by refocusing on the individual rather than the disorder, a more comprehensive picture of the course and outcome of FEP can be captured (Roe et al., 2004).

Authors examining the traumatic nature of FEP have recently commented on the clinical significance of the subjective experience in studying FEP and the usefulness of applying qualitative methods (e.g., Bendall et al., 2006; McGorry et al., 1991; Jackson & Iqbal, 2000; Meyer et al., 1999; Priebe et al., 1998; Shaw et al., 2002). For instance, at the completion of their study, McGorry et al. called for more intensive interview-based methods to be employed to better understand the subjective stress psychosis can cause and how people adapt to this experience. Further, qualitative research is of unique value given that the notion of constructive changes is still an evolving phenomenon (Zoellner & Maercker, 2006a). In particular, intensive case studies or studies of a smaller cohort of individuals are considered beneficial in developing an understanding of the depth and scope of growth responses (O'Leary et al., 1998).

The phenomenological approach is particularly suited to understanding the experience of FEP and the role of the individual in this event (Lepin, 1985). It is specifically relevant to the aims of this thesis as the approach asks the person who has experienced FEP to describe their experiences within the context of their psychosis as well as their lives (Davidson Staeheli, Stayner, & Sells, 2004). Phenomenology couched in psychology wishes to discern the psychological meaning of the phenomena being researched and is therefore interested in understanding the diversity of the human experience. The researcher focuses on individuals' experiences, which become the phenomena studied. Phenomenological research seeks out individuals with first hand experience of the phenomena being studied to examine as closely as possible the way in which the phenomena are experienced within the context they take place. This is referred to as the individuals' lived experience (Giorgi & Giorgi, 2008).

The belief that each person has a “unique story to tell” (Patton, 1990, p. 191) is the main premise which guides this research. Like humanistic therapy, the participant’s point of view is considered central to the investigation. Phenomenological research requires the researcher to enter the experiences of the participant and therefore highlights the importance of maintaining a non-directive and open-ended stance so as to provide the participant with an opportunity to share their experience of the phenomenon being investigated (Willig, 2001). The present study began with the participant’s perspective and explored their story, with the researcher maintaining an open stance. In doing so, the participant’s language, perceptions, and experiences are captured (Patton). The researcher is required to demonstrate flexibility throughout the interviews and to follow the lead of the interviewee and allow the interview process to be open, exploratory, and sharing (Patton).

The phenomenological approach allowed the researcher to recognise the individual’s struggle with FEP and their attempts to cope with it, referred to as a ‘life project.’ A first occurrence of psychosis was examined as an experience which may change one’s view of the world and self, and the meaning a person places on their psychotic episode was considered to directly influence how they deal with and respond to it. Three assumptions essential to characterising the phenomenological approach provided a conceptual framework for considering people as purposefully engaged in meaningful ‘life projects’ that extend over time (Davidson, 1992). These are: (a) intentionality; (b) temporality; and (c) meaning. Intentionality suggests that individuals are active in the pursuit of chosen goals. Temporality acknowledges the longitudinal nature of personal activity which can allow us to understand psychosis in terms of its effect on a person’s life course. Lastly, meaning recognises that actions are related to each other in meaningful ways and as changes happen there are shifts in one’s perception and understanding which influences future actions (Davidson, 1992, 2003).

Interpretative Phenomenological Analysis

Interpretive phenomenological analysis was developed specifically for psychology. Very few studies have applied IPA to the experience of psychosis. The most relevant was a focused on hope following FEP (Perry et al., 2007). However, Perry et al. did not specifically analyse hope within the context of recovery from this illness, the focus of the present thesis. Interpretative phenomenological analysis was adopted in the current study

because of its concern with the subjective experience and its ability to address and understand the meaningful experiences of individuals through an interpretative process (Biggerstaff & Thompson, 2008; Perry et al.). Interpretative phenomenological analysis encompasses the phenomenological approach of understanding and giving voice to participants, as well as an interpretative component, which contextualises and makes sense of the participant's concerns from a psychological perspective (Larkin, Watts, & Clifton, 2006). It focuses upon the person in context and how the individual understands and makes sense of the phenomena being examined (FEP) with regard to their relatedness to and engagement with it (Larkin et al.). The approach is interested in cognitive and emotional aspects of the individuals' accounts, with the researcher focusing on trying to find out what the person thinks and feels about their experience (Smith & Osborn, 2007).

Interpretive phenomenological analysis does not simply describe its results in terms of subjectivity, but recognises that conclusions can also be made about the objective reality or the phenomena being studied (Larkin et al., 2006). Therefore, taking an IPA approach in this study allows participants' accounts of FEP and their engagement with this experience to be used thematically to reveal something tangible about FEP. Interpretative phenomenological analysis is also suited to the longitudinal nature of this study and its aim to address subsequent changes due to the experience of FEP as it allows people to comment on how experiences affect them over time (Perry et al.). Further, a goal of IPA is to provide an intensive and detailed analysis of individual experience with a small number of participants (Larkin et al.; Smith & Osborn, 2007).

Of further relevance to this study is IPA's recognition that the process of exploring participants' experiences also involves the researcher's own views as well as the interaction between the researcher and participant (Smith & Osborn, 2007; Willig, 2001). Interpretative phenomenological analysis acknowledges that understanding people's experiences is done via the researcher's engagement with and interpretation of participants' accounts, hence the word *interpretative* use in the name of this method (Smith & Osborn; Willig). The IPA approach acknowledges that the researcher usually has some preconceived ideas about the subject of study (Alm & Frodi, 2008) and that analysis is informed by distinct theoretical constructs and directed towards answering predetermined research questions (Larkin et al., 2006). While IPA recognises the influence of the

interviewer's own way of thinking and assumptions, the researcher's interpretation is seen as necessary in forming an understanding of the participants' experiences rather than creating a bias (Willig).

The Validity of Qualitative Research

There have been a number of criticisms of qualitative research such as the belief that qualitative data cannot be generalised across populations and can only provide insight into the experiences of the study sample. Such arguments stem from the notion that narratives are superfluous if standardised methods can be used to obtain objective data that can be generalised (Silverman, 2001). Yet, narratives can transcend individuals by identifying common elements and providing an understanding of a particular type of experience (Davidson, 1993; Fossey, Harvey, McDermott, & Davidson, 2002). Thus, even though it is unknown who or how many people share a particular phenomenon, qualitative studies are able to conclude that it is present within a particular group (Willig, 2001).

Another concern is whether or not qualitative data truly addresses the research question (Willig, 2001). Qualitative research focuses on the real world, which Willig claims allows for environmental validity. Qualitative studies permit participants to challenge researchers' assumptions about the concepts and meanings being investigated. Also, investigators engaging in qualitative research are encouraged to continuously review the research process and their role in it, as well as clarify findings with participants wherever possible (Willig). With respect to studying the experience of psychosis, Davidson (2003) contends, if there are still useful things to learn about qualitative research from conducting it with people who are thought to be "less articulate, less verbal, and less socialised" (p. 9), then this provides evidence for the validity and reliability of this research method.

How sound the explanations are that qualitative research offers has also been questioned (Silverman, 2001). This is particularly relevant to studying the experience of psychosis, given the very nature of the illness can cause one to be out of touch with reality. However, even delusional narratives can provide accounts of people actively making sense of their experiences (Roe & Davidson, 2005). Further still, a majority of those who experience psychosis do not stay psychotic, and even when they are experiencing psychotic symptoms they can come in and out of this state (Davidson et al., 2004). Research has also found that accounts of the experience of psychosis can be stable over time, consistent, and

accurate (Centofanti et al., 2005; Cutting & Dunne, 1989). Evidence for the possibility of recovery from psychosis and the person's role in this process makes it essential for the individual's experience of this illness to be studied. Specifically, qualitative studies are required to identify the subjective factors which influence psychosis and adaptation. Researching psychosis using a qualitative approach is considered timely and valuable (Davidson, 2003).

In conclusion, given that FEP is a time of significant change when individuals are most likely to be in the process of developing an understanding of their experience, researching the subjective experience of this event and subsequent recovery is highly relevant. Further, FEP is also when clinicians might be able to contribute most to the client's efforts to develop their explanatory model (Geekie, 2004). Interpretive phenomenological analysis was considered the most appropriate to meet the research aims and methodological needs of the present thesis.

Personal Reflections on the Experience of First-episode Psychosis

Good practice in qualitative research includes disclosure by the researcher of his or her study expectations, preconceptions, values, and orientation (Stiles, 1993). The following section is my personal reflections on, and attitudes about this research topic. It also discusses how I came to develop the idea for my research project.

I have worked in mental health for a number of years and in doing so recognised a high proportion of co-morbid trauma. Despite this high prevalence, trauma did not often appear to be addressed in the treatment of psychosis, even though clients' symptomatology sometimes seemed to be associated with their trauma history. I found this frustrating and neglectful and it led me to explore the relationship between trauma and psychosis. Subsequently, I researched the co-morbidity between PTSD and psychosis and became interested in the relationship between the two disorders. Three relationships have been put forward: trauma may cause psychosis, psychosis may cause PTSD, and both psychosis and PTSD could be a part of a range of trauma responses (Morrison et al., 2003). Without disqualifying the importance of exploring all three relationships, the idea that psychosis could be considered a traumatic event which leads to the development of PTSD resonated

with me.

I remember talking to a friend who had experienced numerous psychotic episodes and had been hospitalised on a number of occasions. She was in tears about her treatment experiences and seemed angry. She described her experiences as traumatic and discussed the effect it had had on her relationships and sense of self. Reflecting on her experiences led me to realise that I had underestimated the impact that psychosis and acute treatment could have on my clients. I realised that I had been caught-up in my own urgency to obtain tangible outcomes in my work with clients rather than take the time to hear their story.

The culture of public mental health services also appears to silence the impact of psychosis and treatment on their clients despite research demonstrating the traumatic nature of these experiences (e.g., McGorry et al., 1991). For example, acknowledging the effect treatment has had on clients could be considered a contentious issue because somehow mental health workers could be held accountable. Overall, I believe this is an issue for the mental health system to address. However, I do think individual services and clinicians can begin the process of understanding and listening to their clients' experiences of psychosis and implement ways of supporting them through these experiences. For example, through conducting this research I became aware of the idea of 'post-seclusion' counselling. Also ORYGEN Youth Health in Melbourne, Australia, is open to understanding the traumatic impact of psychosis and educating clinical staff about this and supporting clients to cope with these experiences during their treatment.

I believe that we cannot decide whether or not someone else's experience is traumatic to them. I think the risk of trying to define trauma, as is done in the *DSM-IV-TR* (APA, 2000), narrows our understanding of people's experiences by restricting the definition of trauma and not adequately acknowledging the subjective experience. As a result the traumatic nature of psychosis has been relatively neglected with only a limited number of studies having investigated this (e.g., Centofani et al., 2005). Although it has been important to research the co-morbidity of PTSD in response to psychosis and acute treatment, in endeavouring to define psychosis as a traumatic event consistent with Criterion A, we have lost the individual's story and an understanding of the range of responses a person can have to this experience.

Most clients I have worked with have experienced long-term chronic mental health issues. Thus, I am interested in working in the area of early intervention, which is one reason why I chose to focus on FEP. In addition, it is a growing area of research and clinical practice. However, I think I was particularly drawn to studying FEP because many people who develop a first occurrence of psychosis are in my age bracket. I could not fathom experiencing an episode of psychosis and this led me to reflect on how it may impact on my life if this was to occur to me. Would I still be me? What would happen to my life? Would my friends still want to be my friends? The focus on the presence of PTSD as a result of psychotic symptoms and acute treatment has discounted the impact these experiences can have on the individual's sense of self, relationships with others, and experience of life.

The other component of my research involves exploring whether the experience of FEP can lead to constructive outcomes. My fourth year research focused on vicarious traumatisation in telephone counsellors. One of the counsellors who returned their questionnaire pack had written a note asking why the research had not considered the positives of working with people who had experienced trauma. This led me to explore the notion of posttraumatic growth, which highlights the potential positive changes that can come about from trauma while recognising the parallel distress. It appealed to me because in the mental health field we tend to pathologise people's experiences and are less likely to acknowledge our clients' capacity to move forward and use their experiences as an avenue for personal transformation. Instead, having a mental illness, particularly psychotic disorder, has been considered to be a life sentence. Although this view is changing in the mental health system, the idea that people might be able to turn their experiences into something positive has generally not been fostered.

The main aim of treating psychosis is to enable symptom resolution and functional recovery. While this is very important, treatment does not tend to acknowledge and facilitate potential constructive change. I believe that a more inclusive understanding of the traumatic nature of psychosis should consider both distressing and constructive aspects of the experiences. Also, acknowledging constructive changes after the psychotic episode might have valuable treatment implications.

Through this project I wished to develop a greater understanding of people's experiences of FEP. I also wanted to provide them with a space to talk freely about their experiences, an opportunity that often seems to be neglected. Further, I wished for their stories to contribute to the treatment of clients with FEP. That is, for clinicians to validate and support their clients in working through the deeper impact of the psychotic episode. In addition, I hoped this research would provide an avenue for people who experienced FEP to facilitate and embrace possible positive transformations. I expected that the people I recruited for my study would identify other distressing features of their psychosis besides their treatment and symptoms, such as a disrupted sense of self. I also imagined that participants would have a capacity to reflect on their experiences and would be able to identify some constructive outcomes.

CHAPTER 5: PILOT STUDY METHODOLOGY AND RESULTS

This chapter presents the description of the sample and of the quantitative and qualitative methods used. The study was prospective and longitudinal in order to track participants' recovery and adaptation. First-episode psychosis participants were interviewed twice, 3 to 5 months post their psychotic episode (Time 1) and 3 months following this (Time 2). An interview with clinicians and loved ones was also completed at Time 2 and information was collected from FEP participants' medical records. Interviews were semi-structured and augmented by quantitative measures, which were used as stimulus material during the interviews and for normative comparisons. By combining several methods of collecting data information, a more substantive picture of the issues being explored could be obtained. Such triangulation gives a mutual confirmation and validation of findings and can broaden, refine, and strengthen the concepts being explored.

Recruitment

Inclusion in this study was restricted to people aged 18-35 who had experienced a first occurrence of psychosis for a number of reasons. A study conducted in Melbourne, Australia by Amminger et al. (2006) found the average age range of admission for FEP for men and women was 21.9 and 22.0 years respectively. Also, a level of maturity is considered important in the development of constructive changes (Milam et al., 2004). Lastly, discussions with research and clinical staff in the area of FEP suggested increasing the age to 35 to improve recruitment rates as a significant proportion of clients presenting at the Alfred Hospital for FEP were over 30 years old.

This research abided by the Australian Clinical Guidelines for Early Psychosis, which state that FEP represents “the first treated episode of psychosis experienced by an individual in their lifetime” (National Early Psychosis Project Clinical Guidelines Working Party, 1998). First-episode psychosis participants were recruited if they (a) had a primary diagnosis of a psychotic illness conforming to the *DSM-IV-TR* (APA, 2000) criteria and confirmed by their treating team and file notes to ensure that participants had experienced FEP and could respond accordingly; (b) had experienced FEP 3 to 6 months prior to

recruitment so they were more able to recall their episode and less likely to have relapsed; (c) as determined by their treating team they were able to clearly reflect on their experiences and were at a point where they were deemed able to give informed consent and participate in the study; and (d) had a family member willing to be involved in the study who could give informed consent. This permitted triangulation of the interview data.

Exclusion criteria were: (a) significant brain damage and/or significant intellectual disability that would affect the ability to participate; (b) very illiterate or having very poor English/unable to converse in or read English without an interpreter as this may impact on participants' ability to complete data collection; and (c) an inability to give informed consent.

Participants were recruited from the Alfred Psychiatric Outpatient Services, Melbourne, Australia. They were being seen by the Continuing Care Teams, the largest component of adult community mental health services. These teams provide non-urgent assessments, treatment, case management, support and continuing care services to adults (aged 16-64 years) with a mental illness in the community. After ethics approval was obtained from Swinburne University of Technology and the Alfred Hospital ethics committees (copies of ethical clearance certificates are in Appendix A), the study was presented to two outpatient clinical teams and advertised via brochures and handouts summarising the research (see Appendix B for copies of the advertising material). Potential FEP participants were screened via clinicians, databases, and/or medical records. Once identified and with their clinician's approval, potential participants were approached about the research. At this time, their appropriateness for the study was confirmed, the study was discussed with the person to gauge their interest, and they were offered brochures and/or a participant information and consent form (Appendix C).

Upon expression of an interest to participate, informed consent was obtained. The person was allowed at least a week to read the participant information and consent form. Contact with all participants was negotiated with clinicians and clinicians were kept informed of participants' contact with the researcher and involvement in the study.

Characteristics of FEP Participants

Participant names have been changed and all identifying information has been removed to preserve confidentiality. Two single men aged 22 (Tom) and 24 (Peter) and one single woman (Sarah) aged 25 years of Anglo-Australian, Greek/Anglo-Australian, and Islander/Anglo-Australian descent respectively, were recruited from Alfred Psychiatric Outpatient Services. All lived with their family, with Tom having returned to the family home when he became unwell. Peter and Sarah were not employed for the duration of the study and Tom became unemployed during his involvement in the research. All participants had completed High School. Tom had finished a tertiary degree at the time of recruitment and re-enrolled in a second course during his participation in the study. Peter remained at University for the duration of the study and Sarah had not entered the tertiary system.

Peter had a history of minimal alcohol use and this remained unchanged throughout the study. Tom had a history of binge drinking and engaged in heavy alcohol use just prior to becoming unwell. He also commenced marijuana use at this time and had used speed and ecstasy once in the past. During the study his substance use had decreased to only drinking alcohol socially. Sarah also had a history of binge drinking which increased prior to becoming unwell. She had used ecstasy in the past and had smoked marijuana several times per week since the age of 17. Throughout the study her substance use had also decreased markedly and she was only drinking alcohol socially.

Tom and Sarah had a diagnosis of Bipolar I Disorder, with psychotic features, while Peter had a diagnosis of schizophrenia. Sarah and Tom had a history of depressive symptoms with Sarah having met criteria for Major Depressive Episodes and Tom having experienced elevated mood in the past. Sarah had a history of self-harm and suicidal ideation, while Tom had a forensic history from the time he was acutely unwell and this involved legal proceedings.

All participants were admitted to hospital, Tom staying in a forensic hospital. Tom and Sarah experienced police involvement to facilitate their admission and Tom had the experience of staying in police cells. For Sarah and Peter, their acute treatment also involved seeing the Crisis Assessment and Treatment Team to facilitate admission and

discharge. All participants experienced seclusion, forced medication, and being placed on the high dependency section of the ward, while Tom and Peter were also restrained. Post discharge Peter had been placed on a Community Treatment Order but this was revoked by Time 2.

Peter was prescribed an anti-psychotic, Risperidone, when he was acutely unwell and for the duration of the study. He was also given a mood stabiliser, Lithium, and a range of benzodiazepines when he was in hospital and when discharged but these were discontinued by Time 1. Sarah and Tom were both prescribed Olanzapine when acutely unwell and at Time 1 but had ceased anti-psychotic medication by Time 2. Sarah was also prescribed an anti-psychotic, Zuclopenthixol, Lithium, and benzodiazepines during her hospital admission. She continued Lithium throughout the study. Tom also took a mood stabiliser, Sodium Valporate, when he was acutely unwell and for the duration of the study.

All three participants experienced multiple significant life events. Sarah had moved to another country as a child and was subsequently separated from her father. Both Sarah and Tom's parents had separated and their father's had died. Tom's father had bipolar disorder and used substances, while Sarah's father abused alcohol. Peter's father had a serious medical condition and lived in a nursing home. Tom experienced physical assault when he was unwell and incarcerated.

Measures

Measure of Symptom Pattern

The Positive and Negative Syndrome Scale (PANSS)

The PANSS was administered at Time 1 and 2 to determine participants' current symptom patterns. It is a semi-structured interview, developed by Kay, Fiszbein, and Opler (1987) and is a measure of severity and quality of psychotic symptoms (i.e., positive, negative, & other symptoms dimensions). The PANSS ratings are based on information pertaining to the previous week and the measure can be used repeatedly for longitudinal assessment of symptoms. In this study, information used to rate the PANSS items came from the interview itself, other forms of data collection used in the broader study, file notes, and discussions with clinical staff. The interview takes approximately 30-40 minutes.

Items from the PANSS include 18 adapted items from the Brief Psychiatric Rating Scale (Overall & Gorham, 1962) and 12 adapted items from the Psychopathology Rating Scale (Singh and Kay, 1975). Of the 30-items, 7 relate to a Positive scale, 7 items are included in the Negative scale, and the General Psychopathology scale includes 16 items. Each item on the PANSS is accompanied by a complete definition as well as detailed anchoring criteria for the 7 rating points (1 = *absent*, 2 = *minimal*, 3 = *mild*, 4 = *moderate*, 5 = *moderate-severe*, 6 = *severe*, and 7 = *extreme*). When assigning ratings, the interviewer refers to the item definition to decide presence of a symptom and then uses the anchoring criteria to determine severity of the symptom. The PANSS is scored by adding the ratings across items. Scores can range from 7-49 on the Positive and Negative scales and 16-112 on the General Psychopathology scale. A Bipolar Composite scale is calculated by subtracting the negative from positive score and can range between -42 to +42 and determines which syndrome predominates (Kay, Fiszbein et al., 1987).

The clinical implications of the PANSS scores were determined by Leucht et al. (2005). They examined corresponding points between PANSS and the Clinical Global Impressions Scale (CGI) from a sample of pooled patient data from seven randomised, double-blind trials with 4,091 patients with schizophrenia (men = 2,671, women = 1,420) to establish cut-off scores for the PANSS. The cut-off scores from Leucht et al.'s research were used in this study and are presented in Table 5.1.

Table 5.1

Range of Scores Associated with Symptomatic Status

Not unwell	Borderline unwell	Mildly unwell	Moderately unwell	Markedly unwell	Severely unwell
under 33	34-57	58-74	75-94	95-115	116 and over

While cut-off scores for borderline unwell and not unwell were not specifically stated by Leucht et al. (2005), the scores for these were extrapolated from a graph in the paper. This was not a crucial detail for the current study thus estimates from the graph are considered adequate.

The PANSS has achieved good distribution and internal reliability, and discriminate, convergent and construct validity was present in a study involving 101 patients with schizophrenia (Kay, Fiszbein et al., 1987). Inter-rater reliability was assessed using 31 people in an acute phase of schizophrenia. Inter-rater reliability on individual PANSS items ranged from .69 to .94 and the mean inter-rater correlations for the positive, negative, general, and composite scale ranged between .83 and .87 ($p < 0.0001$). The PANSS also correlated strongly with the Assessment of Positive Symptoms (SAPS) ($r = .77$) and Assessment of Negative Symptoms (SANS) ($r = .77$) and compared favourably in inter-rater reliability and construct validity (Kay, Opler, & Lindenmayer, 1987).

Measure of Trauma Symptomatology

The Impact of Events Scale-Revised (IES-R)

The current study did not wish to diagnose PTSD but rather obtain the level of traumatic stress experienced in this group. The IES-R (Weiss & Marmar, 1997) is a 22-item questionnaire which assesses subjective distress over the past 7 days related to any specific life event. The scale was developed to parallel three of the four criteria for PTSD: hyperarousal, avoidance, and intrusion. Questions are measured on a 5-point Likert scale (0 = *not at all*, 4 = *extremely*). The test produces three subscales scores (i.e., *hyperarousal*, *avoidance*, *intrusion*) and a total score. The IES-R was developed from modifying the Impact of Events Scale (IES) (Horowitz, Wilner, & Alvarez, 1979). Seven items were added to the original 15-item IES. The 7 items comprise 6 that tap hyperarousal symptoms and 1 new intrusion item that reflects the dissociative-like re-experiencing when experiencing true flash-back. The 7 items were randomly interspersed with the existing 7 intrusion and 8 avoidance items. Also, the item "I had trouble falling asleep or staying asleep" from the IES was split into "I had trouble falling asleep" (assigned to the hyperarousal subscale), and "I had trouble staying asleep" (retained in the intrusion subscale) (Weiss, 2004).

The IES-R was designed and validated using a specific traumatic event as the reference for which people responded to the questionnaire (Weiss, 2004). Weiss recommends that the referent for the IES-R qualify as an event for the *DSM-IV-TR* (2000) diagnosis of PTSD. While the definition of a traumatic event according to the *DSM-IV-TR* does not recognise a psychotic episode, studies (e.g. Shaw et al., 2002) have clearly

demonstrated the traumatic nature of this experience and have argued that it can qualify as a Criterion A trauma. Participants' IES-R ratings and corresponding levels of trauma symptomatology were calculated according to the means and standard deviations reported in Creamer, Bell, and Failla's (2003) study. Creamer et al. researched the psychometric properties of the IES-R in two samples of Vietnam veterans: a treatment-seeking sample with a confirmed PTSD ($n = 120$) and a community sample with varying levels of traumatic stress symptomatology ($n = 154$). The means and standard deviations for the total sample ($N = 274$) were used to determine levels of trauma symptoms in this study (see Table 5.2).

Table 5.2

Means and Standard Deviations used to Determine Levels of Trauma Symptomatology

	<i>M</i>	<i>SD</i>
IES-R total	2.17	1.00
Intrusion	2.17	1.09
Avoidance	1.90	1.00
Hyperarousal	2.55	1.14

Level of trauma as measured by the total IES-R score and the three subscale scores is determined by establishing mean scores. The means scores in Table 5.2 represent moderate distress attributed to the IES-R total score and *intrusion*, *avoidance*, and *hyperarousal* subscales. A review of the literature researching psychosis as a traumatic event only identified one published study by Meyer et al. (1999) that had used the IES-R with psychosis patients. However, means and standard deviations for scores on the IES-R were not reported. A recent unpublished study by Brunet and Birchwood (K. Brunet, personal communication, November 5, 2008) with 25 first-episode psychosis patients reported the following means and standard deviations (see Table 5.3).

Table 5.3

Means and Standard Deviations of the IES-R Scores from Brunet and Birchwood's (2008) Research

	<i>M</i>	<i>SD</i>
IES-R total	1.44	.98
Intrusion	1.27	1.00
Avoidance	1.64	1.12
Hyperarousal	1.42	1.11

Table 5.3 indicates that people with first-episode psychosis may experience lower rates of trauma as measured by the IES-R than Vietnam veterans. However, as Brunet and Birchwood's (2008) sample size was small, ranges of scores corresponding to low, moderate, and high levels of trauma symptomatology were taken from the Vietnam veteran sample (presented in Table 5.4)

Table 5.4

Range of Scores Associated with Levels of Trauma Symptomatology

	Low	Moderate	High
IES-R total	1.16 and under	1.17-3.17	3.18 and over
Intrusion	1.07 and under	1.08-3.26	3.27 and over
Avoidance	0.8 and under	0.9-2.9	2.10 and over
Hyperarousal	1.40 and under	1.41-3.69	3.70 and over

The IES-R has good internal consistency, test re-test reliability, criterion validity (Weiss & Marmar, 1997; Creamer et al.'s 2003) and content validity (Weiss & Marmar), and reasonable construct validity (Creamer et al.).

Measure of Posttraumatic Growth

Posttraumatic Growth Inventory (PTGI)

The PTGI is a 21-item scale developed by Tedeschi and Calhoun (1996) to assess the positive outcomes reported by persons who have experienced traumatic events. It was developed using a sample of 604 undergraduate students, mainly aged 17-25 years, who had experienced a trauma within the last 5 years. The PTGI requires respondents to rate each item on a 6 point Likert scale (0 = *not at all*, 5 = *to a very great degree*) to indicate how much change they have experienced. It includes factors of posttraumatic growth: *new possibilities* (5 items), *relating to others* (7 items), *personal strength* (4 items), *spiritual change* (2 items), and *appreciation of life* (3 items).

Participants' levels of growth were calculated according to the means and standard deviations reported in Bates, Trajstman, and Jackson's (2004) study. They researched the psychometric properties of the PTGI in an Australian sample drawn from the general community who had experience major traumatic events. Seventy five women and 54 men participated in this research and the means and standard deviations for the total score for women and men were $M = 48.4$ and $SD = 21.7$ and $M = 38.4$ and $SD = 21.5$ respectively.

Level of growth as measured by the PTGI total score is determined by establishing mean scores. The means scores in Table 5.5 represent moderate growth attributed to the PTGI total score. The range of scores corresponding to low, moderate, and high levels of growth is in Table 5.5.

Table 5.5

Range of Scores Associated with Levels of Growth

	Low	Moderate	High
Women	26.5 and under	26.7-70.1	70.2 and over
Men	16.8 and under	16.9-59.9	60 and over

The PTGI has been shown to have high internal consistency, good test-retest reliability (Bates et al., 2004; Tedeschi & Calhoun, 1996), discriminant validity, concurrent validity, and construct validity (Tedeschi & Calhoun). The PTGI has also been found to have high factorial validity and a supposition that it is multidimensional. Although a poorer

fit, the model pertaining to a single higher-order factor with five second-order factors was acceptable in interpreting the construct posttraumatic growth. Therefore, the whole scale and each of the five subscales showed high internal consistency and indicate that the total score and subscale scores could be interpreted effectively (Taku et al., 2008)

Measure of Recovery

The Recovery Style Questionnaire (RSQ)

The present research wished to report on participants' recovery style profiles in order to contextualise the discussion of participants' experiences of FEP. Previous research has suggested that recovery style is not a static trait in the early psychosis population (Thompson et al., 2003). Thus, it was administered at Time 1 and 2.

The RSQ was developed by Drayton, Birchwood, and Trower (1998) to measure recovery style in people with psychosis. The questionnaire is based on McGlashan, Levy & Carpenter's (1975) interview measure of recovery style. The RSQ is a 39-item self-report tool which requires the participant to either agree or disagree with the statements. The questionnaire has 13 subscales these being: *curiosity; education; optimism; impact; fear; liking; continuity; ownership; responsibility; help seeking; blame; cause; and satisfaction* (refer to Table 5.6).

The RSQ was worded to reflect the 13 concepts which formed the basis of the Integration Sealing Over Scale (ISOS). The RSQ was piloted on a group of 20 out-patients with a diagnosis of schizophrenia. This process maximised face-validity (Drayton et al., 1998). Participants' responses to items are assigned either a score of 1 or 2. These scores are then added to obtain a score for each of the 13 scale concepts. The participants' response to each of the 13 scale concepts is assigned to either an integration (score = 5 or 6) or sealing over category (score = 3 or 4). Four recovery styles can be classified: integration; mixed picture in which integration predominates; mixed picture in which sealing over predominates; and sealing over (Drayton et al.). Table 5.6 gives the definition of the 13 subscales as quoted in Tait et al. (2003, p. 124).

Table 5.6
Subscale Definitions from the RSQ

Subscales	Definition	Example Item
Curiosity	Curiosity about psychotic experiences and is invested in understanding them	I am curious about my illness
Education	The individual treats the psychosis as a source of new information about himself/herself	My illness taught me new things about myself
Optimism	The individual is able to see positive aspects to having had a psychotic episode	Being ill had good parts too
Impact	To evaluate the psychotic experience having had a strong impact on life	My illness had a strong impact on my life
Fear	To identify the individual's attitude toward mental illness	I am not frightened of mental illness
Liking	The individual liked some of the unusual feelings and ideas experienced during psychosis	I didn't like any of the unusual experiences I had when I was ill
Continuity	Awareness of continuity between thoughts and feelings during the psychosis and emotional conflicts prior and subsequent to the psychotic episode	My illness came on very suddenly
Ownership	Psychosis is experienced by the individual as personal, rather than as alien	My illness is not part of my personality

Table 5.6 continued

Responsibility	The individual feels responsible for psychotic thoughts and acts	I am not responsible for my actions when I am ill
Help Seeking	The individual enlists the help of others in mastering the conflicts related to psychosis	I need help to solve the problems caused by my illness
Blame	The individual blames the illness on own difficulties in coping with life	My illness was caused by stress in my life
Cause	The individual views himself/herself as having had an emotional or nervous breakdown	I have had a nervous breakdown
Satisfaction	Psychosis helped in obtaining satisfaction in life	It's hard to find satisfaction with life following my illness

Criterion-related validity has been assessed for the RSQ using the ISOS as the criterion measure and the correlation between scores on the ISOS and RSQ was very high (Drayton et al., 1998). Drayton et al. discovered that the RSQ was bimodally distributed, which supported the presence of two distinct recovery styles (sealing-over and integration). Test-retest reliability was high and internal reliability was acceptable (Drayton et al.).

Please refer to Appendix D for copies of the IES-R, PTGI, and RSQ. Example questions from each scale of the PANSS are also provided.

Development of the Interview Protocol

This study employed a semi-structured interview style which was designed to be open-ended and adaptable and served as prompts to invite the interviewee to engage in a narrative about their experiences of being unwell. The semi-structured interview style is also considered to be the best form of data collection in IPA (Payne, Joseph, & Tudway, 2007). Participants were informed at the beginning of the interview that the researcher wished to hear their viewpoints in order to develop a greater understanding of the experiences people have when they first become unwell and the subsequent changes they may go through.

The principal concern was to understand peoples' experience of FEP and how one adapts to and recovers from this experience. In exploring this process this study wished to understand the sources of distress associated with first-episode psychosis as well as the restorative and constructive or growth aspects of this experience. Therefore, it seemed important that the interviews allowed participants to discuss both positive and negative aspects of being unwell. Subsequently in assessing the outcomes of being unwell, questions were posed in terms of 'change' to elicit helpful and unhelpful experiences. The interview was broken into two broad sections: (a) understanding the experience of being unwell and (b) the impact the psychotic episode had on FEP participants. The first half of the interview was spent exploring the experiences of FEP participants' psychotic episode and treatment. This provided a space for participants to convey their story in detail. Inquiry about meaning and change then followed. This section of the interview was introduced with a statement that asked participants to consider positive and negative and helpful and unhelpful changes.

The broad areas of the interviews and examples of the questions asked are presented in Table 5.7 As shown in this table, both broader accounts and specific examples of participants' experiences were elicited (e.g., "What was it like to see CATT?" "Can you tell me a particular time that was distressing for you?"). FEP participants were asked open-ended questions (e.g., "I was wondering what it was like for you to be unwell") before the interviewer introduced specific questions (e.g., "was being unwell distressing for you?") in order to minimise interview bias. Probes were only used to encourage the participants to elaborate.

Table 5.7

Main Areas of the Interview Protocols for FEP Participants

Main Areas	Example Question	Example Probe
(1) The experience of being unwell and receiving treatment	What was it like for you to be unwell?	Was being unwell distressing for you?
(2) How FEP participants developed psychosis and were managing this experience	Tell me how things were before you became unwell?	Did you experience anything stressful before you became unwell?
(3) How the psychotic episode impacted and changed the FEP participants	Has being unwell changed how you think about your life?	In what way has your relationship with them changed?
(4) Recovery, the future, and their perceptions of the psychotic episode	What does recovery mean to you?	Do you feel like you are starting to recover?

The experience of being unwell and receiving treatment. Both the psychotic episode and treatment experiences were explored during the first interview with FEP participants and the family member or partner's interview. These questions were more specific and aimed to understand the person's experiences of being unwell and any potential trauma associated with this event. Incorporating the distressing experience questionnaire at this point in the interview aided this discussion and required interviewee to identify the most distressing aspect of their psychotic episode. The questions also allowed an understanding of how the person related to this experience. In order to track the presence of trauma over time the following questions were asked during Time 2 interviews:

Last time we spoke you mentioned that x was the most distressing experience for you when you were unwell. How are you feeling about this experience you discussed last time?

- Is this still on your mind?
- Is this still having an impact on you now?
- How is it affecting you now?
- What are your thoughts about it now?
- How do you feel about it now?

How FEP participants developed psychosis and were managing this experience.

During the interview with family members or partners and the initial interview with FEP participants, interviewees were asked about the time before the psychotic episode and what led to the development of the episode. The interviews also explored how the person had been coping. In addition, their current treatment was discussed and family member or partners commented on the interviewees' current symptom status and compliance with treatment. These questions directed participants to begin to reflect on how the episode developed and how they were currently managing their mental health.

How the psychotic episode impacted and changed the FEP participants. The third group of questions explored the impact of the psychotic episode on the person's self-concept, relationships, and views about life in order to parallel the notion of posttraumatic growth. When discussing their relationship with others, interviewees were asked about the support they received and what it was like for them to talk about their mental illness. In addition, they were asked about any changes that may have occurred in relation to general functioning. During the second interview, they were re-asked if they had experienced any changes in these domains since they had been unwell before being asked if any changes had occurred since the first interview. This helped track the nature of growth over time. This group of questions was introduced to interviewees with the following statement:

Some people say they go through changes after they have been unwell. These changes might be positive or negative, or helpful or unhelpful. I'd like to talk to you about any changes you might have experienced since you were unwell, whether they were positive or negative, or helpful or unhelpful.

To end the interview, participants were asked about their thoughts on recovery and the future and their perceptions on the helpfulness and/or unhelpfulness of the psychotic episode. FEP participants were also asked whether they had had any significant and important experiences since they were unwell. These questions wished to explore their

recovery pattern and how they had come to understand their experience of FEP.

A strict IPA approach was not applied as some additional structure was required in the interview schedule to focus on the issues being researched. This was because it was envisaged that FEP interviewees may experience ongoing low-level symptomatology (e.g., rigid thinking) which could affect their ability to provide a thorough account of their experiences. Questionnaires were also used as stimulus material to aid participants in the interview and provide some structure.

While the interview covered a range of selected areas and had some fundamental questions that provided the framework for the investigation, open-ended questions allowed participants to provide a detailed account of their unique experience. Probes were used to explore issues that arose in the interviews, whether in the realm of the researcher's area of interest or not. This allowed the investigator to pursue other avenues as part of the natural course of conversation, and by way of relating to each interviewee, and to gather information that was of special importance to participants or may not have been thought of when developing the schedule. It was believed that interrupting the flow of participants' thoughts with specific questions may cause the researcher to lose information the participant believed was important and therefore very useful in understanding their experiences.

As guided by IPA, questions were not always asked in the order shown on the interview schedule. Instead, questions were sometimes asked based on what felt natural during the flow of the conversation and where the participant was at in explaining their experiences, although the interviewer found that the order of the interview schedule was generally followed. Due to the nature of FEP, participants' mental health issues and the significance of this experience, allowance was given for questions that had to be asked more than once if the interviewee drifted to a different train of thought or had difficulty understanding or answering the question posed. Questions could be reworded if the participants appeared unsure, to direct the interviewee to a specific point of inquiry or depending on how the participant was responding at the time. Not all participants were asked all questions and some required little prompting as people were generally able to talk very openly and thoroughly about their experiences.

Recruitment of Family Members

Family members recruited for this study were required to be aged 18 and over. When FEP participants' provided informed consent they were asked to nominate a family member to be involved in the study. All participants chose their mothers to be involved in the study. Family members were contacted by phone or spoken to face-to-face and a brochure and participant information and consent forms were given to them or sent in the mail if they expressed interest in participating (see Appendices B and C respectively). They were re-contacted closer to the time they were to be interviewed to arrange an appointment to complete informed consent and participate in the interview. English was a second language for two mothers. However, they were able to converse in English without an interpreter.

Development of the Interview with Family Members

Family members were interviewed to enable a richer understanding of the experiences and changes their family member may have gone through since being unwell. Interviews with loved ones were semi-structured to mirror the issues being discussed with FEP participants so that triangulation of the data could be done. Table 5.8 shows the main areas of the interview with family members.

Interviews with family members followed the same structure and they were told the focus of the interview was their loved one who had been unwell and thus asked to comment on these questions in relation to their loved one. However, the area of insight was not covered in their interview.

Table 5.8

Main Areas of the Interview Protocols for Family Members

Main Areas	Example Question	Example Probe
(1) What was the experience like for family members and loved ones?	Tell me what it was like when x was unwell?	What aspects of the condition were difficult for you?
(2) How family members or loved became aware of the illness and managed it	How did you first become aware that x was unwell?	What did you do?
(3) How FEP participants developed psychosis and were managing this experience	Tell me how things were before x became unwell?	How did x cope with these experiences?
(4) The experience of being unwell and receiving treatment	What do you think it was like for x to be in hospital?	
(5) How the psychotic episode impacted and changed the FEP participants	Overall how has being unwell impacted on x?	How does he/she approach life now?
(6) Recovery, the future, and their perceptions of the psychotic episode	What do you think recovery means to x?	Does x have any plans for the future?

Interview with Clinicians

A short semi-structured interview was developed for FEP participants' primary clinicians to gain their perspective on their clients' experience of FEP and the changes they may have observed while working with them. Clinicians were also interviewed to gain more information on FEP participants' treatment and engagement in this. These interviews were also semi-structured to allow for triangulation of the data. Ideally, case managers were interviewed as they worked more closely and over a longer period of time with FEP participants than psychiatrists. However, the researcher decided to interview one psychiatrist because Tom had recently changed case managers during his involvement with the study. This psychiatrist had worked with the FEP participant for the duration of his outpatient treatment. Table 5.9 outlines the interview with clinicians.

Table 5.9

Main Areas of the Interview Protocols for Clinicians

Main Areas	Example Question or Introductory Statement	Example Probe
(1) Treatment	I was wondering how x has responded to his/her treatment?	Is x open to receiving his/her treatment?
(2) How the psychotic episode impacted and changed the FEP participants	I've been speaking to x about how he/she views life, relationships with others, and how he/she feels about herself/himself and whether his/her attitudes about these things have changed	Do you think he/she has experienced any changes in relation to how he/she thinks about/feels about himself/herself?

Clinicians were asked about FEP participants' treatment, how they had responded to their treatment, how they thought their clients viewed themselves, relationships with others, and life and whether their attitudes had changed due to developing psychosis. They were

asked to comment on both negative and positive changes.

The full interview protocols for FEP participants, loved ones, and clinicians are appended in Appendix E.

Procedure

Risk issues were very uncommon but if they arose during data collection (e.g., suicidal ideation), clinicians were immediately informed of this prior to the client leaving the clinic. File notes were made after significant contact with FEP participants throughout recruitment and data collection and clinicians were kept informed of their clients' involvement. There were two stages to data collection. FEP participants were seen at three-five months (Time 1) after their acute episode and 3 months after the first interview (Time 2). At both Time 1 and 2, FEP participants were asked to participate in a PANSS assessment and a semi-structured interview and complete the IES-R, PTGI, and RSQ. Peter was also asked to complete the list of experiences questionnaire at Time 2, which was developed during the pilot study (please refer to p. 119). Data collection took approximately 2.5 hours. At Time 2 a family member and clinician were interviewed as close to the FEP participant's second interview as possible. Sessions with family members took 1-2 hours and with clinicians no longer than 30 minutes. Data collection took place at either the FEP participant's primary clinical support service or at an office at the Alfred Psychiatry Research Centre. Demographics and detailed information about participants' mental health issues were collected from files and clinicians. A representation of the timeline of interviews is shown in Table 5.10.

Table 5.10

Timeline of Interviews

FEP participant	Time 1	Time 2	Family member	Clinician
Tom	21/12/05	24/3/06	31/3/06	7/3/06
Sarah	22/3/06	15/6/06	13/6/06	14/6/06
Peter	25/5/06	22/8/06	16/8/06	22/8/06

The pilot participants were seen over a three month period and family members were interviewed within a week of FEP participants' second interviews. Two of the clinicians were seen within 1-2 days of FEP participants' second interview. Tom's clinician was interviewed approximately two weeks prior to the FEP participants' interview due to his work schedule.

Interviews were completed with all participants except one family member at the FEP participant's outpatient clinic. Sarah's mother was seen at the Alfred Psychiatry Research Centre as this was closer to her workplace. Each participant had read the information and consent form and had provided informed consent prior to data collection. Demographics and detailed information about participants' mental health issues were collected from files and/or treating clinicians and FEP participants at Time 1 and 2.

In order not to bias the interview process and to allow participants to first be able to provide a detailed account of their experiences in their own words, the PTGI, RSQ, and IES-R were administered after the interviews took place. Given that the concepts of posttraumatic growth and sealing-over and integration recovery styles appear to parallel one another, the order of administering the PTGI and RSQ was alternated at each interview time. To control for order effects the IES-R was always administered first to prime participants to think about their most distressing experience before considering potential benefits of their episode. This format also paralleled the sequence of questions asked in the semi-structured interviews. Given the importance of establishing rapport in order to facilitate participants' engagement in the semi-structured interview, the PANSS was not administered until the end of data collection due to its clinical nature. The quantitative data in this research was not gathered for statistical purposes. Initially the questionnaires were used to compare norms. However after completing the first interview with Tom, it was decided that questionnaires would also be used to improve the nature of the qualitative data obtained. This procedure is detailed on pp. 118-119.

Rapport is central to qualitative research in order to support the interviewee in telling their story. This in turn also contributes to the validity and reliability of the data. Simultaneously, the researcher must have a willingness to enter the interviewee's frame of reference without being guided by their own assumptions and biases (Patton, 1990). Reflective listening techniques, such as clarification, were used to ensure that the

researcher's understanding of the participants' responses was accurate. The researcher also utilised an empathic listening style in order to engage the participants. At the end of the interviews the researcher 'checked-in' to see how participants were feeling. The researcher conducted all interviews. This was considered important to ensure uniformity in the interviewing style.

Analysis of Interview Data

All audio taped interviews were transcribed in their entirety in a WORD document. Transcription was undertaken by the researcher. This allowed the researcher to re-visit the interview and subsequently become better engaged with the data. Three levels of analysis were undertaken in this study. First, in-depth thematic analysis was done in the form of group data to illustrate themes. Case study analysis was also employed to track individuals' adaptation to and recovery from FEP. Presenting in-depth case studies enabled the research to reflect the complexities of the experience of FEP. Lastly, triangulation analysis, (i.e., seeking data from different sources) was completed to validate FEP participants' narrative themes.

Thematic analysis was conducted within an IPA framework. Interpretative phenomenological analysis is flexible and is understood as a perspective from which to *approach* analysis rather than a distinct method. The first aim is to approach the data trying to understand the participant's world and describe what it is like, with a focus on a specific experience such as FEP (e.g., how has FEP been *understood* by the person?). The objective is to produce a coherent, third-person, psychologically informed account which aims to get as close to the participant's view as possible. Then a more overtly interpretative analysis is conducted, which positions the initial description in relation to a wider context. Critical and conceptual commentary on the participant's meaning-making is provided here (e.g., what does FEP *mean* for this person, in this context?) (Larkin et al., 2006).

Guided by the IPA approach, the present thematic analysis was conducted in conjunction with the researcher's interpretation of the participants' interviews. The researcher identified themes and integrated them into meaningful clusters within and across cases. Re-reading and re-organising themes was also central to the present study's data

analysis. The interviews were analysed according to the groups of people, that is, FEP participants, family members, and clinicians, and in this order. This was done to get a sense of each group's perspective as a whole prior to making comparisons across groups. Also, by considering the interview in this order the initial experience of FEP could be understood before obtaining other people's perspectives.

In-depth thematic analysis of group data consisted of eight phases. *Phases 1-5* were completed with FEP participants' interviews. After *Phases 6* and *7* were completed in order to allow for triangulation of the data, *Phases 1-5* were repeated to develop group themes relevant to their own experience of having a loved one who was unwell. *Phase 7* describes how case study analysis was conducted. *Phase 8* describes how the family members' interviews were analysed in order to understand how the experience of FEP impacted on them.

Phase 1. Each interview was read a number of times in order to get a sense of each individual's experiences as a whole. FEP participants' two interviews were read successively before moving onto the next person. During this phase the researcher produced unfocused notes that reflected the investigator's initial thoughts and observations. Key words and sentences were also highlighted. Overall, the researcher examined how participants described and understood the experience of FEP and subsequent adaptation and recovery processes.

Phase 2. Key words and sentences from each individual transcript were documented and grouped into three broad areas: negative aspects of FEP, positive features of FEP, and recovery processes and outcomes. Next, the key words and sentences within each of these three broad areas were clustered according to likeness and given a title which captured what was represented by the quotes (e.g., getting his life back on track). For the purpose of the present study these were named categories.

Phase 3. The researcher looked at which categories were both common and individual to the participants in order to cluster them as thematic units (e.g., changed sense of self, self-esteem) and identify anomalies. The researcher continuously ensured that the clustering of thematic units made sense in relation to the transcripts they originated from. When key words or sentences did not fit under an established thematic unit a new one was created. Thus, thematic units were continuously developed when necessary to account for

the range of experiences that emerged. Thematic units were still clustered under the broad areas identified in *Phase 2*.

Phase 4. Connections between thematic units were made to establish themes (e.g., *separation*). The themes which emerged could be clustered according to negative aspects of FEP, restorative outcomes and processes, and constructive changes. Accounts of the onset of the illness, the meaning of spirituality and religion, and perception about the future were also clustered. However, themes were not identified but rather information was presented descriptively because this information was either too variable or limited.

Phase 5. Definitions of the themes were developed and translated into the researcher's words through a careful examination of participants' quotes (key words and statements). The researcher drew on theory and research to develop the theme definitions, but gave precedence to the experience of the participants. A list of master themes for FEP participants was established with a list of the quotes that illustrated the themes.

Phase 6. Interviews with family members and clinicians were analysed in order to generate another data set which gave insight into the FEP participants' experiences. Key words and statements from family members and clinicians' interviews were compared and contrasted the master list of themes which was formed through analysing FEP participant interviews. This allowed for triangulation of the data.

Phase 7. Initially, family members' interviews were considered in terms of how they described their loved one's experiences of FEP. However, family members took the opportunity to describe how the experience of having a sick loved one had impacted on them. Given the focus of family members' interviews was the impact of FEP themes were not identified. Each family member's interview was read a number of times in order to get a sense of the experience of FEP impacted on them as a whole. Key words and sentences were identified from each individual transcript. Next, the key words and sentences were clustered according to likeness and keeping in mind possible negative, restorative, and constructive processes and outcomes. The researcher continuously ensured that the clustering of these groupings made sense in relation to the transcripts they originated from. Topics or issues identified by loved ones were discussed as features of these groupings.

As explained by Willig (2001), the number of themes under each cluster (e.g., negative aspects of FEP) can vary and depend entirely on the transcripts analysed. Therefore, some clusters had a number of themes whereas others were more narrowly focused. Similarly, there might be many quotes which illustrate a theme, while others are less frequently invoked in the transcript. However, this does not disregard their importance. Some themes were broad, while others represented a narrow but strong characteristic of fewer participants. Analysis was not complete until all that was shared between participants was captured in the themes. Thus, themes were continuously developed when necessary to account for the range of experiences that emerged. When experiences were clustered and described descriptively, the full range of experiences that emerged was still discussed.

Validating the Interview Data

Summaries could not be provided to participants for clarification for a range of reasons. These reasons included: a preference for summaries to be discussed with FEP participants rather than being sent via mail for duty of care reasons, the significant amount of participation time already required of the FEP participants, difficulties following-up FEP participants, and FEP participants often managing a range of ongoing issue and treatment requirements. Therefore, the second interview acted as a confirmation of the person's experiences as did interviews with family members, discussions with clinicians, and file information. The researcher also continuously returned to the data to check the depictions of the experiences conveyed by the participants. This ensured that the qualities derived from the data adequately embraced sufficient meaning and provided clarification that the meanings actually portrayed the phenomenon being researched. Interviewing participants twice also helped this process as themes and meanings could be clarified.

Silverman (2005) argues that other forms of validating the data should be employed which include comprehensive data treatment, the constant comparative method, and deviant-case analysis. In this study all interviews were incorporated and open to repeated inspection. All data fragments that arose were inspected and compared across small to large data sets to find multiple cases that tested the provisional themes. Deviant-case analysis was employed to actively seek out and address anomalies to further ensure that all data was

accounted for.

Coding of the interview data and theme definitions sought agreement between the investigator and one research supervisor to strengthen the reliability of the data. Any disagreements were resolved through discussion.

Results

Pilot results permit ongoing research in understanding a broader notion of the impact of FEP and subsequent recovery process. Detailed case studies of two of the participants are presented in an earlier published version of this pilot research (Dunkley, 2007). An IPA thematic analysis reflects the combined data from the three participants. A series of preliminary core themes were identified from the pilot study. These themes were not mutually exclusive and had some overlapping qualities but are differentiated, based on a dissimilar tone or description of the experience. After group data the impact on family members is discussed.

Quotes were sometimes split if a person discussed more than one distinctly different theme at once. Table 5.11 is a summary table explaining the information provided at the end of each quote.

When a dotted line is present it usually means it is a string of quotes joined together when a participant is discussing a particular issue. In this case the dotted lines represent where the researcher was asking questions or to shorten long quotes without impacting on what the participant is conveying. In some cases the dotted lines represent the participant giving an extended pause. At times some quotes are phrased unusually. This occurred when English was not participants' first language or when participants were conveying something which may have been difficult to articulate. Dotted lines are sometimes used to refine these quotes without impacting on what the participant is saying, but not if this did affect what the individual is trying to convey.

Table 5.11

Definitions of Codes Presented at the End of Each Quote

Code	Explanation
I	The person is talking about the ‘initial’ experience or acute episode
L	The person is talking about ‘later’ adjustment or the recovery phase
1 st or 2 nd	Whether the quote is from the first or second interview
FM	Quote from family member’s interviews
Bold numbers	The bold numbers and text at the end of quotes can be traced to which question participants are answering
Bold comments (e.g., introduction to the changes section of the interview)	Statements at the end of quotes refer to what the participant is responding to when a question has not been asked. For instance, the example provided refers to the statement read to participants to introduce the set of questions about the changes FEP may have caused.

Note. The codes *I* and *L* are only used when it is unclear whether or not the person is talking about their acute episode or later adjustment. Bold numbers and comments can be referenced to the final interview schedules in Appendix E.

The Onset of FEP

The onset of the illness was viewed along a continuum with FEP participants ranging from being unsure about the development of their illness to believing there were discrete triggers to understanding the illness as the outcome of a process which involved an underlying vulnerability. Overall, becoming unwell was viewed as a sign that things had become too much.

*I was **working quite hard**, like I'd work all day at the engineering firm and Thurs, Fri, Sat nights I'd work at the bar so um that's **probably why it caught-up, one of the reasons why stress is why the illness happened in the first place working so hard**, nah I really enjoyed life beforehand, yeah everything was cruising along nicely and I had Perth to look forward to, ready to study law I was saving up for that and yeah life was good (Tom, 1st) 23*

Although Tom believed working too hard probably led to the development of his illness, he also indicates that he was enjoying this lifestyle. Sarah indicated that while the illness may have been unavoidable she could have also done things to cause its onset which she could have controlled. She generally viewed the psychotic episode as an outcome of an underlying vulnerability combined with life experiences. She also framed it as developing over time and considered early warning signs. Sarah questioned her prior behaviour and whether this was due to the onset of Bipolar Disorder. Although the development of the illness was framed negatively Sarah identified a potential positive function of the psychotic episode – that it may have been her body's way of expelling negative energy.

*I was on holiday from work and I think just **accumulation of various things that had occurred during that year and last couple of years had all just come to a halt and I think may be my psyche just couldn't just sort of take it anymore and it just went a bit crazy (laugh). I think that was a way of my body just getting rid of all of that I guess it was negative sort of energy** (Sarah, 1st) 2*

***Genetic factors** but also I think also **outside things brought it on as well** because I think some people can have it genetically but it never occurs whereas others it's **brought forward by other things that happen in their lives** (Sarah, 2nd) 3*

Peter was unclear about why his psychotic episode occurred and was engaging in a reflective process of trying to understand why he developed his illness.

*May be having **a look at what went wrong** sort of thing. I'm still trying to work that out. **I haven't been able to work that out.....I don't know may be it was the pressure from uni.** It could have been the pressure from uni but I don't know whether it was (Peter, 2nd) 53*

The Negative Aspects of FEP

In discussing the negative experiences of psychosis and treatment six themes were identified in the interviews data: *disempowerment*, *separation*, *ongoing concern about relapse*, *perception of the illness as an ongoing problem*, *loss and grief*, and *stigma*. Core themes relating to the negative aspects of FEP and treatment are presented in Table 5.12.

Table 5.12 shows a range of distressing aspects of the psychotic experience which extended beyond the acute episode to the recovery phase of the illness. While the theme *loss and grief* was the least pronounced in interviews, the losses discussed in the interviews could be major ones. The themes *separation* and *perception of the illness as an ongoing problem* were the most prominent as they were broader themes.

Table 5.12

Negative Aspects of the Experience of FEP and Treatment

Theme	Example Quote
<p><i>Separation</i> encompasses an overall feeling of disconnection. This theme includes three sub themes: (a) <i>separation from reality</i> and personal experiences and actions, (b) <i>separation from one's prior self</i> and others and (c) <i>separation from society</i>. The theme <i>separation</i> can be identified within the acute phase or afterwards when one is coming to terms with and adapting to these experiences. It can incorporate a sense of disbelief, shock, realisation, uncertainty, and feeling different.</p>	<p><i>I felt like I'd hit rock bottom....and I was in a place where I couldn't be contacted like my mind was gone....and I was in an alien place locked up in Perth...a horrible place to be and I really did feel like I'd died, I'd lost everything (Tom, I, 2nd) 13</i></p>

Table 5.12 continued

Disempowerment focuses on treatment experiences. It describes being subject to outside intrusive and impersonal discipline, enforced treatment and monitoring in which the person felt they had no control or choice and were obliged to comply with this treatment. This can also include having to take medication to manage the condition. It can encompass feelings of disempowerment, powerlessness, discomfort, resignation, and submission, as well as feeling uncared for.

*I knew it be best to follow their **orders** and do what they told me to do but I was reluctant, I felt reluctant but I knew....if I **tried to stop them from taking me it'd just get worse so I followed what they asked me to do and I found that to be scary cause usually you have a choice in what you have or have not or are not going to do and for someone to say you've got to do otherwise there's going to be worse consequences I just thought oh just got to do it** (Sarah, I, 2nd) 4*

Ongoing concern about relapse is defined as being worried, fearful, and concerned about becoming unwell again. Participants described feeling vulnerable and being cautious and wary of potential triggers. It can be associated with withdrawing from past activities, not taking risks, and taking things slowly in an attempt control the illness and to avoid becoming unwell again. A consciousness of one's health can also be discussed in the context of monitoring oneself to avoid relapse.

*It made me a lot more wary of enjoying myself like I used to just fly off the handle, party or whatever, these days **I'm a bit more docile, a bit more wary of what could happen to me again it's always in the back of my mind, I'm scared of having another breakdown again** (Tom, 2nd) 13*

Table 5.12 continued

Perception of the illness as an ongoing problem. The ongoing nature of the illness, its secondary consequences, and treatment is viewed as restricting and burdening. However, there is also a sense of needing to accept the long-term nature of their illness and adjust one's lifestyle accordingly.

Loss and grief is associated with different aspects of the participants' lives such as, loss of time, one's self, and relationships. While participants also discussed a loss of ability, this is grouped under perception of the illness as an ongoing problem since these issues were not discrete losses.

Stigma reflects stigma on a number of levels: self, others, and society in general. Overall the stigma surrounding one's mental health issues can impact on interactions with others, how one feels about himself/herself, and one's knowledge of mental illness and treatment.

Have to sort of gear my life around that. Around appointments, and seeing doctors, seeing psychologists, going to the doctor and getting check-ups. I'm getting more check-ups now. Rather than being sort of like free I'm having to worry about my health so now I'm more conscious about my health now....I didn't really think of it back then like having diabetes I think about having things like that now.... having an illness (Peter, 2nd) 22

I used to be more bubbly in my personality, it's diminished a lot, um, my self confidence.... I'm getting used to it but I sort of miss how I was before, um, I was more outgoing and happy, I would say, um, I certainly miss it, and, that aspect of my personality (Sarah, 1st)

introduction to the changes section of the interview

I think because of the stigma attached to mental illness...makes it hard for me to open up and disclose it to people I'd rather prefer to keep it to myself if I have the chance....sometimes I don't like the sympathy....so I don't want to say it I think cause they have a preconception of what a person looks like or acts like that I don't want to be put in the same box (Sarah, 1st)

Restorative Processes and Outcomes

Participants also discussed restorative processes and outcomes, as well as their engagement in their recovery process. Four themes were identified: recovery as a gradual process, ownership of recovery, developing acceptance, and social recovery. Core themes related to restorative recovery processes and outcomes are presented in Table 5.13.

The themes *social recovery* and *ownership of recovery* were most prominent in the interviews, while *developing acceptance* was the least prominent. Nevertheless, *developing acceptance* was a strong characteristic of Tom and Sarah's interviews.

Table 5.13

Core Themes Related to Restorative Processes and Outcomes

Theme	Example Quote
<p><i>Recovery as a gradual process</i> demonstrates that participants viewed recovering from psychosis as gradual. However, participants couched the idea of gradual recovery within different time frames. While there can be a desire to get better as soon as possible, developing patience and taking things one step at a time is also often recognised. Recovery is seen as being influenced by medication.</p>	<p><i>When I first had the breakdown and when I was still coming out of it I thought ok I'm out of action for a couple weeks and then lets get back in the swing of things but it wasn't like that at all....it's only now that I'm starting to live a normal life again...I've learnt a lot of patience...I really didn't think it would take this long but obviously with mental health it's something that you can't rush...I feel a lot less rushed now....a bit of perspective on life....good things come to those who wait sort of deal...I'm glad that I wasn't rushed through the process while I was pissed off at the time that I was being held back....I was slowly healing and it was a necessary step in the process (Tom, 2nd) 13</i></p>

Table 5.13 continued

Social recovery is a theme that can describe how people used others to support their interpersonal recovery and/or regained social skills.

*I'm sort of, I'm **getting over the illness sort of thing, I'm being able to express myself more** which is helping me become more, **more outgoing sort of, more interactive with people** (Peter, 2nd) 36*

Ownership of recovery describes the ways participants engaged in a process of influencing their recovery process. Actively dealing with difficulties, coping strategies, goal setting, and reengaging in activities can be discussed, as well as reflecting on the illness. While the importance of medication and support from others is acknowledged, focus is on being self-directed, active and having a choice in their recovery. A wish to cease or reduce medication is included.

I kept a diary on what's been happening and um yeah like that helps just it's very cathartic just writing down how you feeling and stuff and keeping it going....well I may as well write what I have and not shy away from it...it's empowering...in that you can write something and then you've got the description of it and you've got power over it, like you're controlling the illness (Tom, 1st) 20

Developing acceptance participants spoke of accepting and integrating their current circumstances and/or moving forward from it.

In having gone through this sometimes things change, and you can't have it all, I can work on it but...at the moment I should just be happy with the way I amAt first it was hard to come to terms with like I'd get upset and but there's only so much you can do and I should just be happy with how I am cause it may be something that's just gone for the moment and it may come back or it could be like this (Sarah, 1st) 34

Constructive Processes and Outcomes

FEP participants were also asked whether they viewed the illness as unhelpful or helpful and all of them identified it as having aspects of both at Time 1 and/or 2.

Sarah

It is helpful in letting you know that there is something not quite right and there are reasons for your actions and for the way you think and feel but it's unhelpful in that....it's put a what's the word...there's a halt a stop in your life and it's sort of like you have to start all over again...and that can be a bit stressful and...at times you feel that's unfair that it sort of happened to you but everyone has different issues and....I shouldn't feel that way (1st) 48

It enables you to realise where some of your behaviours may have been due to being ill and although it was what you were doing wasn't really you. I think that would be the main one...Just like the side effects of medication I found a bit of a drag (2nd) 52

Peter

It's been unhelpful sort of thing. It's been a waste of time sort of thing but I haven't really wasted any time I've done my two months in the hospital.....but it has been unhelpful. It's just made things harder...Life in general harder sort of thing, having to deal with the changes like medication (1st) 48

It's changed my life.....well it's given me more routine in my life.That's been a helpful thing. I've sort of got my act together sort of thing.....Well now I'm shaving everyday. I'm showering everyday and that's better. And the appointments, yeah routine sort of thing (2nd) 52

Tom

Yeah, I thought sometimes it was a blessing in disguise like um it gave me an opportunity to reassess what's important in life and um work through it...and um with hindsight like I can see it was good to slow down like I graduated then I worked like crazy to save up for Perth then I got to Perth and I was starting a new degree straight away....I should've taken the time off instead of working myself to

the bone and then having this illness and so its also been helpful in that way, given me time to slow down (1st) 48

It opens your eyes and makes you more aware of your mental health like my attitude to mental health beforehand was pretty nonchalant since then I'm a lot more sympathetic to the cause...obviously it's unhelpful as well really unhelpful...it's been one of the most traumatic experiences in my life and like I've lost my father before you know so I've had traumatic experiences but this was the worse.....it puts you in a place you really don't want to be (2nd) 52

This indicates that FEP is not just a negative experience as it can also facilitate important changes and learning processes, as well as provide evidence for the development of constructive changes. A range of constructive changes were identified which reflected a qualitative shift or transformation that came out of the experience of FEP rather than a return to prior functioning. These themes were: *enhanced perspective taking and sense of unity, deepening relationships, confirmation of character and relationships, personal strength, and appreciation of life and changed priorities*. Some themes paralleled domains outlined by Calhoun and Tedeschi (2006) in their definition of posttraumatic growth. Thus, the names of these themes were adopted for the purposes of this thesis. Table 5.14 presents core themes relating to the constructive changes.

The themes *personal strength* and *enhanced perspective taking and sense of unity* were not discussed as often as other constructive changes. However, for Sarah and Tom the former was a pronounced feature in their interviews, while the latter was a distinct issue when discussed, particularly for Sarah.

Table 5.14

Core Themes Relating to Constructive Changes

Theme	Example Quote
<p><i>Appreciation of life and changed priorities</i> describes a greater appreciation for life and a realisation that it is precious and valuable. The psychotic experience can be reframed as providing an opportunity to reassess life. Changes in priorities can be discussed and this might incorporate a greater appreciation for one's health.</p>	<p><i>It's made me appreciate it a bit more, not take it for granted especially my mental health, now that's it's good I want to keep it good so it makes me care about it a bit more.... the illness for me felt like a near death experience and to be that close to what I thought was death just made me really appreciate life a lot more and made me want to get a bit more out of it.... Just, I've got some life ambitions I'd like to get a book published one day, I'd like to own a bar one day, yeah sort of things like that, well I'm only here for what 80 years or whatever so I may as well make the most of it while I can (Tom, 1st) 26</i></p>
<p><i>Personal strength</i> is the discovery of personal strength and/or a desire to be more self-reliant.</p>	<p><i>More self-reliant cause....I guess you can say sort of dependent on friends, but now I've realised that they've got to live there lives too like sometimes you might meet up but a lot of the time you're on your own and that when you go to sleep at night you go to sleep alone so got to look after yourself before you can look after other people (Sarah, 1st) 25</i></p>

Table 5.14 continued

Enhanced perspective taking and sense of unity is a theme that describes self-understanding, shared understanding and togetherness, and compassion and empathy for others. These ideas can be discussed in general and/or in relation to mental illness.

*It's pretty tricky but I mean **there's people that I know now that have gone through similar things that I've gone through so....that sort of made me more aware of that I'm not the only one sort of thing....It's a good feeling. It's better than feeling like you're the only one that's copped it*** (Peter, 1st) 39

Deepening relationships describes a sense of improved relationships which can be evident in a number of ways: development of a closer relationship, shared activities and increased time spent together, a greater appreciation for others and relationships with loved ones, and a desire to put more effort into relationships.

*We sometimes go out for dinner and we **talk while we're having dinner rather than like mum would sometimes when we went out to dinner she'd read or like would or would just sit there and eat and then leave, we actually wouldn't interact at all. It's much better I think it's infused our relationship a lot more. If we're making dinner I'll ask her if she wants some help and we'll do it together*** (Sarah, 2nd) 37

Confirmation of character and relationships is a theme that describes participants realising genuine friendships and support through the experience of being unwell. Associated with this can be being more loyal and appreciative, a sense that loved ones had a deeper understanding of them, and realising the support of significant others.

*It gave me a year off basically and **made me seriously reassess where I was at with my friends and family....I felt like I'd died and the people who actually cared were the ones that stayed in contact with me....like coming back and recovering again lets you know who your real friends and family are*** (Tom, 2nd) 12

The meaning of spirituality and religion and how it was practised was also changed for Peter and Tom due to the illness experience. For Tom, this appeared to be a constructive change; however for Peter this was associated with his symptoms and he had reduced his spiritual practices because of this

Tom

*I'm a lot **more appreciative of it**, when I was in hospital they had church services and I went to them and I had a bit of a chat to the priest every now and then and just seeing **how they handle dealing with people who are crazy and being nice about it and stuff does give you a bit more perspective on how good a job the religious community does** (1st) 29*

Peter

*So from being unwell I've sort of stopped me from, from praying sort of thing. **I don't pray now....It's changed....Now I don't place as much sort of emphasis on it as I would of. Whereas before I would of....It sort of hasn't changed that much but it's still the way it was but there's been a change.....Yeah stronger religious faith because I've been sick....I've been more religious since I've had my psychosis but I've stopped, I've stopped sort of now. I just accept it sort of thing. I wanted to know things** (1st) PTGI*

Participants also discussed how they viewed the future. Sarah and Peter felt nervous and apprehensive but for different reasons. Sarah appeared worried because she did not have any clear life goals, whereas Peter had many but was unsure if he would be able to achieve them.

Peter

*I feel **worried about the future**, worried....**Will I be able to find a job? What sort of living will I be able to make?** No, not really. Besides getting a job and getting some work down pat if I could do that. May be do some music if I could eventually in...may be 3, 4 years down the track have enough lessons. I'm thinking about getting lessons so that's something I'm trying, I mean I don't like to practice but practising is part of it all (1st) 50*

Sarah

A bit nervous about it cause I don't know what the future holds but hopefully I'll gradually get to a situation that I want it to be.....Just having a life that is full of enjoyment and a life that's stimulating....No I'm not sure I'm still very undecided (2nd) 54

At Time 2 Peter still had a number of goals but seemed more relaxed about his future.

I don't know I'll take it one step at a time. I don't know about a job sort of thing. I've got all the information here.....I might go back to TAFE and finish my diploma....Yeah I want to try and may be get into some certifications. Do something like that, the networking sort of thing. But I still haven't got the motivation to do it all....Yeah a long-term goal (2nd) 54

Tom had concrete goals that he felt would be evidence of a bright future and was looking forward to working towards these. He felt that achieving these goals would indicate that his life was back on track. “*Good I'm really looking forward to completing my degree...getting my life on track, I've got a date tonight so that'll be exciting the first time in a while....Yep complete my law degree, travel, and move out of home*” (2nd) 54.

Triangulation of the Data

The core themes identified by clinicians and family members in relation to the negative aspects of the illness, engagement in recovery, and constructive and restorative processes and outcomes are presented in table format. Table 5.15 presents the negative aspects of the experience of FEP which were corroborated by clinicians and family members.

As shown in Table 5.15 it appears that family members may be more aware of the ongoing negative aspects of FEP than clinicians as they confirmed all themes.

Table 5.15

Negative Aspects of the Experience of FEP and Treatment

Theme	Example Quote Family Member	Example Quote Clinician
<i>Ongoing concern about relapse</i>	<i>He said mum can I be sick again. I said oh you have to be careful. You have to take your tablets (Peter) 12</i>	–
<i>Perception of the illness as an ongoing problem.</i>	<i>He's a little bit concerned but I said to him you'll be ok....He's worrying about himself....He said how to work to have money....he's reckons is how I'm going to work. How I'm going to marry (Peter) 53</i>	<i>She's aware she's not functioning as well. She doesn't have the motivation....She can't get out of bed. She's constantly tired. So she's perceived herself as very different. She can't go out drinking so she's depressed about that (Sarah) 3 and to explore issues raised in interview</i>
<i>Loss and grief</i>	<i>I'm sure she would say I feel sad now .I'm really feeling down like that day she said I don't have a life cause she's not enjoying a lot of her friends. (Sarah) 48</i>	–
<i>Stigma</i>	<i>She is very embarrassed to go closer to her workplace.... It's alright you just say hello and then let them go. You don't have to tell them (Sarah) 14</i>	<i>She's very self-conscious. Self-conscious about her weight and it's not easy to speak to people because of her illness (Sarah) end of interview</i>

Note. Dashes indicate that clinicians did not confirm this theme.

Table 5.16 shows triangulation of restorative processes and outcomes. The theme *social recovery* was not discussed by family members or clinicians but both recognised *recovery as a gradual process*. Further, family members did not discuss the themes *ownership of recovery* or *developing acceptance*. These themes were also not strong features of clinicians' interviews. Instead, clinicians and family members predominately focused on FEP participants ongoing difficulties.

Table 5.16

Core Themes Related to Restorative Processes

Theme	Family Member Example Quote	Clinician Example Quote
<i>Recovery as a gradual process</i>	<i>He's much, much better. He's getting a little bit, very slow, takes time. He needs a lot of attention. He needs a lot of things but he start driving.</i> (Peter, FM) 14	<i>I think she's just taking it a day at a time. I think she finds it really hard to set goals for herself..... But I think she's kind of taking a step at a time. I think she sees it very much as a recovery. She doesn't have any focus on what job she wants to do. She's got very few goals, ambitions but then she really didn't have that before</i> (Sarah) 8
<i>Ownership of recovery</i>	—	<i>today he was talking about wanting to, you know when can he stop the medication but he says you know he doesn't have any problem with it but he's still keen to stop the medication</i> (Peter)
<i>Developing acceptance</i>	—	<i>He's accepting that he's had something and he's got to take the medication and may be the doctors are right</i> (Peter) 11

Note. Dashes indicates family members did not confirm this theme.

Core themes relating to constructive changes regarding the domain *relating to others* are shown in Table 5.17. Table 5.17 indicates that both clinicians and family members recognised the theme *deepening relationships* and family members were aware of the themes *confirmation of character* and *enhanced perspective taking*. The themes *appreciation of life* and *changed priorities* were not discussed by clinicians or family members. Further, the constructive changes reported were more often unelaborated.

Table 5.17

Core Themes in Relation to Constructive Changes Associated with Relating to Others

Theme	Family Member Example Quote	Clinician Example Quote
<i>Confirmation of character and relationships</i>	<i>I think she knows more now mum loves me</i> (Sarah) 32	–
<i>Deepening relationships</i>	<i>But our relationship is so good she wants me to cuddle her all the times</i> (Sarah) 32	<i>So I think he's quite enjoying a better relationship with them now than he had before because they're now seeing that he hasn't been well and it's not his fault. So I think he's getting on a bit better with his brothers. I think it's a little stronger his relationship</i> (Peter) 5

Table 5.17 continued

<i>Enhanced perspective taking and sense of unity</i>	<i>He seems to be more tolerant....of people's shortcomings I guess whereas before he wasn't...Tom used to think he was pretty bright and he wouldn't have a lot of tolerance for people who weren't that bright but see now....it doesn't bother him....there's a guy who...lives down the road...there's obviously something not right about him....probably before he'd have a smart comment about it (Tom) 17</i>
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Note. Dashes indicate that clinicians did not confirm this theme.

Sarah, Tom, and Peter's mental health history and quantitative results are presented in Appendix F.

The Impact of FEP on Family Members

Data from family members' interview were presented according to the initial experience of FEP, negative aspects of the illness, and the recovery process.

Peter's mother did not tend to discuss how the initial experience of FEP impacted on her. Tom's and Sarah's mother's engaged in a reflective process in an attempt to examine the illness and understand long-term and short-term indications that their loved one was becoming unwell.

She was so depressed but it never occurred in my mind that it was something serious. I don't know why sometimes I think the culture I was brought up may have contributed to that feeling it doesn't mean that I neglect her or ignore her needs it's just that in the culture I come from we don't have, we don't really have depressed people.... I don't see that where I come from so in a way I always think that she's alright, she will be ok (Sarah, FM) 10

They also expressed a sense of helplessness and disconnectedness in response to dealing with the mental health system and law enforcement.

Oh it was awful, it was awful because, I'll cry, it's like your child and somebody's taken....I could see him the next day and then after that I wasn't allowed to see him at all they just, he was just agitated and it was like every time he did those things they must of put him in seclusion or something I'm not really sure it was just really quite stressful (Tom, FM) 10

Sarah's mother was the only person who identified one positive aspect of acute treatment.

I think the first thing we both appreciated was the CAT team. That was the first help we got. When she was out of hospital there were few of them coming home probably every once or twice, once every two days or something....the way they explain things, the way they talk to us it was so wonderful.....I don't know how she felt but slowly and quietly I sort of accept what has happened to her. So that was the first step...for her recovery 52

In relation to the negative aspects of FEP family members discussed an ongoing concern for their loved one's wellbeing, the emotional, practical and physical toll coping with the impact of the illness had on the family member, how the family's relationship dynamics had changed as a result of FEP, and stigma. All three family members discussed these concerns to varying degrees except stigma was not raised by Peter's mother. Predominately these issues were associated with the recovery phase of the illness but they could also be associated with the experience of the acute illness. "So he's always been a rock you know you could rely on him and I suppose that's changed for me. I think you know that dynamics has changed" (Tom, FM) 36.

I try to see...the doctor and I try to help him at home and that's helped. I find out if you help him, sometimes I can't, sometimes it gets hard for me. I told him oh I'm not coping with you. I'm going to lock you in an he said oh mum don't be like that please (Peter, FM) 40

I've changed my own life as well.... I think like I used to plan to go somewhere without (Sarah) because I trust her. Now I can't..... I want to go and come back what is she doing? Is she eating? What will happen if I go? Whether she's going to sleep all day and no eating (Sarah, FM) 47

*I found is that people don't talk about it....There was one girl that would ask me and who sort of did sort come in and sit down and ask me different things and if everything was going ok and that sort of thing **but nobody else ever asked... it was awful because I thought if your son or one of your children had an accident and they were in a normal hospital people would always say how you going** (Tom, FM) **explored issue raised by participant***

Family members discussed what recovery meant to them in a range of ways. Tom's mother understood it occurring within a two-year timeframe but that it took time. *"I guess I'd thought when he's coming home that he'll be better but I think it hit me then that really he's not better and we've got a way to go here"* (Tom, FM) 11.

This two year thing.....I've known this other woman and she's been quite, actually she's been really helpful. She's a psych nurse and she's got a son with a diagnosis of schizophrenia....She also says like the two year thing. And I say that to him too. I say it's only one so you've still got another year before you're fully well (Tom, FM) 50

Sarah's mother believed recovery was when a person developed insight into their condition and understood who her supports were as well as a general sense of improvement.

*Recovery to me is a stage when **an unwell person becomes to learn that something was happening and at the same time may be there are people involved to try and help her** in other means in terms of tablets or what the talking therapy or whatever to make her, I want say better, **but feel improved rather than feeling down and this is the end of the world** (Sarah, FM) 50*

Peter's mother believed recovery to be a time when she felt relief from the impact of having to care for her son.

Recovery meant a lot of relief and a lot of things to be through but I'm getting better. I'm getting a little bit stressed too. Wasn't only, I was having two places and now I'm getting better. I try to be support to the boy and have the husband too
(Peter, FM) 50

Both Sarah's and Tom's mother actively engaged in seeking support and information and discussed the importance of mutual understanding

I also went to (Clinical Service) and ask if there is a group of relative because I didn't know that I can join so that I want to listen to them, their stories whether and share their experiences and that was really helpful too.... I think the first night I was very upset and after that I knew I was not alone there are other people
(Sarah, FM) 52

(Friend) works in the CATT team where we used to live, we used to live in X so he rang me so we had a big long talk about it...Steve gave me another sort of view on it too so he was really good just listening and just support (Tom, FM) 10

Although minimal, important constructive changes were also identified by Sarah's and Tom's mother. Sarah's mother identified that there were *some positive things change from her more than that negative thing in (her) head* (15) and discussed this in relation to an improved relationship with her daughter. "*There are good things like I mentioned before our relationship.... She listens to me and she helps as well if I say to her would you be able to bring the washing? She does things*" (Sarah, FM) 15.

Tom's mother described clear constructive changes that had developed through the illness experience. She described being more tolerant and understanding of people with mental illness and having more insight into the experience. She identified the experience as one which facilitated personal growth and increased tolerance. "*Just feel like I'm not the same person as I was a year ago. I guess it's made me sit back and think god how can I be more tolerant*" (Tom, FM) 50.

*Like even for me its been a **growth period** because it's amazing how many people once you say, **you mention like mental illness and your experience it's amazing how many people are affected by it but nobody would say it without a prompt** (Tom, FM) 50*

*Look I've always and I've had my own share of experiences in life too but I suppose I've always thought in a way you know you can get by until you know. Whatever happens to you, you can get around it....I still believe that....we just have to change direction and just go another way. **I've just got so much more insight into I guess, psych, depression, just the whole mental health....I'm in health care myself (inaudible) so we've always known mental health....but now I think I understand those issues so much better....I've got friends in that area but I've never understood their issues not like I do now.** And very much I see that the public health money... doesn't give us what we need, very much I can see that I can also see the discrimination out there (Tom, FM) 50*

Summary of Pilot Results

Preliminary themes derived from the pilot study provided evidence for the research questions. Meaningful data relevant to how people experience FEP and the nature of its ongoing negative impact was derived from the interviews (Question 1). Key themes indicated a broader model of trauma and recovery is relevant to FEP. Results showed the traumatic nature of FEP goes beyond the initial experience and a diagnosis of PTSD. For instance, broader notions such as threat to one's identity were raised by FEP participants and secondary consequences were discussed such as ongoing concern about relapse. Some reflection of engagement in managing FEP was discussed (Question 2). In particular, the data gave evidence of restorative and constructive processes of recovery and adaptation to FEP (Questions 3 and 4). Themes generally evolved from a range of interview questions and were stable over time.

Family members and clinicians tended to focus on the illness experience rather than what the experience of the acute episode was like for the FEP participant. They also predominately focused on enduring difficulties and the ongoing nature of recovery rather than gains made or in what beneficial ways the recovery process was managed. Family

members, and in particular clinicians, appeared less aware of potential constructive changes and those reported were often unelaborated. These results do not necessarily imply that constructive changes were illusory. For instance, changes in philosophy of life and sense of self could be considered to be internal experiences and therefore less likely to be recognised by others. As Sarah pointed out in her interview, internal changes are just as relevant as those which can be observed by others. *“I think that **there’s other things that can happen that by observing you don’t actually see, it’s all internal as well**”* (1st) 34.

Further to this, family members corroborated constructive changes associated with the domain *relating to others*, possibly because these changes were more likely to involve them and produce recognisable behavioural changes.

Another noteworthy finding was the impact of FEP on family members. Interviews with family members indicate that the experience of FEP was highly distressing and yet could also produce constructive changes. This supports continued research on a broader application of the trauma framework and family members’ experiences warrant further detailed investigation. Discussing the experience of FEP, including potential constructive aspects, could be a positive and useful experience. Peter commented that it had been a helpful experience in supporting his recovery, specifically having to express himself, and none of the three FEP participants and family members reported an adverse reaction.

Changes Made as a Result of the Pilot Study

From the pilot study a number of changes were made to the methodology which involved adapting the interview schedules, demographics collected, and quantitative measures.

Interview Schedules

Some minor changes were made to the interview questions to enable the researcher to develop a deeper understanding of FEP participants’ and family members experiences. A senior psychologist from the Alfred Hospital’s Psychiatry Unit provided secondary consultation in the development of the interview questions. Her advice was to keep the questions simple and direct (e.g., “What was hospital like for you?”). The pilot interviews allowed the researcher to determine how to ask about change across the two interviews.

During Time 2 it was decided to re-ask how things had changed for them since they were unwell as well as since the initial interview. From piloting the interviews it was discovered that specific examples needed to be elicited from interviewees. Therefore, the researcher had this in mind when interviewing future participants and asked further questions to explore the issues participants presented.

e.g., Can you give me specific examples of these distressing experiences / Tell me a particular time that was distressing for you / Tell me a time when you were really aware of that? / Time when you felt that the most?

The experience list helped the process of thoroughly exploring the distressing aspects of FEP. Further questions were added to the interview schedule to help explore the trauma response in more depth as it was felt this was not adequately addressed in the initial interviews. Participants were also asked about the ongoing impact of their most distressing experience in the second interview. Example questions are in Table 5.19.

Table 5.18

Example Questions Exploring the Distressing Experiences of Psychosis

Main Areas	Example Question	Example Probe
Trauma	There are a number of things people sometimes identify as distressing when they are unwell. Look at this list and rank in order from least to most distressing (experience list)	Can you tell me a time when you were really aware of that?
	Last time we spoke you mentioned that x was the most distressing experience for you when you were unwell. How are you feeling about this experience you spoke about last time?	Is this still on your mind?

Specific questions related to FEP participants' level of insight were added because it was thought that insight may have an effect on FEP participants' ability to reflect on their experiences and engage in a deeper understanding of their psychotic episode. These questions also allowed the interviewer to develop an awareness of how the participants understood what they had experienced and introduced the language they used to describe what had occurred. These questions were asked at both stages 1 and 2 to track level of insight over time. The concept *insight* referred to how participants understood their experiences and whether they viewed it within a mental health framework.

How would you describe what happened to you?

Prompt:

- Do you think any of these things were due to a mental health issue?

Finally a question which gauged how FEP participants felt about the future was included at the end of the interview schedules ("How do you feel about the future?"). This question was also asked of family members but from their loved one's perspective i.e. ("How does X feel about the future?").

While the purpose of this research was to explore the impact of FEP and recovery from this experience, interviews with family members revealed the significant impact of this experience on them. The researcher found it difficult to contain some family members and focus the interview on the FEP participants' experiences. Also, it was decided that this information was pertinent to this thesis given the clinical implications of involving family in FEP clients' treatment. Therefore, a question which asked how the experience had impacted on the family member was added. It was decided that family member or partners would be invited to discuss this at the beginning of their interview. Asking these questions at the beginning of the interview facilitated engagement and containment. Also, if family members or loved ones discussed their experiences this was pursued to support engagement as well as allowing the opportunity to gather information on how the experience had impacted on them.

What aspects of the experience were difficult for you?

Prompts:

- What aspects of the condition were difficult for you?
- What changes as a result of x condition were difficult for you?

To provide further containment, the researcher decided to make it clear at the beginning of the interview that the main focus was on FEP participants. Further, family members sometimes commented that they were unable to answer some questions because the FEP participants had not talked to them about particular issues. To address these issues the following statement was added to the interview with family member or partners:

X may not have talked to you about all the things I'm going to ask you about but I would like to get your opinion and comments on them and your understanding of how x is aware of these things

Interviews with clinicians changed throughout the pilot study. Initially, clinicians were interviewed twice, once at Time 1 and 2. The Time 1 interview was very short and based around FEP participants' treatment and how they had responded to it. It was decided this was redundant as these questions could be asked at Time 2 and the information at Time 1 could be gleaned from file notes.

Given the type of service and the varying nature of clinicians' work with their clients, clinicians were not always able to explore or observe the issues addressed in this research. As a result, questions were adapted to better suit clinicians' involvement and work with their clients. For example, it seemed more appropriate phrase change in relation to the time they had been working with them, rather than since they had been unwell. Also, clinicians commented that they were less able to answer questions that were related to clients' subjective experiences. Subsequently, questions were introduced to clinicians with the following statement:

I've been speaking to X about how he/she views life, relationships with others, and how he/she feels about herself/himself (e.g. sense of self/identity) and whether his/her attitudes about these things have changed as a result of being unwell. We discussed the positive and negative changes. I was wondering if you could comment on your opinion about these things in relation to X?

In addition, it was decided that clinicians would only be asked a few broad questions in relation to their clients' self-concept, relationships, and views about life rather than go into the same detail as the interviews with FEP participants and family member or partners. This was due to the time constraints of clinicians and also that family members were thought to be able to give in-depth accounts of these issues. Questions which were

added to the clinicians' interview were related to FEP participants' daily living skills, ongoing issues, and coping as shown in Table 5.19.

These changes meant that data gathered from clinicians in the pilot study varied. Two clinicians were asked to comment on any practical changes FEP participants' may have gone through as a result of their illness across the areas: work, daily living skills, management of day-to-day life, education, and social activities. Two clinicians were also asked to discuss how the participants were coping with their experiences and one clinician commented on the main issues her client continued to face and worked on in treatment.

Table 5.19

Clinician Questions

Main Areas	Example Question	Example Probe
Ongoing Difficulties	What are the main problems/issues x continues to experience and which he/she needs to too/consider now?	
How is the FEP participant coping	How do you think x has been coping since you've seen him/her?	What helped/hasn't helped him/her cope?
I also talked to x about more practical things such as daily living skills, work, school/university, self-care, involvement in social activities, and day-to-day life.	Have you noticed whether he/she has experienced any changes in these areas since you've worked with him/her as a result of being unwell?	

Measures

After completing data collection with Tom at Time 1, it was decided that questionnaires would also be used to assist participants to respond in more depth to the interview questions and to build on the issues they raised in the interview. After interviewees had completed the measures, they were asked to elaborate on their higher ratings for the IES-R (questions rated ‘quite a bit’ and ‘extremely’) and PTGI (questions rated to a great degree’ and ‘to a very great degree’). These were discussed and responses clarified as part of the interview. In particular, how and why aspects of the illness experience were distressing for them and the nature of their constructive changes. This strategy was unable to be implemented for the RSQ given the agree/disagree responses.

The event which participants were asked to respond to on the IES-R was changed during the pilot study. Initially participants were asked to respond to the IES-R according to the ‘time when you were unwell.’ However, given the broad range of distressing experiences that can be encountered during a psychotic episode and the requirement that the IES-R is rated according to a specific event, the list of experiences questionnaire was developed. This questionnaire was also used to provide a detailed picture on what people found traumatic about their acute episode. It was administered during Peter’s interview at Time 2, but only after he had already described his illness and treatment experiences in an open manner. At this point the experience Peter identified as most distressing was discussed in detail. Peter was also asked to respond to items on the IES-R according to this experience.

List of experiences questionnaire

Items for this questionnaire were developed from previous research (Shaw et al., 1997), clinical experience of the investigator, and through analysis of what pilot FEP participants discussed as distressing in their interviews. There was also an option for participants to include experiences that were not on the list. Initially the list which was administered to Peter at Time 2 consisted of 17 items, however after the pilot study was completed the experience list was revised and more items were added. The final questionnaire is presented in Appendix D.

Participants were initially asked to cross out items they had not experienced when they were unwell and then rate remaining items from least (1) to most distressing. Once this was completed the interviewer and interviewee discussed the most distressing item (highest rated item = 1) in order to identify a specific example of this experience that could be used to respond to the IES-R. For example, if a participant rated their symptoms as the most distressing experience the interviewer asked questions such as “tell me a time when you were really aware of that” in order to identify a specific experience to answer the IES-R in relation to. An example one participant used was when she heard voices continuously all night and could not fall asleep.

Mini International Neuropsychiatric Interview (M.I.N.I.)

Only one measure was added to the research after the pilot study was completed. The clinician rated version of the M.I.N.I. was used to confirm participants’ had psychotic disorder and determine co-morbid Axis I diagnoses and current suicidality.

The M.I.N.I. was considered a more appropriate measure than the much longer alternative of the Structured Clinical Interview for DSM-IV (SCID) for a number of reasons. First, the present study did not require co-morbid Axis I diagnoses to be ruled out. Rather information obtained from the M.I.N.I. was used to aid in-depth descriptions of FEP participants. Also, given that this study was primarily qualitative and required significant time from participants, a long assessment such as the SCID may have affected participants’ desire to participate. The length of the SCID and the in-depth clinical nature of the assessment interview may have also negatively impacted engagement which in turn could have affected the quality of the interview data. The researcher wanted to reduce FEP participants’ perception that they were being clinically interviewed as much as possible so that they were more likely to be open and frank about their experiences. The M.I.N.I is discussed in detail in chapter 6 (refer to p. 128-129), which presents the method derived from these changes.

CHAPTER 6: MAIN STUDY METHODOLOGY

Most of the methodology from the pilot study was retained in the main study. However recruitment and the procedure differed slightly in the main study due to recruitment difficulties encountered during the study and these changes are discussed below.

Recruitment

The inclusion and exclusion criteria from the pilot study was replicated in the main study (please refer to pages 67-68). A total of 104 people were screened for inclusion in the study. Initially, FEP participants were sought from Alfred psychiatric outpatient services, specifically the Continuing Care Teams. Continuing Care Teams are the largest component of adult community mental health services in Victoria. These services provide non-urgent assessments, treatment, case management, support and continuing care services to adults (aged 16-64 years) with a mental illness in the community. The study was approved by the director and manager of the Alfred Psychiatric Research Centre and the Alfred Hospital's ethics committee. The research was then advertised at clinical and research meetings and on posters. The investigator looked for people with a diagnosis of FEP via approaching clinicians and intake workers, screening clinical databases, attending ward round meetings, and screening crisis assessment and treatment team patient lists. People who also had an unspecified diagnosis of psychosis were noted and their medical records checked to discern their diagnosis.

Appropriate clients from Alfred Psychiatry were approached by the investigator either in the community or while an inpatient. If the potential FEP participant was still inpatient, permission was sought from the inpatient clinical team to approach them. Patients were offered a brochure and permission was sought to contact them again post-discharge. They were followed-up post-discharge via their treating team to confirm if they were appropriate and to remind them about the study. A participant information and consent form was offered at this time.

If patients were not seen during a hospital admission they were contacted via their outpatient clinician, at which point their appropriateness for the study was confirmed, the study was discussed with them, and they were offered a brochure and/or a participant information and consent form. If a client chose to participate, informed consent procedures were commenced, allowing at least a week for potential participants to read the participant information and consent form in their own time.

Hospital admission has been central to past research on the traumatic impact of psychosis and its treatment and studies have demonstrated that it can be a highly distressing experience (e.g., McGorry et al., 1991). Therefore, potential FEP participants were only sought if they had required a hospital admission. However, this restricted the number of people that could be approached and, due to difficulty recruiting participants from Alfred Psychiatric services, it was decided that any participant who had experienced a FEP and had required acute treatment (Crisis Assessment and Treatment Team or hospitalisation) would be contacted. This allowed the researcher to recruit from a larger pool of people and arguably provided more accurate representation of this client population. Indeed, given the potential trauma of hospitalisation it has been recommended that community treatment is prioritised where possible, particularly in this younger client group (Spencer, Birchwood, & McGovern, 2001).

Despite implementing this change it remained difficult to recruit from Alfred Psychiatric services. This was partly due to a drop in FEP referrals over the time of data collection and also because the FEP service was in the early stages of being established. However, other difficulties were encountered. Often a potential participant would not be appropriate because they were no longer with the service. This occurred when their details were not in the client database; the client was moving overseas; the client was not linked in with Alfred Psychiatric outpatient services post-discharge from hospital; or the client moved out of the catchment area. Other reasons included, but were not limited to, diagnostic uncertainty, incorrect diagnoses in the psychiatric database, clinicians not wishing their clients to be approached, inability to contact clients, clients declining to participate, clients being too old for the study, clients disengaging with their treating team, and unstable living arrangements. In all, only two FEP participants were recruited from Alfred Psychiatry. A further two FEP participants were withdrawn after completion of

stage one because they were deemed too unwell to continue.

Due to the delay in recruitment at Alfred Psychiatric services the study was completed at ORYGEN Youth Health (OYH). This study was approved by the director of OYH and the Royal Melbourne Hospital ethics committee (see Appendix A). First-episode psychosis participants from OYH were recruited from Early Psychosis Prevention and Intervention Centre (EPPIC). EPPIC is a comprehensive service addressing the needs of young people (aged 15-24 years) with psychotic disorders. It aims to facilitate early identification and treatment of psychosis and therefore reduce the disruption to the young person's functioning and psychosocial development. The research was advertised at clinical and research meetings. First-episode psychosis participants were screened via clinicians, other research projects, and medical records. Due to earlier delays in recruiting participants and a large number of research projects being conducted at OYH, it was decided that all appropriate FEP clients would be approached about the study whether or not they required acute intervention. Again, it is argued that this allowed for a better representation of the client group. Also, after consultation with senior clinicians and academics in the early psychosis field, the time-frame to recruit participants was expanded from 3-4 months post acute episode to up to 6 months. It was initially thought that recruiting participants as close to their psychotic episode would allow for a better account of the distressing aspects of this experience. However, two of the pilot participants were recruited 5 months after their psychotic episode and they were still able to provide detailed recollections of their experiences.

Appropriate FEP clients from OYH were approached about the study in the community. They were contacted via their clinician, at which point their appropriateness for the study was confirmed, the study was discussed with them, and they were offered brochures and a participant information and consent form. Most clients who were screened at OYH were recruited. Reasons for non-participation included: a request by clinicians that their clients not be contacted, clients not meeting the inclusion criteria, and clients declining to participate. If a client chose to participate, informed consent procedures were commenced, allowing them at least a week to read the participant information and consent form in their own time. A total of eight FEP participants were recruited from OYH. Two other people consented, however one withdrew before beginning the study and one could

not be contacted after giving informed consent. All contact with FEP participants was negotiated with clinicians at both OYH and Alfred Psychiatric services. Advertising material and participant information and consent forms are in Appendices B and C.

Characteristics of the FEP Sample

The final sample of FEP participants included seven men and three women aged between 22 and 28. Demographic information was collected from medical records and treating clinicians. Five participants were Anglo-Australian, while two were from Vietnam, one was Hawaiian/Anglo Australian, another was of Italian descent, and one participant was of Croatian descent. Other relevant demographic information is presented in Table 6.1.

As shown in Table 6.1, the majority of FEP participants were employed at some point during the study and had completed High School, with over half of them having completed a university degree or enrolled in further education or training. Most participants lived with their family. Half of the FEP participants were in a relationship or started an intimate relationship during the study, while half were not in a relationship with one individual's relationship ending during the research.

Table 6.1

Demographic Characteristics of the Sample

Demographics	<i>n</i>
Employment status	
Employed	5
Unemployed	3
Gained employment while participating in the study	2
Living arrangements	
Family	8
Moved back with family while participating in the study	1
Housemate	1

Table 6.1 continued

Relationship status	
Relationship	3
Began a relationship while participating in the study	2
Relationship ended while participating in the study	1
Not in a relationship	4
Highest level of education attained	
Completed Year 10	1
Completed Year 11	2
Completed high school	5
Completed a university degree	1
Completed a diploma at TAFE	1

Data on participants' history of trauma and other potentially significant life experiences are presented in Table 6.2.

Six FEP participants had experienced a trauma consistent with Criterion A, while nine had experienced other highly stressful events (see Table 6.2). Two participants did not have a history of trauma or significant life experiences and four participants had experienced multiple events. When assessed using the M.I.N.I., five participants said they had experienced or witnessed a traumatic event as defined by Criterion A of the *DSM-IV-TR* (APA, 2000). However, these Criterion A events were not identified and of these five participants only one person fulfilled a diagnosis of PTSD. Therefore, it is unknown whether the events reported in the M.I.N.I assessment relate to the Criterion A events reported in Table 6.2.

Table 6.2

Trauma History and Significant Life Experiences

Experiences	<i>n</i>
Criterion A trauma	
Physical assault	1
Childhood sexual abuse	1
Witnessed violence	1
Death of a friend (occurred during the study)	1
Death of a family member	2
Other significant life events	
Bullied during school	4
Parents' separation	2
Family members with a mental illness	2
Birth complications	1

Table 6.3 shows the type of acute intervention participants received during their first-episode of psychosis.

Table 6.3

Acute Treatment Experience by FEP Participants

Acute treatment	<i>n</i>
Police involvement during acute treatment	1
Hospital only	1
Youth Access Team only	2
Crisis Assessment and Treatment Team only	1
Hospital and Youth Access Team	3
Hospital and Crisis Assessment and Treatment Team	2
Nil acute treatment and managed by the community treatment team	1

The Youth Assessment Team (YAT) is equivalent to the Crisis Assessment and Treatment Team (CATT). Both manage clients in the community when they are acutely unwell. As Table 6.3 shows, most of the participants had involvement with either CATT or YAT. Three participants were hospitalised as involuntary clients and one participant was initially voluntary but later made involuntary during her admission. One participant required police involvement to facilitate his admission. Table 6.4 lists the medication FEP participants were prescribed during the acute phase of their illness and when seen for the study.

One FEP participant had a forensic history which involved legal proceedings. With regard to outpatient treatment, only one participant was on a Community Treatment Order which means that he was an involuntary client but was allowed to receive his treatment in the community.

Diazepam, Quetiapine, and Olanzapine were the most prescribed medications when participants were acutely unwell (see Table 6.4). Quetiapine was the medication most participants had for the duration of their treatment across the time points. Three participants had ceased medication at Time 2.

Table 6.4

Medication Received in Acute Treatment and at the Time of the Interviews

Medication	Acute <i>n</i>	Time 1 <i>n</i>	Time 2 <i>n</i>
Anti-psychotic			
Quetiapine	5	4	4
Risperidone	2	2	1
Olanzapine	4	2	1
Mood stabiliser			
Sodium Valproate		1	
Abilify	2		1

Table 6.4 continued

	Anti-depressant		
Setraline	3	2	1
Mirtazapine	1	1	1
Citalopram	1	1	
Venlafaxine	1	1	
<hr/>			
	Medication to manage side-effects		
Bromocriptine	1		
Benzhexol	1		
Benztropine			1
<hr/>			
Sedative			
Diazepam	4		1
Temazepam	1		
Zoipillone	1		1

Measures

The Positive and Negative syndrome Scale (PANSS), Impact of Events Scale-Revised (IES-R), Posttraumatic Growth Inventory (PTGI), and the Recovery Style Questionnaire (RSQ) were also administered in the main study. Detailed descriptions of the assessments and comparative norms are given in the pilot chapter (pp. 70-78)

Mini International Neuropsychiatric Interview (M.I.N.I.)

The M.I.N.I. is a short structured diagnostic interview for the *DSM-IV* (APA, 1994) and the *ICD-10* (WHO, 1992). With administration time of approximately 15 minutes, it was designed to meet the need for a short but accurate structured psychiatric interview. The M.I.N.I. includes 17 Axis I diagnoses, Anti-social personality disorder, and a suicidality module. These were chosen because they were the most common amongst data from two major epidemiological studies. Specifically, priority was given to disorders that had a 12 month prevalence of 0.5% (Sheehan et al., 1998). The Anti-social personality disorder

module was not administered in this study.

Concordance with the standard instrument Composite International Diagnostic Interview (CIDI) for the *ICD-10* and Structured Clinical Interview (SCID-P) for the *DSM-III-R* (APA, 1987) for each of the 17 Axis I disorders generated by the M.I.N.I. was assessed by Sheehan et al. (1998) using Cohen's kappa, sensitivity, specificity, positive predictive value, negative predictive value, and efficiency. Good results were obtained when the M.I.N.I. was compared to both measures. Discrepancies between the CIDI and M.I.N.I. could be attributed to the coexistence of psychotic and affect symptoms (Sheehan et al). Also, Sheehan et al. reported excellent inter-rater reliability. Sheehan et al. strengthened several questions on the M.I.N.I. and made other improvements to enhance sensitivity, specificity, and positive predictive values. It has been upgraded to be consistent with the *DSM-IV* (APA, 2000) and its time-frames (Sheehan et al.) and this version was used in the current study. The demographic proforma was also developed to include more information about participants' mental health history and daily living skills. Example questions from the M.I.N.I. are shown in Appendix D.

Characteristics of the Sample Ascertained from the Assessment Measures

The diagnostic features of the FEP participants are presented in Tables 6.5 and 6.6. These data were derived from medical records and the M.I.N.I. The M.I.N.I. only determined the presence of a current or lifetime psychotic disorder. Thus, the psychotic diagnoses in Table 6.5 are from participants' medical records.

Table 6.5 reveals that a diagnosis of schizophreniform psychosis was the main psychotic diagnosis given to participants across all time points. Two participants' psychotic diagnoses changed during their acute phase. The first participant was given a diagnosis of major depressive disorder, with psychotic features and later schizophreniform psychosis. A second participant was initially given a diagnosis of first-episode psychosis but this was changed to schizophreniform psychosis during his admission. One participant had a history of psychotic symptoms in the context of low mood but these resolved spontaneously and were not treated. Thus she was still viewed as a FEP client for the purposes of this study and according to the Australian Clinical Guidelines for Early Psychosis (National Early Psychosis Project Clinical Guidelines Working Party, 1998). The M.I.N.I. indicated that four participants had a current psychotic disorder.

Table 6.5
Diagnostic Characteristics of the Sample

Psychotic Disorder	Prior History <i>n</i>	Acute Episode <i>n</i>	Time One <i>n</i>	Time Two <i>n</i>
Psychotic symptoms	1			
First-episode psychosis		3	2	1
Schizophreniform psychosis		5	6	6
Schizoaffective disorder		1	1	1
Major depressive disorder with psychotic features		3	0	1
Drug induced psychosis		0	1	1

Table 6.6
Co-Morbid Axis I Diagnoses

Axis I Disorder	Prior History <i>n</i>	Acute Episode <i>n</i>	Time One <i>n</i>	Time Two <i>n</i>
Mood Disorder				
Depression	8			
Major depressive episode		1	2	
Major depressive disorder	1			
Major depressive disorder, recurrent			1	
Major depressive disorder, recurrent, with melancholic features			1	
Dysthymic disorder			1	
Past hypomanic episode			4	
Past manic episode			1	
Manic episode		1		

Table 6.6 continued

Anxiety Disorder				
Anxiety	2			
Anxiety disorder	1		1	1
Social anxiety disorder	4		2	2
Generalised anxiety disorder			1	1
Posttraumatic stress disorder			1	
Panic attacks	3			
Table 6.6 continued				
Panic disorder without agoraphobia			1	
Trichotilomania			1	1
Obsessive compulsive disorder		1	2	1
Substance Use Disorder				
Substance use	8		1	
Substance abuse		1	1	1
Alcohol abuse (past 12 months)			2	
Alcohol dependency (past 12 months)			1	
Drug dependency (past 12 months)	1		5	
Drug abuse (past 12 months)			1	
Other Axis I Disorder				
Attention deficit disorder	1	1	1	1
School refusal	1			

The Axis I co-morbid diagnoses listed in Table 6.6 are reported in terms of how they were documented in participants' files and from the M.I.N.I assessment. For instance, the researcher did not change major depressive episode to major depressive disorder even though an episode of major depression would qualify as this diagnosis. Sometimes a specific diagnosis was not specified in participants' files and instead only broad terms were used (e.g., depression, anxiety, panic attacks, & anxiety disorder). Thus, the number and

distribution of specific Axis I diagnoses could not be accurately reported.

Eight participants had a history of mental health issues, which mainly related to depression and a variety of anxiety related concerns. The remaining two participants had used substances in the past. A total of eight participants had a history of using substances. Seven participants had co-morbid diagnosis when recruited for the study and the presence of at least one co-morbid diagnosis was confirmed by the M.I.N.I. According to one participant's file he had a co-morbid diagnosis but this was not confirmed by the M.I.N.I.

Although assessment with the M.I.N.I. indicated four participants had experienced a hypomanic episode and one had a past diagnosis of mania, this was not corroborated in their medical records. The person who had been given a diagnosis of schizoaffective disorder had only experienced a past hypomanic episode according to the M.I.N.I. Trichotilomania and attention deficit disorder were only noted in the participants' medical records as these diagnoses are not assessed by the M.I.N.I. A large number of diagnoses or mental health issues were not carried across from past history to the acute phase or from Time 1 to Time 2. The latter may be due to the M.I.N.I being administered at Time 1 in addition to diagnoses obtained from medical records. Indeed, a large number of co-morbid diagnoses were reported at Time 1 but not Time 2. Diagnoses listed under prior history, acute phase, and Time 2 were only obtained from participants' medical records.

First-episode psychosis participants' level of current suicidality was assessed by the M.I.N.I. and a history of suicide attempts and deliberate self-harm was collected from their medical records. This information is presented in Table 6.7.

Table 6.7

Suicidality and History of Suicide Attempts and Deliberate Self-Harm

Suicidality	<i>n</i>
Low	7
High	2
Moderate	1
History of suicide attempt(s)	3
Deliberate self-harm	1

At the time of the initial interview most participants ($n = 7$) had a low suicidality rating according to the M.I.N.I, while four FEP participants had engaged in suicidal behaviour during the past month and four had a lifetime history of at least one suicide attempt. However, according to two participants' medical records they had a history of one suicide attempt but neither reported this during the M.I.N.I assessment. Table 6.8 shows the mean and standard deviation scores for participants PANSS ratings across Time 1 and 2.

Table 6.8

Scores on the Positive and Negative Syndrome Scale (PANSS)

	Time 1			Time 2		
	<i>M</i>	<i>SD</i>	Range	<i>M</i>	<i>SD</i>	Range
Total score	66.70	5.66	59-76	61.90	7.03	54-72
Positive scale	15.00	4.06	11-23	14.10	4.43	9-23
Negative scale	17.10	4.63	11-24	16.10	5.67	9-25
General Psychopathology scale	34.60	3.17	29-39	31.70	3.83	23-37

Table 6.8 indicates that the group's PANSS scores decreased over time. At Times 1 and 2 the average score on the Negative scale was slightly higher than on the Positive scale. According to the mean total score FEP participants tended to present as mildly unwell at Time 1 and 2.

Table 6.9 lists the different experiences people had during their acute episode and gives the frequency with which they were rated as well as which were the most distressing experiences. Given that the lowest number of experiences a participant encountered was four, the number of participants who rated an experience in the top three as most distressing is listed as well as which experiences were rated as the most distressing.

The top six most frequent experiences during participants' acute episode were: (a) symptoms; (b) being unable to do normal activities; (c), conflict with family and friends; (d) medication side-effects; (e) length of hospital stay unknown; and (f) other patients in hospital. Items (c) and (d) were both rated by six people, while (e) and (f) were both rated by five participants.

Table 6.9

Frequency and Distress Relating to Participants' Acute Experiences

Experience	Frequency	Top three most distressing experiences	Most distressing experience
	<i>n</i>	<i>n</i>	<i>n</i>
Symptoms	9	7	5
Being unable to do normal activities	8	4	1
Medication side-effects	7	1	
Conflict with family and friends	7	5	1
Length of hospital stay unknown	6	3	
Other patients in hospital	6		
Away from family and friends and other important things due to hospitalisation	5	3	1
Other difficulties with family and friends	5	1	
Length of CATT/YAT treatment unknown	5		
Involuntary admission	4	1	1
Sedated	4		
Interviewed by CATT/YAT	4		
CATT/YAT monitoring medication	4		
Police involvement in hospital admission	1		
Seclusion	3		
Enforced medication	3	1	
Visited by CATT/YAT	3		
Contact with police when unwell	3	1	
Hurting yourself when unwell	3	1	1

Table 6.9 continued

High dependency unit	2	
Not told why hospitalised	2	
Unsure why hospitalised	2	
Not told why CATT/YAT visited	2	
Unsure why CATT/YAT visited	2	
Physically hurt by someone or hurting someone else when unwell	2	1
Restrained	1	
Getting into trouble with the law	1	1
Other		
financial problems	1	
thoughts of wanting to hurt myself	1	
“emotionally hurting myself”	1	
Physically hurt in hospital	–	

Note. Dash indicates that no one experienced being physically hurt in hospital.

Only one participant did not rate his symptoms because he did not think the experiences he had were due to a mental illness. Interestingly, some participants did not rate some experiences which were reported in their files (e.g., contact with YAT). This may be because they did not remember this experience or it was not significant to them. Also, some participants rated the item ‘experiencing other difficulties with family and friends when you were unwell’ but did not state what these experiences were. Only two participants reported communication difficulties, specifically, others not being able to communicate with him/her and him/her not being able to communicate with others because they were not listening due to “being somewhere else.” One participant gave a description of her medication side effects reporting that they were tiredness and weight gain. The same participant also described her symptoms as paranoia, thinking people can read my mind, and hearing voices when rating this item

The three items which were most frequently rated in the top three most distressing experiences were symptoms, conflict with friends and family, and being unable to do usual activities respectively. Half of the participants rated their symptoms as the most distressing experience. Participants used their most distressing experience to respond to items on the IES-R at Times 1 and 2. Table 6.10 presents group scores on the IES-R.

Table 6.10

Scores on the Impact-Events Scale Revised (IES-R)

	Time 1			Time 2			Norms	
	<i>M</i>	<i>SD</i>	Range	<i>M</i>	<i>SD</i>	Range	<i>M</i>	<i>SD</i>
Total score	.74	.62	0 - 1.68	.52	.49	0 - 1.36	2.17	1.00
Intrusions	.56	.69	0 - 2.14	.36	.46	0 - 1.43	2.17	1.09
Avoidance	.93	.75	0 - 2.25	.80	.86	0 - 2.75	1.90	1.00
Hyperarousal	.70	.67	0 - 1.43	.37	.43	0 - 1.14	2.55	1.14

Table 6.10 shows that this group were not displaying high levels of trauma symptomatology at Times 1 or 2 when normative comparisons are made with Creamer et al.'s (2003) data for the Vietnam veterans. Trauma symptomatology decreased over time, particularly hyperarousal symptoms. Avoidance symptomatology was rated highest across both time points. Group scores for PTGI are presented in Table 6.11.

Table 6.11

Scores on the Posttraumatic Growth Inventory (PTGI)

	Time 1			Time 2		
	<i>M</i>	<i>SD</i>	Range	<i>M</i>	<i>SD</i>	Range
Total score	50.00	22.94	11 - 97	48.20	22.21	16 - 93
Relating to others	16.50	10.18	2 - 35	15.20	9.03	0 - 31
New possibilities	13.10	7.74	5 - 25	11.90	7.72	4 - 25
Personal strength	9.7	5.40	1 - 19	10.20	6.23	2 - 20
Spirituality	1.90	3.41	0 - 10	2.00	3.43	0 - 10
Appreciation of life	8.80	4.21	2 - 15	8.90	4.51	2 - 15

Table 6.11 indicates that growth seemed to have decreased somewhat over time, particularly on the scales *relating to others* and *new possibilities*. In contrast, scores on the *personal strength*, *spirituality*, and *appreciation of life* scales appeared to increase slightly over time. There were too few FEP participants in this study for analysis of their quantitative results.

Table 6.12 presents group scores on the RSQ. It shows both the overall recovery styles FEP participants endorsed at Times 1 and 2.

Table 6.12

Scores on the Recovery Style Questionnaire (RSQ)

Recovery Style	Time 1	Time 2
	<i>n</i>	<i>n</i>
Sealing-over	0	0
Tending towards sealing-over	0	0
Mixed picture in which sealing-over predominates	1	1
Mixed picture in which integration predominates	3	1
Tending towards integration	4	6
Integration	2	2

As shown in Table 6.12 most people had a tending towards integration recovery style at Times 1 and 2. It also suggests that most FEP participants had a recovery style which incorporated integration. Table 6.13 shows the subscales participants sealed-over and integrated on.

As shown in Table 6.13, the *satisfaction* subscale was most likely to be sealed-over at Time 1, whereas liking was at Time 2. The *optimism* subscale was integrated at Times 1 and 2 by all participants and only one participant sealed-over on the subscale *impact* at Time 1 and on *curiosity* at both time points.

Table 6.13

Scores on the Recovery Style Questionnaire Subscales

Subscales	Sealing-over		Integration	
	Time 1 <i>n</i>	Time 2 <i>n</i>	Time 1 <i>n</i>	Time 2 <i>n</i>
Curiosity	1	1	9	9
Education	3	2	7	8
Optimism	0	0	10	10
Impact	1	0	9	10
Fear	5	4	5	6
Liking	5	8	5	2
Continuity	3	1	7	9
Ownership	3	3	7	7
Responsibility	3	5	7	5
Help Seeking	2	1	8	9
Blame	2	2	8	8
Cause	5	6	5	4
Satisfaction	7	5	3	5

Procedure

FEP participants were seen at up to 6 months after their acute episode (Time 1) and 3-4 months after the first interview (Time 2). Loved ones were also interviewed as close to the FEP second interview as possible. On average loved ones were interviewed 7 days apart from FEP participants.

Initially, FEP participants were asked to nominate a family member to participate in the study. However, one person from OYH requested that his partner be interviewed as he felt she would be more able to comment on his experiences. This person had been in a long-term relationship with his partner and they lived together. Therefore, given that the purpose of these interviews was to speak with someone who knew the FEP participants well, it was decided that offering to interview a family member or loved one was appropriate as long as

the loved one had known the FEP participant prior to them becoming unwell and could comment on any changes observed. It can be argued that the participants in this study were at an age where they were individuating from their family and establishing other significant relationships.

Eight family members and loved ones participated in this research. Four FEP participants requested that their mothers be interviewed for the study. Two long-term girlfriends were also involved, as well as a father and an ex-boyfriend who had been with his partner on a long-term basis. Two people from OYH did not have a family member or loved one who could be interviewed. One family member was non-English speaking and the second individual declined to participate due to working full-time. However, the two FEP clients were retained in the study due to difficulty recruiting from this client population.

The researcher also interviewed clinicians about their clients at this time. A table representing the timeline of interviews is shown in Table 6.14.

Table 6.14

Timeline of interviews

FEP participant	Time 1	Time 2	Loved one	Clinician
Jack	6/12/06	1/3/07	8/3/07	7/3/07
David	5/12/06	7/3/07	8/3/07	7/3/07
Simone	11/12/07	10/3/08	4/3/08	3/3/08
Andrew	4/12/07	26/2/08	11/3/08	11/3/08
Alana	27/11/07	11/3/08	28/2/08	4/3/08
Scott	10/10/07	5/2/08	5/2/08	4/3/08
Chris	23/10/07 & 29/10/07	24/1/08	21/1/08	29/1/08
Daniel	15/6/07	30/10/07	15/11/07	3/12/07
Paul	7/9/07	8/1/08	—	10/1/08
Tessa	3/10/07	29/1/08	—	12/2/08

Note. Dashes indicate that two FEP participants did not have loved ones to interview.

Interviews with loved ones and clinicians were intended to occur within one to two weeks of seeing FEP participants for the final time where possible. However, two clinicians' interviews were delayed by 4-5 weeks due to their work commitments. There were also some difficulties seeing FEP participants at 3 months follow-up. Two participants had been hospitalised prior to follow-up and the researcher was required to wait until they were discharged and deemed by their clinicians stable enough to be interviewed. A third participant and his loved one were difficult to follow-up due to the holiday period, difficulties in contacting them, appointment cancellations, and participants being too busy. This FEP participant also relied on his loved one to transport him to the appointment. One participant could only be seen out of hours and therefore at least one clinician was required to be in the vicinity if needed. Given this, the time-frame to complete data collection was limited and he needed to be seen twice at Time 1. Only the PANSS was done during the second appointment. All other data were collected in the first session.

Data collection with FEP participants and family members or loved ones ranged from under an hour to three hours. The two FEP participants from Alfred Psychiatric services and their loved ones were seen at their primary clinical support service. Data collection with five of the FEP participants from OYH took place at the outpatient clinic. One of these participants was seen for follow-up at OYH's acute services site because he needed to be seen out of hours. Two FEP participants from OYH were seen in their homes and one was seen at the outpatient clinic at Time 1 and at home at Time 2. The loved ones of three FEP participants from OYH were seen at the outpatient clinic, while one was seen at their acute services site, one was interviewed at home, and one was seen at her workplace because it was more convenient for them. Prior to seeing participants in the community, risk issues were ruled out with clinicians. Also, a researcher from another study attended data collection with the two FEP participants who were seen at home at Time 1.

Each participant had read the information and consent form and had provided informed consent prior to data collection. Demographics and detailed information about participants' mental health issues were collected from files and/or treating clinicians and FEP participants at Times 1 and 2.

At Time 1, FEP participants were asked to partake in a PANSS assessment and one semi-structured interview and complete four self-report measures. At Time 2 the M.I.N.I and list of experiences were not re-administered. In order not to bias the interview process and to allow participants to first be able to provide a detailed account of their experiences in their own words, the PTGI, RSQ, and IES-R were administered after the interview took place. Given that the concepts of posttraumatic growth and sealing-over and integration recovery styles appear to parallel one another, the order of administering the PTGI and RSQ was alternated across participants. To control for order effects the IES-R was always administered first in order to prime participants to think about their most distressing experience before considering potential benefits of their episode. This format also paralleled the sequence of questions asked in the semi-structured interviews. Given the importance of establishing rapport in order to facilitate participants engagement in the semi-structured interview, the PANSS and M.I.N.I and were not administered until the end of data collection due to their clinical nature. Inter-rater reliability was obtained for 50% of the M.I.N.I and PANSS interviews. Interview protocols can be seen in Appendix E.

Analysing the Interview Data

Data analysis in the main study generally followed the same procedure as the pilot research. However, fewer steps were taken to analyse the data as the development of themes was informed by preliminary themes from the pilot study. Modification to *Phases 1, 2, 3, 4* and *7* are described.

Phases 1, 2, 3, and 4 were done simultaneously. Each FEP participants' interview was read a number of times in order to get a sense of the experience of FEP impacted on them as a whole. Key words and sentences were identified from each individual transcript and coded under existing preliminary themes from the pilot study. The researcher continuously ensured that the coding of key words and sentences made sense in relation to the transcripts they originated from. When key words or sentences did not fit under an established theme a new thematic unit was established and given a title which captured what was represented by the quotes. The researcher looked at which thematic units were both common and individual to the participants in order to cluster them as new themes and

identify anomalies.

Themes across the pilot and main studies shared similarities, yet they had been expanded and refined in the main research. New themes also emerged and a broader range of clusters were used to group themes. Themes were clustered according to FEP participants' explanatory model of the illness, awareness of the impact of the illness, managing the illness, restorative outcomes, and constructive changes. Themes clustered according to constructive changes were allocated to one of three sub-clusters: improved relationships and view of others, enhanced life view, and developed sense of self. Key words and statements about individuals' perceptions of the nature of FEP, whether the illness was unhelpful or helpful, and the future were also clustered but themes were not identified. Instead information was presented descriptively to account for the various responses. Comments about spirituality and religion were also presented descriptively because they were both variable and uncommon.

Phase 5 was replicated from the pilot study to define FEP participants' interview themes. In addition, the researcher drew on the definitions of themes from the pilot study to develop the main study's themes. *Phase 6* was also repeated. After thematic analysis was completed with the group data, case study analysis was done with four FEP participants. Individuals' scores on the measures were compared to normative scores at Time 1 and 2. This data was then used to augment and enrich thematic analysis to form a comprehensive case study analysis of participants' experiences. Information from their medical records was also used to supplement data derived from the interviews.

Phase 7 from the pilot study was repeated to analyse loved ones' interviews in the main study. However, given there was a larger number of loved ones in the main study data was clustered according to the illness experience, treatment experiences, management of the illness, and restorative and constructive aspects of recovery.

Validating the Interview Data

Validating the data also followed a similar procedure to the pilot study, however additional steps were implemented to analyse FEP participants' data. Agreement was sought between the investigator and *two* research supervisors, instead of one, in order to

strengthen the reliability of the data. The second supervisor provided a 50% agreement rate on coding. Any disagreements were resolved through discussion and clarification of themes. In addition, a letter of attestation can be found in Appendix G in relation to an independent audit completed to review and establish accuracy of the research findings for the main study.

CHAPTER 7: MAIN STUDY RESULTS GROUP DATA

Themes are presented in a temporal format to provide a detailed chronological account of the experience of FEP and adaptation and recovery processes. First reported are themes relevant to participants' understanding of the development of their FEP and the experience of the acute episode and treatment. Following this, themes describing the different elements of the recovery process are discussed. This includes the awareness of the impact of the psychotic episode as well as psychosocial consequences, negative and positive aspects of managing the impact of the illness, restorative outcomes, and constructive changes. An account of whether FEP participants viewed the illness as unhelpful or helpful is then reported along with their perceptions of the future. The manner of presentation of quotes was detailed on page 93. Further examples of all themes can be found in Appendix H. Next, triangulation of participants' data is presented via an analysis of interviews with loved ones and clinicians.

Since the themes identified are overlapping rather than mutually exclusive examples of quotes in which overlap is present are given in Appendix H. Some overlap is to be expected due to the complexity of participants' experiences and the issues discussed. Most of the overlap occurred in the reporting of constructive changes. However, the majority of quotes could be delineated as specific themes differentiated by a dissimilar tone or description of the experience. This sometimes led to quotes being split when two distinct themes were being discussed. Quotes were considered to overlap when individuals' statements referred to more than two or more themes.

The Explanatory Model of the Illness

This section describes how participants viewed the onset of the illness and experienced their acute episode and treatment experience. The accounts are descriptive and give context to the participants' experiences. Themes presented in this section are listed in Table 7.1.

Table 7.1

Themes Relating to the Explanatory Model of the Illness

Main Themes	Sub-themes
Development of the illness	
The psychotic experience	(a) Disintegration
The experience of acute treatment	(a) Perceived enforced treatment

Development of the Illness

Development of the illness provides explanations of how the illness came about from the participants' perspective and describes any stressful experiences encountered before the illness. Participants discussed concerns just prior to the development of the psychotic episode or reflected on long-term issues. Predominately, individuals identified a build up stressors in the context of financial difficulties, work and study, and difficulties with social relationships. "**Work was getting really stressful....Key performance indicator and it was just being monitored all the time by (workplace). That really affected me because I was scared about keeping my job....I wasn't coping. That was the problem**" (Scott) 17.

I was stressed out like financially cause I was working and studying and renting with my boyfriend so that was hard and just the workload was hard and I was doing an arts degree as well and so I felt that was very isolating cause you never saw people twice so I didn't make, really make many friends there (Alana) 17

Yeah it was, it was, soon as I just broke up with my girlfriend things just totally changed....And just finished my job as well so with all the fines and bills and everything on top it makes it really hard (Paul) 2

Leading up to becoming unwell I sort of uni, started doing hospitality full-time sort of thing. I don't know, I think that probably had a major impact on me as well just feeling like I'd wasted all that time and sort of blaming my parents cause of that like and for not encouraging me to do what I wanted to do. Not my hospitality, just in general (David) 23

Experiencing depression prior to the onset of the psychotic episode was also discussed by a number of people.

Before then I was very depressed and I'd say that after, after I went on the medication and Zoloft...before I was on Zoloft I was very tired and I just want to crawl up into bed and go to sleep. I had that sort of depression just didn't want to face anything and I was always in a bad, I've always been in a bad mood with my mum especially (Simone) 17

*I think the whole has been just really distressing and really hard **the whole way through and there was a long lead up to becoming unwell** as well. Well like I think **the depression was my second episode of depression** cause I'd gone to see a GP when I was in Year 11 in 2001 and he was very dismissive and my mum was there with me and she was crying and I dropped out of school and so I had similar things happen then but then it got better. And then **I was up and down a bit in the year that I became unwell** as well (Alana) 4*

Two participants identified substance misuse as a possible trigger for the onset of their psychotic episodes. One of these participants identified past traumas and feeling insecure.

*I thought I got raped....I abused drugs to the point where I'd spend everyday on drugs and didn't really live in this world....I had a panic attack once when I had a fight with my sister she ripped hair out of my head....then there's **general insecurities** on top of all that (Andrew) 17*

It's been a....Broke up with my girlfriend about 2 years ago, and I'm not working, had a drug problem, it was a pretty crappy way of living your life I guess (laugh)...Yeah at times but I kind of self-medicated with alcohol and drugs (Jack)

17

Two participants reported that the development of their illness served a constructive purpose. Daniel discussed initiating his psychotic episode in the context of escaping society's norms and his life situation. Similarly, Chris said the illness developed in the context of trying to fix his life situation, specifically his difficulties navigating interpersonal relationships and managing his father having schizophrenia.

Society was fake. Everybody's chasing materialistic gain you know people measure their happiness by their wealth...And it's all too hollow for me and I've felt it all my life...just before I went and decided to attempt this stuff I was just starting to give up on drugs. I was just starting ditching a lot of friends. I was starting to become a real loner. I was starting to become a real hermit. And I was just sitting there and I was just thinking you know it's now or never. I want to try this. I want to really see if there is more to the world that you can, what five senses can tell you....In this life everybody's got this impression that you've got to have money and you've got it to be happy you know or you've got to go out and you've got to have a family. And you've got to do all this normal run of the mill shit. And I don't want to do it man....I don't think I could handle having a family you know. I don't want a job. I'd be happy if I was poor if I was happy spiritually (Daniel) 18

The unwellness was caused by a situation where I saw no future for myself if I didn't fix these things and that's what I was trying to do. I was thinking, like I figured I had a time limit and I wanted to fix these things about myself as soon as possible and so that's why my thoughts became impulsive... like I noticed that and I noticed a way that I could stop it, I can't really define it, stop it from happening to me so I became really, impulsive and hyper alert...and find out how what I was doing wrong and strategies in making things better for myself (Chris) 3

One participant, Tessa, was unable to identify why she became unwell, which was perhaps due to the sudden onset of her episode. Moreover, she reported nil stressful concerns prior to the onset of her illness or a decline in functioning.

Participants were asked whether or not they thought their experiences were due to a mental health issue. Most viewed their episode as a psychiatric concern but may not have framed it as psychosis. Some participants were unsure if they had experienced a mental illness and other explanations were provided which were not identified as mental health related. Further, some participants did not believe their psychotic episode was a mental health issue. Examples are listed below, including an example of how a participant's (Simone) view changed over time.

Definitely mental health issue....In hindsight now paranoia still comes at times but it's not evident. I don't think about things. I'm not constantly losing focus on people. I don't look for this imaginary ring. My thoughts don't really conjure, I don't think terrible things. I don't over think. I don't over-analyse. I just like to keep things simple now (Andrew, 2nd) 3

I think it's due to my anxiety, stress, and the depression and just feeling a bit isolated during that time. I think yeah it's a mixture of reasons. Well I wasn't at uni during that time I think I was on holidays so it wasn't a stress like that I just think I was a bit, I was unhappy at the time and I wasn't doing much during that time either so that could of sort of come from the depression and wanting someone to communicate to I've just gone to the neighbours sort of thing and it's just sort of grew from there (Simone, 1st) 3

I don't know like I have no idea...Well I still feel pretty sane so I guess I don't feel like it could be a mental health issue...Well I feel like I'm still grounded like I'm still, I'm aware that it's not really true sort of thing but it sort of swept me away when I was in the moment and it sort of seemed so real and freaked me out a lot....May be. It made me feel ill like when I was in the moment. It really stressed me out but I, I, no I couldn't tell if it would be a mental health issue or not (Simone, 2nd) 3

No, course not...It's all structured. It's not something I've made up. It's something very old. It's something a lot of people have gone through themselves and the thing is I was sane and talking coherently before I left and I'm sane and talking coherently now when I'm back. I know, I know it's a mental health, I don't feel sick or...No because the thing is the meds haven't changed me.....I mean the medication probably can't do anything to you if you don't have psychosis in the first place, they're not doing anything to me so that in itself is an indicator that there must be nothing wrong with me in the first place you know (Daniel, 2nd) 3

The Psychotic Experience

The theme *the psychotic experience* provides a descriptive account of the subjective experience of psychotic symptoms and impact of the illness. The experience of psychotic symptoms ranged from being highly distressing to merely an annoyance. Some participants discussed difficulty managing their symptoms and the impact the illness had on their wellbeing and life in general when they were acutely unwell. A sense of disbelief that one had become unwell can also be present. “*It's just like a, a dreadful memory. I sort of like, it makes me question what was, what went on like how could this happen sort of thing as well. Like it seems so unreal*” (Simone, 2nd).

*Best description would have to be that it was the **hardest thing that I've even been through** like having to hear voices cause I didn't know what they were and when they were at their worst I seriously thought that I was just hearing....like a spirits voice. I was really scared and it was really scary cause I didn't know what it was and I didn't know that people could suffer from that sort of thing so it was really scary (Scott, 2nd) 2*

*Well I kind of feel that it **destroyed my life for a period of time**....I'd stopped leaving the house completely and then I stopped leaving my bedroom and the lounge room and I would starve myself during the day because I didn't want to leave the lounge room and, and then when someone went away and they came I was all like skinny. **The medication's made me gain weight** but, and it was obvious that*

I was really sick. Yeah I'd stopped going to uni obviously if I wasn't leaving the house (Alana, 1st) 4

Yet, two participants found their illness experience was both a source of distress and comfort, reassurance, and improvement.

Then I just kept listening out for the noises cause they were sort of comforting and I wanted to hear their advice and see what they had to say and that's how it began and it just grew from there....Or they were commenting on me (Simone, 2nd) 2

I actually felt a lot better...Well I was feeling distressed and stressed but, see I get a pain in my back because of stress and that completely went away and I must of felt so much better in that state because I was believing things that made me feel better. I was achieving something. I was curing schizophrenia. I was, I wasn't that criticism that girl had, put on me, I wasn't that I was actually a hero in a way (Chris, 1st) 4

Daniel was the only participant who did not perceive his psychotic experience to be distressing. Rather, his psychotic episode was considered an entirely positive experience. “*Yeah the whole experience man. All of it, all of it was significant and changed and fucking was amazing and curious and it was all illusions created by myself but it was all insane. It was all fantastic man*” (Daniel, 1st) 47.

For David, the impact of attempting suicide and symptoms of anxiety were more distressing than his psychotic episode.

Especially when I came out of hospital. Sort of felt like my body sort of would never get better. Yeah I don't know coming out of hospital, I don't know, it took a while to get better. I still get anxious a lot but I don't know, I don't know it's not as bad...No I sort of felt powerless to stop feeling anxious and I don't know (inaudible) it was a big impact on my life (David, 1st) 30

Disintegration

A sub-theme of *disintegration* is identified in relation the experience of psychotic symptoms. It is a sense of feeling disconnected from the outside world, everyday life, others, and one's identity, personal experiences, and actions. One's sense of self and identity can appear fragmented and a lack of control over oneself is present.

For example, Andrew discussed an inability to control his situation. *“Because I was doing things that I couldn’t control....when you’re aware of something you’re doing but you can’t stop it, it burns you”* (Andrew, 1st) 15.

Used to be a great story teller when crazy I had nothing to say to anyone. It felt like I was, this is a metaphor, like I was driving myself and then became a passenger and would just sit and watch the world go by but do nothing (Andrew, 1st) 36

David’s quote represents *disintegration* because he described a sense of being disconnected from his environment, which appeared almost surreal.

I don’t know it was probably like I was misinterpreting stuff and sort of everything looked different as well. Like people looked different. And I guess I was, like things sounded different as well. Like, like I remember I think it was the night before or something I could hear a police siren and it just sounded, not a police siren an ambulance and it just sounded I don’t know like not real, I don’t know like imagine you were in a cartoon or something and I don’t know it just sounded weird (David, 1st) 4

The Experience of Acute Treatment

The experience of acute treatment is a descriptive theme outlining how treatment came about for participants and their treatment experiences when they were acutely unwell.

In relation to being hospitalised, participants discussed a range of distressing experiences which related to co-patients, staff, and medication. For some individuals the distress associated with their treatment was related to their symptoms. *“Shithouse man cause the thing is as I said I’m not crazy. I never was. I’m eccentric. And I had to deal with people screaming in the night yelling weird shit....Oh it was bad”* (Daniel, 1st) 9.

The first few days because I was scared of everyone around me, even scared the nurses, because I all thought they were out to get, like drug me and things like that. I was scared of eating because everybody else was sort of, I was really paranoid because....the first night I didn’t have my own food tray thing.....so I was really scared that I was going to get somebody else’s food.....Somebody would go psycho at me. Cause there was a really scary guy....He looked like somebody that could like physically harm me (Scott, 1st) 9

For Scott it provided a clearer understanding of one's difficulties and therefore normalised his presenting concerns. "*Just them **explaining what psychosis was and that it was a common thing**. It made a lot of sense to me. I was just like well it's not a spirit*" (Scott, 1st) 7-8.

For Chris, hospitalisation was time out from the stressors in his life and provided a safe environment.

*It was good. Like see you're in a hyper, like a really distressed state, really vigilant and really paranoid but **I let people still able to reason with me**. You see so **I was still able to see that I was safe inside hospital**. So and like the stress of all, I was removed from my home environment which was stressing me. Like work, removed from work which was also stressing me* (Chris, 1st) 9

Also, as evident in Alana's quote, voluntary admission appeared the preferred option than involuntary hospitalisation.

*I've been back into the ward since then and I had a really different experience like it was much **more positive for me and cause I was a voluntary patient that time...I just felt like it was a break like it was more of a holiday*** (Alana, 2nd) 4

For people who experienced acute outpatient care, treatment seemed less distressing but could still be highly stressful. Difficult aspects of their outpatient treatment were sometimes associated with psychotic symptoms, as well as interactions with staff and medication side-effects. Benefits of treatment were also discussed.

*At that **time I was insane and I didn't trust anyone and thought that everyone was out to get me** so it was difficult meeting ORYGEN people and then meeting...**a different person every time when you really have trust issues, you don't know what the fucks going on, you're scared*** (Andrew, 1st) 13

*I was just really crying all the way through it. **And I didn't know which parts were relevant**. It was like my whole kind of world I had to explain...It was still a good sort of **relief thing although I was distressed**, they had like a, a work experience person or something and she got really distressed. I felt really bad for her* (Alana, 1st) 10

*I never really felt distressed about it. I didn't mind the fact they were here. It kind of gave me something to do because when...you begin to change and something is wrong you notice that the people that you're close to drift away from you so **it was nice to have the company of people for a change** (Andrew, 1st) 13*

Perceived enforced treatment

A sub-theme of acute treatment is *perceived enforced treatment* defined as being subject to outside intrusive and impersonal discipline, enforced treatment and monitoring in which the person can feel they are not listened to and have no control or choice and are obliged to comply with this treatment. Hierarchy can be implied.

Daniel's quote highlights the theme *perceived enforced treatment* because he discussed staff taking away his freedom and was angered by this.

***I'm my own person. You can't do this**.....I was **angry** at the doctors for locking me up....and then they wanted to give me a stronger prescription for not being nice to them. And I'm sitting there, I'm going to them like **I'm angry because you'ves have got me locked up**. I'm not angry because I have a chemical imbalance. **I'm angry because strangers who don't know me have locked me up and taken my freedom**. And I haven't broken the law. I haven't hurt anyone. I hadn't done anything. I hadn't robbed or stolen or anything but **I'd gotten locked up and had my freedom taken away for being me** (Daniel, 1st) 9*

Alana discussed the theme *perceived enforced treatment* in the context of impersonal contact with an ambulance officer and being involuntarily admitted. Of note, family were also involved in her experience of this theme.

***My mother wanted me to stay, stay there longer when they were releasing me and I wanted to go and so we got into a big fight** and she didn't speak to me for days. And the admitting, being admitted into hospital. I went from ambulance to the ORYGEN hospital and the **ambulance guy was saying you're a silly girl, you're so silly, you're very stupid aren't you** and I was trying to sleep and they said that **if I didn't voluntary admit myself they would involuntarily admit me**. No I agreed because my mum told me to in stern words and my partner too (Alana, 1st) 9*

Scott's quote represents the theme perceived enforced treatment because he viewed the seclusion room as a form punishment and adjusted his behaviour accordingly. His quote implies a sense of authority. "*Pretty scary I didn't want to get into trouble like I didn't want to do anything wrong to end up in that room....they made it seem like a punishment for doing something wrong*" (Scott, 1st) 9.

Awareness of the Ongoing Impact of FEP

This section describes how participants experienced the ongoing impact of FEP and their awareness of these issues. Themes presented in this section are listed in Table 7.2.

Table 7.2

Themes Relating to Participants' Awareness of the Ongoing Impact of FEP

Main Themes	Sub-themes
Recognising the illness as an ongoing problem	
Disintegration	
Sense of loss and deficit	
Estrangement	
Stigma	(a) Self-stigma (b) Stigma from others

Recognising the Illness as an Ongoing Problem

Recognising the illness as an ongoing problem involves recognising one's mental health issues and/or its secondary consequences as an ongoing difficulty. One can be aware that the illness is a struggle and requires ongoing management and progress is slow which can produce a sense of disempowerment. This can be explicitly or implicitly expressed.

This theme is distinguished from the theme *sense of loss and deficit* as this is attributed to discrete changes and losses rather than the enduring nature of one's difficulties and how they are progressing. If powerlessness is discussed it is distinguished from *disintegration* because residual symptoms are preventing one from recovering rather than a

lack of control over oneself.

Scott's quote highlights the theme *recognising the illness as an ongoing problem* as he discussed a sense of disempowerment associated with ongoing residual symptoms and reduced capacity to change his situation. He also discussed his slow progress.

*Just in the way that **at the moment I have no control over anything. The voices have affected me so much. The depressions affected me so much and I just feel so powerless to change it. Cause everything's happening so slowly like being treated and things like that. It's happening so slowly. I feel so powerless like I wish I could change it all in an instant*** (Scott, 1st) 30

Simone also discussed this theme in relation to her ongoing residual symptoms and how they impacted on her interactions with others.

My anxiety gets in the way a lot and it makes me think things that don't mean anything. I don't know it's just annoying.....It's like I get worked up about the idea that people can read what I'm thinking and just sometimes it gets a bit overwhelming when I'm stressed out or in social situations (Simone, 1st) 20

Disintegration

For a small number of people, the experience of *disintegration* continued to be experienced. *Disintegration* is distinguished from other themes such as *estrangement* and *sense of loss and deficit* because of a sense of detachment, ambiguity, fragmentation, and uncontrollability of one's experiences.

Paul discussed a sense of disconnection from himself and inability to control his experiences, which included his thoughts and interactions with others. This was related to his residual symptoms

*I'm just at a stage I'm feeling totally different like I'm not myself and that freaks me out...Like the thoughts that I'm thinking and the way that I talk to other people like sometimes it surprise me like I'm talking to someone and yeah they give me the looks and I'm like what did I say, what was my face expression like? **I have no idea what I just said and what was you know my face expression. Was it mad or was it angry or funny I don't know but really inside I'm like yeah I'm just normal and yeah but they just give me the look out of nowhere, **freak me out and my thoughts start going why you know why, why is that and then yeah***** (Paul, 2nd) 31

Andrew's reflection on his illness experience led to feelings of uncertainty and disbelief, as well as a sense fragmentation of the self and disconnection from time.

While I was unwell since when we last saw each other like I considered myself to be of, like I had no worth, no purpose, no being, what the fuck am I doing here, what am I doing with my life, how is (girlfriend) with me, how can I do what I do, why are people talking about me, what the fuck is going on and it slowly just faded away. You know one minute you're not linking about what people are thinking about you and then the next minute you're like how can I let myself go. How can I let myself be like this and you kind of wake up to yourself and go, you wake up and you say to yourself what the fuck am I doing with my life, what the fuck am I doing right now, what have done with the last year? I don't know what the fuck I've done with the last year the last year for me doesn't even exist like I wouldn't even put it on paper (Andrew, 2nd) 17

Sense of Loss and Deficit

Sense of loss and deficit as a result of psychosis or treatment is discussed across a wide range of areas associated with different aspects of one's life. Losses and deficits are either identified specifically or discussed in general. A sense of loss and deficit is present during the acute episode or in the recovery phase; however it is predominately seen in the latter. With respect to loss of relationships, this is distinguished from *estrangement* because it is not framed in the context of a lack of understanding or support from others.

Scott discussed loss and deficit in relation to aspects of his character, such as his a lack of confidence.

It's changed me heaps cause now I'm a lot more timid. Not very outgoing. Very shy sort of person. Lost a lot of confidence. A lot of people have said I've changed physically as well because I've put on a lot of weight from the treatment and things like that so it's changed heaps (Scott, 1st) 22

Alana's quote reflects this theme because she talked about losses and deficits associated with her ability to function, relationships, the life she had before she became unwell.

Well it impacted on my study and my work and my social life. Yeah mainly those things...Like a lot of my friendships fell away and I've just been left with a really good group of kind of core friends rather than the wider you know acquaintances and friends that I used to have and some friends just dropped off completely (Alana, 1st, L) 22

Estrangement

The theme *estrangement* is associated with feeling as though people will not understand or relate to the illness experience and are unable to provide support. This can be the perception of FEP participants or indicative of the behaviour of others and it can manifest in a number of ways. *Estrangement* is distinguished from *stigma from others* and *self-stigma* as it is not associated with being discredited by others or negative self-labelling due to the illness.

Andrew's quote demonstrates *estrangement* as he discussed relationships which ended in the context of difficulty communicating about the illness and others lack of understanding and ability to cope with it.

Before I was unwell I needed 20 hands to count all my friends. After being unwell I can use 2, like people fade away, people drift away, they can't, they don't either want to deal with it or they don't understand or when you try to talk to them they don't listen (Andrew, 2nd) 12

For Scott, a sense of *estrangement* or feeling different was also present through comparative suffering.

Yeah it has I feel different. I don't feel normal when I'm around other people. It's hard to explain like it's hard to talk to people and think that you know they have problems like when they, when they say they are, when they say they are upset and things like that it's hard for me to go oh ok well you must be really upset but I think of it in a way that you know I've been through worse. I feel different (Scott, 2nd)

Estrangement can also present during the acute episode. As shown in Alana's quote, the experience of hospitalisation and one's symptoms can create a sense of estrangement due to the isolation as a consequence of these experiences.

Well cause I was in the hospital for so many days I was just on my own and I didn't have anyone to talk to and people would come visit me a bit but like I was, like there was a party and I missed out on going to that and I really wanted to go.....I think it was just the isolation continuing. Like it was kind of reminiscent of how it was before (at home) (Alana, 1st) 15 & experience list

While the themes *disintegration* and *estrangement* are distinguished from one another, for Andrew the experience of *disintegration*, or disconnection from others due to his symptoms, precipitated a sense of *estrangement*.

You can't reach out to people. You can't talk to people because you're that absorbed in what's going on that you forget to look at a person for who they are and like you think there are just underlying factors behind everything. Spending your days constantly paranoid is hell. Waking up in the morning and like, waking up alone and then thinking may be this is what's happening I'm going to be alone for the rest of my life. Not having anyone who understood me. Thinking I was the only person like me like I'd never met anyone like me before (Andrew, 1st). 19

For Daniel the psychotic episode produced a sense of estrangement from others or society in general due to being different from the norm.

It's just, it's hard trying to fit in around other people. That's the hardest part. But the thing is I don't want to go at fit in with other people....You know you've got to hide it man you know. If I tried showing my mum that she wouldn't understand. She'd think it was a load of garbage (Daniel, 1st) 20

Stigma

Two subtypes of the theme *stigma* were identified: *self-stigma* and *stigma from others*.

Self-stigma

Self-stigma is internally focused and involves negative self-labelling, having a destructive attitude towards mental illness and its treatment, and believing one is unappealing to others because of one's mental illness. *Self-stigma* can be felt both during

the acute phase of the illness and afterwards.

Both Jack's and Paul's quotes reflect the theme *self-stigma* because they labelled themselves with negative terms such as "crazy" and "psycho." Both also had a critical view of what mental illness represented and Paul discussed the belief that others would view him in a negative light because he was receiving treatment at a mental health service.

*I'm still pessimistic...I don't do a lot of things cause I usually think it'll end up bad (laugh) or turn out wrong. I don't go for jobs. I don't look for work....No, since the CAT team coming out...I don't know. **I never used to think that I was crazy (laugh) until I actually had people coming around to the house everyday to make sure I wasn't dead (laugh) ...Frightening to be honest, it's not fun. I hate to think that I'll end one day up in a padded cell with a straight jacket on not knowing my name, that's a bit scary** (Jack, 2nd) 16*

*Just the fact that I'm you know I'm visiting a, what's this place called....A psychotherapy or something yeah....**probably scares other people yeah don't you think I'm a psycho?...but other people when you think about it go what this guys a psycho man you know, I freak them out....Yeah but you can't blame them though. They're probably thinking what have you done to get in here** (Paul, 2nd) 33*

For Andrew *self-stigma* came about due to experiencing *disintegration*. Andrew discussed how an inability to control himself and his interactions with others due to his symptoms led to feeling embarrassed and degraded. "*Like it got pretty **embarrassing** cause imagine speaking to your best mate and you look down and you go oh looking at his hands you know it's, it was **degrading**.*" (Andrew, 1st) 2

Stigma from others

Stigma from others is externally focused and associated with being discredited by people and society in general because of one's mental illness.

Alana identified *stigma from others* specifically in relation to psychosis drawing on the media's negative portrayal of this illness. Subsequently, she identified her problems as depression to others which she viewed as more understandable and acceptable.

*Like people just don't understand at all and so, and people make judgements on your decisions as well like about the medications and so I just don't discuss it with people like if anything I'll say it's depression or...you know I need to take the medication for depression so I don't have a relapse like it's a mood disorder or something. I don't go any deeper into it like, like on **Law and Order the other day they said, someone said oh this person has psychosis and then the woman to me that means murder!**....And there's even this club that we were going to and it's called psychosis...like it was like this cool thing to have or something and I don't want to get into that. I did get into it cause I was a little bit drunk and a little bit cross (Alana, 1st) 39*

Daniel's quote reflects *stigma from others* because he believed his mother reacted to him negatively because of his behaviour and used derogatory terms such as “weird.”

The second I get this job I'm moving out of home, it's time for me to leave home. My mum's starting to see this and she's staring to think well you're using a spell craft and I don't believe in spell craft you're being strange, you're being weird, she starting to watch me harder, she's starting to think things are going wrong (Daniel, 2nd) 37-38

Management of the Experience of FEP

This section describes how participants engaged in managing their experience of FEP. Participants framed recovery as a process which they actively engaged in, which could be both maladaptive and adaptive. Themes presented in this section are listed in Table 7.3.

Table 7.3

Themes Relating to Participants' Awareness of the Ongoing Impact of FEP

Main Themes	Sub-themes
Outpatient treatment	(a) Perception of treatment as restricting
Estrangement	
Conscious avoidance	
Awareness of one's vulnerability	
Viewing recovery as a journey	
Self-direction in recovery	
Interpersonal environment facilitates recovery	
Developing acceptance and moving forward	

Outpatient Treatment

Outpatient treatment is a descriptive theme outlining how one experienced their outpatient treatment. It does not include how an individual used his/her treatment as this is subsumed under the theme *self-directed recovery*. It also does not incorporate how support from clinicians facilitated one's recovery as this is discussed under the theme the *interpersonal environment facilitates recovery*.

Most participants found aspects of their treatment helpful, identifying medication and practical support from their clinicians as facilitating their recovery process. Scott discussed the help he received from his case manager. "***Having a case manager's helped with all of my financial problems. I ended up on sick allowance so I've been getting some money***" (Scott, 1st) 20. Paul reported that medication had been beneficial in his recovery. "***The treatment's going alright. The medication took some effect...it just relax your mind kind of and I guess when you think about it the medicine's there to help you out so just kind of relax a bit***" (Paul, 1st) 21.

Unhelpful aspects of Alana's treatment related to inconsistent clinical support, a delay in receiving these services, and external time constraints.

I didn't get to see the psychologist until really late and so I really think that if I had seen the psychologist earlier it would have helped more. I didn't get a case

worker, (case manager), until, for like a really long time cause it, I don't know why but there was some delay. And obviously the psychiatrist didn't help and my GP didn't really help very much. I saw a different psychologist before that and he didn't really help that much like I think he was a good psychologist but I wasn't ready like it was too advanced (Alana, 1st) 20

Sometimes I feel like I'm on a timer to get better. Like with, cause I'm on a Centrelink benefit you have to hand in medical certificates all the time and I feel like when it comes close to running out like I'm supposed to have gotten well by then and same with at ORYGEN, I know they have the 18 months for good a reason and everything but I do feel like it's, you are, are on a bit of a timer to get better (Alana, 1st) 49

I've had bit of rough patches because my doctor comes and goes a bit. Now she's leaving again so if I could have had one doctor the whole way through I think that would have been good....and so I've seen like six doctors and they're all nice but it would just be nice to have (Alana, 1st) 21

For Simone the only difficult aspect of outpatient treatment was being interviewed by two clinicians, which she found tiring.

If anything when there's two people, when I've got the doctor and (case manager) in together and they're both asking questions it can get a bit tiring but that's about it. And like some of the questions I find difficult to answer and I'll want to answer them but I just find it just, yeah and that will drain me as well just having to repeat stuff (Simone, 1st) 21

At Time 2 David seemed ambivalent about his treatment because of his slow progress. “*I don't know I still sort of sometimes I don't know don't see the point....I don't just cause I don't know I know it's not going to be a quick fix. Things move slowly*” (David, 2nd) 9

Perception of treatment as restricting

Most FEP participants' negative treatment experiences were related to the sub-theme *perception of treatment as restricting*. This theme relates to the experience of treatment as disempowering, burdening, and/or an inconvenience, which can result in disengagement. This can be associated with medication and its side-effects or the implementation of treatment.

Inconvenience at the same time because you have time off you have to go to ORYGEN when you could be doing something with your life...I don't like hospitals, I don't like doctors, I don't like white walls so to me it's like another white wall that I have to go to (Andrew, 1st) 21

Well I know that if on days that I sometimes forget to take my medication that I feel a lot worse and so it's like, it's quick slide down to where I was. So I do feel that I'm a bit controlled by the medication and you know I know that I'll probably always have to go see a psychiatrist and get scripts filled and take my pills and everything like that (Alana, 2nd) 53

It's just shit. Just to see doctors and medication. I don't need the medication. I want to join the army. I can't join the army until I get off their medication but they don't want to let me off the medication because they think it's helping me but I keep telling them that it's not doing anything to me....They're not listening (Daniel, 1st) experience list

Estrangement

The theme *estrangement* is also associated with how a few participants managed the impact of their illness. It is experienced when the FEP participants chose to disengage from relationships or interactions with others. ***"I don't talk about it yeah so...I guess no one will understand and I, who would want to listen to, even if they ask I just ignore it, it's just, it's private, confidential stuff"*** (Paul, 1st) 41.

Because I drifted away from them while I was crazy yeah because you drift away so you don't hurt yourself or you don't hurt them....like the hardest thing now is just picking up the pieces again like I can say there was a year that I here but I wasn't here at all (Andrew, 1st) 38

Conscious Avoidance

Conscious avoidance is the desire to block out the illness experience and not acknowledge it. For instance, not wanting to talk or think about the psychotic episode, using substances to deal with symptoms or block out the experience, placing the illness experience in the past, and avoiding treatment. This theme was not raised often yet striking in interviews when discussed, particularly for Andrew. He discussed the theme in relation to the acute and recovery phase.

I don't want to think about it, I don't want to think about it at all, like I think when I start to think about it I say fuck it I don't need to think about it anymore put it behind you (Andrew, 2nd) IES-R

Awareness of One's Vulnerability

The theme *awareness of one's vulnerability* highlights participants' worries, fears, and concerns about becoming unwell again and they can engage in active attempts to avoid relapse. This can result in withdrawal from past activities and taking things slowly in an attempt to avoid relapsing. Although the latter can be adaptive it is distinct from engagement in a recovery process as it is driven by a sense of cautiousness.

Alana's quote illustrates an attempt to take things slowly and reduce one's commitments in order not to become unwell again, which is phrased as a sacrifice for her health. She is aware of her underlying fragility and uses terms such as "careful" and "overwhelming."

- *Well before I wanted to, to either finish my arts degree and do honours or....may be work in horticultural therapy and then I wanted to be a social worker and now I wonder like it's going to take me a long time to finish my course if I'm doing it part-time and I wonder will I ever be able to work full-time or and, **I'm always going to have to be really careful about overwhelming myself** and so it just puts things like on a timeline that makes it more unattainable....Like ideally I would like, I would have the same dreams I guess but I just don't think it's going to happen and I, like **I understand that that's the price I'm prepared to pay to stay well** but it's still kind of disappointing (Alana 1st) 24*

Scott's and Tessa's quotes reflect this theme through words such as "scared," "relapse," and "worried." Both quotes reflect apprehensiveness about reengaging in prior activities because they were concerned they would become unwell again.

Still very scared about going back to work because I did try to go back to work again but I had a relapse of all of my symptoms and started to get the paranoid delusions again and it was really bad so I'm still really scared about having but hopefully this time round it should be ok (Scott, 2nd) 4

In some ways before the whole travelling I wouldn't worry about but now it's like, yeah... You wouldn't, it's kind of hard when you're travelling alone, yeah, more independent before... May be I'll get sick again... I am worried that I'll get sick again, more if I'll get sick again, I don't know (Tessa, 2nd) 28

Viewing Recovery as a Journey

Recovery is viewed as a gradual and ongoing process, which can be characterised by inconsistent periods, residual symptoms, and problems related to psychosis that need to be endured. Viewing recovery as a journey can include identifying such problems and considering what recovery might be like once achieved. A number of factors are seen to influence one's recovery such as medication and stress levels. This theme differed from the themes *recognition and management of the illness as an ongoing problem* as the illness is not framed as a problem and participants are specifically discussing their progress and recovery process.

These quotes reflect the theme *viewing recovery as a journey* as participants used phrases that reflect the trajectory of their recovery such as "I'm still going through it" and "it's a bit like a rollercoaster." Simone highlighted how recovery can be inconsistent, while Scott identified issues which needed to be endured while he recovered.

Yes but I think it's a bit like a roller coaster it goes up and down. Well with the medication I'd been going really well and now that she's dropped off the medication a little bit and I'm struggling now a little bit but getting through it and it's sort of like you know some days are good some days are bad I've just got to keep on plodding along (Simone, 1st) 49

Gradually getting better....I've been able to go to the supermarket by myself. I still can't catch the train but I can still do some things that I couldn't do before I got into hospital...Just getting back in contact with a lot of friends and things like that (Scott, 1st) 19

One participant did not feel he needed to recover from anything as he identified his experience as positive. "***How can I recover from something that's been a positive affect on me? It means nothing to me***" (Daniel 2nd) 53.

Self-direction in Recovery

Self-directed recovery can be evident when one uses non-treatment related coping strategies or applied treatment strategies to manage their illness. There is a desire to actively achieve change and overcome and/or manage the impact of psychosis and its secondary consequences as demonstrated by David's quote.

I don't know it's probably stayed the same. I don't know I guess I'm not as anxious.....I don't know it might be the drugs or just guess I'm a little more determined to deal with it...Just, I guess it's being aware I don't know I guess I see it more as a fixable problem than I did before....I don't know I guess cause I've got, I don't know I've got better after having a breakdown (David, 2nd) 35

Scott's quote is an example of how one could utilise strategies developed in treatment to further one's recovery. He identified using CBT strategies to manage his auditory hallucinations.

A lot of CBT so that really helps...Well I could hear the voice and it could be really distressing but I could try to change my thought patterns about the voice. Tell myself well it is a voice I'm hearing out of my head who cares? Or it is saying harsh things about me but who cares nobody else can hear it but me. Things like that just changing my thoughts through my behaviours (Scott, 1st) 20

Self-direction can also be evident in an experience of realisation and a reflective process of examination of what went wrong as demonstrated in Chris' quote.

The medication has helped. It has settled me down and allowed me to think better but, also what's been really good is that I've been concentrating, I've been obsessed with figuring out why it happens and I've understood why it happens

and I won't let it happen again.....It's removed massive amounts of stress (Chris, 1st) 20

A desire for self-direction can also cause conflict with treatment. Andrew believed having a healthy lifestyle could help manage his condition and wished to take ownership of his recovery, which meant ceasing medication.

Well part of managing the condition is being, being healthy and if you can't be healthy then you can't be happy so, a lot of people say that you can beat psychosis by having a healthy lifestyle and I want to go off the pills so I want to start looking after myself (Andrew, 1st) 46

Interpersonal Environment Facilitates Recovery

The *interpersonal environment facilitates recovery* is a theme in which interactions with others, including clinicians, are identified as helping facilitate recovery. This can manifest in a number of ways.

For some participants improvement was facilitated by simply being in the company of others or being able to talk in general or about one's experiences. Simone described discussing her experiences as grounding her and challenging the reality of her experiences.

Just talking about what I go through sort of like talking about the nitty gritty of it, all the information and repeating it I guess but in a way every time I repeat what I've been through that tends to make me get better cause I realise that it's not true. Sort of grounds me as well in a way (Simone, 1st) 39

For others interactions with clinicians could facilitate one's recovery through the teaching of new skills. Paul's quote reflects how he used interactions with clinicians to improve his social skills

I don't know we go and discuss with my private stuff, private psychiatrist... It's ok I guess (treatment). Learning new things and experience new stuff.... Like how you interact with other people and communications with other people.... I guess there are little things does help in a way yeah just if you like it or not (Paul, 2nd) 9

The theme *interpersonal environment can facilitate recovery* can also be evident through receiving specific support from others, whether this be emotional or practical. For instance, Scott used phrases such "they've been giving me compliments" and "helped me feel better about myself."

The support from my family and girlfriend has helped me. It's helped me feel better about myself and things like that...Slowly helped me with my confidence and things like that. They've been giving me compliments when I feel so ill and things like that (Scott, 1st) 20

In contrast, Alana discussed how the interpersonal environment hindered her recovery.

I think my partner wasn't really helpful towards the end of our relationship cause he was really angry with me and he would say it's about the illness but I just felt that he was really angry with me all the time and that I was walking in egg shells and I don't think that, that helped my recovery (Alana, 2nd) 53

Developing Acceptance and Moving Forward

There is a sense of acceptance and acknowledgement of the illness and its secondary consequences, as well as a desire to move forward. One can recognise that the illness is changeable experience and part of the life course, and that it cannot be completely controlled. Words or terms in these quotes that reflect this theme include: "remembering," "look/move forward," "face it," "accept," and "not resisting." Chris' quote highlights this theme. "You know it's a real shock to my reality and it's, it's, it's, it's strange but I can only look forward. I can't look back and I'm able to look forward optimistically" (Chris, 2nd) 52.

Before I was unwell I was on a lot of drugs so it's hard to say. I was on drugs all the time because I was escaping from everything....I'd rather face it. Yeah now it's not as simple as lighting up and forgetting. Now you remember and you move forward (Andrew, 1st) 35

I guess just trying to accept the way things are and not resisting I guess... I don't know I just get on with it I guess....I don't know I just don't try and sort of I don't know change things. Sort of leaving it up to my psychiatrist I don't know like I was trying to make myself feel better all the time whereas now if I feel crap I just get through it I don't try and fight it or anything (David, 2nd) 11

Restorative Outcomes

Two restorative outcomes were identified from the interviews with FEP participants. Restorative themes were identified when participants focused on a return to prior functioning and pre-morbid state. Restorative outcomes differed from constructive changes as these themes did not discuss how an individual has transformed because of their psychotic episode.

Functional Recovery

This is a broad theme which reflects a perspective of a return to prior functioning or re-engagement in prior activities. Areas of improvement can involve: symptom resolution, increased self-worth and confidence, improved general health and wellbeing, regaining a positive outlook, and contributing to society. Treatment changing can also be viewed as a sign of recovery.

Words and phrases such as “get back to work,” “get back on track,” and “now they’re slowly coming back” are features of *functional recovery*. Paul reported this theme. “*Means, trying to be a person I am before, trying to live my life, get back on track*” (Paul, 1st) 49.

Well recovery for me would be to get back to work. To get into a very, get back into a good financial position again and that would be a nice full recovery for me. Being confident and being able to go out with all my friends again (Scott, 1st) 49
It’s actually better now. Well because there was such a long lead up to becoming unwell like a lot of things kind of slowly dropped off and now they’re slowly coming back. Living with my mum is really useful. It means there’s always people about. Getting to go back to school. I’m going travelling yeah going to Bali so there’s lots of things that are coming back. Even doing bookkeeping that’s, it means a lot to me even though it’s a simple job. I feel like a productive member of society like otherwise I would just have kind of nothing (Alana, 1st) 23

Social recovery

A sub-theme of functional recovery is *social recovery*. It is evident where the person sees renewal of relationships and re-establishment of social skills as core elements of the recovery process.

Alana's quote demonstrates *social recovery* as she discussed social re-engagement and renewed relationships. "*Like the fact that I'll be able to go back to study at all and I'm going back to work next year and I'm already doing book keeping as well....and my friendships have like been renewed*" (Alana, 1st) 19.

Andrew's quote reflects re-establishing social interactions and social skills as an indication of recovery. While he discussed being a better listener this is a restorative element because he talks about how his social interactions have recovered.

I think I'm a better listener now. I don't, when somebody talks I try to listen to them and listen to what they're saying and learn from whatever they're saying as opposed to listening to it kind of half in one ear, shrugging it off, and thinking something in my head at the same time. Yeah like when you're talking you know I'll listen to what you're saying I'm not getting all like you know she said that, what does that mean you know what I mean? Whatever you say I'm going to listen to take it in and, for one I'm not going to over-analyse it secondly I'm not going to think that what you're saying is the complete opposite of what you're saying (Andrew, 2nd) 34

Constructive Changes

A range of constructive changes were identified from the interviews with FEP participants. These themes could be categorised under three broad areas of change: *improved relationships and view of others, enhanced life view, and deepening self knowledge*. Some of the themes that emerged paralleled domains outlined by Calhoun and Tedeschi (2006) in their definition of posttraumatic growth. Thus, the names of these themes were adopted for the purposes of this thesis. Constructive changes differed from restorative elements of recovery as they discuss a sense of enhancement and transformation as a result of FEP not merely a return to prior functioning. The domains and themes associated with constructive change are presented in Table 7.4

Table 7.4
Themes Relating to Constructive Change

Domains	Themes
Improved relationships and view of others	(a) Development of deeper and closer relationships (b) Increased desire to interact with others and improve the relationship (c) Enhanced perspective taking and sense of unity (d) Confirmation of character of others and quality of relationships
Enhanced life view	(a) Greater appreciation of life (b) New possibilities and direction (c) Spirituality
Developed sense of self	(a) Deepening of self-knowledge (b) Development of a sense of mastery and personal strength

Improved Relationships and View of Others

While some of the changes discussed in the domain *improved relationships and view of others* are a form of *self-development*, they are categorised here when changes to the self are framed in the context of improved relationships with others.

Development of deeper and closer relationships

This theme highlights how participants developed closer relationships due to the psychotic episode. Strengthened and deepened relationships can be explicitly or implicitly discussed. *Development of deeper and closer relationship* is distinguished from other themes in the domain *improved relationships and view of others* when words such as “closer,” “stronger,” and “bond” are used.

The theme *development of deeper and closer relationships* manifest several ways: (a) seeking, receiving, and accepting others support during the illness experience and/or an increase in spending time with others in general since the illness can produce closer relationships; (b) one can recognise the difficulties the relationship has endured because of the experience of psychosis and considers it deepened as a result; (c) more open and intimate communication with others can be present in general or in relation to the illness and associated difficulties; and (d) sharing similar problems to loved ones can produce a closer relationship. These quotes demonstrate each variant of the *development of deeper and closer relationships* theme and are presented in the order described above. ***Closer to my friends...Just see them a lot more and keep in touch with my friends a lot more than I used to*** (David, 1st) **22**

The sheer fact that throughout all the good and the bad that (girlfriend) stuck by me gave me a real appreciation that to possibly you know the meaning of life and what love and you know life together long living would be like (Andrew, 2nd) **19**

It's brought us a lot closer...I wasn't really close with my parents. That's why I ended up moving out of home.....since I've been unwell it's brought me and my parents a lot closer cause I've been able to talk to them about a lot of things. Whereas before I couldn't cause they'd get really upset and things like that...It's helped me in a way that you know I've been able to tell them that my financial situation that I'm in and things like that and now they're a bit more understanding. Whereas, before they'd be like well Scott you're so stupid for doing that you shouldn't have got those things in the first place (Scott, 1st) **37**

Getting closer to my mum and my brother it's just seeing, like my mum's gone through similar problems with drugs, not the same drugs as me but Valium and stuff like that and alcohol. She's good to talk to for me (Jack, 1st) **PTGI**

Increased desire to interact with others and improve the relationship

A new purpose for engaging with people is identified which was not evident previous to becoming unwell and is related to a new realisation of the importance of relationships. An enhanced motivation and desire to improve and put more effort into one's

relationships is present. There can also be a new recognition that people can provide valuable support and acceptance of the need for others. One can be more likely to seek support because of this.

The theme *increased desire to interact with others and improve the relationship* is different from the theme *development of deeper and closer relationships* because the development of deeper relationships is not discussed as an outcome of this transformation. If a closer relationship develops in the context of an increased desire to interact and improve the relationship it is categorised under the theme *development of deeper and closer relationships*.

Simone illustrates this theme in describing her motivation to consider her family's wellbeing.

If anything I'm less snappy, more patient. More understanding, I'm guessing I'm more understanding now than I was....Like I'll, especially when it comes to my family I'll like you know watch out to see if they're ok or if they're feeling ok you know just making sure that everybody's happy not just myself....Maybe because when, when they got back it was like this sudden change. They got back from, my parents got, overseas yeah and when they got back wow I was suddenly wanting to know how they were and I don't know how that came about it was just like, it just happened (Simone, 2nd) 30-31

Jack's quote reflects the second aspect of this theme in his willingness to seek support when needed and which is recognised as okay.

Pretty much comes back to family and (case manager). If I've got an issue that I need some help those people I can talk to whereas in the past I wouldn't have even bothered. I'd just keep it myself and feel like crap. It was but I just didn't see it. Didn't sort of rely on anyone else just wouldn't tell people about my problems I'd just keep everything to myself (Jack, 1st) 49

Enhanced perspective taking and sense of unity

Enhanced perspective taking relates to a realisation and awareness of the difficulties people can experience coupled with compassion and empathy for others. An increased consideration of others in general is also present. These quotes reflect this theme because participants used words and phrases such as "compassionate," "I've got more

understanding,” “I am better able to understand,” and “I don’t judge people.”

*Well before I was very confident sort of semi-arrogant sort of person and I **never used to believe in getting mental illnesses** and things like that, never used to believe in people that was that. I **wasn’t as compassionate towards people who had mental illnesses** and stuff but now my confidence is not as good as what it used to be but yeah I’m a lot happier now. **I can understand what people go through when they have mental illnesses which has made a huge differences in my life cause I’ve got a lot of friends who are suffering similar sort of things and now I’ve got a bit more understanding of what they’re going through** (Scott, 2nd) 12*

***I’m better able to understand, it’s not like a taboo anymore mental illness. I’m able to understand it and I talk about it maturely...I also see the grey areas in life you know I don’t judge people and I try to help people....you can’t predict the things that are going to come your way in life you know** (Chris, 2nd) PTGI*

A sense of *unity* is associated with identification with people either directly or indirectly who have experienced similar difficulties to oneself. This produces a sense of shared understanding and togetherness. *Development of deeper and closer relationships* is distinguished from the theme *unity* when sharing similar problems to loved ones produces a closer relationship.

*Yeah I enjoy music more, like a lot more. **I understand where the artists are coming from when they sing** whereas most people they just listen to music. So yeah it’s amazing that some, **these people have felt what I’ve felt** and yeah I like, **I’m not alone in feeling these things. I’m not crazy. This is real you know?** (Chris, 1st)*

PTGI

Unity can also be shown through an increased willingness to share one’s experiences and provide mutual support in general, which is reflected in Jack’s quote. “**I’ve been chatting to a lot of people on the internet about similar problems. It kinda helps a bit.... Oh I don’t know. I can see that I’m not the only crazy person running around (laugh)**” (Jack, 2nd) 10.

Confirmation of character of others and quality of relationships

This theme includes realising genuine relationships and support, positive qualities in the character of others, and the value of relationships with significant others through the experience of psychosis. In particular this is evident when reflecting on who stood by them during their psychotic episode. One can be more grateful and appreciative of the relationship. This can be discussed implicitly or explicitly. These quotes reflect this theme through words and phrases such as “realised,” “how lucky,” “stand back a bit and like see what I had,” “rely,” and “more than I ever thought I could.” ***“I guess I’m just more grateful for their company. I never used to be. I never used to give a stuff now I do”*** (Jack, 2nd) 37.

Just like, when I was unwell you know my mum was like really worried about me and helped me with my medication and you know are you ok and I just realised how lucky I was you know to have someone like that and my aunty as well was very supportive as well and it just made me sit, stand back a bit and like see what I had and realise you know, I was sort of destroying it in a way. That’s how it felt (Simone, 2nd) 10

I think I know I can rely on my parents and my sister a lot more that I ever thought I could before I was pretty bad..... Yeah they do. Like my sister she would never take me out for dinner or anything like that before, before the illness..... I didn’t need to but then, yeah, when I went nuts they started to help me out a lot (Jack, 2nd) PTGI

Enhanced Life View

Greater appreciation of life

The psychotic experience is reframed as a providing an opportunity to reassess life and facilitates a greater appreciation for life in general or specific things in one’s life. A desire to live life to the fullest can also be identified. A greater realisation that life is precious, valuable, and fragile can be present. Life or one’s wellbeing might be taken more seriously. Overall, a shift in focus on what is important in life is expressed.

Andrew's quote illustrates greater appreciation for specific things in his life that he was not previously grateful for. He uses the phrase "greater appreciation" to reflect this.

A greater appreciation for art. A greater appreciation for music and the true value of music I mean being a musician before I thought about music but now I understand it you know what I mean?... I mean before you listen to the song and you go wow that's a really well constructed song and you listen to the lyrics and you go wow they're pretty cool lyrics but then if you really, really listen to it and you believe it and you can put yourself in the authors shoes and you can understand and as soon as you begin to understand you can feel and appreciate exactly where they were and what they were going through at that current time so yeah a greater appreciation for that. A much greater appreciation for food to be completely honest (Andrew, 2nd) 19

In contrast, Scott discussed a greater appreciation for life in general and an increased awareness that it is valuable. Phrases that highlight this are "I never really realised how important life was" and "I tend to value my own life."

Cause I've been so unwell like, I've never really realised how important life was till I started challenging my being like challenging but I mean like wanting to commit suicide and things like that. Going from thinking that life is just worthless I've gone to thinking that life's you know got a lot of things you know I have cause I've gotten to know myself a lot better and I tend to value my own life very well (Scott, 1st) 25

New possibilities and direction

A qualitative change in one's life-direction as a result of being unwell is evident. It includes re-assessing and thinking about one's goals, interests, priorities, and life-path. This can be expressed as a desire for change or actual changes one has developed and engaged in.

Both Jack and Scott illustrate how one's life path, priorities, and goals could shift as a result of FEP. The opening sentence of Jack's quote immediately reflects this theme, while Scott used phrases such as "I no longer want things I used to."

I've thought about which way I should be heading and it's been a bit different from the past. It kind of brings on depression and things like that cause so much

needs changing it's a bit overwhelming....Well it used to be live hard and die young but not anymore... Now I want to get a job and start making money again, get off the dole... A lot differently. When I see, like my brother still uses all kinds of drugs and I see him and it reminds me what I could be like and I don't want to be that way (Jack, 1st) 26

Well my goals and dream I want to be hopefully a programmer. That's my main goal. My dreams are a lot different cause I no longer want things I used to want like, I used to... Well I used be heavily into drinking. I used to love it and now I don't and never wanted to get fit and now I do and so it's changed a lot (Scott, 2nd) 15

Spirituality

Participants were asked about their views on spirituality and if they had changed as a result of psychosis. However, for many this was not relevant to their illness experience. Therefore a spirituality theme was not established and accounts are provided descriptively.

For Daniel themes of spirituality and religion were associated with his psychotic symptoms and his beliefs had strengthened through the experience of being unwell.

*Because I'm becoming more involved in it. As I said once again it's coming back to that whole flip side of the coin thing. Before I left the very, very first time I was like pretty much everybody else. I only took what reality to be what to be everything that was around me but since I left and **it's getting stronger and stronger and stronger I'm starting to realise what's inside is just as real. So that has changed a lot and it's still now and everyday, everyday my spirituality grows a little bit stronger, it changes a little bit more..... Accepting your own mind (Daniel, 2nd) 21-23***

Andrew and Tessa used spirituality to support them through the illness experience. However, for Tessa this was facilitated by her mother rather than a personal coping strategy. *"I wasn't before but at the time when **I was sick my mum made me go to the temple cause she didn't know what was wrong so yeah I did kind of go and just yeah prayed**" (Tessa, 1st) 29*

*I briefly had...what I believe was a religious experience you know **I thought I had become closer to god in a way because day after day you know I thought that god***

had abandoned me because of what, what happened and then you know one day I kind of started believing you know I believed and I looked, I looked to God for help and Buddha and part of the meditation thing ...It gave me hope, it could have been false hope who knows, but I guess from hope you can gather strength which is you know which is good....It was just a phase basically yeah it was just another change, just a phase (Andrew, 2nd) 18

Andrew also viewed his spirituality as having inner peace which was central to his recovery.

Spirituality for me pretty much be, being aware and being in touch with yourself and you know your inner self knowing who you are, and where you stand and what you're for and what you're about.... If I have something to say now I'll say it. I don't give a fuck. I don't hold back for anything. Yeah you have to, if you don't speak your mind you'll explode (Andrew, 2nd) 20-22

For others their spirituality changed because their experience of psychosis tested their views on spirituality or spirituality was thought to be involved in the onset of their illness so it was decided to be avoided.

I don't know. I, look, I don't see much god in the world I just see humanity as a big mess of people just doing, it's not a bad thing people are just going about their lives.....No I actually believed in god and that's also, it also makes things complicated as well like when you believe in these rules that are right and wrong and sins and things like that it puts a lot of stress on you to like....yeah...I don't know if there's a god but like I know that people can do whatever they want...it's easier for me emotionally not to believe in a god because then I can understand why people are doing the things that they do (Chris, 2nd) 23

I think a lot about karma. I'm not a very religious person but I do have some spiritual beliefs from my home country so I do think about things like spirits and demons and things like that but I don't believe them so much...I believe less in spirits and things like that cause now that I have an understanding of what psychosis is like may be, may be people just back in my home country were experiencing psychotic. That's my way of thinking of it (Scott, 1st) 28-29

*I've kind of put it to the back of my mind I guess. Whereas before I got sick I was trying harder to get well and stuff whereas now I don't know like it's just not something I concentrate on...I just read a lot of books and stuff...I don't know theosophical sort of stuff...**I don't know like, I don't know I think may be it contributed to being unwell** (David, 2nd) 23*

Paul discussed feeling anger towards his spirituality beliefs because these beliefs did not support him through the experience of psychosis.

*Inner peace I guess.....At a stage where you don't know why you're being mad and why you being upset and you just you know, you just really get mad at something you don't know why and **you like talking to Buddha or god and you're thinking why is this happening and get mad (inaudible) don't want it anymore like you're thinking you're no help** and that yeah so you just (inaudible) just up to yourself. **Doesn't matter if you're asking god or whatever to help you you've just got to help yourself.** Yeah they help you in a way if you really believe in them yeah they help (Paul, 2nd) 22*

Developed Sense of Self

Deepening of self-knowledge

Deepening of self-knowledge is a broad theme which describes development of the self, which could directly or indirectly imply increased self-awareness. Changes can be explicit or implicit. A shift in attitude and behaviour due to these changes can also be expressed.

Simone's and Scott's quotes provide examples of how self-development can manifest. Specific changes ("less selfish," "matured") or a general sense of getting to know oneself ("I know myself better") can be discussed.

***It's made me less selfish I think than I used to be and it's made me more harmonious around my family and I think I've matured a bit and don't look at things the same way like things that I would have been worried about or annoyed about now I don't really care about.....I guess petty things with relationships and things that I get worked up about now I just think whatever. Definitely cause it's, it's just a waste of time a lot of the stuff you worry about. I'm still a worry wart but I'm not as bad as I used to be I think** (Simone, 1st) 23*

I'm just happy cause I know myself better now cause I now feel like I've gotten better control of my life in this point of time than what I used to be like....Just cause all this, all of this experience stopped me from drinking and things like that cause when I was, before I ever had any problems with psychosis I was going out every weekend and getting absolutely plastered and it was like a way of life and it was just, it felt very, I felt very sort of fake for a while having to go out and impress people and things like that yeah and now I feel like I know myself better cause I can go out without having to drink and impress people I just be myself (Scott, 2nd)

12

David's quote illustrates aspects of the theme which explicitly discussed increased self-awareness.

I don't know it's probably just about getting to know yourself. It's probably another thing that's changed. Sort of before I went to hospital spirituality sort of meant, I sort of had this attitude that there was nothing wrong with me and anytime there was a problem it was someone else's problem. Whereas now....it's my problem. But things like that I don't know I don't mean that I blame myself for any little thing that's happened but sort of, I don't know it's about being aware of, sort of, like self awareness like, yeah I don't know....And just sort of being aware of in different situations like if I get anxious, instead of just sort of trying to stop feeling anxious. I don't know it's just being aware of how you're feeling I don't know just trying to be with the feeling and not hide it (David, 1st) 27-28

Development of a sense of mastery and personal strength

This theme includes development of mastery and stronger sense of self. It is reflected in two broad ways: (a) one desires to be or has developed more self-reliance and more strong-mindedness, and (b) a general sense of having more control over one's situation and a determination to deal with residual and future difficulties. This can promote increased confidence and acceptance of oneself.

David and Jack both exemplify the second aspect of this theme, that is, the development of self-control and determination. David reflected on how he did not used to do this prior to his episode and now does, whereas Jack developed an awareness of his capacity for self-control. *"It's pretty difficult to stop using drugs, especially intravenous drugs. If you can*

stop that then you can stop doing anything pretty much so that sort of **made me realise that I'm in control of what happens to me**' (Jack, 1st) 49.

I think life's hard but you've got to, I don't know before I was probably going along quite passively and sort of not really taking control of my life and sort of letting things turn out how they turn out I wouldn't, I don't know sort of being active in what I wanted to do....Yeah I sort of, I don't know, yeah I guess when I was leading up to becoming unwell I sort of, sort of blaming other people for my problems and sort of not dealing with them myself (David, 1st) 25

Chris illustrates the development of self-reliance and strong-mindedness as he discussed putting himself first and not fitting in with others.

I think it's been really good like I'm redefining my relationships. I'm doing, like I'm taking myself first, which you have to do and I don't want to fit in so much...if someone doesn't accept me I don't really care anymore like I can form another relationship (Chris, 1st) 19

Perception of the Illness as Helpful or Unhelpful

Participants were asked if they viewed their experience of psychosis as helpful or unhelpful. Participants ranged from seeing their psychotic episode as entirely helpful to identifying both helpful and unhelpful aspects to considering it as only an unhelpful experience. For some people their view changed over time.

Unhelpful aspects of the experience predominately related to the impact the illness experience had on one's life, interactions with others, and future, as well as the distress of experiencing psychotic symptoms. Helpful aspects of the illness were mainly related to constructive changes. Predominately people discussed constructive changes in relation to the domain *improved relationships and view of others* and to a lesser extent *developed sense of self* and *recognition of new possibilities*.

The majority of participants identified the experience of psychosis as both helpful and unhelpful.

It can be both...Helpful in the way that you get to understand yourself a lot better and you're always like say if you're going to, you know yourself a lot better cause

you know that you're going to get stressed. You know that you're going to get depressed. You know that you can do things to prevent the situation, like future things from happening. And just in the way that it's not good, just all the symptoms they were really bad. And the effects of what it can do with your, like how it affects your life (Scott, 1st) 48

It is both helpful and unhelpful. Helpful in the way that it's made me more grateful and happier I think with my family and stuff and like getting along with people. Unhelpful in the way that it's made me so disconnected as well from people when they're talking to me as I might drift off and it can be a bit embarrassing sometimes cause I freak out cause I haven't listened to the entire thing that they've said and I hate that (Simone, 2nd) 52

While Chris acknowledged the impact of the illness, he also viewed it as a helpful experience.

It's, it's sort of just a thing like I had to go through and I'm really happy that I'm able to see the world the way I see it now so, so yeah I, you know it's much easier for me. I'm happy that I'm able to feel relaxed around people. I'm able to be reasonable with people and now I think a different way about the world. I think a different way about relationships. I can choose who I want to be friends with. Who I want to be close with and....I don't like the fact that I got sick but I like the fact that I'm able to see the world in this way. You know I've, well it's sort of like I've been depressed since 8 years old, you know it's a really shock to my reality and it's, it's, it's, it's strange but I can only look forward. I can't look back and I'm able to look forward optimistically (Chris, 2nd) 52

Daniel believed the experience of psychosis itself was entirely helpful, and for him the only negative experience was treatment.

If you're going to do what I did, if you're going to do it right, if you're prepared to take the risk there's nothing but helpful.....Only the doctors other than that nothing. They're all getting in my god damn way. Other than that nothing. You don't get negative side effects what I do (Daniel, 2nd) 52

Paul also believed the experience of FEP had only been beneficial. However, it was unclear if he was discussing how he had improved since experiencing FEP or whether the episode itself had been helpful and facilitated change. Paul attributed improvements to becoming stabilised and having more responsibilities. He also discussed how his illness provided an opportunity to receive practical support with his financial problems, which had come about as a result of being unwell. Further, Paul's psychotic episode gave him an opportunity to take time out. "**Get time off, not the best way but still. Just got an excuse to get away from something you don't want to do and help with the finance**" (Paul, 2nd) 52.

It's true....Well with the fines....it helped me through (inaudible)...it's helping me to get through quite a lot cause I used to be couldn't, couldn't do anything, just lay in one place, couldn't care less and now I actually have more responsibilities....Like to take care of things more and try to remember stuff and try to go out there and get work and hang out with friends and that so it helped me through a lot...Helped me to be stabilised....Just stable there's not specific way it's just stable, try to keep up with everything (Paul, 1st) 48

Although at Time 1 Andrew identified his experience as unhelpful, while discussing this he reported constructive outcomes in the context of the theme *confirmation of character and quality of relationships*.

Being unwell it's not helpful. Being unwell is definitely not helpful. Only, the only thing that it's helped me see is who my real friends are and that family is family for life....Well with your family, whether you like it or not they're your family and they'll always be there for you to support you. If your friends go away and make no effort to see you then they're not your real friends especially when you're in need the ones that, even ones that stick around to say hello even though they know you don't have much to say you know that they're your real friends because they were there. Like it didn't matter what they were doing but they were there anyway (Andrew, 1st) 48

Alana viewed FEP as an unhelpful experience at Time 1 and 2 and believed she did not have to experience psychosis to develop the constructive changes she identified in her interview. "**I don't feel that it was very helpful at all....Like the duration and the after-effects and not knowing the future like before I had a pretty firm plan of my future and**

now I don't" (Alana, 1st) 48.

I would say that it was probably an unhelpful because I probably would have reached some of these conclusions anyway and I don't think that I needed a period of unwellness to get to the place where I am and I would have preferred not to have gone through it.....Just that I'm getting older I think and you can't stay, you know in that 18, 19 year old mind set forever. Eventually you do realise that people need more understanding and I've noticed that with older people as well. They're generally more understanding and don't care what people think as much (Alana, 2nd) 52

For Jack his views on the experience of FEP changed over time from being both helpful and unhelpful at Time 1 to believing it was a helpful experience at Time 2. Conflict with family was noted as an unhelpful outcome of psychosis at Time 1. Helpful aspects of the experience involved improvement in mental state and disengagement in destructive behaviour. The experience of FEP was framed as a 'wake-up call.'

That's pretty right...just sort of opened my eyes a bit I guess...I don't really know (laugh). I know that I'm better now than I was but I don't know why or how....I'm not thinking about killing myself anymore....Arguments with my family. They all want me to stop drinking because of the Hepatitis C I can get really sick so they're all nagging me about that but it's all that I've got left at the moment is the alcohol (laugh) (Jack, 1st) 48

Well I think may be it was helpful because it made me wake up a bit and stop doing things that were negative.....Just drugs, bad behaviour. I haven't been arrested for a while so that's a good thing (laugh)....I guess I would have kept going the way I was going. Who know where I would have ended up, probably in a psych ward or something....I still don't want to do what I used to do...I don't know I guess I'm kind of happy just staying home and drinking and I don't want to go out and risk getting into trouble like I used to (Jack, 2nd) 52

For some participants the experience did not cause significant impact and therefore it could not be considered a helpful or unhelpful. However, this changed over time. *I don't*

know. ***“It hasn’t been really helpful or not helpful so...I think it’s everything’s just like the same”*** (Tessa, 2nd) 52.

It’s been both....Helpful cause it makes you probably think more about lifeJust people around you (inaudible) you should treat them better like just talk to them more yeah family....Unhelpful just.... it was a bad 2 months and you, sometimes the thoughts just come back and you’re scared that it might happen again....Just your experience be brought up....No, you don’t want to, you just don’t want that you know the feeling to come back again....Well it was probably just, you didn’t want to be alone like always have to have someone there yeah like you’re always thinking someone’s there, like up there or something (Tessa, 1st) 48

Perception of the Future

Participants were asked how they felt about their future and if they had any plans at the end of both interviews. A range of responses were given, with some people being future focused and having clear defined goals, while others were more focused on the here and now and did not look too far into the future. Goals that were discussed were typical of young people wishing to establish their lives such as marriage, careers, and study.

The future is, there’s a lot going for the future, heaps....I’ve got big plans. Got a new band coming, going to take care of myself, buy a new dog....we’re going to get married sometime, going to get qualified, going to travel, going to work overseas, got to go to Mexico.....Looking up, looking forward to the future. I don’t mind getting older (Andrew, 1st) 50

One of the main things I’ve learnt is not to worry too much about the future anymore. Just take it day by day. The biggest goal right now in my future is to get a job and move out of home or join the army. If I can get off the medication, join the army, get money. That’s as far as I’m thinking mate. Take it day by day. Yeah will get me fit, get me cash, get me out of home that would solve a lot of my problems man (Daniel, 1st) 50

One participant was both optimistic and cautious about her future, while others felt uncertain or just took it as it came. *“I want to live, just yeah feel good...Not really, nah I don't really have plans, go with the flow”* (Tessa, 1st) 50. *“I don't know still a bit uncertain, hopefully it's better (laugh)...I don't know just in terms of starting to take piano lessons and stuff”* (David, 2nd) 54.

I feel cautiously optimistic...To go back to school, to studying my arts degree...I didn't think I'd go back to do my arts degree I probably thought that I'd go and start my social work degree but I'm just learning to not pressure myself as much. To do them simultaneously (arts and horticulture) (Alana 2nd) 54

It was important for Chris to get better and the medication to be reduced so he could begin to engage in the things he wanted to pursue in the future.

Yeah I want to start making things happen and I don't know I'm able to enjoy, I mean most people have a pretty simple life and I don't know I don't find the things they find interesting, interesting and I'm able to feel good about that so I'm able to, in the future I want to get healthy first and I'm limited by what I can, by the medication as to what I can do in my spare time so I want to get, lower the medication more and more and then be able to pursue things that I want to pursue you know.....it's just, it's like I'm able, like now I'm able, I see the world as like with out any preconceptions and like I find a lot of things interesting you know? So I don't, I don't know how, when I get better I don't know how, I don't know where I'm going to go like what I'm going to do (Chris, 2nd) 54

Some participants' perception of the future was changeable. *“I don't know there's up and downs but yeah you just got to go through what you go through...Travel overseas, meeting new people, yeah be happy”* (Paul, 1st) 54.

Some days not very well and other days I feel very positive....Mostly music and the things that I've put together at home. The little just electronic kits and things like that. When I finish one it makes me sort of proud of my work and happy that I've achieved something instead of just sitting there and doing nothing even though it's only small stuff it passes the time....It's often when I'm pretty drunk. I get pretty, pretty depressed (Jack, 1st) 50

Some participants' attitude towards the future changed over the course of their involvement in the study. Scott's quotes reflect how his perception of the future changed across interviews one and two. This is evident in Scott's quotes. "*I try not to think about the future. I'm just trying to get through now*" (Scott, 1st) 50. "*Future looks bright for me....Well finish my study, get a job, see how it goes*" (Scott, 2nd) 54.

Triangulation of the Data

The FEP participants' primary treating clinician, who for nine participants was their case manager and for one person was their consultant psychiatrist and eight family members or loved ones were interviewed in order to provide mutual confirmation and validation of findings and strengthen the concepts being explored. Two FEP participants did not have a family member or significant other who could be interviewed. The themes corroborated by clinicians and loved ones are presented first. Second, significant discrepancies across interviews with loved ones and FEP participants are reported on. Descriptive themes: development of the illness, the psychotic experience, the experience of acute treatment, and outpatient treatment, spirituality, unhelpful/unhelpful aspects of psychosis, and perception of the future were not provided in table format given their self-evident nature.

Interview with Clinicians

While they were not asked about this, a few clinicians volunteered information about possible precipitants of their clients' FEP in order to understand their clients' presentation. These views both differed and were similar to FEP participants and they discussed both long-term and short-term issues such as a history of learning difficulties and difficulties with social relationships and managing stress. Clinicians were not asked to comment on their clients' subjective experience of acute treatment or the psychotic episode and none volunteered this information. Rather, clinicians discussed the nature of their clients' mental illness from the perspective of the medical model, raising issues such as diagnostic dilemmas and symptom presentations. Therefore, clinicians did not confirm the themes *disintegration* or *perceived enforced treatment* in relation to the acute episode.

Clinicians' confirmation of themes discussed in relation to the impact of FEP are

presented in Table 7.5. The themes that clinicians did not identify were ongoing experiences related to the theme *disintegration* and *stigma* from others. Clinicians were more likely to focus on the negative impact the illness experience had on participants, in particular *recognising the illness as an ongoing problem*.

Table 7.5

Confirmation of the Themes Associated with Awareness of the Impact of FEP

Theme	Loved One
<i>Estrangement</i>	<i>In terms of family members I think he pulled back from family....I think he had an underlying sense of feeling....that he wasn't good enough for his dad...I think with his mum that he has shut her out a little bit as well and I think that comes....it's that self sacrificing thing like him not wanting to you know worry her.....he didn't want to kind of let her know what was going on (Andrew, C) 5</i>
<i>Self-stigma</i>	<i>There is a certain you know fear around kind of the stigma of her having been psychotic and she's really unsure as to whether she should tell people (Simone, C) 3</i>
<i>Sense of loss and deficit</i>	<i>I think he lost a bit of confidence.....a hypomanic period where he'd felt really, really good and really you know on top of the world and like a king and.....you know feeling really paranoid, self-conscious, and you know you've lost your confidence essentially.....initially we saw a big drop in self-esteem and perception of self (Andrew, C) 3</i>
<i>Recognising the illness as an ongoing problem</i>	<i>For him he totally identifies the voices as the main issue for him that you know he's sick of it, he's tired of it, he wants them gone (Scott, C) 12</i>

Table 7.5 continued

<i>Viewing recovery as a journey</i>	<i>He didn't really know where to go. He hadn't really got much direction so he was living in the here and now and see what tomorrow brings but it was very much in small steps (Jack, C) 7</i>
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Table 7.6 shows the themes that were confirmed by clinicians in relation to management of the experience of FEP

Table 7.6

Confirmation of the Themes Associated with Management of the Experience of FEP

Theme	Clinician
<i>Perception of treatment as restricting</i>	<i>Daniel had become noncompliant....it was important to address that because he is on a CTO and he's not taking his medication so we had to make it very clear that we could put you in hospital right now, we could. He was not very happy about that (Daniel, C)</i>
<i>The interpersonal environment facilitates recovery</i>	<i>Talking things through has been the most thing...if you let her speak in a sessions....she's a classic patient who will hear herself speak and say that sounds actually really silly and I can't believe I've been worried....that's often just enough for her (Simone, C)11</i>
<i>Conscious Avoidance</i>	<i>Hadn't really got a lot to look forward to and I think that's why the thought of disengaging with the alcohol was going to be pretty difficult for him...it was scary to actually take that away having leant on things.....Take that away (alcohol) and all he's got is anxiety and you know this residual, mild paranoia (Jack, C) 9</i>

Table 7.6 continued

<i>Awareness of one's vulnerability</i>	<i>I assume he's a little bit fragile still and trying to protect himself and just trying to, you know that same thing around putting your head down and just kind of got to keep going</i> (Andrew, C) 7
<i>Self-direction in recovery</i>	<i>His kind of psychological exploration of what was happening....part of it seemed...driven by his symptoms but at the same time I think that was him trying to understand what was going on so I think that was important for him in coping</i> (Andrew, C)11

As shown in Table 7.6, the only theme that was not corroborated by clinicians was *developing acceptance and moving forward*. These themes were not a major feature of interviews with clinicians. Table 7.7 shows examples of the restorative themes.

Table 7.7

Confirmation of Restorative Outcomes

Theme	Clinician
<i>Functional recovery</i>	<i>Where now he's helping around the house, he's doing things, he's able to cook and do things around the house so he's functioning quite well</i> (Paul, C) 10
<i>Social recovery</i>	<i>When he was unwell I don't, he wasn't going out of the house he wasn't seeing friends now but he's now saying that's going out and visiting friends and seeing, you know so he's re-connected back with his friends and things like that</i> (Paul, C) 5

The recovery themes identified by FEP participants were confirmed by clinicians. However, comments on recovery were minimal and tended to be associated with regaining basic functioning. Tables 7.8, 7.9, and 7.10 report the constructive changes that were

confirmed by clinicians.

The themes *increased desire to interact with others and improve the relationship* and *greater appreciation of life* were not corroborated by clinicians and all of the themes relating to the domain *developed sense of self* were (shown in Table 7.10). Those who identified constructive changes generally focused on FEP participants' relationships with others. Further, constructive changes were also identified within their clients' family unit. Even changes reported in *developed sense of self* were discussed in the context of self and others.

Table 7.8

Confirmation of the Domain Enhanced Life View

Theme	Clinician
<i>New possibilities and directions</i>	<i>It's made him kind of stop and look at where he wants to go in his life. I think that's a positive in that he's you know trying to like consider whether he really wants to be in a call centre for the rest of his life or you know what he really wants and to really contemplate his career and I thinks he's made really good use of having a vocational worker (Scott, C) 5-6</i>

Table 7.9

Confirmation of the Domain Improved Relationships and View of Others

Theme	Clinician
<i>Development of deeper and closer relationships</i>	<i>His relationship with his parents he's actually said that has changed, whereas he was always keeping things apart from them. They were not able to talk about things but he felt.....he could actually express his feelings....everyone say he has always kind of kept quiet and not been able to say what each one is going through but now things are much better. Everyone is able to express their mind so that in itself was a positive for him and even with his brother as well, apparently that relationship has also actually improved in terms of the way he relates with them....he feels like being able to open up...become a protective factor for him (David, C) 4</i>
<i>Enhanced perspective taking and sense of unity</i>	<i>I think his sister, has had psychiatric issues.....Scott says he's so much more understanding now if that sister. I don't know whether this has just happened coincidentally but they're kind of, the rest of the family's kind of reached out to this other sister and now she's back in Australia and they're... taking on some caring roles for her. (girlfriend) certainly says it's kind of really built his compassion for her and you know they're like even thinking moving out together and that sort of stuff so that's big (Scott, C) 7</i>
<i>Confirmation of character of others and quality of relationships</i>	<i>He's still with his girlfriend....he has acknowledged at times you know the importance of that relationship to him. I think it also kind of has at times made him think about how much he wants the whole kind of just one single monogamous relationship now so I think it's triggered a thought process.... I think the positive is that he's thought about it (Andrew, C) 5</i>

Table 7.10

Confirmation of the Domain Developed Sense of Self

Theme	Clinician
<i>Development of a sense of mastery and personal strength</i>	<i>I think I'm saying he's a little more tentative but on the other hand I'm just thinking back when he was applying for some different jobs he....did a days work at one job and really didn't like it and I think you know he probably would have just stuck with it before but I think because he kind of felt that he had some support and some, like he felt that he had more option to say no. So I think in terms of building his assertiveness and allowing him to say what he wants that's certainly changed. So I think probably he's a little more assertive (Scott, C) 8</i>
<i>Deepening of self-knowledge</i>	<i>So he'd say now that there's been a much more clear sense of self and he says that he's less preoccupied with keeping other people happy recognising that he wasn't keeping everyone happy and he wasn't keeping himself happy. So part of the change has been around him being able to be more comfortable with who he is...he has described this big change and...actually having a clearer idea of who he is and potentially being less anxious because it doesn't matter as much what other people think of him that's certainly what he's voicing (Chris, C) 3</i>

Overall the quality of these reports was not as in-depth as FEP participants' responses, and clinicians tended to focus on the negative impact of the illness. Other clinicians suggested it was sometimes difficult to address potential constructive changes with their clients.

*She never really talked about how was uni and how she was managing before and what life was like before becoming unwell.....**she hasn't got a lot to add to that. She can't really, can't talk much about before and after picture** (Alana, C) 7*

I don't think there were any major changes to him. I think he was a bit more comfortable in himself but he was more relieved over the issue that he had reduced his drinking. That was about the extent of it I think (Jack, C) 4

It's really hard to tell cause as I said when we first saw him he was pretty unwell. He was still quite symptomatic. Still quite suspicious and paranoid so certainly the changes that we've seen have been him becoming more confident, and well engaged and much more of a, an equal relationship we've been able to kind of bounce ideas around but I didn't know his personality premorbidly so it's hard to comment. Certainly initially it's all been about symptoms. He certainly reports quite a lot of changes in confidence and as I say having a better idea of who he is but it's hard to know (Chris, C) 4.

In contrast, some clinicians believed their clients' episode of psychosis precipitated a reflective process which had constructive elements. Scott's case manager even queried the impact of the medical model and thought further psychological work would be beneficial.

I think he's more reflective I think he's kind of, it's sort of made him stop and think about you know why he might be feeling the way he does. I think it's made him kind of think about the impact of bullying and that sort of stuff with his growing up. Yeah I think he's sort of trying to become more aware of stress. Think that's kind of been helpful for him. I think the other hand I guess part of what I might imagine would be an identity change, cause you know not knowing him beforehand, but I wonder if you know part of us giving him a medical model kind of gives him a sense of being faulty or there's something wrong with him or confirming may be a belief that he already had that there was something wrong with him (Scott, C) 3

I guess you know one positive in kind of going back to work and you know having a go at it was that he was actually able to say actually I don't really want to work in a call centre....I'm just thinking too the other thing I think he's learning is just about his own vulnerability and work and his own kind of desire to please others

*and you know that whole thing around his **difficulties with his assertiveness and saying what he feels** and you know not ending or feeling taken advantage of. **So I think, yeah thinking about that kind of reflectiveness I think he's thinking about that sort of stuff** and trying to, I don't think he's sure what to do with that yet but he's sort of much more able to identify that and you know he's kind of looking at patterns.... **So it would be really nice to get that kind of psychological stuff going again** (Scott, C) 12*

***Thinking about where he was going in his relationship and what he wanted out of that, thinking about....you know how he puts others needs ahead of his.....it's more of a thought process and I think really important for him to do that because....you know it's part of his personality** (Andrew, C, 8-9)*

Simone's clinician related the positive changes her client had experienced to the effectiveness of treatment. Similarly, at times Simone thought her positive changes may be due to treatment, but she was ambiguous about this. "*She had such a **really negative sense of self to begin with** in fact if anything that's kind of **improved but really because of the kind of the intervention**" (Simone, C) 3.*

***She's certainly experienced better family relationships. Her family's sort of much better, a much better unit they would describe since...being treated....There's much more openness in the family than there was before. There's more support and...a follow on effect her relationship with her brothers....is much better than it used to be and even with her mother there's less kind of conflict. So that's been a positive kind of shift and she, her, both her parents can recognise** (Simone, C) 5*

*I've always been in a bad mood with my mum especially. We used to have a lot of fights but **since I've been on the medication I've just been able to get along with her so much easier**. Yeah and it's really bizarre it seems like now we have a real good relationship and **I don't know if it was from the Zoloft or the other stuff** (Simone, 1st) 17*

Discrepancies

Interestingly, although clinicians corroborated most themes, some identified themes their client did not. For instance, Simone's clinician reported *self-stigma* but this was not raised in Simone's interviews. Likewise, some clinicians did not identify a theme that their clients had discussed. However, the main discrepancy between clinician and FEP participants' interviews was clinicians' tendency to focus more on the negative impact of FEP than the FEP participants themselves. For instance, problems identified by clinicians were not always considered detrimental by FEP participants. A case in point is that Alana did not perceive the break-up with her boyfriend as damaging, whereas her clinician did.

Look I think that without (boyfriend) there I think is basically going to become a housebound cripple and that's what I'm really afraid of. I think it'll be difficult, well mum will bring her to the odd appointment, but I think she's probably going to lose her whole social network.... It's going to be really difficult for her.....will have missed at least a week or so of her TAFE course. She probably won't want to go back there because she's lost her confidence through that so you know for a while she was going to the gym with a girlfriend but that kind of fell apart....late last year.....but....she still had (boyfriend) and that was a major thing in her life. Yeah I think in a couple of months time we're going to have a more bleak picture of things (Alana, C) 7

Well even though my partner of 7 years and I broke up my mood has plummeted like it did plummet initially but it hasn't impacted me the way that I thought it would. I think I'm just a stronger person now like particularly in the last two weeks cause he only broke up with me two weeks ago....but I've, I've been getting along by myself quite happily (Alana, 2nd) 11

Similarly, David did not consider the illness to have had a significant impact on his life despite his clinician's concerns. Perhaps the impact of having a psychotic episode was devastating, as demonstrated by his suicide attempt, but in the longer term he did not think it had a profound impact on him. While David's clinician acknowledged that he was coping well, he tended to focus on the negatives. "I don't know, I don't know I think, it *wasn't*

really a helpful or unhelpful experience it's just, I don't know yeah I don't think it's sort of change my life that much" (David, 1st) 48.

It's really impacted a great deal on him. It also puts the long-term kind of sort of risk with him I think even though he kind of understands what's going on I'm not sure he's actually come to terms with it and the fact that he feels like his life may be has sort of come to an end because of the illness and that's something I've been trying to work on with him, with the psychologist as well, actually moving on in life....I think he still has that kind of, you know like a shadow behind him that reminds him of what has happened sort of thing (David, C) 7

Look I think he's been coping alright you know probably more than we actually thought that things would actually work out so I think he's coping ok. One thing that he does identify and we also acknowledge with him the fact that he does need ongoing support you know for him and he understands that (David, C) 11

Interviews with Loved Ones

Loved ones provided detailed accounts of the psychotic episode as well its precipitants and exacerbations and they generally corroborated the experiences of FEP participants. Some loved ones provided accounts of the illness experience and how it came about which were not addressed by FEP participants. For instance, when discussing precipitants, a number of loved ones explained long-term issues, whereas FEP participants identified immediate and medium-term stressors.

*I think when he was younger he was, he, he was **bullied at school and I think that made him very introverted and may be being at home and doing these, it just gave him an outlet, that there's something better*** (Daniel, FM) **question to facilitate further exploration of topic**

Yeah well I met him when I was 16 he was 17 and he'd always been up and down with his mood and hadn't really done anything to stabilise, oh he'd gotten on medication once and just hadn't continued. It was like every 6 months he might get a huge downfall like cry about it and then he'd be fine, he probably wasn't fine but yeah he'd always been up and down a bit like a yo-yo (Scott, FM) 9

And, you know I sort of felt the whole time she was never a confident kid and she really got put in the deep end and it was too much. She never had a great time at high school with friends, shocking time, never had good friends (Simone, FM6)

Like FEP participants, the acute episode was generally framed as a negative and distressing experience. Daniel's view of the episode as entirely helpful was corroborated by his mother. Table 7.11 presents the themes which were confirmed by loved ones with respect to the experience of the psychotic episode and acute treatment.

Table 7.11

Corroborated Themes in Relation to the Experience of the Psychotic Episode and Acute Treatment

Theme	Loved One
<i>Disintegration</i>	<i>I think he just felt lost. I think that is just, he lost his identity, he didn't know who he was anymore, he was confused, he didn't understand why this was happening to him, he was angry, angry with himself that he couldn't cope...I remember him just always saying I don't know who I am anymore like that's, yeah (Andrew, FM) 6</i>
<i>Perceived enforced treatment</i>	<i>I mean it would have been horrendously frightening. I don't doubt it...you know you're in a place where it's very regimented. The doors' locked. Your rights, not rights in sort of human rights but I suppose your rights as a person are taken sort of thing and the other people around you....he went back he'd tell (psychiatrist) quite often how frightened he was (David, FM) 8</i>

As shown in Table 7.11, loved ones identified the experience of *disintegration* and *perceived enforced treatment*. Table 7.12 shows the themes which family members confirmed in relation to the impact of FEP

Table 7.12

Confirmation of the Themes Associated with Awareness of the Impact of FEP

Theme	Loved One
<i>Estrangement</i>	<i>He still doesn't see all of his old friends but I think that's because he was estranged from them from this cause it was hard to keep in contact with them and he was just always isolated and it's hard to go back to that after so long of being distanced....they use a lot of drugs and so he feels like it's too risky to sort of hang out with them...So it's changed him in relation to who he's friends with. He doesn't have as many friends as he did before and I think that's hard on him (Andrew) 16</i>
<i>Self-stigma</i>	<i>I think very anxious of people seeing him there as you would be...that you know they're going to think that I'm this crazy person and I'm in this crazy place (David) 8</i>
<i>Stigma from others</i>	<i>Just things like society I guess. Like you go for a job what do you say I mean you say something like that they don't want to hire you so he's said he's been on holiday which is probably the wrong thing to do but, yeah just the stigma of mental illness, yep pretty much is what I've noticed (Scott) 14</i>
<i>Sense of loss and deficit</i>	<i>I don't think he'd have any trouble getting a job. And he's not motivated by laziness. I think it's a complete lack of self-confidence.....I'd say that it's dented his self-confidence quite a lot and his self-respect I would say (Jack) 15</i>

Table 7.12 continued

<i>Viewing recovery as a journey</i>	<i>More slowly I guess the medication may be improved his mood but probably only a couple of weeks, recovery in the sense like he would do a bit more cleaning, so slow, may be a couple of months ago but like not a lot of progress, slow, slow progress (Scott) 52</i>
<i>Recognising the illness as an ongoing problem</i>	<i>The hardest thing for him just hoping, not knowing whether he's going to get better, be normal if there's normal. But obviously stop hearing voices...people say oh well what if doesn't get better, what if can't hold down a job (Scott) 11</i>

Table 7.12 shows that most themes relating to the impact of FEP were corroborated except *disintegration*. Table 7.13 identify the themes relating to managing the experience of FEP.

Table 7.13

Confirmed Themes in Relation to Managing the Experience of FEP

Theme	Loved One
<i>The perception of treatment as restricting</i>	<i>He was frustrated he just wanted to get out because we were holding him back from finishing his quest (Daniel) 7-8</i>
<i>The interpersonal environment facilitates recovery</i>	<i>Generally like he finds really helpful that they understood him and...that he stayed there and keep working.....What I see, like when he comes home he's actually....relaxed and talks sometime what's happened there and they have few jobs. Sometime he has drink but he, with them on Friday....And the way he talks generally about what's going on, what's happening (Chris) 40</i>

Table 7.13 continued

<i>Conscious avoidance</i>	<p><i>Interviewer: Difficult to talk about his experiences?</i></p> <p><i>Loved one: Yes I would say it is</i></p> <p><i>Interviewer: How?</i></p> <p><i>Loved one: Well sometimes if I want to talk to him about things....and he'll want to change the subject and I figure well if he's like that with me he'd be even worse with a stranger or someone he doesn't know as well or may be he would be better with them because he doesn't really feel as inhibited (Jack, FM) 39</i></p>
<i>Awareness of one's vulnerability</i>	<p><i>Her ideas of what she's going to achieve now and what she's going to do is very different she sort of...cause she knows she probably won't finish university and she's pretty much convinced she won't get her old life back to where she wanted it to be and she's always worried about having a relapse so she's very resistive of trying things to, in case she gets unwell again and gets stressed about things again. Very over cautious (Alana) 17</i></p>
<i>Self-direction in recovery</i>	<p><i>I mean look he was open to different medications when it was happening a while back at the moment no. At the moment, I guess he isn't as open to the treatment because he feels like he's doing alright on himself and he's not the type of person that wants to depend on other people (Andrew) 13</i></p>

Table 7.13 shows that all of the themes related to the negative or maladaptive ways of managing the impact of FEP were recognised by family members. Like clinicians, family members did not identify *developing acceptance and moving forward*. Table 7.14 lists the restorative themes corroborated by loved ones.

Table 7.14

Confirmation of Restorative Outcomes

Theme	Loved One
<i>Functional recovery</i>	<i>For Chris I think it means like to go back normally to the life he was a lot.....to go back to the normal life. Working to go normal to work to go out with his friends and to enjoy normal things that he was for him before (Chris) 51</i>
<i>Social recovery</i>	<i>He appears to be recovering very well but, and he appears to be really good at times, I mean there are times when he's down and there's no doubt about that. And of late he's come to lots of family things and he's really good. He's very, you know, he's talkative for (David)...He tells you what he wants to tell you when he wants to tell you. He'll answer questions. He'll talk to other people. He's taking part (David) 11</i>

As shown in Table 7.14, both restorative outcomes that were corroborated. Table 7.15 shows the core constructive themes associated relating to others which loved ones identified. Table 7.15 shows that all constructive themes in the domain *improved relationships and view of others* were confirmed by loved ones.

Table 7.15

Confirmation of the Domain Improved Relationships and View of Others

Theme	Loved One
<i>Increased desire to interact with others and improve the relationship</i>	<i>He still always had a good relationship with his family, but he was sort of didn't really see them much especially with his hours and if he'd still go out and stuff whereas now he sees them more like spends more time with them and really seems to show that he appreciates them more, especially with his dad, he's always had a good relationship with his mum but his dad....yeah....more effort yeah (Andrew) 36</i>
<i>Confirmation of character of others and quality of relationships</i>	<i>I think he knows how much people care about him and love him now....I suppose blew us away that he didn't know that....but now he sees it to.....a huge depth of love and support and I think that overwhelmed him. I really do. He knows that everybody is there for him and ready to sort of you know be there for him (David) 48</i>
<i>Enhanced perspective taking and sense of unity</i>	<i>He's probably more sympathetic to other people that are gong through similar crisis. I mean you know we went to his cousins wedding and one of the bridesmaids had, had a psychotic episode. I didn't know and, and my sons girlfriend was sort of, must of said something about oh she's not a very friendly person or she gives you the glare or whatever and David sort of said but she's had a psychotic episode give her a break sort of thing (David) 29</i>

Table 7.15 continued

<i>Development of a deeper relationship with others</i>	<i>Closer in that she realises she has to be more of a mum and like he needs her more than ever like he'll ring her and be like night mum. Like he would never do that in the past like being a male things like that whereas now he'd be like, or he'll need a hughe feels that he can rely on them a more than he's needed to in the past. That's a positive yeah I'd say (Scott) 34</i>
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Table 7.16 identifies the themes that were confirmed by loved ones in relation to the domains *enhanced life view* and *developed sense of self*.

Table 7.16

Confirmation of the Domains Enhanced Life View and Developed Sense of Self

Theme	Loved One
<i>Greater appreciation of life</i>	<i>Maybe his cooking, like his work that's really meaningful for him. I think our relationship is and his family like he always talks about you know my family like my friends... I think because going through that was so hard that everything now he wants to make the most out of, yeah take advantage of, yeah (Andrew) 19</i>
<i>New possibilities and direction</i>	<i>He is less likely to engage in like risk taking behaviours and more motivated to do stuff for the future like, I don't know like save and go on holidays. You know he's more focused on his career like hugely more focused on his career and yeah more focused on yeah sort of I don't know building a future (Andrew) 17</i>

Table 7.16 continued

<i>Development of a sense of mastery and personal strength</i>	<i>Well it seems to have motivated, he seems to feel that he has more control over his life now because of these delusions. If he wants something he feels that he can now cast a spell and he'll get it so in, in that way it's made him more motivated. He thinks things aren't now beyond his reach (Daniel) 15</i>
<i>Deepening of self-knowledge</i>	<i>It's allowed her to grow up a bit I think. She probably didn't mature for a long time when it was all chaos and I think she has matured now (Simone) 15</i>

As shown in Table 7.16 all themes relating to the areas of enhanced life view and developed sense of self were confirmed. Yet loved ones were still more aware of the negative impact of FEP and restorative elements of the recovery process. While constructive themes were confirmed, not many examples were found of the some of the themes. Mostly, changes relating to the theme *deepening of self-knowledge* and the domain *improved relationships and view of others* were corroborated.

Discrepancies

A number of discrepancies were highlighted during interviews with loved ones. Like clinicians, loved ones identified themes that their significant other did not and so provided further avenue of information for understanding the impact of FEP and constructive processes and outcomes. For instance, David did not relate to the theme *enhanced perspective taking and sense of unity*, whereas his mother discussed this in her interview. Further to this, loved ones sometimes provided another layer to themes or to what their loved one with FEP had discussed. For example, Andrew's partner spoke of him being more rational. "*I think that he, **he appears more rational now than he did before even before he became unwell...I don't know like he thinks things through, he doesn't jump to conclusions, he doesn't read into things***" (Andrew, FM) 37.

Although Andrew also discussed issues relating to the theme deepening self-knowledge he did not raise this specific change. Instead, in his interview this change was framed as an aspect of social recovery rather than constructive change. Similarly, David's mother drew on spirituality to describe David's constructive changes in relation to the theme greater appreciation of life

I think he feels that he's very spiritual and his father is very spiritual as well....I mean not in a religious way but believes in, sort of a very spiritual kind of life....even a sort of Buddhist and Tibetan sort of way of life that kind of thing and he's got an interest like his dad, they love reading the same books and material etc. and so I think I like to say that yes he has found that you've got to live for now and you've got to live.....see success as a range of things. It doesn't matter what qualifications people have or, so I think yes he has in some ways. He wants, I guess I say yes he wants to (David, FM)18

In contrast, David provided very limited evidence of a greater appreciation of life in his interview and instead identified spirituality as increased self-awareness. Further, his mother identified other aspects of self-development which David did not.

I think he is more confident and I'm seeing that as weeks go by because you know he'll come to a family function and I mean you know he used to have a few drinks to give him a bit of bravado but he's like this without even, you know without that. So he'll talk to people and that is a change. Very much so (David, FM) 32
He talks about it, those things a lot but there's also a part of him that really wants to be successful in an academic way. I don't know that he'd tell you that easily but I can see that side that, that is still important to him. You know as much as he doesn't want it to be so important it is important (David, FM) 18

This quote also suggests that other issues may influence the development or acknowledgement of constructive changes such as one's preexisting beliefs. In fact, overall David's mother appeared much more able to articulate potential constructive changes than David.

A loved one and person who had FEP may have a different explanatory model of the illness or level or type of distress associated with the experience and this could influence the recognition and reporting of constructive themes. For instance, while Jack

identified a range of constructive changes, his father identified none and said the illness had been entirely unhelpful. ***“I don’t think it helped him in any way shape or form”*** (Jack, FM) 48.

Alana’s partner’s interview was overwhelmingly negative in comparison to Alana and as a result there were a number of discrepancies throughout their interviews. Alana’s partner was ambivalent about any potential constructive changes Alana may have experienced, while Alana was able to identify a range of positive processes and outcomes. However, it is not believed Alana was being unrealistic in her interview as she was very aware of the negative aspects of the illness experience. Rather, Alana’s boyfriend had ended their relationship due to the impact the illness had on him, Alana, and their relationship. This frame of mind and his personal experiences of the illness are likely to have impacted on his ability to recognise potential constructive changes.

I’m probably in a very cynical frame of mind today so, I mean in some ways, I think she’s aware which is a step because before she was just kind of ignoring and not allowing change to happen but now she’s aware of what she’s up against so I guess in that sense is a positive thing. Hopefully she can use that and work with it (Alana, FM) 52

And doesn’t seem to matter what I say about being positive or trying to do things or even just meditations or relaxations or putting it out there and taking chances it doesn’t, she doesn’t do any of it or seem, see any benefit from it. And I find that’s the hardest part.....Which is part of the reason I’m sort of stepping away as well....I don’t know if it will help her but it will help me (Alana, FM) 41

Interestingly, Scott’s girlfriend and David’s mother recognised the potential for constructive changes but were unsure whether their significant other had experienced these. The constructive changes described were akin to the themes *greater appreciation of life, development of a sense of mastery and personal strength, and new possibilities and direction*. ***“Well if it was me that was sick it would make my life seem more important but I don’t know if that’s had the effect on him sometimes it can have the opposite effect”***(Scott, FM) 17.

*I keep telling myself that **one day because of this experience it might give him meaning and the experience itself meaning and a path somewhere. I don't know when it will happen but I hope that that will, you know make him take some course or do something or be someone** (David, FM) 49*

*I don't know I just feel like I'd get a near death type thing just I guess, but I think it has to make you a stronger person. I don't know may be in the sense that I would feel like I would have all this motivation to like achieve everything which I don't think he's still got... like my friend had cancer in Year 7....she's so like life is so precious to her which I don't know if he has that sort of attitude. I think he might be still a bit like I don't know if I want to be here type thing still....yeah I'd be like really grateful. But then I don't know I haven't through it so I can't really say I might be angry at the world too (Scott, FM) **explored issue raised by loved one***

*Wish that it never happened but I guess what makes you, doesn't break you makes you stronger or whatever they say. **If this is going to happen to you try and take...notice about it I guess...but...I think it might take him a long-time to look back and see that. I don't think he can see something straight away** (Scott, FM) 49*

This indicates that loved ones can apply the notion of potential for developing constructive process and outcomes as a result of FEP but may not always notice these changes in their loved ones. For instance, David did actually identify constructive changes in relation to the theme *new possibilities and direction* and Scott had also talked about developing a *greater appreciation for life* but did not identify *development of a sense of mastery* or *personal strength*. At the end of her interview, Scott's girlfriend said she wanted to ask him about some of the issues raised.

Summary

The themes that emerged from the interview data confirmed the broad areas identified in the pilot study. However, preliminary themes derived from the pilot study and theme definitions were sharpened. Results indicate that there is evidence of a range of negative experiences associated with FEP that goes beyond understanding its impact in

relation to PTSD. Further, in the recovery phase of the illness people manage or cope with FEP in a range of ways which are both adaptive and maladaptive, and restorative and constructive processes are both evident. Constructive themes were not only reported when FEP participants were asked about their responses to the PTGI but in response to a range of questions. Also, all of the constructive themes were corroborated by six to eight FEP participants. This further supports the presence of these transformational changes. All non-descriptive themes were stable over time except the theme *perceived enforced treatment*, which was only discussed at Time 1 because it related to the acute episode.

Interviews with clinicians provided a source of triangulation as well as relevant clinical information such as the focus of treatment and FEP participants' responses to this. Therefore, clinicians' interviews were not as detailed as loved one's and FEP participants' interviews and questions required differed. Yet, clinicians focused consistently on the negative impact of FEP rather than potential constructive changes. Even accounts of engagement in the recovery process and restorative elements were limited, although they did refer to functional recovery when these issues were raised.

Loved ones confirmed most themes, but like clinicians their interviews mainly focused on the negative experiences of FEP, and to a lesser extent functional recovery. However, interviews with loved ones provided confirmation of constructive changes, particularly themes *relating to others* and *self-development*. They also reflected other areas of positive change and showed a capacity to question the possibility of constructive changes even when they were unsure if their loved one had experienced these processes as a result of their episode.

In conclusion, interviews support a broader understanding of the trauma of psychosis and the presence of both restorative and constructive elements of recovery. Therefore, it is argued that a more complete picture of the impact of FEP and subsequent recovery and adaptation is provided by the inclusion of constructive processes and outcomes. Chapter 8 presents a closer examination constructive change following FEP. Four case studies were chosen to illustrate the different trajectory and nature of constructive change following a first occurrence of psychosis and the role these processes play in recovery.

CHAPTER 8: CASE STUDIES TRACKING THE EXPERIENCE OF CONSTRUCTIVE CHANGES FOLLOWING FEP

Four case studies were selected to demonstrate the varying nature of constructive change and its trajectory. In particular, whether or not constructive change is illusory or real is examined in each case, as well as how these changes interact with the experience of FEP and restorative outcomes. Overall, case studies examine these issues in the context of ongoing adaptation to FEP. Quantitative results are drawn upon to further explore these issues.

Case study one is of a person who reported minimal constructive changes and those which were discussed were not representative of significant long-term transformation. Case study two is of a person who appeared to experience illusory growth because his reports of constructive change were simplistic and unrealistic and appeared to play a protective role. Also, his constructive changes were not corroborated by his clinician and only to a limited extent by his loved one. Case study three is of a person who appears to experience both real and illusory constructive processes. This individual's constructive changes were consistently reported and his level of growth increased over time. Further, he was aware of both the pleasure and pain of FEP and engaged in a meaning-making process in order to understand his illness. His constructive changes were also confirmed by significant others. However, there was also evidence that his constructive changes acted as a buffer against the negative impact of FEP. Case study four is of an individual who appeared to experience real growth. He reported high levels of distress and disruption due to his illness and there was no evidence that his constructive changes served a protective role. This individual engaged in a process of understanding and managing his psychotic episode. Also, significant others corroborated his experiences of constructive changes.

Some quotes from the previous chapter are repeated in the case studies when deemed the best example of a theme. Background information and quantitative results of participants who were not presented as case studies in chapter 8 are in Appendix F.

Case Study One (Tessa): Minimal Constructive Change

Tessa was a 22 year old Vietnamese woman who came to Australia as an adolescent. She lived with her family and was in an intimate relationship. Tessa worked casually in the family business and was completing a marketing certificate TAFE course after finishing Year 12. Her grandmother died 18 months prior to her psychotic episode. She had tried MDMA in the past but this was a year prior to her episode. A loved one was not available for interview, however her clinician was.

Initially, when in hospital, Tessa was thought to have a major depressive episode with psychotic features but this changed to schizophreniform psychosis when she was discharged. According to the M.I.N.I. assessment she had experienced a psychotic disorder in her lifetime. Her psychotic episode was sudden with no decline in prior functioning. When acutely unwell, Tessa was experiencing ideas of reference, thought insertion, paranoid ideation, formal thought disorder, and visual and auditory hallucinations. She also experienced poor sleep, decreased energy, psychomotor retardation, and became socially withdrawn and markedly decreased her fluid and food intake with weight loss. Tessa presented as tearful, distressed, and confused. She had contact with the CATT and the YAT and she was admitted as a voluntary patient; however she identified being admitted against her will during data collection. She experienced being restrained and sedated while in hospital.

At Time 1 Tessa presented as mildly unwell according to the PANSS total score (62) and at Time 2 (approximately 4 months later) she was borderline unwell (54). Negative symptoms predominated at both time points. At the second interview Tessa's family life, education, relationships, and employment remained unchanged. Her mood was stable and she was reporting symptomatic recovery from her psychotic symptoms. Tessa was experiencing anxiety but found this manageable. Her diagnosis and medication type remained unchanged.

Tessa reported minimal constructive change in her interviews. She discussed changes in relation to the domain *improved relationships and view of others*, particularly *confirmation of character of others and quality of relationships* and *increased desire to interact with others*. To a lesser extent she also discussed a *greater appreciation for life* but

this was also reported in relation to her relationship with others. Tessa's constructive changes did not appear to be profound or maintained over time when examining the interview data. Of note, references to most of these changes were evident in the initial interview and in the context of how she felt during her acute episode and the very early stages of her recovery. This suggests that her constructive processes may have provided short-term adaptation rather than represent a significant transformation.

*When I was going through it yeah a little but now I don't know I just, **not think about it that much....Like you just, may be felt like your friends and family were more special yeah...cause I saw them being there for me*** (Tessa, 1st) 25

We're a bit closer but just yeah pretty much the same....We talk more and yeah (inaudible)....Yeah it wasn't that much like it was like yeah just when I go out and stuff...Yeah I appreciate them more cause they were there and I got them worried and now it's like yeah (Tessa, 1st) 37

When I went through...yeah appreciate life more. At the time I thought...sometimes you thought you were going to die yeah because yeah cause I knew I wasn't eating, sleeping so I was thinking you know that yeah...like yeah you kind of got scared like why didn't I do this and that....Just like spend time with family more (Tessa, 1st) 31-32

Tessa's minimal constructive processes and outcomes could be attributed to the lack of impact FEP had on her. While Tessa described her psychotic episode and acute treatment as a "scary" (1st 4), "confusing" (1st, 2), and "uncomfortable" (1st, **experience list & 16**) experience, she reported no trauma symptoms at Time 1 and 2 after rating the IES-R according to the experience of hearing voices saying "hello, hello" when she was trying to sleep. She also described a complete recovery, achieving pre-morbid functioning after a short-period of upheaval. "*Before it was you know like staying around thinking about what you went through and stuff you feel and kind of scared you but now yeah slowly just everything's just in the past*" (Tessa, 1st) 44.

*Well at the start yeah you were kind of like nervous seeing people just scared couldn't talk to people liked to be alone but I think right now it's just normal.... Yeah the first few weeks probably was kind of, didn't really want to talk to people yeah but you kind of **get back to yourself again**... You see people slowly and then you start going out and then yeah, go to school (Tessa, 1st) 36*

Tessa's clinician also suggested that the psychotic episode had had minimal impact on her functioning. In support of Tedeschi and Calhoun's (1999) model of posttraumatic growth, Tessa's lack of ongoing distress and negative consequences probably restricted the facilitation and development of potential constructive changes.

*Again it doesn't really seem to have, in that **she's gone back to university. I think she's back full-time or you know the equivalent of whatever she was studying before. She's passing her exams. She's socialising** you know with her family and with her boyfriend so **I don't think it's had a major impact** (C, 7)*

So it was a very acute onset and a very acute offset so I can't, I wish I could kind of expand more on these issues but they don't seem to be a big issue for her. And that's the same with our appointments with her they're pretty quick and even thought they're superficial I don't think she's been guarded or she's not consciously minimising anything. I think genuinely things are ok may be she's not much of a thinker or an analytical person (C, 12)

Tessa's scores on the PTGI corresponded to her interview data. Although her total scores reflected moderate growth at both interviews (39 & 37 respectively), her levels of growth were at the low end of moderate. At both time points she rated highest growth on the domain *relating to others* (17, $M = 2.43$ and 16, $M = 2.23$ respectively), which is consistent with her interview data. Her scores on the other PTGI domains at Time 1 were *spiritual change* (4, $M = 2$), *personal strength* (7, $M = 1.75$), *appreciation of life* (5, $M = 1.66$), and *new possibilities* (6, $M = 1.2$). At Time 2 she rated *new possibilities* (7, $M = 1.4$), *personal strength* (7, $M = 1.75$), *spiritual change* (3, $M = 1.5$), and *appreciation of life* (4, $M = 1.33$). Her score on *new possibilities* had changed the most, increasing over time.

The development of growth requires persistent cognitive processing about the trauma (Calhoun & Tedeschi, 2006). Therefore, Tessa's minimal constructive change could

also be reflective of her experiences related to the themes *conscious avoidance* and *awareness of one's vulnerability*. “**Sometimes you think about it in kind of, yeah, I don't really want to think about it again**” (Tessa, 1st) 39.

In some ways before the whole travelling I wouldn't worry about but now it's like, yeah... You wouldn't, it's kind of hard when you're travelling alone, yeah, more independent before...May be I'll get sick again....I am worried that I'll get sick again, more if I'll get sick again, I don't know (Tessa, 2nd) 28

Further to this, Tessa's interviews were short and lacked substance. This hypothesis is corroborated by Tessa's scores on the RSQ. Even though she did not present with PTSD symptomatology, her results on this scale suggest that she may have actually found the illness experience highly distressing and was apprehensive to examine her illness experience. She had a 'mixed picture' recovery style with sealing-over predominating at Times 1 and 2.

A closer examination of Tessa's subscale scores on the RSQ revealed that she had a sealing-over style on *fear, liking, satisfaction, education, blame, continuity,* and *responsibility* at both time points, as well as *help seeking* at Time 1 and *cause* at Time 2. This indicates that Tessa did not treat the illness as a source of new information about herself; was fearful of the illness; did not like any of her psychotic experiences; was not aware of the continuity of herself before, during, and after the illness; did not feel responsible for her psychotic thoughts and acts; did not blame the illness on her own difficulties in coping with life; and did not find the illness helpful in obtaining satisfaction in her life. At Time 1 she did not seek support from others in dealing with her illness related difficulties and at Time 2 she did not consider herself to have experienced an emotional or nervous breakdown. These results are likely to have influenced her low minimal growth. For instance, the development of growth requires a person to make comparisons before, during, and after the trauma (Tedeschi, 1999), make sense or find meaning in the experience (Tedeschi & Calhoun, 1999), and engage in self disclosure about the trauma (Calhoun & Tedeschi, 2006).

The notion that Tessa's minimal constructive changes could be related to her reluctance to engage in an in-depth exploration of her illness was also supported by her clinician.

*You know **she doesn't expand a lot** like I said so she's pretty kind of, she's not clipped in her responses, but she's just kind of tell you what she, you know enough not more...**I guess we see that a fair amount of times probably 5,10% of people once it's happened they just don't want to go there again** (C, 5)*

*That was an episode....**you know I had psychosis....but I'm ok now. There's not much questioning or why me or why this has happened.....she's seems to have just sort of accepted it in a fairly superficial way I think** (C, talking prior to the formal interview questions)*

It is concluded that Tessa showed minimal constructive change as a result of FEP. The changes she did report were not maintained and instead appeared to enable her to cope in the short-term. While Tessa found the experience of FEP distressing and was aware of her vulnerability, her psychotic episode did not significantly disrupt her life. Further, her 'mixed picture' recovery style with sealing-over predominating and reluctance to examine her experience of psychosis may have impacted on the development of growth.

Case Study Two (Daniel): Illusory Constructive Change

In contrast to Tessa, Daniel reported very high levels of constructive change but these changes appeared illusory. Daniel was a 24 year old single unemployed man who had completed Year 11 and lived with his family. Prior to becoming psychotic, Daniel seemed to have difficulty relating to society and was bullied as a child. He experienced low self-esteem and had a history of depression and a suicide attempt and had been prescribed antidepressants in the past. Daniel had a history of heroin, amphetamine, and marijuana use. He was thought to have ceased all substances 6 months prior to becoming unwell. He had a long-standing interest in spirituality and conspiracy theories.

Daniel's initial diagnosis was unclear and his treating clinicians were considering schizophreniform psychosis, substance abuse, and drug-induced psychosis. On discharge from hospital he was diagnosed with schizophreniform psychosis. According to the M.I.N.I assessment he had a diagnosis of substance dependence during the last 12 months and a current psychotic disorder. At Time 2 Daniel had a diagnosis of schizophreniform

psychosis with elevated mood and clinicians were also considering drug-induced psychosis or a manic episode. Delusional disorder was also being assessed.

Daniel became progressively unwell over a period of one month. He lost his job and had become socially withdrawn. When acutely unwell Daniel experienced auditory hallucinations and grandiose delusions, was preoccupied with religious themes and displayed bizarre behaviour, living in the bush for one week and becoming dehydrated because of this. Daniel was seen by YAT prior to his admission, which was facilitated by the police because he resisted hospitalisation. He was an involuntarily patient and experienced the high dependency unit and seclusion. Daniel was placed on a Community Treatment Order when he was discharged.

Daniel had gained employment since Time 1 but became unemployed again. He continued to live with his family and remained single and generally socially isolated, although he had recently seen some friends. Daniel had also recently reported occasional marijuana use. His Community Treatment Order had been revoked because he had gone missing again and stopped his medication several months prior. Police facilitated his second hospital admission after he self-presented at a police station. At this time he appeared manic and expressed similar ideas to his last acute presentation. On presentation he denied perceptual disturbances but he was smirking and often laughing aloud. He talked with many gesticulations and was elated. Daniel had time on the high dependency unit during this hospital admission and YAT were involved in his discharge.

Rather than withdrawing Daniel from the study because he had relapsed in-between Time 1 and Time 2, he was allowed to remain to portray a realistic account of the heterogeneity of the FEP population. Further, he provided an opportunity to examine how relapse may impact on the traumatic nature of psychosis and restorative and constructive processes. When seen for the study, Daniel's results on the PANSS suggested he was mildly unwell at both time points (total score = 71 and 68 respectively) with positive symptoms predominating.

Daniel experienced ongoing conflict with clinical staff regarding the management of his presenting issues, which was associated with the theme *perceived enforced treatment*.

Right now, right, the support, the way they're getting in my way is by locking me up, making me take pills, telling me I have to live a normal life and the way I want to be supported is just to be left alone (Daniel, 1st) 41

Consistent with this Daniel reported that his involuntary admission was the most distressing experience and rated the IES-R according to this experience. Recalling his involuntary admission may have been distressing as it provided evidence that he was actually psychotic, which would be a direct threat to his explanatory model. Corroboration of this was Daniel's moderate *avoidance* symptoms (8, $M = 1$) at Time 1. His total score on the IES-R (17, $M = .77$) and *hyperarousal* (5, $M = .71$) and *intrusion* (4, $M = .57$) subscales were low.

Conflict with clinical staff stemmed from Daniel's explanatory model of his illness. Daniel did not agree that he had experienced a psychotic episode, especially at Time 1. He reported initiating the experience himself which described as a spiritual journey and an attempt to deal with his emotions. "*It was about learning about drawing myself deeper into the whole spiritual world alright. This second time I bolted off, it was about conquering emotions and that's kind of like now you can see me*" (Daniel, 2nd) 6.

I don't need it (medication) and I don't want it. Nobody fucking listens and everybody's taking away my rights to choose. The pills don't have an effect on me. Like they don't do anything to me. They're designed to stop voices and anti-psychotic behaviour but as I said to you man, everything I did was not, I brought it on. I caused it to happen. It was not something that just happens. So it's kind of like they're pills can't even really do anything to me (Daniel, 1st) 21

Daniel experienced a second psychotic episode prior to Time 2 and seemed more conscious of his mental illness. He returned himself to hospital after absconding from the ward and was more aware of his abnormal behaviour "*Because I'm going crazy man. I can't explain to you right I'm going crazy. I'm fully going crazy and my parents are starting to see it in me. I'm changing, I'm acting differently you know?*" (Daniel, 2nd) 37-38.

*I ended up making a runner from the ORYGEN Youth Centre. They gave me an hour's leave and I just didn't come back (laugh). **I dobed myself in purely cause I got back and went I'm a missing person I know I've broken my CTO. I have to go back to ORYGEN** (Daniel, 2nd) 1*

I'll try to talk to people and there's that little voice in the back of my mind that's going but you're crazy Daniel. I don't know how to put it properly it's just getting harder and harder to talk to people because I'm looking at the world in a different way....I'm not a part of the norm anymore. I've gone completely flipside and I am by all medical standards absolutely crazy" (Daniel, 2nd) 35-36

Further, he appeared to have an increased awareness of how his life experiences had impacted on him.

All through school, I used to get picked on a lot through school because I was a really soft kid, I'm a really peaceful person right. And one of the things that, that done to me when I was at school was I started hating being myself. I didn't want to be me you know I thought there was something wrong with me (Daniel, 2nd) 31-32

Daniel's quantitative results at Time 2 extended his interview data. He reported low *avoidance* symptoms (5, $M = .63$) which suggested he no longer avoided reminders of his involuntary admission. His total score on the IES-R (8, $M = .36$) and *intrusion* subscales remained low (3, $M = .43$) and he reported no *hyperarousal* symptoms. This increased awareness also corresponded with his integration recovery style on the subscale *continuity*. This result suggests that Daniel was aware of the continuity between his thoughts and feelings during the illness and emotional conflicts prior to and after initial episode.

Consistent with this, Daniel's clinician identified that Daniel was beginning to think about his previous life experiences and future.

*I suppose last week was really good...he....**was prepared to get into a bit more dialogue about his life and his social connectedness or lack of and....how he fits into his family and whether that's working for him.** He pretty much had previously, by and large brushed that aside or tried kind of skate across it* (C) 1

There does seem to be some positive circuit breaker....his life prior to getting unwell the first time if you like was very much caught up in....an emotional disconnection from his family and largely from his friends and a lot of dope smoking and other drugs, sporadic employment in unskilled work that he wasn't happy with.....getting some depressive features....and I won't say that he's been transformed or anything but....he's questioning kind of a fairly sort of narrow life path he'd carved out for himself (C) 3

Consistent with the model of posttraumatic growth (e.g., Tedeschi, 1999), this capacity to reflect on his life experiences and mental health concerns could have facilitated the development of Daniel's constructive changes. Throughout both interviews Daniel discussed a range of constructive outcomes and processes which related to the themes *deepening of self-knowledge, greater appreciation of life, new possibilities and direction, and development of a sense of mastery and personal strength*, as well as stronger spirituality. He did not report any constructive changes in the area *improved relationships and view of others* most likely because his explanatory model of his experiences conflicted with other people's understanding of his illness. ***"I appreciate life a hell of a lot more now. I really do. I found the purpose in life is no purpose at all. So therefore be happy in the fact that you're just here"*** (Daniel, 1st) 26.

*Well I was thinking along the lines of, the priorities in life are, have you ever heard of the saying, how does it go, **how can you change the world if you can't change yourself. When I ticked that one because my priorities have gone rather than concentrating so much on the world outside me what's more important is changing the world inside of me. Fix your mind and then you can fix the world. That's kind of what I mean*** (Daniel, 2nd) PTGI

*The fact that I've started to be a lot more happier....**To be a happier man is a big change. To be, that in itself is a huge change. I don't know how else to put it. To change the inside of yourself, to make yourself happy when you were depressed what greater change can there be?*** (Daniel, 2nd) 11

Daniel's mother also identified some constructive changes as a result of the psychotic experience. "*Trying to be healthier may be he is appreciating his life a little bit more. He wants to be around to enjoy it*" (FM) 17.

A lot better than the first time...more motivated....he's more health conscious as well he's trying to give up smoking. He doesn't want me to order pizzas anymore. He's started walking yes so he seems to be improving in all different ways (FM) 14

Yes he told me once he feels trapped which I couldn't understand cause I couldn't understand how a young healthy unattached guy could feel trapped he's got the world at his feet but he told me he felt trapped...he didn't have the motivation to get those things that used to worry me...since the illness he actually seems a bit more motivated (FM) 24

Interview data corresponded with his scores on the PTGI. According to Daniel's total score (69) he was experiencing high levels of growth at Time 1. He gave the maximum rating to the changed *spirituality* (10, $M = 5$), *new possibilities* (25, $M = 5$), and *appreciation of life* (15, $M = 5$) domains. *Personal strength* (16, $M = 4$) was also rated quite high and *relating to others* was rated very low (3, $M = .43$). At Time 2 Daniel's overall score (61) on the PTGI had reduced over time but remained high. Maximum scores for the domains *spiritual change* (10, $M = 5$) and *personal strength* (20, $M = 5$) were reported and *appreciation of life* remained very high (14, $M = 4.66$). His score on *new possibilities* had reduced over time (17, $M = 3.4$) and he did not rate on *relating to others*.

However, while there appeared to be evidence of some constructive processes it is likely they were illusory for a range of reasons. Daniel was unrealistically optimistic about his illness experience. He perceived his experience of FEP as entirely beneficial and was reluctant to acknowledge any negative impact or disruption other than issues associated with the theme *perception of treatment as restricting*. "*When the doctors say I don't have to take medication anymore...I don't think I ever had to recover. Why try to recover from something that was a bonus man?*" (Daniel, 1st) 49. "*Look it was something I've been wanting to do my whole life so none of it was distressing. It was all interesting. It was interesting as hell man. I learnt things from it*" (Daniel, 1st) 4

Like by the time I'm in my 30s I think I'm going to be a very, very, very, very, isolated person. I don't care though. Look I don't care cause once again in the end I'd rather be a loner achieving what I want than be a real sociable person and be depressed. I mean once again look at the fact, I used to be a really, really popular person after I left school...I used to have a lot of friends but I was still always depressed.....I've lost most of those friends through deciding to take up all of this stuff and I'm happy (Daniel, 2nd) 35-36

Corroborating this was Daniel's explanation for his rating on the avoidance item 'my feelings about it were kind of numb.' He rated this item 'extremely' but said this was because he no longer cared about his involuntary admission.

Look I don't think about it anymore now that I'm out. That was one of the things I learnt from this whole experience. Don't concentrate on the past, the past is bullshit, it's over and done with. You know at first, at first when I came in here yes it used to linger on my mind a lot but it doesn't anymore (Daniel, 2nd) 4

Daniel's increased awareness of his mental health concerns and its impact at Time 2 seemed to create a dilemma in coming to terms with the illness and his susceptibility to psychosis. For instance, his second episode led to increased tension between upholding his explanatory model of the illness and acknowledging he had experienced a psychotic episode.

In their defence, even though I shouldn't really be defending these people, a lot of it is psychotic behaviour because the old shamanistic practices it's about inducing psychotic episodes within yourself but it's all controlled.....It's all controlled psychosis. So in their defence they are right, I have had a psychotic episode but I've induced it myself, I bought it all on myself (Daniel, 2nd) 2

Considering the idea that he had experienced psychosis was threatening and so Daniel tried to remain steadfast in his explanatory model.

Keeping my faith in the fact that I know that I am right and everyone else is wrong about me. That's what's helping me because if I give up, if I slip in, if I give up and go right they must be right I'm all psychotic it's all just going to ruin everything and I'm just going to give up on life mate. So the fact that I know I'm right and everybody else is wrong is what helps me cope (Daniel, 2nd) 7

It is likely that in order to uphold and justify his explanatory model he reported more constructive changes in the interview at Time 2 even though his scores on the PTGI had decreased slightly over time. Daniel's constructive changes seemed to provide a more manageable framework for his illness experience than the notion that he had suffered a psychotic episode and therefore served a protective role. *"Since I last saw you and since I've come back for the second time around, I'm a very, very happy man now. Things have gone up, things have improved"* (Daniel, 2nd) 6.

Yeah cause you've got to remember I, a lot of this stuff that I'm talking about is changes in my reactions only happened the second time I bolted off into the bush mate. So yeah since I last saw you once again just the whole positive thing, just the whole looking at life differently, looking positively rather than negatively that's the biggest change (Daniel, 2nd) 17

While Daniel did not report significant PTSD symptoms, it is likely that acknowledging he had experienced FEP would be very distressing for him. Indeed, his case manager recognised that further mental health complications were likely to make him at risk of self-harm or suicide.

Well the potential is there certainly for a relapse in mood symptoms I would say. And it will be difficult for him to....recognise that's what they are and to integrate them.....he'll understand that there's a more, a more philosophical, kind of my personal epiphany again so that's going to be tricky and he's going to have deal with.....there's a risk of what, what follows involuntary treatment.....more immediately where his kind of sense of helplessness with being caught in this thing is going to trigger.....will be risky for him you know in terms of self-harm.....he's got the profile certainly of a boy who'd jump into a car and drive into a tree at great speed. I mean he fits the profile....you know isolated, you know becomes psychotic, some time drug user, you know perhaps without hope, impulsive when his mood is affected so that's a risk I reckon, that's the very real risk 12

Daniel also discussed his underlying fragility, which also reflected the frailty of his constructive changes. Thus, his experience of growth was unlikely to be adaptive in the long-term or reflect a sign of lasting outcome.

You feel like being caught in a rat race. You can't escape it you know? Everyday you wake up and you have to get out there and you have to battle it again... You know and that's kind of me....even now it still makes me feel hopeless in that I've gone out and I've tried to change the way I think and I've learnt this great miraculous thing about just being you, just being happy but I'm still trapped in a rat race...I can't just...go walk outbecause I've got family ties. I've still got social ties you know?...You judge whether you're a normal person based on the people around you...that's still happening to me...and I don't want that anymore (Daniel, 1st) 30

Further, Daniel's constructive changes appeared to act as a buffer for past negative experiences. For Daniel perceiving his illness as entirely beneficial gave him an exaggerated sense of control and acceptance. "*Cause I didn't think you could control your destiny. I thought that you were a useless pawn in life and that you just got buffered around by the wind and you had no control but that has changed*" (Daniel, 2nd) 24.

You know just starting to learn to accept....In starting to go through all of this and starting to realise that what a minute I was right and all these other people that were telling me I was wrong are actually wrong themselves. I don't mind be me anymore. I'm actually, I don't want to be someone else anymore. I like being me. I don't care. I don't care if people don't, can't accept who I am. I'm happy being me and I had to make myself like that. I had to go off and do what I thought was right (Daniel, 2nd) 31-32

Yes of course cause well before I started all this I used to be that type of person. Your not in control of your life you know, you're destiny is what rules you. You destiny's what controls you. But when you start all of this stuff and you start going through it you begin to realise no you're in complete control of your own life. You are the one who has all of the power and once again it all starts from in here to bring out to there so yeah I've started to change. I'm starting to feel better about that and just the simple fact that I know that my life is completely under my control (Daniel, 2nd) 16

Fate is real. Whatever most likely will happen. Whatever most likely will happen will most likely happen. That is fate. Just accept it.... You know accept life the way it comes mate. That's how you've got to deal with it....I was so angry man. I was just annoyed at things. I was annoyed at the world. I was annoyed it didn't go my way (Daniel, 1st) **PTGI**

Daniel's case manager and mother also suggested that his positive changes added meaning to his life and fostered a positive sense of self. Further, they appeared connected to residual psychotic symptomatology "**He thinks he's special cause he can do these things**" (FM) 31-33. "**He was bullied at school and I think that made him very introverted and may be being at home and doing these, it just gave him an outlet, that there's something better**" (FM) explore. "**Well it seems to have motivated, he seems to feel that he has more control over his life now because of these delusions.....He thinks things aren't now beyond his reach**" (FM) 15.

Yes and you get a new lease on life, well that seems to have happened to him yeah cause we used to have to push him to get work....I just feel it's because he's happier, that's just my opinion. He's found some new purpose in life and it's just made him happier....well this magic...life to him is not as dull and, as it was before (FM) explore

In terms of a function for Daniel you'd sort of see a narcissistic defence in terms of his belief system and also his kind of quite passionate defence of his belief system given that he's an intelligent young man you know sort of underachieved at school, underemployed and perhaps from a family that wasn't particularly interested in anything kind of creative or esoteric and you know he talked about not enjoying school because he was bullied.....perhaps he was a sensitive soul....personality style. Gentle and perhaps a bit passive, yeah, and so you sort of see a response to that.....The kind of empowered and having this special knowledge and sort of insight that no one else has that makes him special.....all of a sudden he's not a loser from the Western suburbs anymore he's something....sort of wonder that when he's been on medication for a while in fact

what he's fleeing is not, his insight, you know cause he's starting to develop insight and it's pretty uncomfortable....I suppose but if I was to say I don't see the positive change though Daniel he'd say well that's all in here (point to self), I've got it all, it's all, you know (C) 11

Daniel's tendency to provide simplistic, vague, and contradictory responses also suggests these positive changes might be illusory. "**Just be content. Just be happy you're alive**" (Daniel, 1st) 22.

*It's made me calmer. If I had a job right now. **If I was working and I was making money so I was going somewhere I would be right now the happiest person on the planet because I've learnt not to worry about being rich but just being happy. All I need is a job to makes some cash to move out and I'll be happy as man. Because I've learnt to just be content. Just be content** (Daniel, 1st) 22*

Daniel's clinician also identified an inconsistency in Daniel's reporting of his experiences which support the argument that his constructive processes are illusory.

There's been a fair bit of inconsistency.....not just in terms of the core belief system but....his kind of life's goals....I mean from being completely apparently goal-less except for this mission and not having any interest in family or vocation or straight society. He's become somewhat different to that and his last appointment....some of the things that we previously talked about and he'd kind of scoffed at....last week....wanting to improve his education and....we almost didn't even talk about his belief system (C, exploring issues raised in interview)

In further support of the hypothesis that Daniel's constructive changes were illusory, he tended to externalise blame for his illness on society and previous life experiences. His illness was something he felt he had to initiate to overcome these issues.

*Society was fake. Everybody's chasing materialistic gain you know people measure their happiness by their wealth...**And it's all too hollow for me and I've felt it all my life....In this life everybody's got this impression that you've got to have money and you've got it to be happy you know.... and you've got to have a family. And you've got to do all this normal run of the mill shit. And I don't want to do it man.... I don't want a job. I'd be happy if I was poor if I was happy spiritually** (Daniel, 1st) 18*

His recovery style supports this interview data. According to the RSQ Daniel had a ‘mixed picture’ recovery style in which integration predominated at both Times 1 and 2. He sealed over on the following subscales at both time points: *curiosity, education, help seeking, blame, and cause*. At Time 1 he also sealed over on *continuity*. It is likely that he sealed-over on these subscales because he did not believe he had experience a psychosis. Daniel’s sealing-over style on the subscales *education* and *curiosity* suggests he was not invested in understanding his illness and did not believe it had taught him new things about himself, which further indicates that his constructive changes were illusory.

In summary, Daniel’s explanatory model of his illness in the context of his personal history suggests his growth was illusory. Consistent with the literature on illusory growth (e.g., Maercker & Zoellner, 2004; Taylor, 1983; Zoellner & Maercker, 2006a), his accounts of growth appeared to play a protective role in managing his current and past concerns. They seemed to reflect denial, avoidance, and self-enhancement in order to cope with the distress of having experienced FEP. Further, Daniel’s constructive changes were inconsistent and unsophisticated and there was lack of third-party confirmation.

Case Study Three (Chris): Real and Illusory Constructive Change

In contrast to Daniel, Chris’ constructive changes appeared to have both real and illusory qualities. Chris was a 25 year old single man of Croatian descent living with his family. He was employed full-time and had completed Year 12 and a degree in mechanical engineering. Chris had a trauma history of witnessing a person sustain serious physical injury from another individual. His father had a diagnosis of Schizophrenia which was causing Chris stress prior to him becoming unwell. Also, he was experiencing increased stress associated with his work. Chris was described as having difficulty with interpersonal relationships and was bullied in Year 12 which resulted in him engaging in a physical altercation with another peer. Chris had a history of depression and would sometimes drink alcohol to improve his mood. He had a history of occasional binge drinking and marijuana and cocaine use.

Chris was diagnosed with schizophreniform psychosis. According to the M.I.N.I assessment he had experienced a past manic episode, had a diagnosis of alcohol abuse over the last 12 months, and had a lifetime psychotic disorder but was not currently psychotic. Chris had a prodrome period of approximately two months.

When Chris was acutely unwell he experienced paranoid and persecutory delusions, grandiose beliefs, passivity phenomena, thought broadcasting, ideas of reference, and auditory hallucinations and he was thought disordered. Chris was irritable, feeling depressed, anxious, and confused, had withdrawn socially, and was experiencing poor sleep, concentration and attention. His work performance had declined and he experienced conflict with colleagues. Subsequently Chris lost his job. He was also experiencing increased conflict at home. Chris self-presented for treatment with the support of his mother and had contact with CATT and YAT and was admitted involuntarily (although Chris did not report being admitted against his wishes during data collection). He re-presented soon after being discharged and was admitted for a second time as a voluntary patient to facilitate a medication change. Chris experienced being sedated while in hospital.

According to his PANSS scores Chris was mildly unwell at both interviews (total score = 71 and 68 respectively) with positive symptoms predominating at both time points and which increased over time. At Time 2 Chris was described as being preoccupied with making sense of his illness and life, displayed a rigid thinking style, and continued to experience interpersonal difficulties.

Unlike Daniel, Chris' constructive processes and outcomes appeared to be reflective of real growth as the changes he reported were consistent over time and clear and detailed. In his interviews he discussed issues relating to all areas of change: *improved relationships and view of others, enhanced life view, and developed sense of self*. Some examples are provided.

I think it's been really good like I'm redefining my relationships. I'm doing, like I'm taking myself first, which you have to do and I don't want to fit in so much...if someone doesn't accept me I don't really care anymore like I can form another relationship (Chris, 1st) 19

Well you know before because I couldn't have things I wanted....I'd always been pretty interested in academic things and the average people around me weren't interested in it...I always wanted to do it more whereas now I just see it as....something that I could do with my time...just because you can't have some things you want it more. So that's changed for me....Yeah it's not like that anymore...so yeah I've relaxed a bit you know (Chris, 1st) 31

Yeah we talk more and previously like, in society it's like, it's shameful to have a problem, so you don't want to share your problems with your, with your mother or your father that's the rules that your taught um whereas really they should be counselling you because you're young and you don't understand things.... Yeah I talk to her more and like um you know with this town house thing we're talking more and um yeah I can go to them more and talk to them more because I don't see it as um a shameful thing to have a problem (Chris, 1st) 37

It's, it's sort of just a thing like I had to go through and I'm really happy that I'm able to see the world the way I see it now so, so yeah I, you know it's much easier for me. I'm happy that I'm able to feel relaxed around people. I'm able to be reasonable with people and now I think a different way about the world. I think a different way about relationships. I can choose who I want to be friends with. Who I want to be close with and....I don't like the fact that I got sick but I like the fact that I'm able to see the world in this way (Chris, 2nd) 52

Corroborating his interview data, Chris endorsed the domains of posttraumatic growth consistently over time. At Times 1 and 2 he did not score on the *spirituality* subscale, while he scored highest on *new possibilities*, *appreciation of life*, *personal strength*, and *relating to others* in that order over time. In contrast to Daniel, Chris' quantitative results on the PTG also indicated real growth as his scores increased over time. This supported the notion that the development of growth is a gradual process (Calhoun & Tedeschi, 1998). He reported moderate growth (total score = 55) at Time 1 and it reached a high level (70) at Time 2. Chris' subscale scores at Times 1 and 2 were: *new possibilities* (21, $M = 4.2$ and 25, $M = 5$ respectively), *appreciation of life* (12, $M = 4$ and 15, $M = 5$

respectively), *personal strength* (14, $M = 3.5$; 19, $M = 4.75$ respectively), and *relating to others* (8, $M = 1.14$ and 11, $M = 1.57$ respectively).

Dissimilar to Daniel, Chris' clinician and mother both identified concrete positive changes they had observed and discussed with Chris. In particular, the themes *development of a sense of mastery and personal strength* were confirmed and Chris' mother also identified changes in relation to the domain *improved relationships and view of others*.

So he'd say now that there's been a much more clear sense of self and he says that he's less preoccupied with keeping other people happy recognising that he wasn't keeping everyone happy and he wasn't keeping himself happy. So part of the change has been around him being able to be more comfortable with who he is...he has described this big change and you know actually having a clearer idea of who he is and potentially being less anxious because it doesn't matter as much what other people think of him that's certainly what he's voicing (C) 3

He describes actually potentially being happier now because he's not so led, he certainly feels that one of the big influences was about trying to keep other people happy and trying to be all things to all men and he says that not having to do that anymore. Realising that that's fruitless is quite a big, you know has been quite big change to his life.... Not being as dependent on you know the judgements of others (C) 8

I think it improved toward his father. I think he now thinks he had experience he understand a little bit more....before he used to be upset with him like he is passive or doesn't do this, doesn't do that and now like he's more he'll say just let him go mum, leave him alone or things like that...No, not really and I think he talks with him more with his father than he used to....Yeah I think that's good (FM, 36)

One good may be thing, may be more understanding and more openness between all of us. Cause for me was very hard to talk, you know how my husband was sick they always was like why he's like that and I did explain to them what's that sickness is but it's hard for kids to accept it (FM) 48

Chris' clinician also believed he was psychologically minded and developing an explanatory model was central to his recovery. "*He's very psychologically minded in lots of ways and has been able to look back over his life and pull these strands together....to have a meaningful explanatory model for him so I think that's been really important*" (C) 11. Chris' engagement in this reflective process was likely to have facilitated real constructive changes (Park & Helgeson, 2006).

Like Daniel there was a sense from Chris that he did not acknowledge his own fragility as playing a role in the development of the illness and was ambivalent about the nature of this illness. This is consistent with his tendency to externalise the source and experience of FEP and therefore to see the illness as something separate from his real self.

There was a situation at home where my father used me as like, cause I trusted him so much and because I'd always took it easy on him because he had schizophrenia he actually used me as a weapon against my mother in trying to get out of things. It was not that he couldn't do it's just that he didn't want to do it and I found that really morally wrong because I'd put so much trust in him and then I thought who should I trust? I became paranoid because I couldn't even trust my father with something so moral and so right. It was a big eye opener and then I thought to myself, I felt really stupid about that because I'd defended my father for 8 years...how could I be dumb about this and for me it caused me a lot of stress. It made me feel really stupid... And then I thought to myself well what's the truth? So much of my reality had been based on what my parents had taught me and what they believed was real I believed was real. Then that caused me a massive amount of stress realising that your reality is not real, and realising that you're naive, and realising that shit nearly everybody around me could be lying to me and there were people who were lying to....that's why I became really paranoid because I never actually checked what was real and what wasn't real. I never actually checked people's facial expressions I just sort of tried to fit in. Try to be a good person (Chris, 1st) 2

*I say that it was a mental health issue but, I don't see it as a disease I see it as more like a, a logical occurrence.....something that's not dealt with you know? Something that's unresolved.....if I could have been convinced....ah you know the way that I was thinking was like if there was somebody, **if there was somebody to um counsel me and may be let me see like things that, in, in a way that wasn't black and white um I believe that could have helped you know?** (Chris 2nd) 3*

*I became very paranoid because of, mainly that thing that I experienced with my father cause....I never imagined that he could do such a thing. **So these things highly distressed me and made me feel really stupid and making these observations whether truthful or not truthful made me feel better because I could understand why this was happening to me and understanding why this could happen to me I could prevent it from happening. I could change to become normal or, which is what I tried to do in the first place I tried to think in a more normal way....I decided that was the reason why I wasn't fitting in because I was a moral person and I try to be nice to people and I wasn't putting myself first basically and this is a big shock** (Chris, 1st) **after the formal interview***

Corroborating Chris' interview data, he sealed-over on the *responsibility* subscale on the RSQ at Times 1 and 2. This suggests that he did not feel responsible for his thoughts and behaviour during his psychotic episode.

His clinician also discussed issues relating to Chris' tendency to externalise the source and experience of the illness, particularly in relation to his father.

I think he at times has been a bit of resentment towards his dad and I think Chris certainly.....seems to feel that part of his psychosis was brought about.....in a secondary way through his relationship with his dad and not being equipped with how to behave as a man and not being equipped for the world and you know socially because of he feels of some of the deficits his dad has. So I think certainly initially there was some resentment about dad **not really being a role model* (C) 5*

This may indicate his constructive changes were illusory. Yet, Chris was aware of both the negative and positive features of his illness. These quotes highlight that FEP had a significant impact on his sense of self, relationships, and worldview. He also reported

ongoing secondary consequences such as issues relating to the themes *estrangement* and *stigma*.

Well my friends ah I've tried to talk to them about it but they don't want to talk about it....in my recovery I've just gone from strength to strength but um I believe that um if ah I hadn't gone from strength to strength the people around me would have walked away (Chris, 1st) 40

There is a bit of um shame at the stories that I made up because I realise that I made them up so really I could see a person that's sick, I could see why they'd want to hide that and they'd want to believe that it actually happened where it didn't actually happen (Chris, 1st) 39

Over time Chris appeared to find it increasingly difficult to adapt to his experience of psychosis. His recovery style went from an integration recovery style at Time 1 to tending towards integration at Time 2. Further, he sealed over on the subscale *liking* at Time 2, which implied that he no longer liked some of the unusual feelings and ideas he experienced when he was unwell. He also sealed-over on the subscale *cause*, which indicated that he did not think he had experienced an emotional or nervous breakdown. Also, while he reported no trauma symptomatology at Time 1, at Time 2 he was experiencing low symptoms (IES-R total score = 3, $M = .14$). Chris did not rate on the *intrusion* subscale but his scores on *avoidance* (2, $M = .25$) and *hyperarousal* (1, $M = .14$) were low. He rated the IES-R according to the belief that everyone was turning against him when he was unwell. In particular, he remembered thinking this when his mother was driving him to see a private psychologist. He did not know if the psychologist was going to help him or lock him away. Therefore, Chris' interview data and increase in PTGI scores over time may have been reflective of real change as it is believed that an ongoing struggle with the trauma is required to facilitate growth (Tedeschi & Calhoun, 2004).

Further to this, Chris was more realistic about some of his constructive processes at Time 2.

Well right now I'm a little bit boring all I do is spend my time thinking about what happened or previously I've just, in the last 2 weeks I've sort come to the

conclusions that I've.... Yeah and now I'm looking at moving on taking on new hobbies...I'm thinking about building some town houses with my family and we all want to get involved in it and I've got to do something for my parents (Chris, 1st) 23

I've realised that I'm too emotional about some things and I should let them go and um you know you can have dreams but you've got to be realistic about them as well. What can you realistically achieve in a certain amount of time and why do you want to take such a big risk you know? Life's not too bad the way it is (Chris, 2nd) 8

I've been able to, like this house thing it was just, I felt emotionally about it because I wanted to get out of the environment but I realise it's not going to happen....there's a lot of work that I've got to put in and I've got to be reasonable about this and, and then I can achieve. If you're unreasonable you're always going to be disappointed by what you do (Chris, 2nd) 17

This may indicate that earlier constructive processes were not reflective of true transformation but rather illusory growth. Indeed, like Daniel, Chris reported unrealistic benefits of experiencing FEP at Time 1.

What happened was, was what I believed happened I felt so stupid and so shit as a human being that I needed to achieve something to feel better and I decided that I was going to cure schizophrenia by getting it....it was making me feel less stupid and I, I think in a way achievement has always been like a drug for me my whole life, feeling stupid and not fitting in (Chris, 1st) 2

I must of felt so much better in that state because I was believing things that made me feel better. I was achieving something. I was curing schizophrenia. I was, I wasn't that criticism that girl had, put on me, I wasn't that I was actually a hero in a way (Chris, 1st) 4

Also, at Time 1 Chris spoke about always trying to consider things in a positive light, which may have defended him against the negative impact of the illness.

*I always was able to put a positive spin on things and look at things in a positive light so, it's the way you look at things, um, **if you see things as a negative they're going to be a negative impact on your recovery and I was always able to look at things in a positive way and take your mind in a positive light** (Chris, 1st) 49*

This hypothesis is consistent with the notion that illusory growth could decrease over time and lead to actual change (Park & Helgeson, 2006; Zoellner & Maercker, 2006a). However, it is also possible that Chris' reports of constructive change could be reflective of illusory growth at Time 2. Like Daniel his perception of his illness gave him an exaggerated sense of control. He believed his experience of FEP enabled him control possible future episodes

***I've gone through a lot and I feel like I'm free now of all this stuff you know and I'm happy about that and I feel you know like I've really recovered well and I was always afraid of mental illness growing up and like now I feel like I've confronted it, I understand it and although I know if I get off the meds it can happen again. I believe it can happen to anybody put in a certain situation so I believe in that way somehow like, I, I will be immune you know and I like that you know, I like that. I've like, I've confronted everything like very fear that I had while I was sick I confronted it** (Chris, 2nd) PTGI*

Similar to Daniel, Chris' constructive changes may have served a protect role counteract the negative experiences of having FEP. For instance, it is possible that he did not wish to view himself as the same as his father, who had schizophrenia, and his constructive changes acted as a buffer against this. "*When I got sick but **I wasn't like my father I didn't choose to take it as the end of the world***" (Chris, 1st) 5 and exploring issues raised in interview

*We've become closer and I'm able to talk to my father more about his illness um and I don't see it as a taboo anymore and **like I'm even trying to help my dad with things because he's got the wrong views on some things** (Chris, 1st) 37*

Consistent with this, Chris' mother also reported that he became fixated with proving that he was alright during his acute episode. It is possible that his constructive changes were an extension of his desire to convince himself and others that he was not inherently faulty, which is perhaps how he perceived his father who was unwell and Chris believed had recently behaved immorally.

*And probably for Chris he didn't find him in situation that he, that's he's wrong like until then at uni and high school everything was going fine. **And now like whatever he does it's not good, it's wrong so....in that period I notice what even before he give up job probably he was asking himself what's wrong with him. He started doing those IQ tests on-line...I think it came more like obsession to prove himself that he's alright** (FM) 10*

In support of the hypothesis that Chris' constructive changes also suggested illusory growth, his mother viewed some of his positive processes and outcomes in a negative light.

*I notice that he's....**doesn't notice so much other people around himself. Like the attention to others is missing....so something happened to somebody like....doesn't touch him so much like used to....I know that this sickness has impacted on it that he somehow doesn't see other people's priority like it's more his priority and he doesn't see that other people have some needs...yeah like he's more for himself now than he used to be** (FM) 15*

He's sees himself a little bit different than other people...he said the, all feelings that he had he's different than others....probably he's seeing that the way they want to do things like he's more cautious than probably his friends because of that, this experience. He doesn't want to get involved in silly stuff when they get up....Once he mentioned that he's so, during that period that he saw like from other side somehow....Like that's not everything's so rosy really and the way he said my life was sick all those feelings that I experienced I'm seeing things differently now and more like he's, if something is not like for him he's going to pull out. He's not going to say oh yes I'll go to here....like before he would say yes even without thinking what's involved. Now like he would step back.....A lot more cautious and

doesn't want to deal with such stuff like it's not fun or him anymore or something
(FM, 33)

Chris' clinician also discussed defence mechanisms Chris used to cope with the illness experience and reported an underlying fragility.

I think he's intellect has been really important for Chris. I think that's how he's negotiated his way through this. I think at times emotionally it was probably quite difficult but he wouldn't voice a lot of that. I think he's always come across as kind of intellectual you know and trying to figure out what, you know was going on (C)

11

I think it impacted significantly on his life and certainly the idea of having been unwell and acknowledging that he's been unwell has been a big thing because initially....there was very little insight but as the insight grew and the realisation that he'd been unwell kind of came home I think that was a massive thing because as I said his dad has been unwell.....I think probably fear of turning out like his dad has been a big thing. The fact that he wasn't able to work, the fact that he wasn't able to trust his intuition and his cognition I think was big as well because Chris describes himself as being quite analytical kind of person. He'll normally evaluate situations and his brains normally pretty quick and can figure stuff out and I think with this coming along it's been quite frightening to realise that he can't trust his judgement all the time and that you know at times it led him astray and when he was paranoid it wasn't helpful at all.....I think the need to know why it broke has been really important and to prevent that happening again
(C) 7

Back to work full-time within a month of so of recovery it was very, very early. I think he found it quite hard at the start and he put that down largely to medication.....but we also wondered about cognitively.....that was actually quite important to him because of the way that he views the world and the importance of his job....that's quite important for his self-esteem and to have to have that role...and that he's not a psychiatric patient, that's not his job (C) 10

I think if he was to relapse again that would be a massive challenge for him because I think then the issue of may be a I do have an illness or may be I do have a disorder that needs to be managed medically could come up and I think that could be big.....he's kind of said well there was a number of kind of unique factors going on at that time I've figured it out now I'm not going to get into the same trap again. I wanted to bring it on in a way. I knew it was coming on and....I thought I had control of it so part of it was that I let it run ramped when you know I could have stopped it earlier if I wanted to but I wanted to try it out. I think if it came back again that would shatter that sense of control which would be a big thing for him I think. That would be really challenging and then he would be confronted with things like am I going to experience a similar progress to my dad and you know does it mean that this is a chronic thing for me (C) 12

Overall, Chris' experience of constructive change appeared to be both real and illusory. Like Daniel, aspects of his constructive changes seemed to act as a buffer for his presenting concerns and features of his explanatory model of FEP suggested illusory growth. However, unlike Daniel, Chris was psychologically minded, engaged in an exploratory process to understand his psychotic episode. His clinician and mother both identified constructive changes and his pattern of growth over time was consistent with Tedeschi and Calhoun's (2004) model of posttraumatic growth.

Case Study Four (Andrew): Real Constructive Change

Andrew was a 21 year old man of Italian descent living with his family and in an intimate relationship. He had finished Year 12 and was completing an apprenticeship. Prior to becoming unwell Andrew had reasonable social and occupational functioning. He had a history of childhood sexual abuse, depression, and panic attacks. He had seen three clinicians who had suggested he may have bipolar II or schizophrenia. However, it was not known if he had been prescribed medication and the context of his mental health issues were not reported in his file. Given that it was unclear if he had been considered psychotic or received treatment for these disorders, Andrew was still recruited for the study as an FEP client. Andrew also had a six year history of marijuana use and it was unclear at the time of

recruitment if he was still using this substance. Additionally, he had used amphetamines and hallucinogens infrequently and engaged in occasional binge drinking.

According to the M.I.N.I., Andrew had a lifetime diagnosis of panic disorder and over the last 12 months had met criteria for alcohol abuse and both substance (marijuana) dependence and abuse, although it was unknown if he was using substances at the time of the study. During his acute psychotic episode he was diagnosed with schizoaffective disorder. Andrew's mental state had deteriorated over one year. During this time he had experienced periods of depression and manic episodes and was misinterpreting social exchanges and was suspicious of others' intentions. He had also withdrawn socially and managing daily living skills had become increasingly difficult. Andrew experienced paranoid, grandiose, and bizarre and non-bizarre delusions as well as ideas of reference, thought broadcasting, nihilistic thoughts, visual perceptual disturbances, and thought disorder. He self-referred to psychiatric services with his girlfriend's support. Andrew was not hospitalised but instead was supported at home by the YAT before being linked in with outpatient treatment. Andrew's compliance with his medication fluctuated over the course of his acute and outpatient treatment.

When he was first seen for the study his PANSS total scores suggested he was mildly unwell (63) and at Time 2 he presented as borderline unwell (56), with positive symptoms predominating at both time points. At Time 2 Andrew had ceased medication and disengaged with treatment. He had changed jobs but continued to work full-time in the same field. His sleep, self-care, and daily living skills had improved and he had started meditation.

Unlike Daniel and Chris, for Andrew the experience of being unwell was highly distressing and had a significant impact on him. "My *confidence and ego had been left shattered*" (Andrew, 1st) 35.

Central to this distress was a lack of control associated with his illness experience and this was related to the theme *disintegration*. The experience of *disintegration* could also produce *estrangement*. "*I was doing things that I couldn't control....when you're aware of something you're doing but you can't stop it, it burns you*" (Andrew, 1st) 15.

*It's a nightmare, it's a fucking **nightmare**. You can't talk to people because you're looking at them in a way that they don't understand you. You can't reach out to people because....people don't want to reach out to you when you're like fucked up and they look at you different and they talk to you differently because once they know that there's something wrong things change like **friendships change**.*

***Everything that I did and the way that my life ran changed. I kept changing....(girlfriend) said she couldn't never keep up with me....People were scared of me, people didn't understand me** (Andrew, 1st) 4*

Andrew's girlfriend also discussed issues relating to the theme *disintegration*, specifically a disruption to Andrew's sense of self and a lack of control. "*He **didn't feel like himself he felt like he'd lost his identity** he was sad depressed and sometimes very agitated, irritated*" (FM) 2.

***I think he just felt lost. I think that is just, he lost his identity, he didn't know who he was anymore, he was confused, he didn't understand why this was happening to him, he was angry, angry with himself that he couldn't cope...I remember him just always saying I don't know who I am anymore like that's, yeah** (FM) 6*

*When he was unwell yeah **feeling powerless...Well he didn't know how to deal with what was going on in his mind and that made him feel powerless. He didn't know how to stop everything. He didn't know how to get better. He had yeah no sense of control** (FM) 24*

Consistent with the interview data, Andrew's total scores on the IES-R also reflected distress. At both time points he was experiencing moderate trauma symptomatology (37, $M = 1.68$ and 27, $M = 1.23$ respectively), although his symptoms had decreased slightly over time. At Time 1 this was related to moderate *avoidance* and *hyperarousal* symptoms (18, $M = 2.25$ and 14, $M = 2$ respectively). His score on *intrusions* (5, $M = .71$) was low. At Time 2 only moderate *avoidance* symptoms (22, $M = 2.75$) were reported, while his scores on *hyperarousal* (4, $M = .57$) and *intrusion* (1, $M = .14$) were low. Andrew rated the IES-R according to the experience of paranoia, specifically the belief that everyone was talking and laughing at him. This could be related to his sealing-over recovery style on the subscale *liking* which indicated that he did not like some of the

unusual feelings and ideas he experienced when he was unwell.

At Time 1 there was a sense from Andrew that he wished to distance himself from his illness and move forward and attending clinical appointments was preventing him from doing this.

Inconvenience at the same time because you have time off you have to go to ORYGEN when you could be doing something with your life...I don't like hospitals, I don't like doctors, I don't like white walls so to me it's like another white wall that I have to go to (Andrew, 1st) 21

His moderate avoidance symptoms could have been related to this. However, Andrew initially engaged well in treatment. It is possible that the distress associated with his moderate hyperarousal symptoms was significant enough for him to seek support at Time 1.

Talking about anything is really good because you're going somewhere because you have a condition and if you're going there to talk about normal regular things then it's just kind of like a friendly visit. It's not so intense and not so oh you need to do this, you need to do that and try to focus on this it's just normal (Andrew, 1st) 21

Yet, it appears that Andrew found it increasingly difficult to focus on his psychotic episode over time. Andrew did not want to recall his illness experience and desired to regain control over his recovery process. As a result he had disengaged with treatment at Time 2.

Every time I thought I was getting better I went into ORYGEN and I left ORYGEN feeling worse every time. Every single time I went in with high hopes and feeling great and you know things are getting better and I'm controlling myself and every thing's going great and I swear to you every time that I left ORYGEN I felt more crazy than when I walked in...It just seemed the further I got from the place the better (Andrew, 2nd) 9

A decrease in hyperarousal symptoms and the presence of moderate avoidance symptoms, which had increased slightly over time, may have influenced his disengagement.

Andrew's disengagement from services at Time 2 does not correspond with his integration recovery style, which suggests that he should have been keen to receive support for his concerns. It is likely that this was associated with his desire to regain control over his illness and adhering to treatment did not allow self-reliance. His partner and clinician also recognised his desire to control his recovery process. They discussed issues of medication compliance and Andrew remaining at work despite his significant mental health issues. Therefore, it appears that Andrew continued to struggle with his ongoing adaptation to FEP and this was directly influenced by his explanatory model that the psychotic episode was uncontrollable.

He tried about 4 or 5 medications and he didn't sort of really like any of them and I don't think he really wanted to take any in the end... he sort of had his own ideas about how he wanted to try and get better....I think after a while talking to them didn't really help because he didn't have as much to talk about. I guess as some of....his bizarre ideas started to go away he had less to talk about (FM) 7
I know that sometimes you shouldn't be working if you're unsafe things like that but it gave him something to do and it gave him some meaning and it made him feel he do something because at the time he still was capable. So I think that really helped a lot (FM) 53

He was open, he wasn't always compliant. I think he had his own ideas of what....was going to help him and so at times he would kind of start on medication and he did a lot of chopping and changing. I think he got to a point where he kept sort of getting a little bit improved and then would stop medication and get unwell again or sort of within the same episode....got to a point where he said to us please don't let me play doctor stop me, you know can you please tell me if I'm....trying to control this too much.....that certainly did get in the way of him getting better (C, 1)

*I think work was helping him to cope...he felt really confident with what he was doing and he felt really able to do that so I think that **helped him just you know keep a sense of being capable you know when everything else was kind of a bit out of control** (C, 11)*

Andrew's desire to control his own recovery process, disengagement with treatment, and avoidance symptoms may have also been related to the theme *self-stigma*, which both Andrew and his partner discussed.

*I never felt worthless before I was unwell. I may have had problems but **never felt worthless until I started to go insane and then I thought I'm just another number now I'm just a crazy. Who am I, who are my friends to want to see me because I'm a fucking, I'm going to destroy their good time** (Andrew, 1st) 35*

*I think he himself feels better and so he thinks that if he keeps accessing treatment or coming to see ORYGEN or ORYGEN coming to see him he says to me that, that makes him feel worse **may be because he's associating himself with like psychotic people I don't know and may be that makes him think about it more** (FM) 14*

*I think he lost a bit of confidence.....a hypomanic period where he'd felt really, really good and really you know on top of the world and like a king and.....you know feeling really paranoid, self-conscious, and you know you've lost your confidence essentially. So in some ways we saw you know a big reduction in his confidence....I think **he was able to.....reflect on some of the symptoms in a way that did I guess make him feel, understand more about his own kind of lack of self-esteem. I guess initially we saw a big drop in self-esteem and perception of self** (C, 3)*

Andrew's avoidance of reminders of his experience and absence of perceived control during his psychotic episode could have impeded his ability to work through his illness experience, which his clinician identified.

*I think he identifies as having had mental health problems and....I think that **kind of changes in some ways your perception of yourself....in some ways it hasn't been hugely disruptive to his own kind of vocational pathway so....I'd interpret that as wanting to sort of forget about it in some ways and wanting to kind of not have***

to delve into stuff that's really difficult so....I assume he's a little bit fragile still and trying to protect himself and just trying to, you know that same thing around putting your head down and just kind of got to keep going, got to keep going (C, 7)

I think that he probably does have an illness....that's going to need to be managed and I don't think he totally understands that yet. I think that he sort of feels that it's you know pretty much gone so he's kind of safe from it...I think he's a trial and error sort of person and he's someone who's got to kind of you know work it out for himself and you know it's that whole thing of not wanting to rely on people as well and needing to, this kind of having this sense of needing to be self-reliant.....I think it would help....to reflect on what's happened and to get more of a sense of what he's understanding of what's happened.....he gets the connection between drug use and psychotic symptoms and that's been hard for him as well cause I think he kind of blames himself for some of what's happened (C, 12)

However, despite Andrew's disengagement from services, he was acknowledging the impact of the illness. Unlike his clinician's reports and Daniel and Chris, he was aware of his underlying fragility and the ongoing nature of his recovery process. ***“Yeah I let myself go and now I'm back into training got the weights out, looking after my health yeah got to do the right thing, can't let myself just wither away”*** (Andrew, 1st) PTGI. ***“I had no idea what recovery was. I didn't think I was going to recover...It's between very and somewhat so it's up there somewhere”*** (Andrew, 2nd) 53.

Instead, avoiding treatment gave him a sense of self-reliance and in turn he felt as though he was regaining control and responsibility for his illness, which was arguably adaptive and facilitated his own self-management. Andrew's integration recovery style at Times 1 and 2 also suggests that he was working through the psychotic episode and reflecting on what happened. ***“Once I got on the medication I actually took a look at what I was doing and then I realised that everything was wrong and just if you can't be yourself who can you be”*** (Andrew, 1st) 17.

It's more a positive thing now cause I can look at it in hindsight. I look at it as like there was a square that I've stepped out of and I can look back and see where I went wrong (Andrew, 1st) 15

Look back and go why the fuck was I like this. You have to be assertive. You have to take care of yourself. When you have to say something you've got to say it. If you need to get the job done get the job done don't ask questions do your fucking thing. Failure is not an option... You can let it consume you or you can fight it and I chose to fight it (Andrew, 2nd) 31

When I look back just makes me, just stronger I guess.....I've become more mentally tough like my mentality is very, very, not so manipulated so to speak. After, after looking back at that and realising you know everything was bollocks at the end of the day. Yeah I think I got a lot tougher (Andrew, 2nd) 4

His clinician also recognised the protective role of Andrew's avoidance and the opportunity it gave for self-management. This is consistent with Tedeschi (1999) suggestion that some distance from the trauma promotes a reflective process needed to facilitate growth.

I think he just was driven to keep going....it's interesting I think that in some there's some stigma there but I think in many ways he was really open and he knew something had been you know wrong for him for a long time. So I think he was you know driven to try and fix it....in his way he was trying to kind of you know work out what was going on. I think that did help him. And in some ways that kind of closing down of you know I think not wanting to have involvement with us at the moment....isn't about stigma....I think that's kind of a good thing that's helped him cope is that he's kind of open and intrigued and you know it sort of sparked an interest in understanding psychology and you do lots of reading about different theories. So I think that interest in you know trying to self-healI think that did kind of keep him together (Andrew, C) 11

Unlike Daniel but similar to Chris, Andrew was aware of the pain of his psychotic episode as well as the positive aspects of it, which is central to an integration recovery style and true growth. ***“Being unwell it’s not helpful. Being unwell is definitely not helpful. Only, the only thing that it’s helped me see is who my real friends are and that family is family for life”*** (Andrew, 1st) 48.

The unhelpful aspect is getting paranoid about what you hear...and you know tearing your mind apart but the helpful thing is like you learn to appreciate things more such as you know the arts and music you know for me cooking so it does have its ups and downs. I think there’s more positive that’s come from this than negative (Andrew, 2nd) 52

Like Chris and consistent with his integration recovery style, Andrew’s clinician identified that he engaged in a search for meaning of his psychotic experience and explored the illness for personal information. It is likely this also facilitated the development of real constructive change. ***“Thinking about where he was going in his relationship and what he wanted out of that, thinking about....you know how he puts others needs ahead of his”*** (C, 8-9). ***“Friends he definitely pulled back from and felt mistrustful of at times and sort of really questioned the value and the reciprocity of friendships. I think he felt that he’d sometimes given a lot”*** (C, 5)

I think his mood changed and at times his perception of himself changed but in terms of his sense of who he is....may be a sense that he’s more vulnerable....one thing I think he did question was who was important to him and his friendship groups.....I think it was sort of you know perspective taking on at the end of the day who’s important to you I think that kind of changed for him (C, 4)

Like Chris, Andrew discussed constructive processes across all three broad areas of change: *improved relationships and view of others, enhanced life view, and deepening self knowledge*. Examples are listed below.

Well with your family, whether you like it or not they’re your family and they’ll always be there for you to support you. If your friends go away and make no effort to see you then they’re not your real friends especially when you’re in need the ones that, even ones that stick around to say hello even though they know you don’t have much to say you know that they’re your real friends because they were there.

Like it didn't matter what they were doing but they were there anyway (Andrew, 1st)

48

I more concerned about myself than anyone else now like I put myself first and you know that's, before I would put anyone first except me I would put you know I'd pick up a fucking stone under my shoe and say you know this can go first. Now it's like you know you've got to have a bit of fucking pride. Sometimes, at the end of the day you've got to take care of yourself (Andrew, 2nd) **30-31**

My priorities now save, travel, experience life, make the most of what I have as opposed to in the past it was this is what I want this is what I need dream about it but I'd never do anything about it (Andrew, 1st) **PTGI**

Corresponding to his interview data, Andrew experienced the greatest change in relation to the domains *appreciation of life* (15, $M = 5$ and 15, $M = 5$ respectively) at both time points and *relating to others* (35, $M = 5$) and *new possibilities* (24, $M = 4.8$) at Times 1 and 2 respectively. On the PTGI his total scores (97 and 93 respectively) indicated that he was experiencing high levels of growth at Times 1 and 2, although it decreased over time. His scores on the other subscales were: *personal strength* (19, $M = 4.75$), *new possibilities*, (23, $M = 4.6$), and *spiritual change* (5, $M = 2.5$) at Time 1 and *relating to others* (31, $M = 4.43$), *personal strength* (17, $M = 4.25$), and *spirituality* (6, $M = 3$) at Time 2. However, in contrast to his interview data and results on the PTGI, Andrew sealed over on the subscale *satisfaction* at Times 1 and 2. This suggests that he did not think psychosis had helped him in obtaining satisfaction in life. Perhaps the opposing results indicate the presence of illusory growth. However, it is also possible that constructive changes and recovery styles are independent constructs that can influence one another or serve different functions in ongoing adaptation to FEP.

Andrew's awareness of the significant impact of the psychotic episode coupled with his integration recovery style at Times 1 and 2 and desire to manage his illness may have allowed new models of the self and world to emerge and subsequently influenced his high levels of growth over time. This also indicated that his constructive changes were more likely to be real rather than illusory.

*Things have sort of picked up and I started caring about myself. Trying to get the right amount of sleep, trying to get the right kind of food, **trying to have a healthy mentality and be positive about things and things got better and still continue to get better** (Andrew, 2nd) 8*

The presence of constructive processes and outcomes were confirmed by his clinician and especially his partner, which indicates that they are likely to be indicative of actual rather than illusory change. Unlike Chris' and Daniel's loved ones, Andrew's partner identified a range of constructive outcomes. Each of the quotes provided demonstrate different aspects of constructive change reported by Andrew's girlfriend and clinician.

***He sort of found out for himself what's most important for him and what people in his life are most important to him.** Like you know there were some friends that were sort of more supportive than others so I think it sort of just reiterated that, **he's never really taken anything for granted but I think this has made him not take anything for granted even more** (FM) 15*

***I think he's a little bit more serious and he's a lot more focused and he's also sort of more organised** before he was just sort of all over the place and I guess he had some goals but they were just all sort of muddled and but now he's sort of yeah more organised **he knows what he wants, he's not confused about that** (FM) 32*

***I think so he's had to find, like he's had to sort of develop a new sense of himself. Develop a new sort of identity....** before he was unwell I guess he was sort of, he still is easy going but he was much more easy going and just sort of in that hole sort of rock, metal sort of drug taking thing, that's not all he was but like, but **now he's still into the same thing and still appreciates music and everything like that but he's found other things to define him and he's more involved in other things as well....** Well I guess like his family, his relationship, his work, and still music but not in the same sort of sense (FM) 33*

***He's more motivated to get healthy. Like not only with his like mind but his body as well.** I think may be that's helped. So like he's started eating better and at the*

right times and yeah he's more motivated to look after himself. I think he has more, what would the word be, you appreciate yourself more, self-worth (FM) 41

*He approaches my family much differently like he's much more mature and trying to sort of point out things to me that I don't see like how I get along with my parents he's very good at that....**He is just sort of more into the future now and yeah just seems more mature (FM) 17***

*I think it can be unhelpful because if, I don't know I guess he was lucky cause he sort of got treated at a pretty good point but if you're not you might not get the result you want, you might go back to a level of functioning but **I think because he did it was beneficial for him because now he looks at life differently and his priorities have changed a little bit (FM) 48***

*He's still with his girlfriend....**he has acknowledged at times you know the importance of that relationship to him. I think it also kind of has at times made him think about how much he wants the whole kind of just one single monogamous relationship** now so I think it's triggered a thought process.... I think the positive is that he's thought about it (C) 5*

The development of constructive outcomes emerged as a process developing over time, which is consistent with Tedeschi and Calhoun's (2004) model of posttraumatic growth. Andrew was less able to articulate these changes in comparison to his girlfriend and clinician. He had some tendency to compare how things had changed in relation to the psychotic episode rather than prior to the episode and articulated that he could not remember how he was before he was unwell. This might be due to his long duration of untreated psychosis. Therefore, constructive processes and outcomes may evolve over time as the person is better able to establish some distance from psychotic episode. This is consistent with Tedeschi's (1999) claim that some distance from the trauma and distress associated with it is needed to promote growth.

My bond, the bond that I share with my mum and dad is better. Before I didn't want to reach out to them, didn't want to talk to them I mean I did but at the same time, I just got closer to them you know they help me out a lot which is good... Since I started getting better in the last 3 months I got a lot closer with my family whereas before you know they were trying to help me but I was kind of still keeping them in the dark (Andrew, 2nd) 37-38

I don't remember what I was like before. I have no memory of what I was like or who I was before I got sick. It's like waking up and just realising that you're a new person from scratch...cause I don't remember anything about my old life.....it's like my memory has been wiped out (Andrew, 2nd) 35

Nevertheless, it remains likely that Andrew's changes reflect true growth. A key difference between his interview data and Daniel's and Chris's interviews was an absence of evidence that his constructive changes could be self-enhancing or serve a protective role.

Summary

Overall, these case studies highlight that to different degrees, people can actively engage in examining the experience of their psychotic episode and its impact and develop an explanatory model of the illness, which is influenced by an individual's personal history. Further, a more comprehensive understanding of the impact of FEP includes a broader range of distressing experiences during the psychotic episode and recovery phase. The case studies indicate that the recovery process includes how a person manages the illness and the development of restorative outcomes and constructive changes. How these elements of recovery influence each other occurs in the context a person's explanatory model and their ongoing adaptation to FEP.

The case studies provide detailed evidence for different recovery pathways. Constructive change can vary from little or no growth to illusory and real change. Chris' and Daniel's case studies showed that both illusory and actual change is important in the recovery process and how one adapts to the experience of FEP. The case studies also demonstrate that the development of constructive changes is a dynamic, flexible, and

ongoing process. Andrew's and Chris' case study showed the development of real constructive change requires FEP to have caused significant impact and for the individual to engage in an ongoing struggle with the illness and a reflective process. Andrew's case study also suggested some separation from the illness is also necessary to produce growth. Yet, Chris' and Andrew's case studies illustrated that a high level of PTSD symptomatology is not essential to growth. Rather, it appears that for growth to occur it is necessary to have an impact on one or more of the person's sense of self, their relationships with others, or their life and world views.

Detailed clarification from family members and clinicians largely validated the importance of considering both restorative and constructive factors in understanding recovery from FEP. Any disconfirmation or differing opinions of these processes from significant others or treating professionals did not disregard the importance of these elements of recovery.

CHAPTER 9: THE EXPERIENCE OF LOVED ONES GROUP RESULTS

This chapter presents group results on the experience of loved ones over the course of their loved ones FEP. Results are presented in four broad areas: the impact of FEP, treatment experiences, ongoing management of the illness, and issues relating to restorative recovery and constructive changes.

The Impact of the Illness Experience

Interviews with loved ones revealed that the experience of having a relative or intimate partner with FEP produced high levels of distress. In describing the acute episode loved ones referred to: the nature and experience of the psychotic episode, the role of supporting loved ones, a lack of understanding about psychosis and how to manage the illness experience, and the impact of the illness on relationships and the loved one.

The experience of the actual episode appeared traumatic for most loved ones. Intense anxiety and fear for loved one's wellbeing as well as their own were common.

Well it meant that I'm happy to go back home after work or to be at home instead of going into the city and walking around for 2 or 3 hours because I was frightened of being in my own house because he might do something to upset me or I might inadvertently do something unintentionally to upset him. And I used to do that I used to walk around the city looking at shop windows at night too scared to go into my own family home (Jack, FM) 50

And just as I said very, very aggressive and very frightening.....had a wall of photographs by the front door and he just smashed them all to smithereens....just physically getting very irate and you know spent sort of minutes jumping on the spot shouting and shrieking.... he was drawing sort of demonic pictures in the newspaper.....So I guess it was scary....we locked up knives.... You know it was very frightening for my husband because I work all day and he's at home....I'd be ringing him, is everything alright? I didn't want to go to work....it was tough.

....it was a very frightening...the aggressive side him...was very new (David, FM)

5

*Oh well not knowing what, he was hearing voices telling him to do things, so worrying what the voices would tell him to do. **I was worried that he might be suicidal so that was the biggest concern for me....It was really stressful like I said cause I thought he might be suicidal....the second time he took off we knew that he'd taken off and I didn't know what he was doing that he might think that he has to kill himself** (Daniel, FM) 2*

For two loved ones, concerns about their family members were also related their own personal experiences.

*I mean my job is, **I'm CEO of a foundation that looks after people with acquired brain injury**, so you know I mean **I'm on high alert**. I'm thinking hypoxic brain injury.....**just thinking the absolute worst as I could** (David, FM) 6*

*And perhaps **my personal one, my father was schizophrenic all his life**.....it was something that **all of a sudden took me back to my childhood and life of you know of my father when he became very violent and aggressive etc**.....it was just sort of frightening thinking **oh my goodness you know I'm the one, I'm the one that's going to have someone that's got a mental illness sort of thing so I guess it was just reality that you know** (David, FM) 6*

A few loved ones found the development of the illness sudden and confusing, while others began noticing potential warning signs earlier on but may have coped using denial. This can be associated with a lack of knowledge about mental illness. “**Well I was very confused like there was no warning signs I didn't know...It was very sudden**” (Daniel, FM) 1. “**I guess it sort of did happen progressively but for like the first half of it I just found excuses for everything I don't know how but it's amazing**” (Andrew, FM) 3.

I mean a year before it really happened this is not good signs like I saw that he's a bit nervous but you don't want to like say to yourself that your child is getting sick.....start continue something else then he leaves somewhere and he forgets

where they are and looking always for something and then he would accuse somebody took his stuff and things like that and I wasn't thinking this not really good but you always hope it's going to turn better and go away (Chris, FM) 5

*I guess not knowing what was going on. **Having absolutely no idea about anything to do with psychosis or anything like that so I had no idea what she was going through at all.** She didn't really talk about it she just sort of tried to keep going so when she was going to the doctors and stuff **it was very confusing and disconcerting. Especially when she went to hospital....that was a huge thing** cause you know **it sort of went from you know she was just having, feeling depressed and tired to having all this come to ahead really, really quickly. Yeah I knew something was wrong but didn't know what or how to identify it or what to do about it in anyway** (Alana, FM) 2*

Associated with this was uncertainty about how to manage the condition, and loved ones expressed feelings of helplessness and inadequacy, as well as a lack of control over the situation.

*I mean you'd hear these stories and some of the things that he'd say or be worried about obviously were figments of his imagination but other things that happened at the same time were real and probably didn't help the situation too much....**I mean I obviously knew he had a problem, but sometimes you might had, had four things in the day that might have been real or might not have been real and you didn't know.** You can't ring the CAT team every five minutes and ask their opinion on things like that (Jack, FM) 4*

*I wanted to treat him like I normally would. **I guess the hard part for me was not knowing how to treat him.** I know that sounds really simple but that was really hard for me because **I wanted to treat him like I normally would but I couldn't because he was experiencing everything else** (Andrew, FM) 2*

Hard like the hardest thing I think I'll ever have to do ever. The hardest thing is that my mood depends on his mood that really sucks... Yeah just probably just about the hardest thing, not really understanding, not being in control I think that's the hardest things cause I'm a perfectionist a bit of a control freak yes probably that (Scott, FM) 11

Significant others coped with the illness in a number of ways which included specific ways of responding to symptoms, not telling others about the illness, and preparing oneself for the worst. *"We shouldn't have done but telling him, trying to talk him out of his beliefs which I realised there's no point trying to do that....and that used to agitate him we don't understand, we don't understand"* (Daniel, FM) 14.

And he talked a lot to me because I knew already that I let him to talk inside real things....I didn't disagree with him I would say because I knew already from my husband if you disagree with them just made them more angry (Chris, FM) 8

The biggest thing I think....every time I go to uni I'd have to like to prepare myself, convince myself that he might be dead when I come back....as weird as that sounds....because he was just so unstable and...but I just, yeah and I sort of dealt with it by myself (Scott, FM) 1

It's not really something that you talk about very much anyway....I'm pretty private so I didn't really tell friends like they knew, they just thought it was depression which people finds that easier to understand....And just my parents like they're really supportive people but they would have made me move home and I didn't want him to have to move back with his family straight away cause they're just a bit different....probably the most challenging thing ever....cause I'd have to come home as soon as I could (Scott, FM) 2

And his family were very supportive as well but my family sort of still don't know what was going on and this is only minor but it was sort of hard when he would come over because people would be like what's the deal, what's wrong, whatever and I didn't think they would understand (Andrew, FM) 2

Some loved ones also discussed denial or blocking out the experience, as well as a desire to flee it in an attempt to cope with it.

Hard, I kind of like blocked a lot of it out so it's hard to really think about it. Cause it's not really at the time that I was thinking about it does that make sense? Kind of like afterwards or when things, you become aware of it (Scott, FM) 1

So I would say sort of obviously concern and fear and a definite frustration to not be able to talk him out of it or do much about it myself until it reached a stage where we called the CAT team in...I started to still feel a little daunted and uneasy when things weren't getting better after a few weeks or a few days may be I expected too much...thought of running away and creating a new identity and just disappearing myself which may sound very strange and very selfish but I thought of it (Jack, FM) 2

Some personalised the experience of FEP in relation to their perceived role in the onset of the illness and their loved one's symptoms and interactions with them. Associated feelings included guilt, regret, and self-blame. "It was a little bit frustrating as well because all the things he was experiencing I would personalise and think it was about me when really it wasn't really about me" (Andrew, FM) 1.

You feel somehow like you missed, like you made mistakes somewhere couldn't you do something more to prevent not to happen.....it was like still I'm asking myself what could of I have done better you know like to so that he feels better (Chris, FM) 2

He would get nasty towards me like sometimes he would stare or he would accuse me that I'm guilty because my husband got sick and things like that. Then when coming from your child like you know that he is sick, that he's unwell but touches you even harder than when my husband was sick. Somehow I don't know but you know some, you are trying to tell yourself oh that's not really true, that's not what he really meant....but in meantime like when that passes he would say sorry mum I didn't mean it like that (Chris, FM) 2

And I guess I felt guilty as well because he started experiencing some symptoms like some psychotic symptoms within like the first 7 months of our relationship....for some reason I just thought I was a huge part of why this had happened to him and I didn't know, that guilt got in the way of me helping him
(Andrew, FM) 2

A significant impact for people who were in a romantic relationship with the person who was unwell was the change in their relationship dynamics both during the acute and recovery phase. They discussed the burden of the carer role, breakdown in communication, and loss of support from their loved one.

Eye opening....it's a bit scary that like during those periods like people, doctors would be there and they'd be like you know he'd be dead if it wasn't for you and I'm like oh my god like. You know just the pressure of like I have to be there. I have to survive cause if I don't he wouldn't and I really don't think he would of
(Scott, FM) 11

He totally didn't need me like it went from, it was really strange because like I'd call and he wasn't really interested in the calls he was just interested in being there. So that totally transferred like, from him needing me to needing them. Yeah it was really hard (Scott, FM) 8

You can't really rely on him for anything which I find really hard because like, you feel like you're 21 and you're with a boyfriend you can't really rely on to do things.....I think I've been let down so many times because of his illness (Scott, FM) 45

I think she feels supported by me but she only relies on me. She doesn't rely on anybody else.....short of the practical she doesn't rely on anyone else emotionally for support....Yeah I feel like I'm just her carer and there's nothing else really there apart from that (Alana, FM) 40

*I helped him because I was always there but I think I also didn't help him because **I had these huge expectations of him and like I was always thinking about my needs at some points....So I think having a partner sometimes can help a lot but sometimes it adds extra pressure and stress because that's person has expectations and needs and they don't always under, well I didn't always understand that he couldn't meet them at that point in his life*** (Andrew, FM) 14

The loss of one's relationship with their loved one was also discussed by some participants. "*Well just sort of thinking that **I'd been robbed of a normal son. When was my normal Jack going to be there again you know?***" (Jack, FM) 2.

*It's just, I seemed to spend a lot more time with him before he had it like we'd go out and have meal together and shopping together and all those sorts of things and **it's pretty rare we do that sort of thing now*** (Jack, FM) 36

David's mother also spoke of the devastating impact of his suicide attempt and the grief and loss associated with this as well as her attempts to continue to function in her own day-to-day life.

*I hadn't really broken down until this.....And they basically said you know it's probably going to get a lot worse and prepare that this is probably what you'll take home and he'll go to rehab for months and months and months and whatever and it's like a stroke patient and so at that stage **I just went out into the corridor and sat by the window and just cried and cried and cried.....we just couldn't believe that this is, you know may be what was going to be our beautiful child.... in-between I'm trying to go to work and trying to, you know just manage everything and function and whatever thinking I've got to function*** (David, FM) 6

Two people were aware of the potential stigma their loved ones may experience and were concerned about this.

*First week he wasn't ready to go back to work but he wanted to go back to work and that's it because **still he would say something nonsense** and you know how other people, **other people take advantage of that and make fun of you and I was worried about that but I couldn't stop him*** (Chris, FM) 14

Just that people freak out, or they, you know if they talk about it with someone at a job they're not going to hire you it's a reality like very few would yeah just talking about it in general (Scott, FM) 39

However, while the experience of the psychotic episode can be highly distressing it can also bring relief for loved ones. Simone's mother described the illness experience as having beneficial outcomes because it provided an explanation for their loved one's behaviour and an avenue for support. It also validated the difficulties they were experiencing with their loved one.

Well once we knew what was wrong with her it was better because there was a reason for it, it wasn't just bad behaviour. I just thought I was the most hopeless mother in the world to have a child behaving like this who was well into her 20s ..And it was almost like we were glad it happened in the end because ok lets out a name on it we've got people who can deal with it and the medication of course was calming her down and making her better so we were glad it came to a head (Simone, FM) 2

Treatment Experiences

There were mixed responses about treatment from loved ones. Some framed interactions with clinical services in a positive light. *"But the CAT team were very good. They gave me quite a bit of advice and all that sort of thing"* (Jack, FM) 2.

She said to me we're going to section David and we want him to stay and I just, I said that's not bad news. I, I said I thought you were going to come out and tell me I'm going to have to take him homeso that was the least frightening thing of all (David, FM) 6

I saw when he's all day home like he wanted, I was scared he wanted to go somewhere....I don't want to let him to go by himself....and then at night he wouldn't sleep properly so I wouldn't sleep at all.... I was trying like as much as I could like when he's, if he is going to go somewhere that someone of us go with

him. And then if he's down in hospital like was better for me to I know that he's in safe place (Chris, FM) 8

However, for one loved one the experience of visiting her partner in hospital was very a difficult. “*Well from my point of view it was awful, weird, I hated it cause I visited it everyday*” (Scott, FM) 7-8.

A number of loved ones also discussed frustration with clinical services in relation to a range of issues. This was not limited to mental health services but included a range of professionals who were involved in their loved one's treatment. Problems included poor communication between services and with family and their loved one, inadequate assessment, being disregarded in their loved one's treatment, and slow progress in treating the illness.

Like he went from (hospital) medical unit to the psych unit at (hospital) which was hopeless....I wrote them a letter because and they were terrible about giving the (hospital) reports and we were told nothing in there....David was told nothing. He was handed a new anti-psychotic one day and just sort of said here take this and not told what it is and he refused to you know and I said don't treat him like he's an idiot. You're dealing with the wrong person here. He'll question everything and, you know, but we hardly ever saw anyone (David, FM) 7

Can you not realise that you're dealing with psych problems here as well not just physical problems? And so you have to be very careful what you say to him and what he's been through. This is not a loser kid. This is not some loser who's you know tried to kill himself etc. He's a very unwell young man who is just struggling with his life so don't treat him like a loser and I said if you're going to tell him something I know he's an adult, I know he's 24 years old, but even so can you make sure one of us is there with him to support him (David, FM) 6

Because I had experience with my husband and I saw, I knew that something is wrong from a psychological side....I can't say 100% how he explained to the doctor because he gave him just Zoloft and did he explain exactly to him what's

going....I personally think sometimes they don't take care enough like usually they should be assessed with really professional person and spend a little bit more time. You can't like in ten minutes with those patients really realise what's really going on (Chris, FM) 3

I wasn't happy she was just GP and was another psychologist and then I just tried to explain to her because she was asking Chris something I can't remember because whatever he said wasn't real, and I just tried to explain to her, like I was trying to explain to her briefly what's going on so that she can get real story because he would start one story then another story.....she got upset she said can you please leave I just want to talk to him (Chris, FM) 3

Ongoing Management of the Illness

A range of issues were discussed by loved ones in relation to the ongoing management of FEP. Loved ones discussed being worried about their loved one's ability to function, how they dealt with the illness, and the recovery process. A few loved ones recognised the impact this may have on the person who was unwell.

The first few months were sort of really hard because, like once again like I just didn't know how to respond to everything like I wanted to treat him normally but then I was getting paranoid about you know his experiences and always sort of looking out for things and I felt like that was interfering with me treating him like a normal person which is all he really wanted. Like I was just getting obsessed with little things he might be thinking and that was eating me up and so I couldn't, I wasn't even being normal sort of thing so that was really hard (Andrew, FM) 14

So you never know is that going to come, if you stop taking medicine is that going to come back and he's going to be worse or what's going to happen. And you're always scared of the worst thing....and what's going to happen in his life like for me, for a mother cause I saw my husband like...he really never went to work after that and was really hard for family and things like that and when you have your

*son you are always thinking Jesus Christ is **he going to go through all that or, that's what's hard** (Chris, FM) 48*

*I just wonder does he think, you know, do they, are we talking about him? Are we, what are we thinking? **I know he worries about me and...when I'm looking at him I'm analysing and thinking that this is wrong or that's wrong and he sees that as a real negative and I'm trying so hard not to let on....It's really difficult but I try as hard as I can to just be this happy hi how are you? I haven't noticed that you're a bit down or that you forgot to do that** (David, FM) 11*

Chris' mother found it very difficult to talk about her son's illness, which may have produced a sense of estrangement for her.

***And I find really hard I never said to nobody what's really happened to Chris. I don't know even today I find really hard to talk and with my friends or anybody. Somehow it took me while about my husband to discuss with anybody but I don't know for him I really, I talked even to my sister, I can't really, I really can't talk like something completely shuts me down** (Chris, FM) 8*

David's mother also feared he would attempt suicide again and was often reminded of his past suicide attempt.

***That phone call is something that is etched in my memory to the point that I hate Sundays...I've got to go and visit someone or go shopping, or because if I just have to sit around and not doing anything and relax on a Sunday it's nightmare for me.....it's just every parent's worst nightmare without a doubt, without a doubt. And sadly for me I suppose more than anybody else I just am not sure that, you know that it won't happen again....it is my greatest fear that I'm going to out live my son. It's still at the back of my mind** (David, FM) 8*

Like FEP participants, family members also discussed the theme *viewing recovery as a journey* and believed changes in treatment were indications of recovery.

***Well when the CAT team probably decided that they didn't need to come every couple of days and handed it over to you guys he was well on the road to recovery then I'd say, well on the road to recovery** (Jack, FM) 52*

You know how people sometimes they take like a step forward and then they take 5 steps back it's like that so I don't really want to jinx myself...I'm probably a pessimist these days but I mean it's good that he's done it.....so he's definitely better but I know, I've seen how he can get better and then get worse so (Scott, FM) 12

Well I see it as ongoing and I hope it progresses. I suppose that's that, that's the way I see it. I can see yes she's recovered this amount how much more recovery or is this as good as it gets you know. I don't know what their ideas are on medicating her whether this goes on forever or does she get off the tablets and I suppose that's a trial and error thing. But does recovery mean being off medication I suppose that's something. I don't know (Simone, FM) 50

Look I guess recovery for me is a day by day. Recovery for me is that David's stable. That he's alive.....and he's able to manage his life. Recovery is.....I don't know that I see an end.....but that it's probably a life of medication and up and down sort of you know, and I don't know if that's because of my father or because, I don't know, I just feel in the short term at the moment recovery is a long way off. Real recovery if ever, you know recovery will be David being able to live his life in a reasonable way but it will be under medication or psychiatric counselling or help or whatever in some way (David, FM) 50

I guess I was hoping for a lot....the medication has been really haphazard. The side effects have been awful for her. She's gone from huge weight gain to the shakes to not being able to sleep for weeks on end so she's had a very rough time with that so that's been very hard.....I don't think she's really recovered in any particular way (Alana, FM) 50

Loved ones also talked about their role in the recovery process; however this was not always an easy journey for them.

Well with, now that you can talk to her. You can tell her things so I suppose we're trying to catch up for lost time because we did have a lot of lost time so we're

trying to sort of you know get her to be an adult and get her to do all the things she has to do and try and advise her and but also hold back and let her do it herself....Yeah without trying to take over because she has to do it yeah that's the sort of support and you know she's asking for advice and we give advice (Simone, FM) 40

I always sort of had faith and I never really gave up. I guess I was sort of may be always sort of available to talk if he had stuff on his mind....And just trying to be understanding I mean half the time I wasn't understanding so that wasn't supportive but the times when I were like, when I was understanding you know would just be understanding at the time that he wasn't well and may be he couldn't do the things that he would usually do and not holding it against him. And trying to be a bit more easy going (Andrew, FM) 40

Yeah I guess pressure doesn't help the recovery like you can't make someone, like if you have someone being like do this do that....I think at times may be I tried to do to and it doesn't work it sends then backwards....I think it's just time and you've got to try and convince everyone around them that time is the best thing.....What's not helpful I think that people when they get, they help someone, support someone they obviously get run down and putting their own pressure on to him. I think I saw myself and his mum do it at times like go back to work for me....which is awful but I guess I just didn't know any other way.....they can't survive themselves so how are they going to handle your pressure as well so...yeah you sort of start to become, not selfish, but like you're like oh my god I'm going to pop (Scott, FM) 52

It's really difficult because you know I've had screamed at me so many times you're interfering....and you've got to let me go...and you're looking for things to be wrong with me. That was what happened in the hospital...So now I have this real dilemma when he comes....it's sort of small talk....We start a conversation up that way rather than me going in with the personal stuff.....then I just let him

come with it. I don't push it, you know. I don't know whether I should or I shouldn't but you know I just, every day is a new day for us and I just sort of go with it (David, FM) 40

Restorative Outcomes and Constructive Changes

Loved ones predominately focused on restorative recovery. However, some also discussed constructive changes. Although loved ones are speaking about their significant other's recovery, these themes relate to what they perceive recovery to be rather than what they believe FEP participants think about it. Thus, they are not associated with triangulation of FEP participants' interview themes.

Family members identified recovery as the development of contentment and enjoyment and establishment of new relationships or maintenance of old ones. They identified the importance of regaining functioning and/or one's prior self. Regaining functioning did not always mean complete symptom resolution but rather coping with life. *"Finding yourself, being able to go back to sort of everyday activities, finding some joy out of them. What else? Maintaining relationships you know getting back out there in the community"* (Andrew, FM) 50. *"That he wants to live, that he's happy, probably just to be happy within himself and not worry about anyone else around him"* (Scott, FM) 50.

Well I want him to be able to live a normal life even though that's not what he wants he has to be able to feed himself, put a roof over his head. He can have these beliefs as long as he can't hear voices telling him to do things and he has to be able to hold down a job so that's what I want...I mean there's lots of religious people who believe a lot of strange things it's just that hearing voices that's completely different (Daniel, FM) 50

Well...in a perfect scenario she'd be back to the way she was two years ago but I mean in a way that she can see some sort of way forward and be able to move towards that and be able to set goals and say this is where I want to be in 6 months, this is where I want to be in a year. You know I'm going to work towards these. This what I want to achieve so and be able to put those into play (Alana, FM) 50

I'm hoping that he won't push people away because it's in meeting new people, I mean god I go to bed praying every night some beautiful young man will come along and sweep him off his feet. You know that's every mother's sort of dream about their children. They want someone to sweep them off their feet and make them happy, yet you don't want them to be alone (David, FM) 14

A number of loved ones described positive outcomes as a result of FEP, suggesting that for significant others the experience can also be transformational.

Well I have to say that I, it's a good outcome that something bad happened so, because it is so much better than it was. Not perfect of course but it's a lot better so I have to say that it's more positive. It is more positive now (Simone, FM) 48

I said something about, you know we've all had the worst experience but it's funny there are some good things that come out of bad things and for me it was when you spontaneously hugged me. I'll never forget it (David, FM) 16

There've been some incredible good things that come out of bad things. Isn't it funny? You know the relationship with his brother even the relationship with us and just within the family so it's not all bad (David, FM) 53

Scott and Andrew's girlfriends reported specific constructive changes which could be categorised under three broad areas of change: *improved relationships and view of others, enhanced life view, and developed sense of self*. Scott's loved one discussed all areas of change. "People will probably say I've changed. **Changed in the sense that I'm so much stronger than I thought I ever was. Like yeah just stronger. Like I could feel like I could sort of survive anything sort of**" (Scott, FM) explored issue raised in interview. "I think he like made me feel sorry for like everybody out there that has illnesses" (Scott, FM) 48.

I look at it like as a positive as in we've survived like some people can't survive it at 30, 40, 50, 60, do you know I mean? I'm like well we're only 20, 22 and we went through that, money problems, housing problems, you know like he tried to die, I stayed around so I look at it like we survived.....So positive in the sense that like

we can get through it together like I care about him that much that I'm willing to, do you know what I mean? I don't see it as like something I had to, like I don't see it as a negative as in like people will be like did you have a choice, I'd be like no I didn't have a choice but to me that's not a negative that's a positive. I would always do it for him not because I had to do it....I had to do it but like I had to do it cause I love him so much....Like and people are like well aren't you wasting you know like relationship time or whatever but I guess it's just like it's a small part of my life and it kind of obviously makes me who I am anyway. Yeah it was hard, yeah I probably didn't go out and that yes people have fun relationships and they're going out but I just see it as, I don't really think about it. I mean I do ever so often I'm like oh my god I could just run away but I just see it as like, like, I'm meant to be doing it, like it's different to everyone you know what happens changes who you are anyway so (Scott, FM) 37

And just that more motivated, oh no I was already really motivated but like do what, do what you can sort of quickly. Does that, you know I want to finish my degree now like I only, I changed and like started a new one last year so that was only my first year so I've still got 2 to go but like I just want to do it. I want to save. I want to go on holidays. Just, just, actually just enjoy life pretty much that view point like don't take things for granted pretty much (Scott, FM) explored issue raised in interview

Andrew's girlfriend reported constructive change in the area of *improved relationships and view of others.*

It sort of brought us closer together I think because like I think we both feel like you know it's a pretty huge thing to go through and like if we can sort of go through that then may be we can get through anything sort of thing (Andrew, FM) 49

Summary

Interviews with loved ones revealed the experience of FEP as highly distressing for them. Further, their interviews revealed that both restorative and constructive processes were relevant in understanding how they adapt to the experience. The issues they discussed both paralleled and differed from themes raised in the interviews with FEP participants. There were similarities around themes of trauma especially in relation to the feelings brought about by FEP such as fear, uncontrollability, and loss. However, a closer examination showed that these feelings could occur for different reasons such in their role of supporting loved ones and a lack of understanding about psychosis and how to manage the illness experience. Like FEP participants, loved ones discussed ideas relating to the themes *functional* and *social recovery*. Also, the constructive changes Scott and Andrew's partners discussed were analogous to the domains identified from interviews with FEP participants. Further, loved ones' explanatory models of the illness also influenced the aspects of FEP they found distressing and the restorative outcomes and constructive changes they reported. Overall, the data from the interviews with loved ones also support the broader model of the trauma of psychosis and the presence of both restorative and constructive elements in recovery.

CHAPTER 10: GENERAL DISCUSSION

This chapter presents a discussion of the integrated findings of the main study. A revised model of understanding recovery from FEP is proposed on the basis of the IPA analysis of the interview data. This model guides consideration of each of the research questions addressed in the thesis and subsequent theoretical implications. Each part of the model is examined in detail in relation to the research question to which it pertains. The implications of the findings for therapy and the methodological limitations of the thesis and directions for future research are also considered.

A Model of Recovery from FEP

Overall, the present thesis provides much evidence relevant to a broader understanding of the impact of FEP, which incorporates potential constructive changes. The aim of this thesis was to develop a comprehensive understanding of the process of recovery from FEP derived from the lived experience of people who have suffered FEP. The current research explored how people understood FEP, considering the traumatic nature of this experience and the recovery process. The present research demonstrates that the traumatic impact of FEP goes beyond a diagnosis of PTSD to include a range of distressing responses associated with the acute episode and subsequent adaptation. Further, the recovery process has been shown to include a broader range of elements than those identified in previous writings on FEP. These include awareness of impairment, ongoing management strategies, restorative outcomes, and constructive changes. Interpretative phenomenological analysis data evidenced significant positive personal change as an outcome of FEP. Figure 10.1 presents a model of the impact of FEP and subsequent recovery process that reflects the findings of the current research. This temporal model comprises two stages: (a) the initial experience of first-episode psychosis or the acute episode, and (b) the recovery phase.

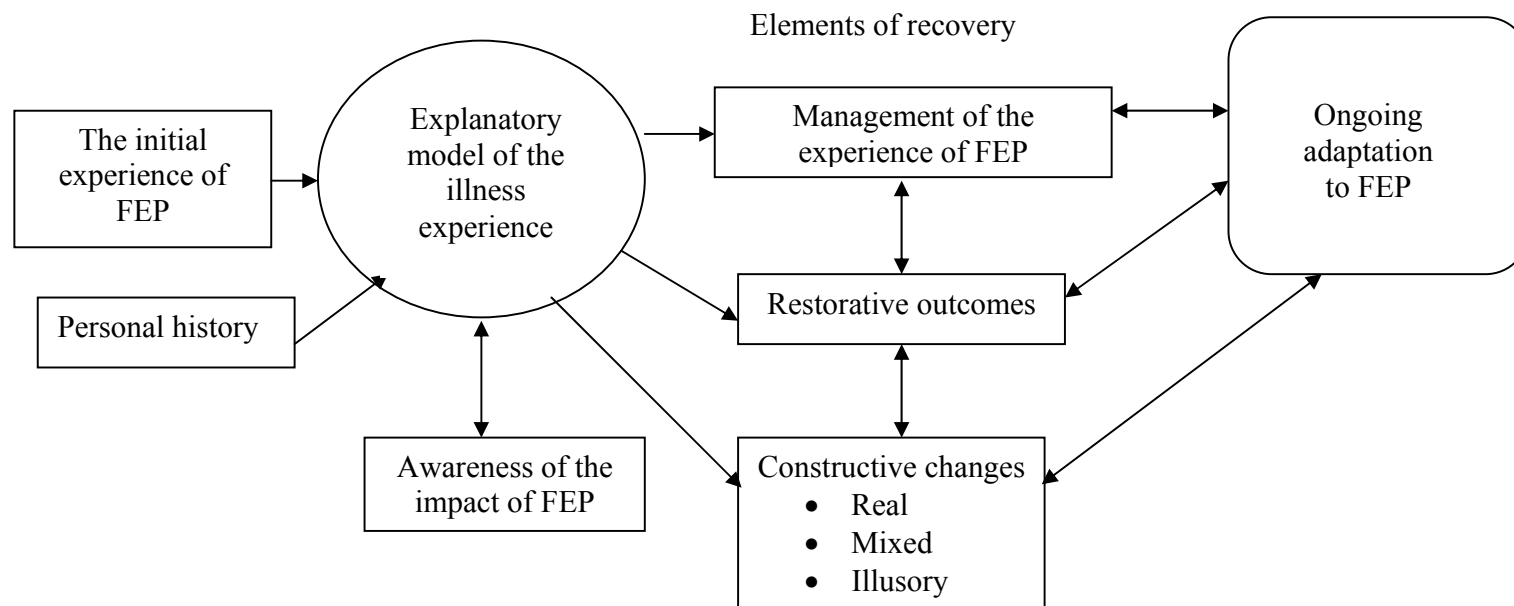


Figure 10.1. A model of recovery from FEP

Central to adapting to FEP is an individual's awareness of the impact of FEP and explanatory model of the illness they develop. The interpretative phenomenological analysis demonstrated that an individual develops an explanatory model of their experience of FEP which is influenced by their personal history. Further, the person's explanatory model of FEP has a reciprocal and flexible relationship with one's awareness of the impact of the illness. This relationship can change over time as the person adapts to the experience of FEP. Interpretative phenomenological analysis showed that the impact of FEP is characterised by a range of distressing secondary consequences such as *stigma* and *estrangement*, which can be more pertinent than PTSD symptomatology in determining recovery.

Past research has not incorporated a constructive model into the understanding of recovery from FEP. The present results indicate that an individual's explanatory model and awareness of the impact of FEP mediates the development of three elements of recovery: *ongoing management of FEP*, *restorative outcomes*, and *constructive changes*. These processes and outcomes were shown to influence one another throughout the recovery process, as well as an individual's ongoing adaptation to FEP. In turn, how a person adapts to the experience of FEP affects the nature of these recovery elements. The reciprocal relationships among the features of this recovery model are represented by directional arrows in Figure 10.1.

Research Question 1: How do People Experience a FEP and what is the Nature of the Ongoing Impact of the Illness?

This section discusses how people experience FEP and the nature of the ongoing impact of the illness, which is depicted in Figure 10.2. As shown in Figure 10.2, the present data suggests that people develop an explanatory model of their illness based on the initial experience of FEP and personal history. In turn, the person's explanatory model of their illness was shown to be both to influence and to be influenced by their awareness of the impact of FEP. Themes associated with the initial experience of FEP were: *development of the illness, the psychotic experience, disintegration, the experience of acute treatment, and perceived enforced treatment*. Themes related to awareness of the impact of FEP themes were: *recognising the illness as an ongoing problem, disintegration, sense of loss and deficit, estrangement, self-stigma and stigma from others*.

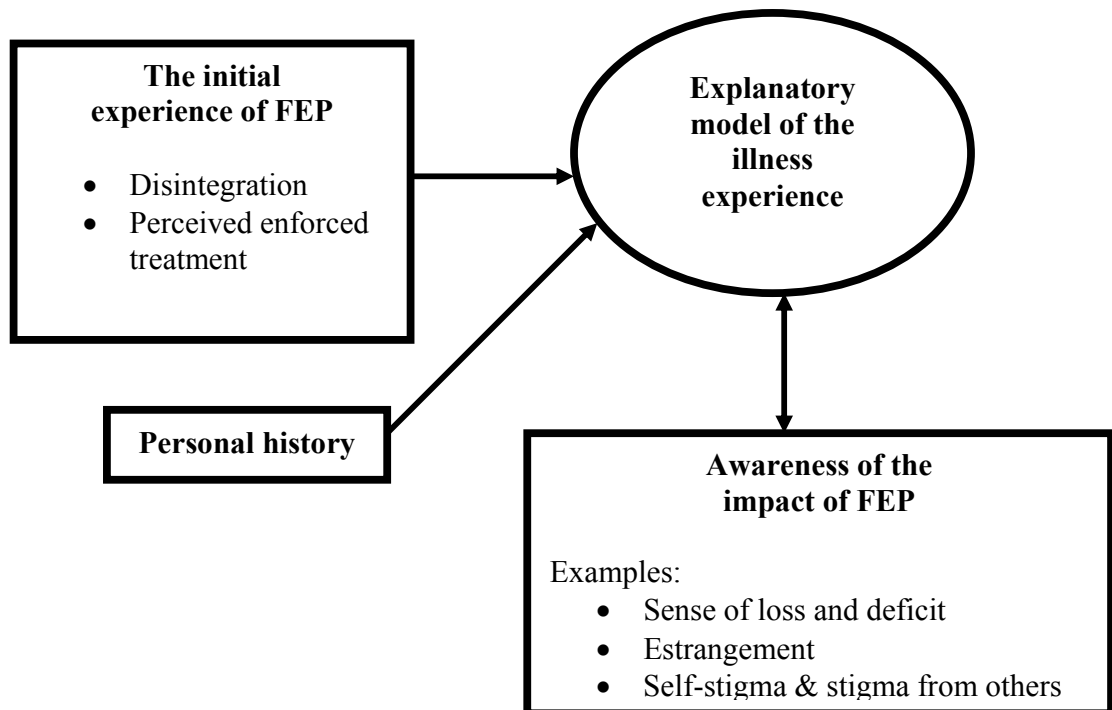


Figure 10.2. A model of the development of the explanatory model of FEP and awareness of the impact of the illness.

The main contribution of the present research was its focus on the subjective experience of FEP, which permitted a thorough examination of the acute distress and ongoing impact of the experience. Contrary to previous studies (Centofanti et al., 2005, Shaw et al., 1997), participants were able to clearly distinguish the distressing aspects of their illness and treatment experiences. The relevance of a trauma framework in understanding the experience of FEP was confirmed, as was the value of looking at a broader model of distress. Although the experience of FEP was traumatic, the endorsement of specific trauma symptoms was low. People's accounts ranged from those who experienced no trauma to those who experienced moderate levels. As Jackson and Iqbal (2000) asserted, the influence of FEP on how an individual views him or herself, the world, and others appeared to be central determinant of the degree of distress of this experience. Similar to Tarrrier et al.'s (2007) findings, the present findings indicate that the trauma of FEP extends beyond the initial experience to include a range of secondary consequences (e.g., *stigma, sense of loss and deficit, and estrangement*).

As previously shown (e.g., Brunet & Birchwood, 2008), psychotic symptoms were a major source of distress and were rated as the most traumatic experience of FEP. However, symptoms themselves were not the main focus for the majority of participants. Instead, some interviewees placed more emphasis on the experience of *disintegration*. In contrast to previous research (e.g., Brunet & Birchwood), a perceived lack of control over *one's self* and *one's interaction with others* due to psychotic symptoms was more central to *disintegration* than the powerlessness associated with the symptoms or episode per se. This occurred in the context of the experience of fragmentation of and disconnection from the self. Notably, FEP participants rated *being unable to do one's usual activities* in the top three most distressing experiences and a few reported a sense of disbelief that they had become unwell. Therefore, the fragmentation of the self appears to be a pressing issue in understanding the distress associated with experiencing an acute episode of psychosis, which is consistent with preceding literature on psychosis (e.g., Lysaker & Lysaker, 2000). For example, the current findings corroborate Williams-Keeler et al. (1994) description of the trauma of psychosis as an experience of dislocation and self-disintegration that is difficult to communicate.

A sense of disempowerment could also be associated participants' treatment experiences as shown in the theme, *perceived enforced treatment*. While this supports previous research findings highlighting the distress caused by coercive measures (e.g., Meyer et al., 1999), the present research shows how experiencing these forms of treatment created distress. Specifically, the source of trauma was the lack of control associated with coercive treatment. Yet, people gave different reasons for feeling powerless during their hospitalisation. Some people described an urgency to get out of hospital and found being unable to do so distressing. Daniel, whose interview largely focused on the theme *perceived enforced treatment*, felt that his rights to act freely had been taken away from him. Consistent with this, Alana viewed her voluntary admission very differently to being involuntary, with the latter removing her freedom to choose and the former being perceived as a break. While Scott did not experience seclusion, he perceived it as a form of punishment and feared staff would implement it which led him to monitor his behaviour. Scott's experience shows that merely witnessing coercive measures can cause distress and warrants future research.

Applying a broader model of distress allowed the present research to examine a range of traumatic experiences associated with the acute episode. As in previous research (e.g., TARRIER et al., 2007), co-patients, staff, and medication were also found to contribute to distress in hospital. However, unlike prior studies (e.g., McGORRY et al., 1991), the present research also examined the experience of acute outpatient treatment. Overall, it appeared less distressing for people to be treated in the home rather than in hospital. Nevertheless, outpatient support did cause some level of distress for FEP participants. For one person this related to the theme *perceived enforced treatment*, whereas for others difficulties arose during interactions with staff and medication side-effects. Consistent with Bendall et al. (2006), the present results show that the distress associated with acute treatment was sometimes enmeshed with psychotic symptomatology. For instance, for Scott and Andrew their symptoms caused them to be suspicious of and fear staff and co-patients. These findings underscore the importance of examining the subjective experience of FEP.

It appears that many factors need to be considered in addition to psychotic symptoms and acute treatment when understanding the negative experiences associated with the acute episode. Participants' spoke about the impact the illness had on their wellbeing and life in general while they were acutely unwell. This could also explain why *being unable to do one's usual activities* was rated in the top three most distressing experiences. For example, Alana spoke of being unable to leave her home and attend university, while Scott's symptoms impacted on his ability to work. *Conflict with family and friends* was also rated in the three most distressing experiences. Interviews clarified that conflict with significant others was experienced in the context of psychotic symptoms, substance misuse, and *perceived enforced treatment*. For instance, Alana discussed having an argument with her mother in the context of her involuntary hospital admission. However, direct conflict was rarely discussed in interviews. Rather, disruptions to relationships, which could be associated with the theme *disintegration* was frequently the focus. For example, Andrew referred to his relationship with his girlfriend as a "roller coaster ride" and acknowledged that his relationship with his family was difficult because they did not understand what was happening for him. In relation to the theme *disintegration*, Andrew experienced a lack of control over his thoughts and feelings in the company of others, which he related to paranoia. These findings suggest that a broad range of experiences need to be considered when examining the trauma of the acute episode.

The present research supports Bendall et al.'s (2006) suggestion that research should to refocus its attention on understanding the ongoing traumatic nature of FEP. In this thesis the distress associated with FEP was found to be extended beyond the initial episode to include a range of secondary consequences associated with impact to one's sense of self, functioning, and relationships with others. This is consistent with Tarrier et al. (2007) and MacDonald et al.'s (2005) research. Themes associated with FEP participants' awareness of the impact of their illness included: *disintegration*, *estrangement*, *recognition of the illness as an ongoing problem*, *sense of loss and deficit*, and *self-stigma* and *stigma from others*. Interview data showed that most of these themes related to both the acute illness and the recovery phase. Thus, people were aware of the impact of FEP even at times when they are often considered to be 'out of touch with reality.' Moreover, impairment is likely to continue even after acute symptoms have resolved and as the person attempts to

rebuild. A complex relationship was evident with the ongoing secondary consequences of FEP. For example, findings suggest that a sense of *disintegration* contributed to other areas of ongoing impairment. Andrew discussed how an inability to control himself and his interactions with others and his fragmented identity produced experiences consistent with the theme *estrangement*. For Andrew experiences of disintegration also led to *self-stigma*. As such, *disintegration* emerged as central to the distress of FEP both during the acute and recovery phase of the illness.

The interview data showed that people with FEP engage in a reflective process of understanding the development of their illness and the episode itself, which is consistent with prior research (e.g., Andresen et al., 2003). Not all participants understood the episode to be related to mental health or a psychotic episode. For example, Daniel provided an existential understanding of his psychotic episode. From the perspective of a mental health professional, it could be argued that having alternative views of one's mental health issues reflects a lack of insight. Yet, the interviewees understanding of their illness was more complex than this. Individuals gave meaningful accounts of their difficulties in terms of their personal history, and referred to a range of precipitators. For instance, Chris believed his illness was related to unresolved issues related to his father's illness and social development and that FEP came about in order for him to deal with these. Significantly, not everyone viewed the illness experience as highly distressing. For Simone it was framed as a stressful, annoying, and comforting experience, while for Chris hospital represented a safe environment because it provided a break from his stressful life circumstances which were associated with psychotic symptom. Daniel framed his acute episode as entirely constructive.

The explanatory model of the illness also related to participants' awareness of the ongoing impact of FEP. For example, David did not view the illness as having a significant impact on his life and therefore reported fewer ongoing secondary consequences. In contrast, Alana identified that FEP as having "destroyed" her life, affecting a range of areas such as relationships, work, and education. She reported significant ongoing impact across a range of areas. Similarly, Scott took on board the medical model's explanation of FEP and this was stable over time. A diagnosis of psychosis provided relief because the medical model was a less threatening framework for his illness. Initially, Scott believed his auditory

hallucinations to be a spirit. This was related to his cultural background and deeply distressing for him. Consistent with the medical model, Scott mostly discussed the themes *sense of loss and deficit* and *recognition of the illness as an ongoing problem*. This implied a sense of feeling faulty and powerlessness to change his situation. Therefore, it is important to understand how one views FEP in order to gauge their distress associated with this experience and ongoing secondary consequences.

Research Question 2: How do People Engage in Managing the Experience of FEP?

This section addresses how people engage in managing the experience of FEP. The interview data demonstrate that individuals actively interpret and manage their experience of FEP and its ongoing impact. As shown in Figure 10.3, people's explanatory models of their illness influenced how they managed their illness experience. Themes associated with managing the experience of FEP were both destructive and constructive and involved independent coping strategies and the support of others. Total themes that related to managing the experience of FEP included: *outpatient treatment*, *perception of treatment as restricting*, *estrangement*, *conscious avoidance*, *awareness of one's vulnerability*, *viewing recovery as a journey*, *self-direction in recovery*, *interpersonal environment facilitates recovery*, and *development of acceptance*.

As Jackson et al. (1999) suggested the manner in which people coped with their illness experience and engaged in adaptation appeared to be influenced by their attitude towards their disorder. Consistent with previous authors (e.g., Perry et al., 2007), the results showed that interviewees engaged in a meaning-making process to understand their illness experience. As shown in Figure 10.3, the interview data suggest that through an interpretation of the illness or explanatory model, people produce ways of managing their experience of FEP. For example, Jack viewed the illness as related to his substance misuse and therefore engaged in *self-directed recovery* by ceasing drug use and discussed *developing and acceptance and moving forward*. However, Jack continued to abuse alcohol and disengaged from clinical services in order to block out or *consciously avoid* his experience of FEP and his *awareness of (his) ongoing vulnerability*. Jack's engagement in these destructive ways of managing his illness experience appeared related to the theme

self-stigma, which in turn was associated with his explanatory model of FEP. Jack's appraisal of FEP was associated with unhelpful stereotypes. He referred to himself as "crazy" and feared ending up in a "padded cell." While some participants had clear and consistent views about their illness, other individuals had explanatory models that were vague, fragile and in a state of flux as they continued to adapt to FEP. Therefore, managing FEP was a complex and varying process.

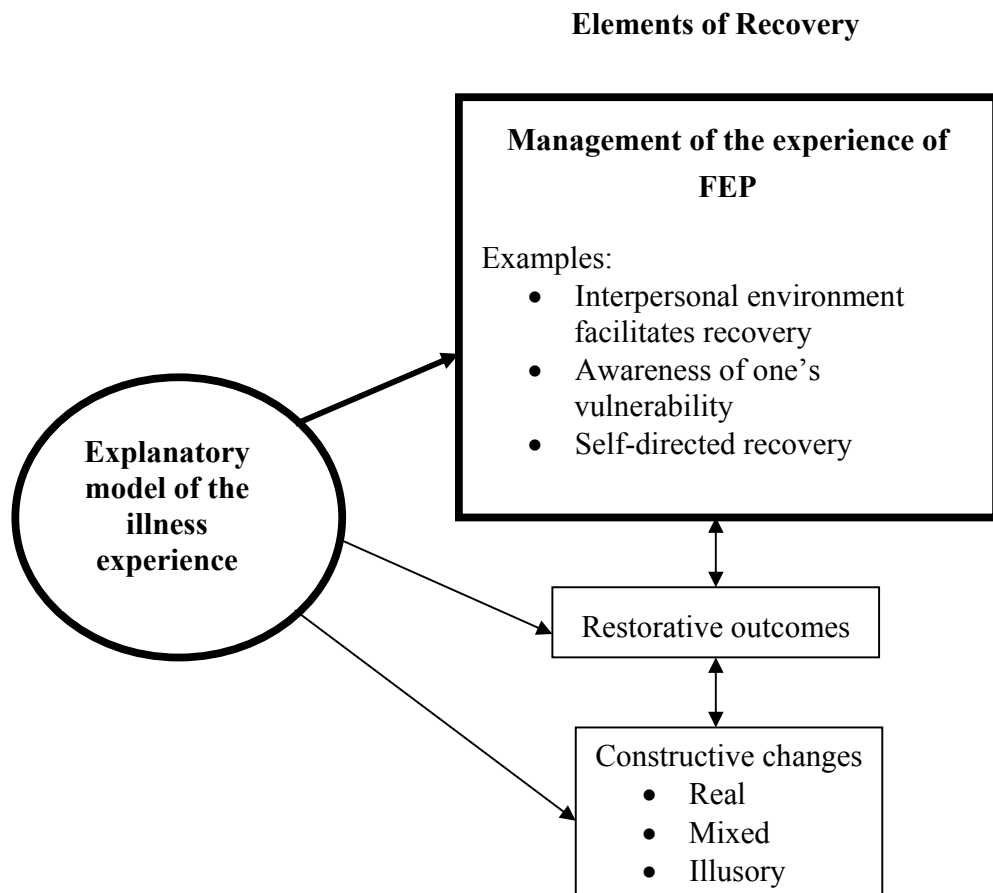


Figure 10.3. A model of managing the experience of FEP during the recovery phase.

First-episode psychosis participants developed appraisals of how long their illness would last. For most people, recovery was ongoing and viewed as a gradual process characterised by fluctuating difficulties and parallel improvement. How people approach management of their illness was divided into: using others' support and the development of

independent coping strategies. However, both types of coping strategies interacted and influenced one another. For instance, a desire for *self-directed recovery* could lead people to take up and implement treatment strategies, or a desire to be autonomous could conflict with one's treatment.

Engagement in outpatient treatment was predominately associated with the sub-theme *perception of the treatment as restricting*, which could relate to the medication or interactions with clinicians. For some participants, varying degrees of conflict with one's treatment was present which reflected a desire for self-control, while for others the burden of treatment was associated with resignation. Also, interactions with people, including their clinicians, could be viewed as imperative to recovery and this may be used positively to further adaptation. This was reflected in the theme *interpersonal relationships facilitating recovery*. For some, reengaging in relationships was a rebuilding process stemming from the experience of *estrangement*. In contrast, Paul disengaged from others to manage the illness experience. This indicates that people's understanding of relationships with others, both professional and personal, is important for them during their recovery and impacts on how they adapt to the illness.

The themes *awareness of one's vulnerability* and *conscious avoidance* suggest that the ongoing trauma associated with the illness includes a fear of relapse and a desire not to recall the acute episode or recognise the true character of the illness. These themes parallel previously documented notions of recovery such as sealing-over and denial and withdrawal, which are framed as initially adaptive but in the long-term maladaptive (e.g., Jackson & Iqbal, 2000). Yet, all but two participants had recovery styles in which integration was dominant but still endorsed the themes *conscious avoidance* and *awareness of one's vulnerability*. Further, while some recovery models have described these strategies as occurring during the initial stages of recovery (e.g., Andresen et al., 2003), other authors view these processes as developing and changing over time (e.g., Tait et al., 2003). In this study these themes were present over time. It could be argued that this is because the first 6-10 months after a FEP, when people were seen for this study, is still early on in recovery. However, it also suggests that these coping strategies may aid assimilation of the episode and facilitate psychological recovery and be important in what appears to be a dynamic and flexible recovery process. Consistent with this, these themes did not prevent people from

acknowledging their illness or actively dealing with it as reflected by the themes *developing acceptance and moving forward* and *self-direction in recovery*.

Overall, this research shows that people are active agents in their own recovery process, which is consistent with previous recovery models (e.g., Baxter & Diehl, 1998). Also, although group results showed that these themes were consistent over time, the application of strategies varied across individuals and at different time points in their recovery. This finding corroborates McGorry's (1992) assertion that people will engage differently in managing their illness. Extending previous research, the current results also show that how one chooses to engage in the management of their illness can be associated with their explanatory model of the illness.

Research Question 3: To Explore the Presence and Nature of Restorative and Constructive Processes of Recovery from FEP

This section discusses the restorative and constructive processes of recovery from FEP. As shown in Figure 10.4, this research found that restorative and constructive processes were relevant to recovery from FEP. These elements of recovery were influenced by how an individual understood and engaged in managing their illness experience. Themes relating to restorative outcomes were *functional* and *social recovery*. Constructive changes could be categorised into three domains: improved relationships and view of others, enhanced life view, and developed sense of self. Themes included: *development of deeper and closer relationships, increased desire to interact with others and improve the relationship, enhanced perspective taking and sense of unity, confirmation of character of others and quality of relationships, greater appreciation of life, new possibilities and direction, deepening of self-knowledge, and development of a sense of mastery and personal strength*.

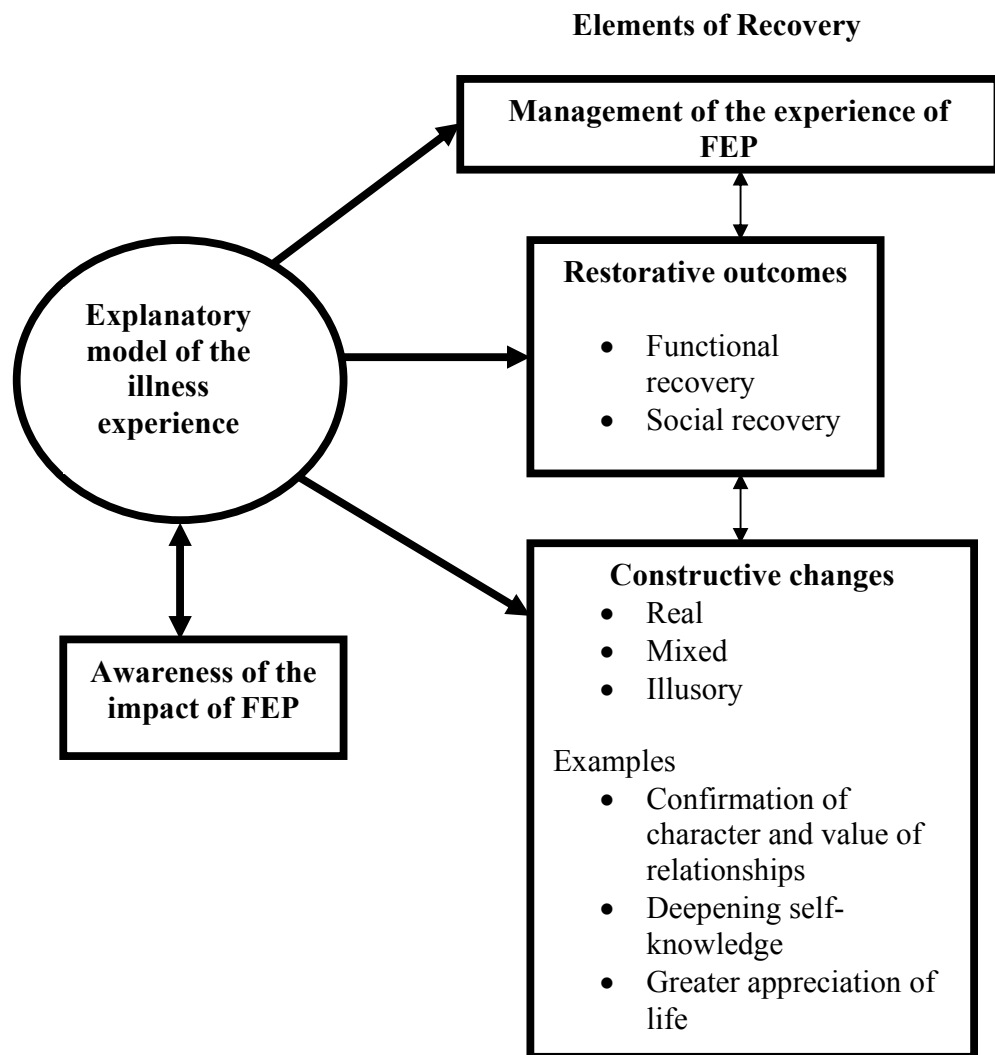


Figure 10.4. A model of the restorative and constructive elements of recovery from FEP.

A key finding of this research is the importance of recognising the potential for constructive changes in how one recovers from FEP. Despite the distressing impact of FEP, most participants viewed the illness as having helpful and unhelpful consequences. Interestingly, most of the helpful aspects of the illness identified by participants related to constructive changes. For instance, Andrew said the illness had helped him see who his real friends were which is associated with the theme *confirmation of character and quality of relationships*. Only Alana viewed the experience as entirely unhelpful but even she reported numerous constructive changes (e.g., *deepening self-knowledge* and *enhanced*

perspective taking and sense of unity). Although, Alana believed these experiences of growth would have come about irrespective of her experience of FEP. Corroborating the interview data, all participants integrated on the *optimism* subscale on the RSQ at Times 1 and 2. An integration recovery style on this subscale suggests that individuals considered the illness to have good parts and could recognise positive aspects of their illness. The participants' understanding of the helpful and unhelpful aspects of their illness experiences either evolved over time or remained stable. Whether or not participants believed their illness had been a helpful or unhelpful experience was related to their understanding of FEP and recovery process. This consisted of three elements: managing the experience of FEP, restorative outcomes, and constructive changes (refer to Figure 10.4).

A return to functioning is the dominant view of recovery from FEP in medical and rehabilitation models (e.g., McGorry, 1992). The themes *functional* and *social recovery* showed that restorative outcomes are significant in recovery from FEP. As highlighted in Figure 10.4, restorative outcomes appeared to be related to the negative impact of the illness. Thus, it seemed important for participants to regain what they may have lost during their episode. For instance, restoring one's relationships and re-learning social skills could be important in managing *disintegration* and *estrangement*. Also, aspects of functional recovery such as re-engagement in prior activities like work and study, increased self-worth, and contributing to society may counteract associated *stigma* and *sense of loss and deficit*. As depicted in Figure 10.4, it was also apparent that one's explanatory model of the illness could influence which restorative themes were more relevant for the individual. For example, Scott understood FEP from a clinical perspective which emphasises a return to prior functioning and symptom reduction. Subsequently, he tended to focus on functional recovery such as returning to work, losing weight, symptom alleviation, and developing confidence. Thus, an individual's view of FEP, which is influenced by their awareness of the impact of the illness, is important in understanding which aspects of restorative recovery are likely to be important to the person.

However, the interview data showed that recovery went beyond restorative outcomes, which is consistent with previous recovery models (e.g., Davidson & Strauss, 1992). This was evidenced by interview data showing transformational change as a result of FEP, complemented by an overall moderate level of growth according to the PTGI at Times

1 and 2. Constructive changes incorporated processes and outcomes and were reported in relation to the self, others, and philosophy of life. Relevant themes paralleled and expanded on those identified by Calhoun and Tedeschi (2006). In contrast to and Calhoun and Tedeschi model of posttraumatic growth, development or deepening of spirituality was not a significant issue for most FEP participants. Only Daniel reported a deepening of his spiritual beliefs but this was associated with his psychotic symptoms.

As shown in Figure 10.4 the type of constructive change experienced is influenced by an awareness of the impact of FEP as well as restorative outcomes. Consistent with MacDonald et al.'s (2005) research, a major impact of psychosis was on the participants' relationships and the theme *social recovery* was important in this sample. Interestingly, the most dominant area for constructive change was *improved relationships and view of others*, with four themes related to this domain. A closer examination of individuals' experiences of FEP also showed a reciprocal relationship between the impact of FEP, restorative outcomes, and constructive changes. For instance, Scott's FEP negatively impacted on his self-confidence and this was related to his inability to work. Yet, an area of constructive change for Scott was the theme *deepening self-knowledge* and this was associated with *functional recovery*. Scott discussed re-engaging in work as well as developing a deeper understanding of himself in relation to his education and career path. Sometimes the constructive changes reported appeared to help the person to deal with disruptions to their life which may have occurred during the prodromal phase of the illness. For example, Simone reported having long-term and recurrent arguments with her family, especially her mother, prior to the development of FEP. However, she reported an increased desire to put more effort into her family relationships, being more grateful and appreciative of them, and experiencing improved family relationships. This finding suggests that constructive changes due to FEP could be associated with improved wellbeing.

The literature suggests that constructive change takes place when it is preceded by, or occurs together with significant subjective distress (e.g., Calhoun & Tedeschi, 1998). Amongst individuals who have experienced FEP high levels of distress associated with PTSD symptomatology were not necessary to precipitate the development of constructive processes and outcomes. Instead, some level of significant disruption is warranted in one's sense of self, relationships with others, and worldview which causes a significant level of

ongoing negative impact or ‘break’ in one’s life and a distinction between pre and post-FEP self (Adame & Hornstein, 2006). This is evident in a detailed examination of case study one. Tessa reported minimal constructive change and the illness did not cause significant disruption to her life. Although her psychotic episode was likely to be highly distressing, and she was aware of her ongoing vulnerability, she experienced complete recovery within a short timeframe. In addition, Tessa did not experience a progressive decline in functioning or untreated psychotic symptoms prior to her FEP. Further, the interview data indicated that her minimal reports of growth were generally not maintained over time and discussed in relation to the very early stages of her recovery. Thus, her constructive changes were likely to be indicative of initial adjustment rather than significant transformation. This finding supports Tedeschi and Calhoun’s (2004) assertion that growth occurs in the context of significant trauma and upheaval. Still, Tessa’s earlier reports of growth may be important in initiating the recovery process. While the majority of FEP participants reported constructive changes, case study one also shows this is not a necessary element of recovery and adaptation to FEP.

As Figure 10.4 shows, the present findings indicate that how one manages the impact of the illness facilitates constructive changes. In particular, engagement in a reflective process of FEP appeared important for a successful outcome, which is consistent with Calhoun and Tedeschi’s (2006) model of posttraumatic growth. For example, at Time 1 Paul was moderately unwell (refer to Appendix F) and he endorsed numerous experiences consistent with the theme *disintegration* at Times 1 and 2, which indicates ongoing distress and disruption. However, he did not engage in an active process of understanding and reflecting on his illness experience. For instance, his main way of managing the illness was related to the theme *developing acceptance and moving forward* and in his interviews he did not engage in an in-depth understanding of his illness, providing superficial responses. As expected, Paul did not report any constructive changes in his interviews. This is consistent with Tedeschi and Calhoun’s (1999) model of posttraumatic growth, which identifies engagement with the distress caused by the trauma as central to the development of growth.

Growth may come about over time when the person is able to achieve some distance from FEP. Andrew's level of growth remained high at Times 1 and 2. Even so, he had difficulty articulating the constructive changes he experienced and tended to compare how things had changed in relation to FEP rather than prior to the illness. He said he could not remember how he was before psychosis. While Andrew actively engaged in managing the illness as reflected by the theme *self-directed recovery*, he also endorsed the theme *conscious avoidance* and disengaged with clinical services at Time 2 suggesting he was trying to get some distance from his experience. This is indicative of Tedeschi's (1999) assertion that some separation from the impact of the trauma is needed to facilitate posttraumatic growth. These ideas also parallel McGlashan et al.'s (1976) recovery styles sealing-over and integration, which suggests that those who integrate the experience of psychosis work through their illness experience. Therefore, it could be assumed that people with an integration recovery style would be more likely to report constructive changes than those who sealed over.

The present thesis indicates that the relationship between recovery style and constructive change is complex. Only Tessa had the 'mixed picture' recovery style in which sealing-over predominated at Times 1 and 2, and this appeared to be reflective of her endorsement of the theme *conscious avoidance*. As presumed, she reported minimal growth in her interviews. All other participants Tessa reported greater levels of integration, with most having a recovery style of tending towards integration at Times 1 and 2. However, a recovery style which was more reflective of integration did not always suggest significant growth. For example, David had a tending towards integration recovery style at Time 1 and 'mixed picture' recovery style in which integration predominated at Time 2 (see Appendix F). His interview data suggested he had experienced constructive changes, yet his responses tended to be superficial and limited. Also, as shown in Chris and Daniel's case studies, an integration recovery style did not necessarily imply real growth. Consistent with the literature, recovery styles are malleable over time (Thompson et al., 2003).

In the present study participants reported growth three to six months (Time 1) after their psychotic episode. Although areas of growth were stable over time across the participant sample, looking at individual reports of constructive changes demonstrate that the trajectory of growth is not linear and can change in relation the individual's explanatory

model and recovery process. Findings showed that growth can change over time in a number of ways including in intensity, type of constructive change (illusory or real), and area of change (*improved relationships and view of others, enhanced life view, and developed sense of self*). Further, like Tedeschi (1999) suggests, the present study indicates that constructive change in one domain does not imply change in another area. Also, endorsement of one theme (e.g., *enhanced perspective taking and sense of unity*) in a specific domain does not mean another theme (e.g., *confirmation of character and value of relationships*) in this area will be experienced. Some participants reported growth in all areas of change, while others focused on fewer aspects of growth. While group results revealed stable growth over time, case studies showed that the trajectory of constructive change could alter over time depending on other elements of recovery and how individuals engaged in their recovery process. This could account for mixed findings on the temporal course of growth (e.g., Affeck et al., 1987; Frazier et al., 2001; Milam et al., 2004). Further, constructive changes served different functions at different points in a person's recovery from FEP. For example Chris presented with both illusory and real constructive changes which served different functions throughout the course of his recovery.

Detailed examination of the case studies revealed that the ways in which the elements of recovery developed and related to one another was associated with the individual's personal history and explanatory model of the illness. Thus, it is argued that the results should be interpreted in the context of how one understands FEP. For example, Chris tended to externalise the source of his illness by attributing it to the impact of others, such as not being adequately socialised in the absence of a paternal role model. As a result, Chris discussed lacking social confidence and he did not appear to have a coherent sense of self. He believed FEP enabled him to redefine his relationships and develop self-acceptance. It could be argued that constructive changes merely act as a defence against the negative impact of FEP and are subsequently illusory (e.g., Zoellner & Maercker, 2006a). While constructive change appeared to play a protective and adaptive role for a few participants, this was complex and multifaceted. Case studies two and three show that illusory growth is just as relevant as real growth in understanding how one manages FEP and provide valuable insights into this process. For example, it is possible Chris did not wish to view himself as the same as his father, who had chronic schizophrenia, and

perceiving benefits from FEP may have prevented him from seeing his illness as the same as his fathers. Also, Chris’ case study showed that both illusory and real growth could occur in parallel with one another. Illusory and real growth existed alongside one another in the same area of constructive change and they were evident in different domains. Therefore, the *role* constructive changes play or the *purpose* they serve in the recovery process appears to be dynamic. Consistent with Taylor’s (1983) argument, illusory growth is important in recovering from FEP and understanding this process.

Research Question 4: What is the Process of Adaptation and Recovery from FEP?

How the various elements of the recovery model relate to an individual’s ongoing adaptation to FEP are discussed in this section. As demonstrated by Figure 10.5, how interviewees engaged in managing their experience of FEP and experienced restorative and constructive recovery processes influenced their ongoing adaptation to FEP. In turn, these adaptive processes affected these elements of recovery.

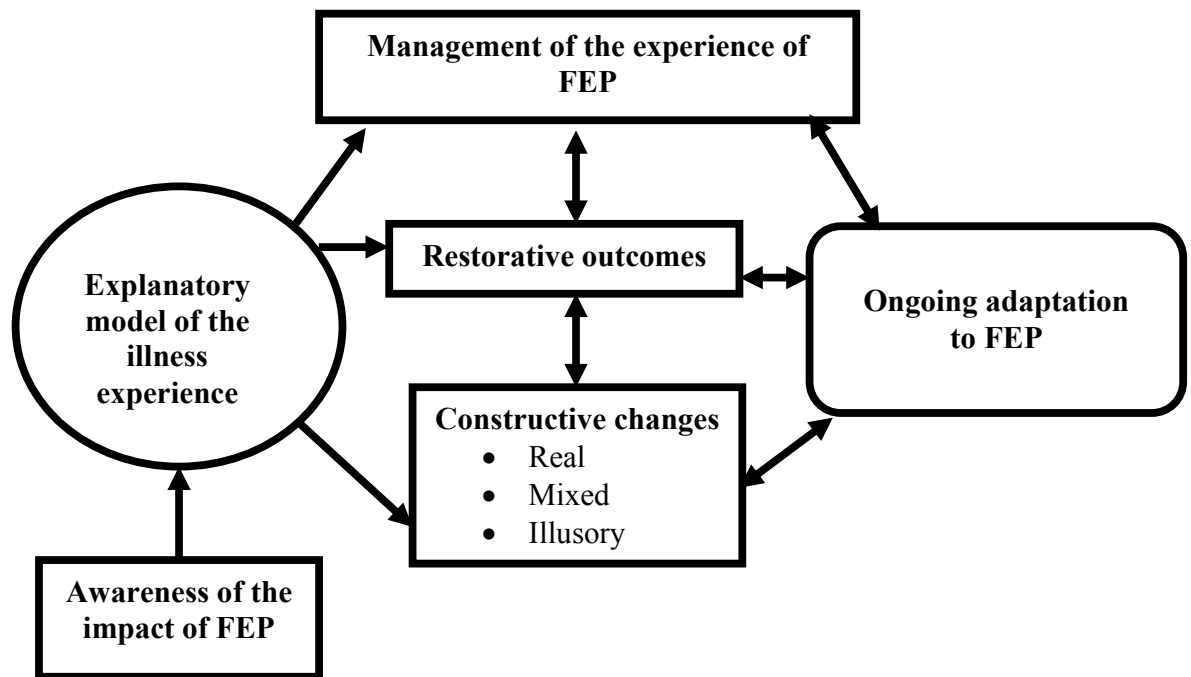


Figure 10.5. A model of recovery and adaptation from FEP.

In-depth focus on the subjective experience of FEP allowed a thorough examination of the role people play in their recovery and adaptation process. This thesis found that individuals are active and central in their recovery and adaptation from FEP, which is consistent with previous recovery models (e.g., Andresen et al., 2003). It also supported Anthony's (1993) model which applied a multidimensional approach to recovery considering clinical, functional, and psychological recovery. As shown in Figure 10.5, adaptation to FEP emerged as an ongoing process rather than a separate state or final outcome with a range of factors influencing its course. These include: awareness of the impact of FEP, explanatory model of the illness experience, management of FEP, restorative outcomes, and constructive changes. This thesis did not find that people move through stages of managing the experience of FEP but rather the elements of recovery identified occur in parallel and have a reciprocal relationship which is associated with their awareness of the impact of FEP and how they understand their illness.

Consistent with previous recovery models (e.g., Anthony, 1993), interview data showed that the medical and rehabilitation models of recovery are too narrow as recovery did not cease once restorative outcomes were achieved. Although the sample was considered mildly unwell at Times 1 and 2 and the participants' interview data suggested ongoing difficulties, those who had achieved a level of restorative recovery associated with the themes *social* and *functional recovery* continued to report constructive changes, which is an element of the recovery process. Constructive changes reflected both a process and an outcome of recovery. Participants reported a distinct awareness of the constructive changes being a stable outcome of FEP. Growth was also viewed as a process because it evolved over time as a result of interchanges between a person's awareness of the impact of FEP and how they understood and managed this experience. For example, Jack reported a distinct awareness that he had become closer to his brother and mother but also framed this as a process which continued to develop as they talked about their common difficulties. Interview data showed that the development of constructive changes required some level of upheaval and trauma and engagement in processing this distress. The distress associated with FEP went beyond the acute episode and was not resolved if a person had achieved functional or social recovery. Instead, it also related to coming to terms with this experience and how it impacted on the self and one's relationships with others and view of the world.

Therefore, a main finding of this research is that recovery is not a fixed state but rather continues to evolve within the broader context of adaptation to FEP. This finding supports research which has found recovery to be an ongoing and dynamic process (e.g., Anthony; May, 2004).

Central to this adaptation and recovery process is the individual's explanatory model of FEP. Participants' explanatory models could remain stable or fluctuate over time, while other participants expressed an ambiguous or fragile understanding of their illness. Participants' understanding of FEP developed in relation to ongoing adaptation to their illness and their struggle to make sense of the experience. How people understood their illness also directly impacted on how they engaged with the three elements of recovery shown in Figure 10.5. Two examples of this process are provided.

Daniel understood his illness from an existential perspective and believed it had been an entirely beneficial experience. While he staunchly defended his explanatory model over time, it appeared particularly fragile at Time 2 due to an increased awareness of his mental health issues. Daniel's interview data indicated greater positive change at Time 2. It is possible that a second psychotic episode impacted negatively on his explanatory model and in order to cope with this he reported more constructive changes in the interview. This could have been related to his constant attempts to prove to others the validity of his explanatory model which directly opposed clinicians' and his family's medical model of his illness. Indeed, Daniel did not report any constructive changes in the area *improved relationships and view of others* most likely because his explanatory model conflicted with other people's understanding of experiences. He also did not report themes related to management of the impact of FEP or restorative outcomes. Data showed that Daniel expressed very high levels of growth in relation constructive domains *enhanced life view* and *developed sense of self*. Daniel's growth was likely to be illusory due to his underlying fragility stemming from a lack of self-worth and being bullied as an adolescent. Even so it is argued that his illusory growth was adaptive and played a protective role.

The focus of Simone's experience of FEP and recovery process related to her experience of interpersonal relationships. Most of Simone's premorbid difficulties were associated with social problems, a tumultuous relationship with her family, and learning difficulties. Interestingly, the nature of her symptoms focused on interactions with others

such as believing others were reading her mind. This personal history and the nature of her symptoms appeared to be associated with her explanatory model of FEP. At Time 1, Simone related her illness to feeling depressed, anxious, and isolated, and believed her experience of hearing voices was associated with the latter. These concerns had also led to a fragile sense of self. As expected, much of Simone's awareness of the impact of FEP focused on how the illness had affected her interactions with others and relationships, as well her difficulties managing university in the context of the themes *recognising the illness as an ongoing problem* and to a lesser extent *disintegration*. For example, she described being disconnected from others. Simone predominately focused on the theme *the interpersonal environment facilitates recovery* to discuss how she managed the illness.

Simone's personal history, understanding of the illness, its impact on her, and her management of FEP influenced the constructive change she experienced. Simone predominately discussed constructive changes relating to the domain of improved *relationships and view of others* and the theme *deepening self-knowledge*. The theme *deepening self-knowledge* was also expressed in the context of how she dealt with her relationships with others. Constructive changes were a focus of Simone's recovery process and she reported very few restorative outcomes. For Simone, the main influence of her illness was not its ongoing negative impact but rather that it had facilitated a process of dealing with her prodromal difficulties. For example, she reported a much closer relationship with her mother and a desire to make her family more harmonious. Even though Simone identified the illness as a "dreadful" memory, she did not appear overly traumatised by the experience, describing it as frustrating and stressful and found some comfort in her symptoms. Yet, Simone's explanatory model of her illness changed over time and she was ambiguous about her experience of FEP at Time 2. Simone was unsure whether or not she had experienced a mental health issue because she did not feel unwell, yet still referred to her experiences as "paranoia" and "psychosis." This could be reflective of her uncertainty about the cause of her constructive changes. While Simone reported distinct constructive changes, she did not know whether these changes were due to FEP, her treatment, or getting older.

Simone's experiences also indicate the importance of a support network in one's recovery from FEP, as well as the person playing an active role in their recovery. It is possible that this support, both from treatment and relationships with others, and subsequent self-disclosure facilitated her constructive changes, which Tedeschi and Calhoun (2004) claim is associated with the development of growth.

The present research shows that a comprehensive model of recovery adds much to our understanding of the experience of FEP. There is a real possibility of constructive changes after FEP and overall recovery involves an ongoing adaptive process. Overall, a complex relationship exists between the nature of a person's first occurrence of psychosis, their engagement in the recovery process, and the development of constructive changes. These processes influence and are influenced by ongoing adaptation. Further to this, there is evidence that one's recovery environment and how one engages with it can influence the development of growth. Central to this recovery process is the persons' explanatory model of the illness.

Triangulation of FEP Participants' Data

Overall, interviews with loved ones and clinicians corroborated most themes derived from FEP participants' interviews and provided evidence for the recovery model presented in 10.1. However, the clinicians' endorsement of constructive changes was particularly limited. Clinicians were found to focus consistently on the negative impact of FEP rather than potential constructive changes. Even accounts of managing the illness and restorative outcomes were limited and management was generally framed in a negative light. Yet, some clinicians did report evidence of constructive changes and this was particularly evident when these discussions had been raised in treatment by FEP participants or loved ones or had been observed by the clinician. These results reflect the clinicians' explanatory models of FEP. In the present study these models were framed most often in the context of the medical and rehabilitation models. Clinicians who viewed the impact of the illness and subsequent recovery more broadly were more likely to report negative and positive changes in the FEP participants' sense of self, relationships with others, and views of the world, and to have raised these issues in treatment.

Loved ones also tended to focus on the negative impact of the illness rather than aspects of growth. However, overall they appeared more aware of growth or the possibility for constructive changes. It is possible that loved ones were more aware of FEP participants' constructive changes due to their intimate relationship with the person who has been unwell. Constructive changes were reported to varying degrees by loved ones. Some loved ones did not identify any constructive changes and viewed the illness as entirely unhelpful, while others reported beneficial outcomes. A few noteworthy results emerged from some loved ones' interviews. Chris' mother reported the observed changes in Chris which he also discussed in his interview. However, she viewed these processes and outcomes negatively whereas Chris viewed them as beneficial. Interestingly, Scott's partner believed the experience of FEP had the capacity to bring about growth but she was unsure if Scott had experienced these changes. David's mother reported more beneficial outcomes than David and also a desire and hope for constructive change. Lastly, Andrew's girlfriend was better able to articulate the changes which she and Andrew both observed. Therefore, how constructive changes are understood and recognised by loved ones also appears to be associated with their understanding of the illness, which was more commonly related to clinical recovery. The impact of the illness on loved ones is also likely to influence whether or not they recognise constructive processes and outcomes as a result of FEP. Overall, this study showed that loved ones can provide a valuable source of information for clinical practice in relation to the impact of FEP and subsequent recovery.

Previous research called for corroboration of constructive changes as evidence of real or illusory growth (e.g., Linley & Joseph, 2004). However, it is argued that while this certainly provides useful insights, it should not be the only way of deciding whether or not constructive changes are illusory or real in this population. Instead, information from loved ones and clinicians should be used as one source of understanding constructive changes amongst the FEP population given the range of factors that influence their development, such as the person's explanatory model of their illness. The role of the explanatory model of the illness in the development of constructive changes highlights the importance of the subjective experience rather than simply assuming that growth is only real if confirmed by others. Also, because psychosis is an internal experience, it is to be expected that some constructive processes and outcomes are not understood or seen by others.

The Impact of FEP on Loved Ones

Loved ones reflected on the illness and made sense of it in their own terms. They were significantly impacted by the experience of FEP in their loved one and some produced accounts relevant to restorative and constructive processes, which confirmed the importance of implementing a broader view of the trauma of FEP.

Issues raised in interviews with loved ones both paralleled and differed from themes identified in FEP interviews. Examples of similar themes were ongoing concern about relapse and stigma, while a unique topic was the negative impact on their relationship dynamics. Interestingly, the constructive changes that were discussed by loved ones addressed the same broad areas of change as FEP participants. For instance, for both client groups there was a deepening of relationships. Loved ones also spontaneously raised experiences of growth in their interviews. This further supports the validity of constructive changes as a highly relevant concept in understanding the impact of FEP and adaptation to this experience.

Important clinical implications can also be drawn from interviews with loved ones. For example, facilitating the development of constructive changes amongst loved ones may strengthen their own adaptation to FEP and in turn enable them to be stronger supports for clients. Further, addressing the potential for constructive outcomes may be beneficial in counteracting their negative beliefs associated with FEP. Also, while it appears important for loved ones to consider how they may help in the facilitation of recovery, clinical intervention may also include de-personalising the experience for significant others and help them find strategies for not over-protecting their loved one (Barker et al., 2001). Central to this appears to be supporting loved ones to reduce their anxiety.

Overall, findings indicate that loved ones need to be included in the treatment of FEP clients both during the acute and recovery phase, as well as have their own opportunity to process the experience of FEP and be provided emotional and practical support. This can be highlighted by the following quote.

*I've told the story so many times but that's my way of coping and dealing.... think it makes, it helps you.....The way I deal with things is you just **talk about them over and over and over and eventually they don't hurt as much when you talk about***

*them over and over and over. You know they never go away but you learn to put them in a place and, ...Everybody asks me are you angry at David and anger has been one emotion that I have not ever felt and yet that's the first thing any outside people ask you. Are you angry because he's done this to you? I said what has he done? I said this kid is so unwell and tortured. I said how could I be angry?I mean it's an experience you don't wish on anyone and it's an experience I wouldn't want to go through again (David, FM) **issue raised by participant***

Clinical Implications

A range of clinical implications can be drawn from this research. Chiefly, recognition that people with FEP have self-awareness and can engage in a meaning-making process is important in understanding their illness experience. Central to this is the finding that the person's explanatory model is fundamental in understanding how they manage the illness experience, which has been suggested by other authors (e.g., McGorry, 1992). Therefore, consistent with literature, the present research suggests that it is important to recognise the role of the subjective experience, to begin to have meaningful conversations with people about their experience of FEP, and to facilitate their capacity to create narratives and an explanatory model about their illness. Supporting individuals who have a vague and fragile perception of FEP to clarify an explanatory model that makes most sense to them may be beneficial. In contrast, facilitating a broader understanding of the illness when working with people who have a rigid explanatory model could also be helpful. However, few authors have recognised that these discussions should include both the helpful and unhelpful impact of FEP. The present study suggests that exploring the changes people have experienced as a result of FEP in the context of both constructive and destructive processes and outcomes can provide a more comprehensive understanding of the impact of the illness and approach to interventions.

Previous research on the trauma associated with treatment and symptoms experiences has focused on the diagnosis of PTSD (e.g., McGorry et al., 1991; Shaw et al., 2002). However, the current research indicates that it is also important to consider broader notions of the distress associated with the acute phase and with subsequent adaptation.

While, clinicians identified most themes associated with the negative impact of FEP, their interviews did not address disintegration and stigma from others. It would appear that how the illness impacts on the person is an important issue to address in treatment as well as the identification of distressing experiences. For instance, with regard to the theme *disintegration*, it was the lack of control over the self caused by the symptoms which was distressing rather than the symptoms themselves. The themes identified in this research suggest that factors such as the impact a client's sense of self and relationships; their perceived vulnerability and fear of relapse; feelings of hopelessness; and lack of control are likely to be important foci in treatment. Therefore, working through the emotional aspects of psychosis appears to be a treatment priority (Jackson & Iqbal, 2000).

The current findings suggest a need for clinical interventions to focus on the active role clients play in their recovery and adaptation process. Both loved ones and clinicians failed to recognise the theme *developing acceptance and moving forward*. This may reflect their tendency to view the illness as a problem that needs to be actively dealt with. Indeed, clinicians were particularly aware of the negative impact of FEP and issues relating to achieving premorbid functioning. Instead, it would appear that some level of recognition in conjunction with a sense of freedom to move beyond the illness experience is important for people who experience FEP. Such recognition might be empowering, particularly for people who felt out of control during the episode. This needs to be differentiated from avoidance and withdrawal from the illness experience. Therefore, it appears important that clients feel as though they are involved in treatment decisions and that treatment focuses on clients' strengths and fosters ownership over one's recovery.

Most models of treatment (e.g., COPE, Linszen & Birchwood, 2000) are based on the notion that, for most people, psychosis has a negative impact. While this study also confirms this and the importance of addressing these issues in treatment, a major clinical implication of this research is to consider the role of constructive changes in how people recover from and adjust to psychosis. Calhoun and Tedeschi's (2006) model of posttraumatic growth can be applied to existing treatments used to address FEP. For example, their model could be considered compatible with cognitive behaviour therapy (CBT) and the goals of COPE therapy because it emphasises a reflective and analytical informed style of cognitive processing and promotes adaptation to trauma (Tedeschi &

Calhoun). For instance, the therapeutic aims of COPE are to promote hopefulness and integration and reduce engulfment (Henry, 2004). Examples of strategies used in CBT and COPE which may promote growth are: establishing clients' understanding of their illness (Brabban & Turkington, 2002), cognitive restructuring, the development of new skills, and the analysis of goals, priorities, and self-concept. However, the goals of these interventions have been to reduce distress rather than facilitate personal growth (Zoellner & Maercker, 2006b). It is suggested that clinicians be open to the possibility of constructive change following FEP and recognise and support client's views of trauma and positive change (Calhoun & Tedeschi, 1998) in their treatment of FEP.

Acknowledging, exploring, understanding, and facilitating constructive processes and outcomes may improve the long-term trajectory of recovery from FEP. For instance, addressing constructive changes could improve treatment adherence and therapeutic collaboration if disengagement is due to the traumatic impact of FEP. It could also facilitate ways for clients to understand their psychotic episode and engage in a meaning-making process. Further, supporting individuals to reflect on how they handled FEP by focusing on their strengths and capabilities before, during, and after the episode and what was learned from the experience could foster coping strategies to manage the ongoing negative impact of the psychotic episode, secondary morbidity, and future episodes. For example, a sense of disempowerment was a key issue identified by FEP participants when they discussed the impact of their psychotic episode. Therefore, drawing on constructive processes which focus on a sense of personal strength and new possibilities and direction could be very important in counteracting these concerns and empowering clients in their recovery process. It could produce a sense of hope and support people to develop their capacity for resilience and strength, as well as promote a sense of mastery and the potential for action to be taken in their recovery.

This research demonstrated that the psychotic episode can impact negatively on individual's sense of self and worldview. However, it also showed that constructive changes can lead to a positive identity and view of life. Thus, facilitating growth could support people to reassess their expectations and values and allow new representations of the self and world to develop and promote integration (Tedeschi & Calhoun, 2006) of FEP. Allowing clients to discuss potential positive outcomes could also de-stigmatise, address

negative over-identification with the role of psychiatric client, help clients develop self-efficacy and a sense of self that is separate from the illness, help disband the pessimistic view of psychosis, and foster hope. For example, fostering issues related to the theme *deepening of self-knowledge* could offset these processes by promoting a sense of value in the aftermath of their experience of FEP. Facilitating the development of constructive changes could also counteract the negative impact of FEP on one's relationships and promote social recovery. For example, David pointed to the capacity of treatment to facilitate the domain *improved relationship and view of others*.

We're probably a bit more open yeah....Like before I used to just shut them out and not talk to them much....I don't know just trying, well being more honest with them I guess. I guess sort of not doing things to please them just....I don't know just probably cause I had to do a few psych sessions with my parents (David, 2nd)
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This quote also highlights the importance of including people who provide social support in treatment and strengthening relationships to facilitate constructive changes and reduce distress. Further, supporting loved ones to adapt to and cope with FEP and facilitate their own constructive changes could promote client's recovery. Also, facilitating constructive processes and outcomes is likely to support restorative recovery and the development of a positive interpersonal environment, which has been shown to be important in engagement in treatment. Therefore, the facilitation of growth should be considered to be a legitimate therapeutic aim (Linley & Joseph, 2004) in treating the trauma of FEP.

This study also indicates the relevance of understanding illusory growth, which has clinical implications for this population. A case in point is Daniel's case study. An analysis of his data indicated that challenging his illusory beliefs too hastily was likely to have a significant impact on his wellbeing as they served a protective role and provided meaning in the context of underlying fragility. Further, positive illusions appeared to help both Chris and Daniel assert control over a situation that may have otherwise seemed uncontrollable. This is consistent with Jackson et al.'s (1999) assertion that an aim of treating FEP should include assisting individuals to have some control over their situation and future. Therefore, it is argued that positive illusions can be psychologically beneficial (Taylor, 1983) and

enable a person to make sense of and manage FEP. However, it is also possible Daniel's illusory growth was reinforcing and maintaining his symptoms and preventing him from acknowledging the difficult aspects of his illness and integrating it. Thus, it appears important to consider whether these illusions support or hinder adaptive recovery from FEP (Zoellner & Maercker, 2006b). On the whole, positive processes and outcomes, whether real or illusory, should be addressed these therapeutically.

Overall, early intervention should include an opportunity for clients to work through the disruptive nature of psychosis as well as draw on constructive aspects of the psychotic experience, providing a more rounded approach and understanding to recovery. However, the distress of FEP should not be downplayed or suggested as being good. Riedesser (2004) wrote about a patient who identified that psychosis provided an opportunity to get to know one's self. However, this patient also warned that psychosis should not be glorified as an experience one must have to develop an improved understanding of the world. Constructive changes should not be presumed to be present in all people who experience distress and the presence of positive changes should not be assumed to preclude distress. Nor should an absence of growth be considered a negative outcome or enforced or produced by clinicians (Tedeschi & Calhoun, 2006). Rather, it is asserted that a broader view of trauma and recovery from FEP should allow for the *possibility* of both positive and negative outcomes and be open to this in practice.

Methodological Issues and Directions for Future Research

The present research allowed for an examination of experiences that could not be attained by large-scale quantitative research. The IPA approach of this research allowed for an in-depth analysis of the impact of FEP and subsequent recovery and adaptation processes. This approach made possible a detailed examination of the participants' experiences of FEP, particularly the distress associated with the acute episode and secondary consequences apart from PTSD symptomatology. It also provided examination of constructive changes yielding evidence for the relevance of constructive changes in understanding how people adapt to and recover from FEP. The present study also addressed a number of methodological issues called for by prior researchers. For instance, its

exploratory nature and longitudinal design was considered an optimal approach to researching constructive changes (e.g., O’Leary, 1998; Zoellner & Maercker, 2006a) as it allowed growth to be tracked over time and enabled these changes to be captured as both outcomes and processes in understanding how one adapts to FEP. Further, the small sample allowed for an intimate depiction of individual experience of FEP and subsequent adaptation. The present study formed the basis for future research. Two major areas relating to the nature of the sample are discussed: (a) the clinical sample and (b) time-frame of recruitment.

It is likely that this study captured people who wished to understand their illness and were willing to engage in a reflective process. For instance, most participants had a recovery style in which integration predominated. The next step would be for investigators to research a larger number of people in which comparisons can be made between these factors using both qualitative and quantitative approaches. This would also enable the relationship between various elements of the model to be researched with a larger sample and further tease out the complex relationship between growth, level of trauma, and recovery styles.

A strength of the present research was that people were seen at similar times after their acute episode of psychosis and providing another avenue for control and comparability. This also provided evidence for the ongoing adaptation to FEP. Longer time periods for follow-up are recommended in future research to track these concepts over a significant period of time and to see how the elements of recovery presented in Figure 10.1 develop in relation to the individual’s ongoing adaptation to FEP. While recovery from FEP can be relatively quick, for some people it can take years and is marked by numerous relapses, or a chronic pattern can develop. Indeed, Daniel’s presentation was quite different to the rest of the group and it is possible that this was due to the nature of his illness and his relapse in between interviews. As well, it would be interesting to see how the impact of psychosis and elements of recovery change according to different illness trajectories. Exploring these concepts amongst people at risk of developing psychosis and following those who transition to first-episode psychosis would also be a helpful way of tracking the relevance and expression of constructive processes and outcomes over time. Indeed, some participants in this study had difficulty comparing how things had changed for them from

before their illness to afterwards.

The present research also provides a comprehensive model which contributes to the trauma literature in general. Further research could also examine the application of the recovery model in Figure 10.1 with other trauma populations. Also, this recovery could be applied to other mental health issues such as bipolar disorder. Other patient characteristics which could be investigated in future studies are: gender, co-morbidity, multiple psychotic episodes, trauma history, type of acute and outpatient treatment, duration of untreated symptoms, type of psychotic symptoms, and ongoing residual symptoms. Examining the clinical utility of applying the notion of constructive change in working with people recovering from FEP is also recommended for future research. Finally, future research could also extend on this study's findings relating to loved one's experiences of FEP and apply the recovery model in Figure 10.1 to enable an examination of constructive changes.

Conclusions

The current research investigated the adaptation and recovery process of a first occurrence of psychosis and the aim was to explore how people understand the experience of FEP and the potentially distressing, restorative, and constructive outcomes. The results of this study show that a trauma framework is highly relevant in understanding the impact of FEP and subsequent recovery and adaptation. However, considering the impact of acute treatment and psychotic symptoms in the context of developing PTSD as done in previous research (e.g., Centofanti et al., 2005; Meyer et al., 1999) is too limited. Instead, the trauma of FEP is associated with ongoing impact to the self, relationship with others, and perception of life. A more balanced approach to understanding the trauma of FEP should also consider the potential for parallel constructive processes and how they relate to people's ongoing adaptation.

The results of this study show that both restorative and constructive elements are important in understanding recovery from FEP. Further, recovery emerged as a dynamic and ongoing process influenced by the individual as they engage in adapting to the experience of FEP. Therefore, it is important to address the subjective experience of FEP and to understand how this experience has impacted on people not only what aspects of the

illness have been difficult. Indeed, clients' explanatory models of their illness have been shown to mediate the relationship between awareness of the impact of FEP, how one manages this experiences, restorative outcomes and constructive changes. Therefore, this research shows that each person's way of recovering and adapting to psychosis is different (McGorry, 1992) thereby pointing to the importance of recognising individual disparity and appraisals when attempting understand the experiences of FEP, clients' needs, and recovery pathways.

Overall, this study found that people can actively engage in examining the experience of their psychotic episode and that a more comprehensive understanding of the impact of FEP, the elements of recovery, and subsequent adaptation includes both negative and positive experiences. In conclusion, recognising the potential for constructive change should be considered in clinical practice and future research. A preliminary model of recovery is provided to guide this.

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APPENDIX A

All conditions pertaining to the clearance of Swinburne University of Technology, Alfred Psychiatry, and Royal Melbourne Hospital's ethics committees were properly met. All requested reports have been submitted. Evidence of clearance from each of the ethics committees is provided.

To: Ms Jane Dunkley/Assoc Prof Glen Bates, LSS

Dear Glen and Jane

HREC Proj 05/36 Understanding Adaptation to First-Episode Psychosis: Trauma and Growth Responses

Investigators: Assoc Prof Glen Bates (Swinburne Supervisor), Ms Jane Dunkley et al

Duration: (20/12/05) to 31/12/08

Chair of Swinburne's HREC has given consideration to the most recent documentation submitted for the above project (dated 9 December 2005), part of which is a response to previous HREC consideration of your project at HREC Meeting 8/2005 held on 8 November 2005, and some of its modifications/additions to previously submitted protocols.

I am pleased to advise that the Chair has approved the modified project subject to co-requisite clearance of the modified protocols by The Alfred HREC. A photocopy of The Alfred HREC ethics certificate should be forwarded to my office as soon as practicable for the record. All things being equal, the ethics clearance conditions set by The Alfred HREC should be acceptable to Swinburne as regards further amendment to the project, as well as monitoring and reporting requirements in line with the National Statement on Ethical Conduct in Research Involving Humans. Copies of progress reports and protocol modification requests/clearance submitted to/issued by The Alfred should be forwarded to my office for Swinburne HREC noting or endorsement; separate or additional Swinburne formats will not at this stage be required.

Please contact me if you have any queries about co-requisite on-going ethics clearance from Swinburne's HREC. And if you would still like to have a signed ethics clearance certificate from Swinburne, additional to this formal email communication and to supplement that from The Alfred, please let me know.

Best wishes for your project.

Keith Wilkins
Secretary, HREC

To: Assoc Prof Glen Bates/Ms Jane Dunkley, FLSS

Dear Glen and Jane

SUHREC Project 05/36 Understanding Adaptation to First-episode
Psychosis ... (Alfred HREC Proj 182/05)

I am pleased to advise that Swinburne's Human Research Ethics Committee (SUHREC) has endorsed the amendments and extension to included ORYGEN Youth Health to SUHREC Project 05/36 as given in your submission of 1 December 2006 (by email and hardcopy). The endorsement has been given on the basis of the ethical review carried out by The Alfred and Melbourne Health HRECs respectively and citing of documentation of a SUHREC delegate. For the record, please could you forward to my office a photocopy of any ethics clearance certificate granted to the amended project by The Alfred or Melbourne Health, as with any annual/final progress reports submitted to or approved by them. Please contact me if you have any queries or concerns about SUHREC on-going ethics clearance. The Swinburne project number should be cited in communication.

Best wishes for the amended/extended project.

Yours sincerely

Keith Wilkins
Secretary, SUHREC



ETHICS COMMITTEE CERTIFICATE OF APPROVAL

This is to certify that

Project No: 182/05

Project Title Understanding Adaptation to First-Episode Psychosis: Trauma and Growth Responses

Principal Researcher: A/Professor Glen Bates

Participant Information and Consent Form version 6 dated: 29-Oct-2005

Participant Information and Consent Form for Family Members version 6 dated: 29-Oct-2005

*has been considered by the Ethics Committee and is **APPROVED**.*

Approval date: 02-Nov-2005 **Expiry date:** 02-Nov-2007

It is the Principal Researcher's responsibility to ensure that all researchers associated with this project are aware of the conditions of approval and which documents have been approved.

The Principal Researcher is required to notify the Secretary of the Ethics Committee, via amendment or progress report, of

- Any significant change to the project and the reason for that change, including an indication of ethical implications (if any);
- Serious adverse effects on participants and the action taken to address those effects;
- Any other unforeseen events or unexpected developments that merit notification;
- The inability of the Principal Researcher to continue in that role, or any other change in research personnel involved in the project;
- Any expiry of the insurance coverage provided with respect to sponsored clinical trials and proof of re-insurance;
- A delay of more than 12 months in the commencement of the project; and,
- Termination or closure of the project.

Additionally, the Principal Researcher is required to submit

- A Progress Report every 12 months for the duration of the project (*forms to be provided*);
- A Request for Extension of the project prior to the expiry date, if applicable; and,
- A detailed Final Report at the conclusion of the project.

The Ethics Committee may conduct an audit at any time.

All research subject to the Alfred Hospital Ethics Committee review must be conducted in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).

The Alfred Ethics Committee is a properly constituted Human Research Ethics Committee in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).

SPECIAL CONDITIONS

None

SIGNED: 
Chair, Ethics Committee (or delegate)

Reissued
DATE: 30/3/09

Please quote Project No and Title in all correspondence

**R. FREW
SECRETARY
ETHICS COMMITTEE**



Ethics Committee

Certificate of Approval of Amendments

This is to certify that amendments to

Project **182/05 Understanding Adaptation to First-Episode Psychosis:
Trauma and Growth Responses**

Chief Researcher: **A/Professor Glen Bates**

Information Sheet & Consent Form **Version 7 x 2** dated: **11-Dec-2005**

have been approved in accordance with your amendment application on the understanding that you observe the National Statement on Ethical Conduct in Research Involving Humans.

It is now your responsibility to ensure that all people associated with this particular research project are made aware of what has actually been approved and any caveats specified in correspondence with the Ethics Committee. Any further change to the application which is likely to have a significant impact on the ethical considerations of this project will require approval from the Ethics Committee.

Chair, Ethics Committee (or delegate)

Date: 30-Jan-2006

R. FREW
SECRETARY
ETHICS COMMITTEE

All research subject to Alfred Hospital Ethics Committee review must be conducted in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).

The Alfred Ethics Committee is a properly constituted Human Research Ethics Committee operating in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).



Ethics Committee

Certificate of Approval of Amendments

This is to certify that amendments to

Project **182/05 Understanding Adaptation to First-Episode Psychosis:
Trauma and Growth Responses**

Chief Researcher: **A/Professor Glen Bates**

Amendment date: **15-Mar-06**

have been approved in accordance with your amendment application on the understanding that you observe the National Statement on Ethical Conduct in Research Involving Humans.

It is now your responsibility to ensure that all people associated with this particular research project are made aware of what has actually been approved and any caveats specified in correspondence with the Ethics Committee. Any further change to the application which is likely to have a significant impact on the ethical considerations of this project will require approval from the Ethics Committee.

Chair, Ethics Committee (or delegate)

Date: 28-Mar-2006

**R. FREW
SECRETARY
ETHICS COMMITTEE**

All research subject to Alfred Hospital Ethics Committee review must be conducted in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).

The Alfred Ethics Committee is a properly constituted Human Research Ethics Committee operating in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).



Ethics Committee

Certificate of Approval of Amendments

This is to certify that amendments to

Project **182/05 Understanding Adaptation to First-Episode Psychosis: Trauma and Growth Responses**

Chief Researcher: **A/Professor Glen Bates**

have been approved in accordance with your amendment application on the understanding that you observe the National Statement on Ethical Conduct in Research Involving Humans.

It is now your responsibility to ensure that all people associated with this particular research project are made aware of what has actually been approved and any caveats specified in correspondence with the Ethics Committee. Any further change to the application which is likely to have a significant impact on the ethical considerations of this project will require approval from the Ethics Committee.

Chair, Ethics Committee (or delegate)

Date: 18-Apr-2006

**R. FREW
SECRETARY
ETHICS COMMITTEE**

LE

All research subject to Alfred Hospital Ethics Committee review must be conducted in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).

The Alfred Ethics Committee is a properly constituted Human Research Ethics Committee operating in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).



Ethics Committee

Certificate of Approval of Amendments

This is to certify that amendments to

Project **182/05 Understanding Adaptation to First-Episode Psychosis:
Trauma and Growth Responses**

Chief Researcher: **A/Professor Glen Bates**

Participant Information & Consent Form **Version 8** dated: **05-May-2006**

Participant Information & Consent Form **Family Members Version 8**
dated: **05-May-2006**

have been approved in accordance with your amendment application on the understanding that you observe the National Statement on Ethical Conduct in Research Involving Humans.

It is now your responsibility to ensure that all people associated with this particular research project are made aware of what has actually been approved and any caveats specified in correspondence with the Ethics Committee. Any further change to the application which is likely to have a significant impact on the ethical considerations of this project will require approval from the Ethics Committee.

Chair, Ethics Committee (or delegate)

Date: 22-May-2006

R. FREW
SECRETARY
ETHICS COMMITTEE

All research subject to Alfred Hospital Ethics Committee review must be conducted in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).

The Alfred Ethics Committee is a properly constituted Human Research Ethics Committee operating in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).



Ethics Committee

Certificate of Approval of Amendments

This is to certify that amendments to


Project **182/05 Understanding Adaptation to First-Episode Psychosis: Trauma and Growth Responses**

Principal Researcher: **A/Professor Glen Bates**

Amendment: **Revised Module One**
Interview Questions - Family Members
Interview Questions - Stage 1 (First episode psychosis participants)
Clinician Questions (stage 1)
Interview Questions - Stage 2 (First episode psychosis participants)
Experience/Rating Participant questions
The Impact of Events Scale - revised
 Participant Information & Consent Form **Version 9** dated: **17-Nov-2006**

have been approved in accordance with your amendment application on the understanding that you observe the National Statement on Ethical Conduct in Research Involving Humans.

It is now your responsibility to ensure that all people associated with this particular research project are made aware of what has actually been approved and any caveats specified in correspondence with the Ethics Committee. Any further change to the application which is likely to have a significant impact on the ethical considerations of this project will require approval from the Ethics Committee.


 Chair, Ethics Committee (or delegate)

Date: 13-Dec-2006

R. FREW
SECRETARY
ETHICS COMMITTEE

All research subject to Alfred Hospital Ethics Committee review must be conducted in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).

The Alfred Ethics Committee is a properly constituted Human Research Ethics Committee operating in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999).

PO Royal Melbourne Hospital
Parkville Victoria 3050
Telephone: 61 3 9342 8530
Facsimile: 61 3 9342 8548
Email: research.directorate@mh.org.au
Website: www.mh.org.au/research
ABN 73 802 706 972



RESEARCH DIRECTORATE

Director Research

Dr. Gad Trevaks

Manager

Dr. Angela Warr

Assistant Manager

Ms Michelle Clemson

Research Ethics

Manager-

Mental Health

Dr. Stacey Gabriel

Chairs

Human Research Ethics
Committee

A/Prof. Peter Colman

Animal Ethics
Committee

Prof. Colin Chapman

Institutional Biosafety
Committee

Prof. Stephen Jane

Mental Health
Research &
Ethics Committee

Dr Tom Peyton

6th November 2006

A/Prof Glen Bates
Faculty of Life Sciences
Swinburne University of Technology
Po Box 218
HAWTHORN 3122

Dear Glen,

Re: MHREC 2006.057 Understanding adaptation to first-episode psychosis: Trauma and growth responses

I am writing to advise you of the decision made by the Mental Health Research and Ethics Committee on the November 1 2006 regarding the above named protocol.

The Committee **approved** the project subject to following modifications. Once all the modifications have been approved the approval certificate and letter will be issued.

1. Could you please incorporate the answer to Question 1 from the scientific reviewer into the proposal in Section 1.16 of Module 1.
2. Could you please explain how you are integrating the qualitative and quantitative data.
3. Could you please clarify how you are to use the data-individually or collectively.
4. Could you please provide more information on how you are to analyse the qualitative data.
5. In Module 1, 1.27 (h) could you please justify why the research is in the public interest.

Participant Information and Consent Form:

1. Could you please rewrite the Section 2. **Purpose and Background** Section of the Family Consent Form to more accurately reflect the participation of a family member.
2. In Section 6. **Privacy, Confidentiality and Disclosure of Information of the Family Consent Form** could you please state that also client confidentiality will also be maintained.
3. In Section 11. **Participation is Voluntary** of the Family Consent Form, could you please remove the second paragraph as it is not relevant. Could you also remove the last sentence of the 4th paragraph.

1. All amended documents are to be accompanied by a clean copy of the original, a "Marked up" copy of the original with the changes clearly identified using strikethrough and underlining as required, and a clean copy of the new version, which has a new version number and date clearly noted in the footer.
2. Only complete responses to this letter are forwarded. Where a number of changes, comments and/or additional documents are required, these should be forwarded together in the one package. DO NOT REPLY TO THIS LETTER IN TWO OR MORE SEPARATE STAGES.

Please forward 1 copy of the above documentation at your earliest convenience.

Yours truly,



Dr Stacey Gabriel
Manager
Mental Health Research and Ethics Committee

PO Royal Melbourne Hospital
 Parkville Victoria 3050
 Telephone: 61 3 9342 8530
 Facsimile: 61 3 9342 8548
 Email: research.directorate@mh.org.au
 Website: www.mh.org.au/research
 ABN 73 802 706 972



Research Directorate – Mental Health Research and Ethics Committee Approval Form

Telephone: 9342 7098 Facsimile: 9342 8548

This is to certify that

MHREC Project No: 2006.057

Approval date: 01.11.06

Expiry date: 01.11.09

Project Title: Understanding adaptation to first-episode psychosis: Trauma and growth responses

Sponsored by: N/A

Principal Investigator: A/Prof Glen Bates

Protocol No: N/A

Anticipated commencement of Study: December 2006

Participant Information and Consent Form: Version 1, 13/10/06

Investigator Brochure: N/A

Other enclosures: N/A

Conducted at: **ORYGEN Youth Health has been approved**

It is now your responsibility to ensure that all people conducting this research project are made aware of which documents have been approved.

This approval is subject to ongoing, current and valid insurance coverage throughout the duration of the conduct of the study.

You are required to notify the Secretary of the Human Research Ethics Committee of

- Any change in the protocol and the reason for that change together with an indication of ethical implications (if any) by submitting an amendment to the study.
- Serious adverse effects on subjects and the action taken to manage them, including amended Plain Language Statement and Consent Form where appropriate.
- Any unforeseen events.
- Your inability to continue as Principal Investigator, or any other change in research personnel involved in the study.
- A delay of more than 12 months in the commencement of the project.
- The actual date of commencement of the study.

You are required to submit to the Human Research Ethics Committee

- An Annual Report every twelve months for the duration of the project.
- A detailed Final Report at the conclusion of the project.

The Human Research Ethics Committee may conduct an audit at any time.

An extension of the project beyond the stated conclusion date should be sought from the Human Research Ethics Committee.

Signed:

Dr Stacey Gabriel

Manager

Mental Health Research and Ethics Committee

PO Royal Melbourne Hospital
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Email: research.directorate@mh.org.au
Website: www.mh.org.au/research
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RESEARCH DIRECTORATE

7th December 2006

Director Research
Prof Ingrid Winslip

Manager
Dr. Angela Warr

Assistant Manager
Ms Michelle Clemson

Research Ethics
Manager-
Mental Health
Dr. Stacey Gabriel

Chairs
Human Research Ethics
Committee
A/Prof. Peter Colman

Animal Ethics
Committee
Prof. Colin Chapman

Institutional Biosafety
Committee
Prof. Stephen Jane

Mental Health
Research &
Ethics Committee
Dr Tom Peyton

A/Prof Glen Bates
Faculty of Life Sciences
Swinburne University of Technology
Po Box 218
HAWTHORN 3122

Dear Glen,

RE: MHREC 2006.057 Understanding adaptation to first-episode psychosis: Trauma and growth responses

Thank you for your correspondence requesting approval for amendments to the above project.

Your amendment requesting:

1. *The addition of the MINI as a screening tool for Axis I diagnosis*

A new Participant Information and Consent Forms Version 2 dated 17/11/06 for participants and family have been included.

Was reviewed and approved by the Mental Health Research and Ethics Committee on the 6 December 2006.

The current contract will cover the approval given for the above amendment to proceed.

Yours Sincerely,

Manager
Mental Health Research and Ethics Committee

PO Royal Melbourne Hospital
 Parkville Victoria 3050
 Telephone: 61 3 9342 8530
 Facsimile: 61 3 9342 8548
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RESEARCH DIRECTORATE

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Chairs

Human Research Ethics
 Committee

A/Prof. Peter Colman

Animal Ethics
 Committee

Prof. Colin Chapman

Institutional Biosafety
 Committee

Prof. Stephen Jane

Mental Health
 Research &
 Ethics Committee
 Dr Tom Peyton

20th December 2006

A/Prof Glen Bates
 Faculty of Life Sciences
 Swinburne University of Technology
 Po Box 218
 HAWTHORN 3122

Dear Glen,

Re: MHREC 2006.057 Understanding adaptation to first-episode psychosis: Trauma and growth responses

Your protocol was reviewed and approved by the Mental Health Research and Ethics Committee on the **01.11.06**.

Enclosed please find a copy of the signed approval certificate.

On behalf of the Committee may I wish you the very best in your research and we look forward to hearing your results.

Yours Sincerely,

A handwritten signature in black ink, appearing to read "A. Gabriel".

Dr. Stacey Gabriel

Manager

Mental Health Research and Ethics Committee

PO Royal Melbourne Hospital
 Parkville Victoria 3050
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 Facsimile: 61 3 9342 8548
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RESEARCH DIRECTORATE

8 August 2007

Director Research
 Prof Ingrid Winslip

Manager
 Dr. Angela Warr

Assistant Manager
 Ms Michelle Clemson

Research Ethics
Manager-
Mental Health
 Ms Michelle Clemson

Chairs
 Human Research Ethics
 Committee
 A/Prof. Peter Colman

Institutional Biosafety
 Committee
 Prof. Stephen Iane

Mental Health
 Research &
 Ethics Committee
 Dr Tom Peyton

A/Professor Glen Bates
 Faculty of Life Sciences
 Swinburne University of Technology
 Po Box 218
 HAWTHORN 3122

Dear Glen,

RE: MHREC project 2006.057 Understanding adaptation to first-episode psychosis: Trauma and growth responses

Thank you for submitting the following correspondence:

A *Request for Approval of Amendments* form dated 30 March 2007 enclosing:

- Amendment Number 2;
- Updated Module One, Question 1.19;
- Participant Information and Consent Form Version 3 dated 5/7/07; and
- Participant Information and Consent Form for Family Members Version 3 dated 5/7/07.

The Mental Health Research and Ethics Committee have reviewed and **approved** the above amendment at its meeting on Wednesday 1 August 2007.

Amendment 2 to MHREC project 2006.057 may now proceed.

Yours sincerely,

Ms. Michelle Clemson
 Manager, Mental Health Research and Ethics Committee

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RESEARCH DIRECTORATE

18 March 2008

A/Professor Glen Bates
 ORYGEN Research Centre
 Department of Psychiatry
 University of Melbourne

Dear Glen,

RE: MHREC 2006.057 Understanding adaptation to first-episode psychosis: Trauma and growth responses

Thank you for submitting the following correspondence:

- An email dated 11 February 2008 requesting for a participant to have both the interview tapes and transcriptions of his interviews as he is keeping a record of his personal journey with psychosis.

The Mental Health Research and Ethics Committee have reviewed and **approved** the above request at its meeting on Wednesday 5 March 2008.

Yours sincerely,

A handwritten signature in black ink, appearing to read "Michelle Clemson".

Ms. Michelle Clemson
 Manager
 Mental Health Research and Ethics Committee

**Executive Director
 of Research**

Prof Ingrid Winslip

Manager

Dr. Angela Wah

Assistant Manager

Ms Angela Gray
 Dr Sarah Rickard

Research Ethics

Manager:

Mental Health
 Ms Michelle Clemson

Chairs

Human Research Ethics
 Committee
 Prof. Peter Colman

Institutional Biosafety
 Committee
 Prof. Stephen Jane

Mental Health
 Research &
 Ethics Committee
 Dr Tom Peyton

APPENDIX B

Advertising material was adapted to suit the clinical service participants were recruited from but the general layout was the same. Due to this only the clinicians' research summary and brochures that was used to recruit from ORYGEN Youth Health is provided. Posters were only used to advertise the main study at Alfred Psychiatric services. They are presented in the following order: clinician research summary, poster, FEP participants' brochure, loved one's brochure.

ADAPTATION TO FIRST-EPISODE PSYCHOSIS: TRAUMA AND GROWTH RESPONSES



BACKGROUND AND RATIONALE

This study will focus on first-episode psychosis because it has been suggested that it is a critical period that can influence the long-term course of the illness and is especially responsive to intervention. It is arguable that first-episode psychosis and adjustment to this event can be understood within a trauma framework. Recently, there has been increased recognition that psychosis can potentially be a traumatic experience. In particular, psychotic symptoms and treatment experiences have been identified as traumatic. Despite this, there is little empirical research on the stressful impact of psychosis and how people adjust to its onset.

One way of understanding psychosis is to draw upon ideas of how people integrate and adapt to this traumatic experience. Post-traumatic growth is a relatively new concept that focuses on the positive adaptation to a traumatic event. This concept considers the positive experiences that can come out of traumatic events as well as recognising the parallel pain and anguish trauma can cause. Posttraumatic growth does not occur as a direct result of the trauma; instead it develops through a person's struggle with the new reality that the trauma has caused. Posttraumatic growth is an experience of improvement. The five domains of posttraumatic growth are: a greater appreciation of life and changed sense of priorities; warmer, more intimate relationships with others; a greater sense of personal strength;

recognition of new possibilities or paths for one's life; and spiritual development. Even though the relationship between psychosis and posttraumatic growth has not been investigated, authors have indicated that people who have experienced psychosis can have experiences that are consistent with the notion of growth.

It is hoped that this study will develop a deeper understanding of peoples' personal experiences of first-episode psychosis and of the things that help people adapt to having been unwell. This project may reveal important areas to address during treatment of first-episode psychosis and influence the management of this experience.

The results of this research will be used to help Jane Dunkley obtain her Professional Doctorate in Clinical Psychology degree at Swinburne University of Technology.

AIM OF THE STUDY

This study will explore first episode psychosis as a traumatic event and examine whether posttraumatic growth occurs as a result of this traumatic experience. Further, if posttraumatic growth is evident this study will examine whether posttraumatic growth facilitates adaptation to first episode psychosis. In particular the research will aim to:

1. Explore the utility of the trauma framework/perspective in understanding first-episode psychosis.
2. Investigate whether constructs pertinent to posttraumatic growth are relevant to people's accounts of recovery from first-episode psychosis.

PARTICIPANTS

We are seeking 10-15 people who have experienced a first-episode of psychosis (aged 18-24 years) and their family members (aged 18 years and over).

WHAT DOES THE STUDY INVOLVE?

The research will be prospective. There will be two stages to data collection. It is envisaged that first-episode psychosis participants will be seen at approximately 3 – 6 months (stage 1) and approximately 6 – 9 months (stage 2) after their acute psychotic episode (i.e. after

discharge from hospital or YAT involvement). Stage 1 involves three face-to-face interviews and the completion of four questionnaires, while stage 2 comprises of two interviews and three questionnaires. Sessions with psychosis participants will take approximately 2.5 hours. At stage 2 a family member will also be interviewed to further explore the experiences and changes the first-episode psychosis participants have been through since they were unwell. Sessions with family members will take approximately 1 hour. Demographic information will also be collected from the participants' files and clinicians. Additionally, clinicians will be asked to comment on how their clients' have responded to treatment, how they are coping, and any changes they may have gone through. Participants will be offered reimbursement for time and inconvenience associated with the study on completion of their participation.

INCLUSION CRITERIA

- Have recently experienced an acute first episode of psychosis as defined by the presence of significant psychotic symptoms that require psychiatric intervention.
- Have a primary diagnosis of a psychotic illness conforming to the DSM-IV-TR criteria and confirmed by the participants' treating team and the clients' file notes.
- Have now reached complete, or near complete, remission and are at a point where they are deemed able to give informed consent and participate in the study as determined by the participant's treating team.
- Have a family member that is willing to be involved in the study and whom can give informed consent.

EXCLUSION CRITERIA

- Significant brain damage that would affect their ability to participate.
- Significant Intellectual Disability that would affect their ability to participate.
- Illiterate or very poor English/unable to converse in or read English without an interpreter
- Inability to give informed consent

BENEFITS

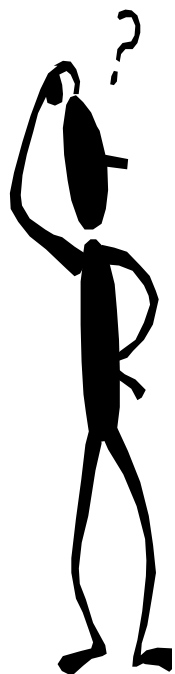
If first-episode psychosis participants consent to allow researchers to give clinicians an individual summary of their results this may provide clinicians with new information about their client. Additionally, this information may promote discussion about participants' experiences of being unwell and could assist their ongoing treatment and recovery.

Participants might also find it helpful to have the opportunity to discuss their experiences and giving participants a written summary of group data may provide them with mutual support and understanding. An indirect benefit is the opportunity to help people who have experienced a first-episode of psychosis by contributing to our understanding about what this experience is like and the things that may help people adapt to and cope with this event.

WHO CAN I CONTACT?

If you have a client that might be a suitable participant for this study or you would like more information please contact – Jane Dunkley (0402 133 104/ 9214 4681) and A/Prof Glen Bates (9214 8100) from Swinburne University of Technology

WHAT WAS IT LIKE FOR YOU TO EXPERIENCE A FIRST OCCURENCE OF PSYCHOSIS?



YOU ARE INVITED.....to participate in a study which will explore what it is like to for people to experience a first-episode of psychosis and how people adjust to this experience.

We are encouraging people who have had a first experience of psychosis and their family members to participate. We are interested in hearing your viewpoints, as we would like to learn from you and your experiences.

On completion of your involvement you will be offered reimbursement for your effort and the time associated with participating in the study.

If you are interested in participating in this project or you would like more information please speak to....

- ❖ **Your Case Manager or Doctor**
- ❖ **Glen Bates (9214 8100) or Jane Dunkley (9214 4681) from Swinburne University of Technology**

HELP US UNDERSTAND

If you are interested in participating in this project or you would like more information please speak to.....

Your Case Manager or Doctor or

Glen Bates (9214 8100) or Jane Dunkley (9214 4695) from Swinburne University of Technology



**ORYGEN Youth
Health
&
SWINBURNE
UNIVERSITY OF
TECHNOLOGY**

**WHAT WAS IT LIKE
FOR YOU TO
EXPERIENCE A
FIRST OCCURRENCE
OF PSYCHOSIS?**



HELP US UNDERSTAND

You are invited.....

To participate in a study that will explore what it is like for people to experience a first-episode of psychosis and how people adjust to this experience.

We are encouraging people who have had a first experience of psychosis and their family members to participate. We are interested in hearing your viewpoints, as we would like to learn from you and your experiences.

Your information will contribute to our understanding of what it is like for people to experience first-episode psychosis and the things that may help people cope with this event. Also, your information may reveal important areas to address during treatment.

You might find it helpful to have the opportunity to discuss your experiences.

What is involved?

Your participation will involve some interviews and questionnaires spread over two sessions.

We wish to talk to you about:

- Your experiences of being unwell
- Your treatment experiences
- Any symptoms you might be experiencing
- How you have been coping since you were unwell
- Any changes you may have gone through since being unwell
- Your recovery
- How you feel about the future

The questionnaires will collect information about similar issues.

We will also like to talk to a member of your family and your Case Manager or Doctor about some of these things too.

On completion of your participation you will be offered reimbursement for the time and inconvenience associated with the study.

What will happen to my information?

The information will be used to help Jane Dunkley obtain her Professional Doctorate in Clinical Psychology degree at Swinburne University of Technology.

We plan to discuss and publish the study. However, your information will be given in such a way that you cannot be identified. Therefore, any information obtained that can identify you will remain confidential.

If you give us your permission we will provide your Case Manager and Doctor with a summary of your results. This information may assist your ongoing treatment and recovery.

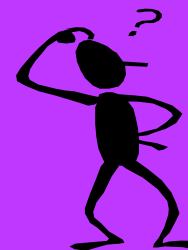
If you would like more information, or you need to speak with a researcher before you are contacted to arrange a meeting time please call:

Glen Bates (9214 8100) or Jane Dunkley (9214 4695) from Swinburne University of Technology



**ORYGEN Youth Health
&
SWINBURNE
UNIVERSITY OF
TECHNOLOGY**

**WHAT WAS IT LIKE
FOR YOUR FAMILY
MEMBER TO
EXPERIENCE A FIRST
OCCURRENCE OF
PSYCHOSIS?**



HELP US UNDERSTAND

You are invited.....

To participate in a study that will explore what it is like for people to experience a first-episode of psychosis and how people adjust to this experience.

We are encouraging people who have had a first experience of psychosis and their family members to participate. We are interested in hearing your viewpoints about your family member's experiences.

Your information will contribute to our understanding of what it is like for people to experience first-episode psychosis and the things that may help people cope with this event. Also, your information may reveal important areas to address during treatment.

You might find it helpful to have the opportunity to discuss your family member's experiences.

What is involved?

Your participation will involve one interview.

We wish to talk to you about:

- ◆ Your family member's experiences of being unwell.
- ◆ How your family member has been coping since they were unwell.
- ◆ Any changes your family member may have gone through since being unwell.
- ◆ Your family member's recovery.

On completion of your participation you will be offered reimbursement for the time and inconvenience associated with the study.

What will happen to my information?

The information will be used to help Jane Dunkley obtain her Professional Doctorate in Clinical Psychology degree at Swinburne University of Technology.

We plan to discuss and publish the study. However, your information will be given in such a way that you cannot be identified. Therefore, any information obtained that can identify you will remain confidential.

APPENDIX C

Due to the similarity of participant information and consent forms across services, only forms for loved ones and FEP participants for ORYGEN Youth Health are given. These consent forms were printed on ORYGEN Youth Health letterhead.

Participant Information and Consent Form

Version: 3, **Dated:** 5/7/07

Site: ORYGEN Youth Health

Full Project Title: Understanding Adaptation to First-Episode Psychosis: Trauma and Growth Responses

Principal Researcher: A/Prof Glen Bates

Associate Researcher(s): Ms. Jane Dunkley, A/Prof Paul Fitzgerald, Dr. Ruth Parslow and Dr. Bruce Findlay.

This Participant Information and Consent Form is **8** pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project. This Participant information Statement contains detailed information about the research project. Its purpose is to explain to you as openly and as clearly as possible all the procedures in this project before you decide whether or not to take part in it.

Please read this Participant Information Statement carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project as outlined below.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background

There are two main purposes of this study. The first is to explore what it is like for people to experience a first occurrence of mental illness ('first-episode psychosis'). The second aim is to assess how people adapt to having experienced their first-episode of psychosis. It is important to have a clear understanding of peoples' first experience of psychosis and how they cope with having been unwell as this could influence the course of their psychosis. However, there is little research on the impact of psychosis

and how people adjust to this experience. Therefore an in-depth study is needed to properly understand these important issues.

It is hoped that this study will develop a better understanding of peoples' personal experiences of psychosis and of the things that help people adjust to having been unwell. This project may reveal important areas to address during treatment of first-episode psychosis and influence how people manage this experience.

We are seeking a total of 30 – 40 people to participate in this project; 15-20 people who have experienced a first-episode of psychosis and 15-20 family members. This study invites you to participate because you have recently experienced a first-episode of psychosis. This study will also invite a member of your family to participate. Family members are asked to participate in this research to enable a richer understanding of any experiences and changes you may have gone through.

The results of this research will be used to help Jane Dunkley obtain her Professional Doctorate in Clinical Psychology degree at Swinburne University of Technology.

3. Procedures

Participation in this project will involve two sessions. The first session will occur approximately three months after you were unwell and the second session will happen approximately three months after you participated in the first session (six months after you were unwell).

During the first session you will be invited to participate in three face-to-face interviews and the completion of four questionnaires. The second session will be the same as the first, however it will only involve two interviews not three. Sessions should take around two and a half hours. You will be able to have a break(s) during this time if you want a rest.

During the sessions we wish to talk to you about any stressful things you may have experienced before you became unwell, your experiences of being unwell, any changes you may have gone through since being unwell, any significant experiences you may have had since you were unwell, and how you have been coping since you were unwell. Also, we would like to talk to you about your current treatment experiences, your recovery, and how you feel about the future. We would also like to discuss any mental health issues you might be experiencing to measure how troubling these may be for you at the time of the assessment. The questionnaires we would like you to complete will collect information about your current symptoms, how you are coping with your mental health, the things you experienced when you were unwell, and the changes you might have gone through since you became unwell.

Sessions can be held at Orygen Youth Health or your home. However, it is preferable if sessions are held at Orygen Youth Health.

A second person might be present when you are interviewed about your mental health issues. They will only be involved to ensure that the interview procedure is reliable. This person will not be a researcher from this study. If you do not want a second person present during this interview please let us know and you will only be interviewed by a researcher from the current study.

Researchers would also like to interview a member of your family. Family members will be asked about their perceptions of your experience of being unwell, the changes you

may have gone through since being unwell, any stressful things you might have experienced before you became unwell, how you have coped since you were unwell, any important or significant experiences you may have had since you were unwell, and your recovery. You will be asked which family member you would like us to speak to before they are contacted.

Additionally, participating in this study will involve collecting information from your treating team and your medical file(s). We would like to speak to your treating team about your symptoms and treatment, how you have responded to treatment, how you have coped with being unwell, and the changes you might have experienced. Information collected from your file will include relevant information about your mental health and treatment and demographic information.

Lastly, we would like to give your treating team a summary of your individual results. However, if you do not wish this to happen just let us know.

If there are any questions you do not want to answer during the interviews or completion of the questionnaires just let us know at the time. You are free to withdraw from the study at anytime.

4. Possible Benefits

We cannot guarantee or promise that you will receive any benefits from this project. You might find it helpful to have the opportunity to discuss your experiences of being unwell. Also, giving you a written summary of group data (which will be available for participants at the end of the study) may provide you with mutual support and understanding. If you consent to allow us to give your clinician an individual summary of your results this may promote discussion about your experience of being unwell which in turn may assist your recovery. An indirect benefit is the opportunity to help people who have experienced a first-episode of mental illness by contributing to our understanding about what it is like to experience psychosis and the things that may help people adapt to and cope with this event.

5. Possible Risks

It is unlikely that there will be any risks associated with this study. Nevertheless, we would like you to be aware that talking about your experiences of being unwell might be distressing. If you do not wish to reveal certain information or discuss certain issues that are raised this is fine. If you find any of the questions distressing we will not continue with these questions. You can decide to suspend or even end your participation in the project at anytime. Counselling will be made available to you, should you require it, if you become distressed or wish to discuss anything raised during the interview. There may be additional unforeseen or unknown risks.

6. Privacy, Confidentiality and Disclosure of Information

Any information obtained in connection with this project and that can identify you will remain confidential. Information will only be disclosed with your permission, except as required by law. Your treating team will only be given a summary of your results if you give your consent for this to occur. If issues of concern are raised or you become distressed during the study researchers may inform your treating team for your own wellbeing.

Any results gathered from your participation in the study will not include your name or contact details. Your results will be stored in a locked filing cabinet in a way that cannot identify you. Although the consent form will have your name on it and we will

have your contact details, this information and your results will be stored separately. Only the researchers listed above will have access to your results and other information. In accordance with hospital guidelines information from this study will be kept for as long as it is needed, after which it will be destroyed.

If you sign this consent form you will be allowing researchers to have access to your medical file(s). Researchers will collect relevant information about your mental health and treatment and demographic data from your file(s). Direct copies of your file(s) information will not be taken. Your name and contact details will not be included with information that is collected from your file(s). Information collected from your file(s) will only be discussed between researchers and will be stored in a locked filing cabinet in a way that cannot identify you.

If you give us permission by signing the consent form, we plan to share, discuss and publish the results of the study in journals, at conferences, and with relevant professionals. As interviews are the main part of this project, you will be quoted in any written or verbal form of this study. However, all information that might identify you will be removed from quotes and not published or discussed. All other reported data will be group data. Therefore, in any publication or discussion about the study, information will be provided in such a way that you cannot be identified.

You may access information kept about you in accordance with hospital policies.

7. New Information Arising During the Project

During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation. In all cases, you will be offered all available care to suit your needs and medical condition.

8. Results of Project

When the study has been completed a summary of the group findings will be available to all participants. We will ask you when the study ends if you would like to receive a copy of the group results. Your individual results will also be made available to your clinician if you consent to this.

9. Further Information or Any Problems

If you require further information or if you have any problems concerning this project, you can contact A/Prof Glen Bates (9214 8100) and Jane Dunkley (9214 4681) at Swinburne University. The researcher responsible for this project is A/Prof Glen Bates.

10. Other Issues

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact

Name: **Dr Stacey Gabriel**

Position: **Manager, Mental Health Human Research Ethics Committee**

Telephone: **(03) 9342 7098**

You will need to tell **Dr Stacey Gabriel** the name of one of the researchers listed above.

11. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with ORYGEN Youth Health.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team before you withdraw. This notice will allow that person or the research supervisor to inform you if there are any health risks or special requirements linked to withdrawing.

12. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Research Involving Humans* (June 1999) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by The Human Research Ethics Committee of Melbourne Health, the Alfred Hospital and Swinburne University of Technology.

13. Reimbursement for your costs

On completion on your participation you will be offered reimbursement of up to \$50 for the time and inconvenience associated with the study.

CONSENT FORM

Version: 3, dated 5/7/07

Site: ORYGEN Youth Health

Full Project Title: Understanding Adaptation to First-Episode Psychosis: Trauma and Growth Responses

I have read and I understand the Participant Information version 3, dated 5/7/07.

I freely agree to participate in this project according to the conditions in the Participant Information.

I agree to allow researchers to:

Access my file

Interview my clinician

Interview my family member

I will be given a copy of the Participant Information and Consent Form to keep

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant's Name (printed)

Signature Date

Name of Witness to Participant's Signature (printed)

Signature Date

Researcher's Name (printed)

Signature Date

Note: All parties signing the Consent Form must date their own signature.

RELEASE OF INDIVIDUAL RESULTS

Version: 3, dated 5/7/07

Site: ORYGEN Youth Health

Full Project Title: Understanding Adaptation to First-Episode Psychosis: Trauma and Growth Responses

I give my permission for researchers to give my treating team a summary of my individual results.

Yes

No

Participant's Name (printed)

Signature

Date

REVOCATION OF CONSENT FORM

(To be used for participants who wish to withdraw from the project.)

Full Project Title: Understanding Adaptation to First-Episode Psychosis: Trauma and Growth Responses

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with Orygen Youth Health or associated Community Mental health Services

Participant's Name (printed)

Signature

Date

Participant Information and Consent Form for Family Members

Version: 3, **Dated:** 5/7/07

Site: ORYGEN Youth Health

Full Project Title: Understanding Adaptation to First-Episode Psychosis: Trauma and Growth Responses

Principal Researcher: A/Prof Glen Bates

Associate Researcher(s): Ms. Jane Dunkley, A/Prof Paul Fitzgerald, Dr. Ruth Parslow, and Dr. Bruce Findlay.

This Participant Information and Consent Form is **6** pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project. This Participant information Statement contains detailed information about the research project. Its purpose is to explain to you as openly and as clearly as possible all the procedures in this project before you decide whether or not to take part in it.

Please read this Participant Information Statement carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background

There are two main purposes of this study. The first is to explore what it is like for people to experience a first occurrence of mental illness ('first-episode psychosis'). The second aim is to assess how people adapt to the experience of first-episode psychosis. It is important to have a clear understanding of peoples' first experience of psychosis and how they cope with having been unwell as this could influence the course of their psychosis. However, there is little research on the impact of psychosis and how people adjust to this experience. Therefore an in-depth study is needed to properly understand these important issues. This project may reveal important areas to address during treatment of first-episode psychosis and influence how people manage this experience.

This study invites you to participate because a member of your family has recently experienced their first-episode of psychosis. You are asked to participate in this research to enable a richer understanding of the experiences and changes your family member may have gone through since being unwell. Gaining a second perspective

about these issues allows researchers to obtain a better, more substantive picture of the issues being explored in this research.

We are seeking a total of 30 – 40 people to participate in this project; 15-20 people who have experienced a first-episode of psychosis and 15-20 family members.

The results of this research will be used to help Jane Dunkley obtain her Professional Doctorate in Clinical Psychology degree at Swinburne University of Technology.

3. Procedures

Participation in this project will involve two sessions. The first session will occur approximately 3 months after your family member was unwell and the second session will happen approximately 3 months after the first, that is, 6 months after your family member was unwell.

You are invited to participate in a face-to-face interview during session two (we will arrange a time to meet with you). This interview will take approximately 1 hour and you will be able to have breaks during this time if you need to.

During the interview we would like to talk to you about your family member's experience of being unwell and the changes they may have gone through since being unwell. Also, we would like to discuss any stressful things your family member may have experienced before he/she became unwell, how your family member has coped since he/she was unwell, any important or significant experiences your family member has had since they were unwell, and your family member's recovery.

Sessions can be held at ORYGEN Youth Health or your home. However, it is preferable if sessions are held at Orygen Youth Health.

If there are any questions you do not wish to answer during the interview just let us know at the time. You are free to withdraw from the study at anytime.

4. Possible Benefits

We cannot guarantee or promise that you will receive any benefits from this project. You might find it beneficial to have the opportunity to discuss your experiences of having a family member who has been unwell. Also, providing a written summary of group data (which will be available for participants at the end of the study) may provide you with mutual support and understanding. An indirect benefit is the opportunity to help people who have experienced a first-episode of psychosis by contributing to our understanding about this experience and the factors that may help people adapt to and cope with this event.

5. Possible Risks

It is unlikely that there will be any risks associated with this study. Nevertheless, we would like you to be aware that talking about your family member's experiences of being unwell might be distressing. If you do not wish to disclose certain information or discuss certain issues that are raised this is fine. If you find any of the questions distressing we will not continue with these questions. You can decide to suspend or even end your participation in the project at anytime if distress occurs. Counselling will be made available to you, should you require it, if you become distressed or wish to discuss anything raised during the interview. There may be additional unforeseen or unknown risks.

6. Privacy, Confidentiality and Disclosure of Information

Any information obtained in connection with this project and that can identify you will remain confidential. Information will only be disclosed with your permission, except as required by law.

Any results and information gathered from your participation in the study will not include your name or contact details. Your results will be stored in a locked filing cabinet in a way that cannot identify you. Although the consent form will have your name on it and we will have your contact details, this information and your results will be stored separately. Only the researchers listed above will have access to your results and other information. In accordance with hospital guidelines information from this study will be kept for as long as it is needed, after which it will be destroyed.

If you give us your permission by signing the Consent Form, we plan to share, discuss, and publish the results in journals, at conferences, and with relevant professionals. As interviews are the main part of this project, you may be quoted in any written or verbal form of this study. However, all information that might identify you will be removed from quotes and not published or discussed. All other reported data will be group data. Therefore, in any publication or other presentation of the study, information will be provided in such a way that you cannot be identified.

Your family members' confidentiality will also be maintained according to these procedures.

You may access information kept about you in accordance with hospital policies.

7. New Information Arising During the Project

During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation. In all cases, you will be offered all available care to suit your needs and medical condition.

9. Results of Project

When the study has been completed a summary of the group findings will be available to all participants. We will ask you when the study ends if you would like to receive a copy of the group results.

9. Further Information or Any Problems

If you require further information or if you have any problems concerning this project (for example, any side effects), you can contact the principal researcher, A/Prof Glen Bates, (9214 8100) or Jane Dunkley (9214 4681). The researcher responsible for this project is A/Prof Glen Bates.

10. Other Issues

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact

Name: **Dr. Stacey Gabriel**

Position: **Manager, Mental Health Human Research Ethics Committee**

Telephone: **(03) 9342 7098**

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11. Participation is Voluntary

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Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

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The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Melbourne Health, The Alfred Hospital, and Swinburne University of Technology.

13. Reimbursement for your costs

On completion of your participation you will be offered reimbursement of \$10 for the time and inconvenience associated with the study.

CONSENT FORM

Version: 3, dated 5/7/07

Site: ORYGEN Youth Health

Full Project Title: Understanding Adaptation to First-Episode Psychosis: Trauma and Growth Responses

I have read and I understand the Participant Information version 3, dated 5/7/07

I freely agree to participate in this project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant's Name (printed)

Signature

Date

Name of Witness to Participant's Signature (printed)

Signature

Date

Researcher's Name (printed)

Signature

Date

Note: All parties signing the Consent Form must date their own signature.

REVOCATION OF CONSENT FORM

(To be used for participants who wish to withdraw from the project.)

Full Project Title: Understanding Adaptation to First-Episode Psychosis: Trauma and Growth Responses

I hereby wish to WITHDRAW my consent to participate in the research proposal described above and understand that such withdrawal WILL NOT jeopardise my family member's treatment or relationship with Orygen Youth Health or associated Community Mental health Services

Participant's Name (printed)

Signature

Date

APPENDIX D

The Impact of Events Scale-Revised

Below is a list of difficulties people sometimes have after stressful life events. In this case I want you to think about the questions in relation to the most distressing experience you had when you were unwell (_____)

Please read each item, and then indicate (*tick*) how distressed and bothered by these difficulties you were DURING THE PAST SEVEN DAYS.

	not at all	a little bit	moderately	quite a bit	extremely
1. Any reminder brought back feelings about it					
2. I had trouble staying asleep					
3. Other things kept making me think about it					
4. I felt irritable and angry					
5. I avoided letting myself get upset when I thought about it or was reminded of it					
6. I thought about it when I didn't mean to					
7. I felt as if it hadn't happened or wasn't real					
8. I stayed away from reminders about it					
9. Pictures about it popped into my mind					
10. I was jumpy and easily startled					
11. I tried not to think about it					
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them					
13. My feelings about it were kind of numb					
14. I found myself acting or feeling as though I was back at that time					
15. I had trouble falling asleep					
16. I had waves of strong feelings about it					
17. I tried to remove it from my memory					
18. I had trouble concentrating					
19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart					
20. I had dreams about it					
21. I felt watchful or on-guard					
22. I tried not to talk about it					

Posttraumatic Growth Inventory

Indicate (*tick*) the degree to which the change reflected in the question is true in your life as a result of being unwell, using the following scale.

	I did not experience this change	I experienced this change to a very small degree	I experienced this change to a small degree	I experienced this change to a moderate degree	I experienced this change to a great degree	I experienced this change to a very great degree
1. I changed my priorities about what is important in life						
2. I have a greater appreciation for the value of my own life						
3. I developed new interests						
4. I have a greater feeling of self-reliance						
5. I have a better understanding of spiritual matters						
6. I more clearly see that I can count on people in times of trouble						
7. I established a new path for my life						
8. I have a greater sense of closeness with others						
9. I am more willing to express my emotions						
10. I know better that I can handle difficulties						

11. I am able to do better things with my life						
12. I am better able to accept the way things work out						
13. I can better appreciate each day						
14. New opportunities are available which wouldn't have been otherwise						
15. I have more compassion for others						
16. I put more effort into my relationships						
17. I am more likely to try to change things which need changing						
18. I have a stronger religious faith						
19. I discovered that I'm stronger than I thought I was						
20. I learned a great deal about how wonderful people are						
21. I better accept needing others						

Recovery Style Questionnaire

Written below is a list of statements about your illness. Please read them carefully and tick the box to show if you agree or disagree.

	Agree	Disagree
1. There was a gradual build up to me becoming ill		
2. My illness is not part of my personality		
3. I am responsible for what I think when I am ill		
4. I am not interested in my illness		
5. My illness taught me new things about myself		
6. I need help to solve the problems caused by my illness		
7. My illness was caused by my difficulties in coping with life		
8. I have had a nervous breakdown		
9. I can see positive aspects to my illness		
10. My illness had a strong impact on my life		
11. I am not frightened of mental illness		
12. I liked some of the experiences I had when I was ill		
13. My illness has helped me to find a more satisfying life		
14. My illness came on suddenly and went suddenly		
15. My illness is part of me		
16. I am not responsible for my actions when I am ill		
17. I am curious about my illness		
18. I understand myself better because of my illness		
19. I can manage the problems caused by my illness alone		
20. Others are to blame for my illness		
21. I have had a medical illness		
22. Nothing good came from my illness		
23. My illness has had little effect on my life		
24. I am frightened of mental illness		
25. I didn't like any of the unusual experiences I had when I was ill		
26. It's hard to find satisfaction with life following my illness		
27. My illness came on very suddenly		
28. My illness is alien to me		
29. I am responsible for my thoughts and feelings when I am ill		
30. I don't care about my illness now that I am well		
31. I want to be the person I was before my illness		
32. Others can help me solve my problems		
33. My illness was caused by stress in my life		
34. I have suffered an emotional breakdown		
35. Being ill had good parts too		
36. I'm not really interested in my illness		
37. I liked some of the unusual experiences I had when I was ill		
38. My life is more satisfying since my illness		
39. My attitude to mental illness is better now than before I was ill		

Due to the size of the PANSS and M.I.N.I. it was not feasible to put the measures in the Appendix. Further, these measures are commonly used in research and therefore well known. Thus, example questions from each measure are provided.

PANSS

General Psychopathology Scale

Data on anxiety (G2)

Have you been feeling worried or nervous in the past week?

If no: Would you say that you're usually calm and relaxed?

If yes: What's been making you feel nervous (worried, un-calm, unrelaxed)?

Just how nervous (worried etc.) have you been feeling?

Have you been shaking at times, or has your heart been racing?

Did you get into a state of panic?

Has your sleep, eating or participation in activities been affected?

Negative Scale

Data on "passive/apathetic social withdrawal" (N4)

How do you spend your time these days?

Do you prefer to be alone?

Do you join in activities with others?

If no: Why not?

If yes: Can you explain?

Tell me about it?

Do you have many friends?

If no: Just a few?

If yes: Why just a few?

Close friends?

If no: Why not?

Positive Scale

Data on "hallucinatory behaviour" (P3) and associated delusions

Do you once and a while have strange or unusual experiences?

Sometimes people tell me that they can hear noises or voices inside their head that others can't hear. What about you?

If no: From God or the devil?

If yes: What do you hear?

Are these as clear and loud as my voice?

How often do you hear these voices (noises, messages, etc.)?

Does this happen at a particular time of day or all the time?

If hearing voices:

Can you recognise whose voices they are?

What do the voices say?

Are the voices good or bad?

Pleasant or unpleasant?

Do the voices interrupt your thinking or your activities?

Do they sometimes give you orders or instructions (if yes, for example)?

What do you make of these voices (or noises): where do they really come from?

Why do you have these experiences?

Are these normal experiences?

M.I.N.I.

Psychotic Disorders

Now I am going to ask you about some unusual experiences that some people have

L1 a) Have you ever believed that people were spying on you, or that someone was plotting against you, or trying to hurt you?

NOTE: Ask for examples to rule out stalking

b) If yes: Do you currently believe these things?

L6 a) Have you ever heard things other people couldn't hear, such as voices?

NOTE: Hallucinations are score "bizarre" only if patient answers yes to the following:

If yes: Did you hear a voice commenting on your thoughts or behaviour or did you hear two or more voices talking to each other?

b) If yes: Have you heard these things in the past month?

Posttraumatic Stress Disorder

11. Have you ever experienced or witnessed or had to deal with an extremely traumatic event that included actual or threatened death or serious injury to you or someone else?

NOTE: Examples include: serious accidents, sexual or physical assault, a terrorist attack, being held hostage, kidnapping, fire, discovering a body, sudden death of someone close to you, war, or natural disaster

12. Did you respond with intense fear, helplessness or horror?

13. During the past month have you experienced the event in a distressing way (such as dreams intense recollections, flashbacks, or physical reactions)?

Major Depressive Episode

A1 Have you been consistently depressed or down, most of the day, nearly every day, for the past two weeks?

A2 In the past two weeks, have you been less interested in most things or less able to enjoy the things you used to enjoy most of the time?

A3 Over the past two weeks, when you felt depressed or uninterested did you:

b) Have trouble sleeping nearly every night (difficulty falling asleep, waking up in the middle of the night, early morning wakening or sleeping excessively)?

List of Experiences Questionnaire

Step 1. Cross out the things you did not experience

Step 2. Now rate the things you did experience from most to least distressing
(1 = least distressing)

<i>EXPERIENCE</i>	<i>RATING</i>
Involuntary admission to hospital (admitted against your will/wishes)	
Police being involved in your hospital admission	
Being locked in a room by yourself in hospital (seclusion/isolation)	
Being on a closed ward (e.g. high dependency/HDU)	
Being physically hurt in hospital (e.g. by other patients)	
Being surrounded by others who are unwell in hospital	
Being away from family and friends and other important things in your life because you were in hospital, e.g. work and study	
Not being told why you were hospitalised	
Not understanding why you were hospitalised	
Not knowing how long you were going to be in hospital	
Being restrained	
Being sedated	
Being forced to take medication	
Side effects from medication	
Your symptoms (e.g. voices, delusions)	
Being interviewed by CATT	
Being visited by CATT	
Not being told why CATT were visiting you	
Not understanding why CATT were visiting you	
Not knowing how long CATT would be visiting you for	
Having CATT monitor your medication	
Being physically hurt by someone or hurting someone else when you were unwell (e.g. got into a fight)	
Getting into trouble with the law when you were unwell	
Having contact with police when you were unwell	
Experiencing conflict with family and friends when you were unwell	
Experiencing other difficulties with family and friends when you were unwell (please specify what difficulties)	

Hurting yourself when you were unwell	
Being unable to work, go to school or do other things you would normally be able to do because you were unwell	
Other (please specify)	

APPENDIX E

Please note that these are the final versions of the interview protocols which were used in the main study. Given that few changes were made to the interviews as a result of the pilot study and changes are discussed in detail on pages 124-129, the pilot interview protocols are not given. Pilot results can be reviewed in-conjunction with the final interview protocols and changes discussed on pages 124-129.

First-Episode Psychosis Participants

Time One Interview

Through my research project, I would like to develop a greater understanding of the experiences people have when they first become unwell and the changes they may go through since being unwell. I am interested in hearing your viewpoints, as I would like to learn from you and your experiences.

- 1. What brought you to x?**
- 2. How would you describe what happened to you?**
- 3. Do you think any of these experiences were due to a mental health issue? (what tells you they were/weren't?)**
- 4. I was wondering what it was like for you to be unwell/x?**

Prompts:

- Was being unwell difficult for you?
- *If yes*, in what ways was it difficult for you?
- *If no*, why wasn't it difficult for you?
- Was being unwell distressing for you?
- *If yes*, in what ways was it distressing?
- *If no*, why wasn't it distressing?

- 5. What were you experiencing when you were unwell (symptoms)?**

Prompts:

- What was this like for you (personal reactions)?
- Examples of symptoms

6. Were you in hospital?

If participants were hospitalised:

7. Why were you hospitalised? / Can you describe how you came to be in hospital?

8. How were you hospitalised (e.g. police involvement)?

9. What was hospital like for you?

Prompts:

- Some people say that being in hospital is difficult. Was being in hospital difficult for you?
- *If yes*, in what ways was it difficult?
- Can you give me specific examples of these difficult experiences / Tell me a particular time that was distressing for you / Tell me a time when you were really aware of that? / Time when you felt that the most?
- *If no*, why wasn't difficult?
- Some people say that being in hospital is distressing. Was being in hospital distressing for you?
- *If yes*, in what ways was it distressing?
- Can you give me specific examples of these distressing experiences / Tell me a particular time that was distressing for you / Tell me a time when you were really aware of that? / Time when you felt that the most?
- *If no*, why wasn't it distressing?

10. Were you seen by CATT/YAT when you were unwell?

If participants saw CATT/YAT:

11. When did you see CATT/YAT?

12. How did CATT/YAT become involved?

13. What was it like to see CATT/YAT?

Prompts:

- Some people say that seeing CATT/YAT is difficult. Was seeing CATT/YAT difficult for you?
- In what ways was it difficult?

- Can you give me specific examples of these difficult experiences / Tell me a particular time that was distressing for you / Tell me a time when you were really aware of that? / Time when you felt that the most?
- *If no, why wasn't it difficult?*
- Some people say that seeing CATT/YAT is distressing. Was seeing CATT/YAT distressing for you?
- In what ways was it distressing?
- Can you give me specific examples of these distressing experiences / Tell me a particular time that was distressing for you / Tell me a time when you were really aware of that? / Time when you felt that the most?
- *If no, why wasn't it distressing for you?*

(If said nothing was distressing or difficult)

14. You said you did not find hospital and CATT/YAT distressing or difficult, what was the most negative time for you when you were unwell?

Prompts:

- What was this a negative experience for you
- Can you give me specific examples of negative experiences / Tell me a time when you were really aware of that? / Time when you felt that the most

15. There are a number of things people sometimes identify as distressing when they are unwell (list) look at this list and rank in order from least to most distressing

- Why was this the most distressing experience for you?
- In what way was this distressing?
- Can you give me specific examples of negative experiences / Tell me a time when you were really aware of that? / Time when you felt that the most

16. How are you feeling about this experience now?

Prompts:

- Is this still on your mind?
- Is this still having an impact on you now?
- How is it affecting you now?
- What are your thoughts about it now?
- How do you feel about it now?

17. Tell me how things were before you became unwell/all this happened to you?

Did you experience anything stressful before you became unwell?

Prompts:

- *If yes*, I was wondering what these were?
- How did you cope with these stressful things?
- *If no*, what was going on for you before you became unwell? / What were you doing before you became unwell?

18. Tell me about the time just before hospital/you became unwell, what was going on for you then?

19. How have things been for you since you were unwell?

20. I was wondering how you've been coping since you were unwell?

Prompts:

- What's helped you cope?
- What do you do to help yourself cope?
- Has there been anything that hasn't helped you cope?

21. How are you finding your treatment at the moment?

Prompts:

- Has your treatment helped you?
- *If yes*, how has it helped?
- *If no*, how hasn't it helped?

Some people say they go through changes after they have been unwell. These changes might be positive or negative, or helpful or unhelpful. I'd like to talk to you about any changes you might have experienced since you were unwell, whether they were positive or negative, or helpful or unhelpful.

22. Overall, how has being unwell impacted on you?

23. I was wondering whether being unwell has changed your life?

Prompts:

- *If yes*, in what way has your life changed?
- Could you please describe what your life is like now? / Could you please describe what your life been like since you became unwell?
- Could you please describe what your life was like before you became unwell?

24. Have your goals and dreams changed since you were unwell?*Prompts:*

- *If yes*, how have they have changed?
- *If no*, could you please describe your dreams and goals?

25. Has being unwell changed how you think about your life?*Prompts:*

- *If yes*, how has this changed?
- *If yes*, how do you think about life now?
- *If no*, how do you think about life?

26. Have you found new meaning in life since you became unwell?*Prompts:*

- *If yes*, what gives you meaning in life now?
- *If no*, what gives you meaning in life?

27. What does spirituality mean to you?**28. Are you a spiritual person?***Prompts:*

- *If yes*, In what way are you spiritual?

29. Has your spirituality changed since you have been unwell?*Prompts:*

- *If yes*, how has it changed?

30. Some people talk about feeling powerless to influence their life? Have you experienced something like this?*Prompts:*

- *If yes*, what makes you feel powerless to influence your life?
- *If no*, what stops you from feeling powerless to influence your life? / Helps you to not feel powerless?

31. What does experiencing life to the fullest mean to you?**32. Are you able to experience life to the fullest since being unwell?***Prompts:*

- *If yes*, how do you do this?
- *If no*, what stops you from experiencing life to the fullest?

33. Could you please describe yourself?

34. Have you changed since you became unwell?

Prompt:

- *If yes*, in what ways have you have changed?
- *If no*, in what ways haven't you changed?

35. I was wondering whether being unwell has changed how you feel about yourself?

Prompts:

- *If no*, how do you feel about yourself?
- *If yes*, what's changed?

36. Has being unwell changed how you generally relate with others?

Prompts:

- *If yes*, how has this changed?
- *If no*, how do you relate with others?

37. Has your relationship with your family changed since becoming unwell?

Prompts:

- *If yes*, in what ways has your relationships with them changed?
- *If no*, what is your relationship with your family members like?

38. Has your relationship with significant others (e.g. friends) changed since becoming unwell?

Prompts:

- *If yes*, I was wondering how these relationships have changed?
- *If no*, what are your relationships with significant others like?

39. Is it difficult for you to talk about your experiences of being unwell with other people?

Prompts:

- *If yes*, how is it difficult for you?
- *If no*, in what way is it not difficult? / how come it is not difficult?

40. Do you feel supported by others in coping with your experience of being unwell?

Prompts:

- *If yes*, who has supported you? How have they supported you?
- *If no*, how have they not supported you? What kind of support would you like?

41. I was wondering whether you have experienced any other changes since being unwell?

Prompts:

- *If yes, what other changes have you experienced?*

42. Do you work?

What do you do at work?

What is like work for you?

Have you experienced any changes in relation to work since you became unwell?

(e.g. completing tasks, attendance)

- *If yes, what changes have you experienced?*

43. Do you go to school/university/TAFE?

What do you do at school?

What is school like for you?

I was wondering if you have experienced any changes in relation to school/university/TAFE since you became unwell?

(e.g. attendance, assignments/school work)

- *If yes, what changes have you experienced?*

44. Could you please describe what your day-to-day life is like?

How do you manage day-to-day life?

Have you experienced any changes in being able to manage day-to-day life since you were unwell?

(e.g. getting to places on time, handling money)

- *If yes, what changes have you experienced?*

45. Could you please describe how you look after the home?

Have you experienced any changes in being able to look after the home since you were unwell?

(e.g. cooking, cleaning, shopping, laundry)

- *If yes, could you describe what changes you have experienced?*

46. Do anything for leisure/recreation?

Have you experienced any changes in your leisure time or recreational activities since you were unwell?

- *If yes*, I was wondering what changes you have experienced?

47. Have you had any important or significant experiences since you were unwell?

Prompts:

- *If yes*, what were these experiences?
- Were any of these experiences unhelpful?
- Were there any of these experiences helpful?

48. Some people say that being unwell can be both a helpful and unhelpful experience.

What are your thoughts about this?

49. I was wondering what recovery meant to you?

Prompts:

- Do you feel like you are recovering?
- When did you start to recover?
- What's helped your recovery?
- Has there been anything that hasn't helped your recovery?
- Do you feel in like your control of your recovery?

50. How do you feel about the future?

Time Two Interview

Through my research project, I would like to develop a greater understanding of the experiences people have when they first become unwell and the changes they may go through since being unwell. I am interested in hearing your viewpoints, as I would like to learn from you and your experiences. You may recognise some of these questions covering the same areas we talked about last time but this is because I'm wanting to see what's changed or if anything else has emerged for you since we last caught-up 3 months ago?

1. What brought you to X?

2. How would you describe what happened to you?

3. Do you think any of these experiences were due to a mental health issue? (what tells you they were/weren't?)

4. Last time we spoke you mentioned that x was the most distressing experience for you when you were unwell. How are you feeling about this experience you spoke about last time? (nominated last time)

Prompts:

- Is this still on your mind?
- Is this still having an impact on you now?
- How is it affecting you now?
- What are your thoughts about it now?
- How do you feel about it now?

5. Overall, how have things been since you were unwell?

6. Tell me how things have been since we caught-up 3 months ago

7. I was wondering how you've been coping since you were unwell?

Prompts:

- What's helped you cope?
- Has there been anything that hasn't helped you cope?
- What do you do to help yourself cope?

8. Tell me how you have been coping since we caught-up 3 months ago

- What's helped you cope?
- Has there been anything that hasn't helped you cope?
- What do you do to help yourself cope?

9. How are you finding your treatment at the moment?

Prompts:

- Has your treatment helped you?
- *If yes*, how has it helped?
- *If no*, how hasn't it helped?

Some people say they go through changes after they have been unwell. These changes might be positive or negative, helpful or unhelpful. I'd like to talk to you about any changes you might have experienced since you were unwell, whether they were positive or negative, helpful or unhelpful.

10. Overall, how has being unwell impacted on you?

11. What has changed the most since we last met?

12. I was wondering whether being unwell has changed your life?

Prompts:

- *If yes*, in what way has your life changed?

- Could you please describe what your life is like now? / Could you please describe what your life been like since you became unwell?
- Could you please describe what your life was like before you became unwell?

13. Has anything specifically changed in your life since we caught up 3 months ago?

Prompts:

- Could you please describe what has changed?
- How is it different to when we last met?

14. Have your goals and dreams changed since you were unwell?

Prompts:

- *If yes*, how have they have changed?
- *If no*, could you please describe your dreams and goals?

15. Have your goals and dreams changed since we caught-up 3 months ago?

Prompts:

- *If yes*, how have they have changed?

16. Has being unwell changed how you think about your life?

Prompts:

- *If yes*, how has this changed?
- *If yes*, how do you think about life now?
- *If no*, how do you think about life?

17. Since we met have you changed how you think about life?

Prompts:

- *If yes*, in what way?

18. Have you found new meaning in life since you became unwell?

Prompts:

- *If yes*, what gives you meaning in life now?
- *If no*, what gives you meaning in life?

19. Have you found new meaning in life since we last met?

Prompts:

- *If yes*, in what way?

20. What does spirituality mean to you?

21. Are you a spiritual person?

Prompts:

- *If yes*, In what way are you spiritual?

22. Has your spirituality changed since you have been unwell?

Prompts:

- *If yes*, how has it changed?

23. Has your spirituality changed since we met 3 months ago?

Prompts:

- *If yes*, in what way has it changed?

24. Some people talk about feeling powerless to influence their life? Have you experienced something like this?

Prompts:

- *If yes*, please describe

25. Have you experienced feeling powerless since you were unwell?

Prompts:

- *If yes*, what makes you feel powerless to influence your life?
- *If no*, what stops you from feeling powerless to influence your life? / Helps you to not feel powerless?

26. Have you experienced feeling powerless since we caught-up last?

Prompts:

- *If yes*, what has made you feel powerless to influence your life over the last 3 months?

27. What does experiencing life to the fullest mean to you?

28. Are you able to experience life to the fullest since being unwell?

Prompts:

- *If yes*, how do you do this?
- *If no*, what stops you from experiencing life to the fullest?

29. Have you been able to experience life to the fullest since we caught-up 3 months ago?

Prompts:

- *If yes*, how do you do this?
- *If no*, what has been stopping you from experiencing life to the fullest?

30. Could you please describe yourself?

31. Have you changed since you became unwell?

Prompt:

- *If yes*, in what ways have you have changed?
- *If no*, in what ways haven't you changed?

32. Have you changed as a person over the last 3 months?

Prompts:

- *If yes*, in what ways have you have changed?
- *If no*, in what ways haven't you changed?

33. I was wondering whether being unwell has changed how you feel/think about yourself?

Prompts:

- *If no*, how do you feel about yourself?
- *If yes*, what's changed?

34. Has how you feel/think about yourself changed since we last met?

Prompts:

- *If no*, how do you feel about yourself?
- *If yes*, what's changed?

35. Has being unwell changed how you generally relate with others?

Prompts:

- *If yes*, how has this changed?
- *If no*, how do you relate with others?

36. Have you changed how you generally relate to others since we last met 3 months ago?

Prompts:

- *If yes*, how?
- *If no*, how do you relate with others now?

37. Has your relationship with your family changed since becoming unwell?

Prompts:

- *If yes*, in what ways has your relationships with them changed?
- *If no*, what is your relationship with your family members like?

38. Over the last 3 months has your relationship with your family changed?

Prompts:

- *If yes*, in what ways has your relationships with them changed?
- *If no*, what is your relationship with your family members like?

39. Has your relationship with significant others (e.g. friends) changed since becoming unwell?

Prompts:

- *If yes*, I was wondering how these relationships have changed?
- *If no*, what are your relationships with significant others like?

40. Has your relationship with others, e.g. friends, changed since we last saw each other?

Prompts:

- *If yes*, how have these relationships have changed?
- *If no*, what have your relationships with significant others been like over the last 3 months?

41. Is it difficult for you to talk about your experiences of being unwell with other people?

Prompts:

- *If yes*, how is it difficult for you?
- *If no*, in what way is it not difficult? / how come it is not difficult?

42. Do you feel supported by others in coping with your experience of being unwell?

Prompts:

- *If yes*, who has supported you? How have they supported you?
- *If no*, how have they not supported you? What kind of support would you like?

43. I was wondering whether you have experienced any other changes since being unwell?

Prompts:

- *If yes*, what other changes have you experienced?

44. I was wondering whether you have experienced any other changes since we caught-up 3 months ago that we haven't spoken about?

Prompts:

- *If yes, what other changes have you experienced?*

45. Do you work?

What do you do at work?

What is like work for you?

Have you experienced any changes in relation to work since you became unwell and since we last saw each other?

(e.g. completing tasks, attendance)

- *If yes, what changes have you experienced?*

46. Do you go to school/university/TAFE?

What do you do at school?

What is school like for you?

I was wondering if you have experienced any changes in relation to school/university/TAFE since you became unwell and since we last saw each other?

(e.g. attendance, assignments/school work)

- *If yes, what changes have you experienced?*

47. Could you please describe what your day-to-day life is like?

How do you manage day-to-day life?

Have you experienced any changes in being able to manage day-to-day life since you were unwell and since we last saw each other?

(e.g. getting to places on time, handling money)

- *If yes, what changes have you experienced?*

48. Could you please describe how you look after the home?

Have you experienced any changes in being able to look after the home since you were unwell and since we last saw each other?

(e.g. cooking, cleaning, shopping, laundry)

- *If yes, could you describe what changes you have experienced?*

49. Do anything for leisure/recreation?

Have you experienced any changes in your leisure time or recreational activities since you were unwell and since we last saw each other?

- *If yes, I was wondering what changes you have experienced?*

50. Have you had any important or significant experiences since you were unwell?

Prompts:

- *If yes*, what were these experiences?
- Were any of these experiences unhelpful?
- Were there any of these experiences helpful?

51. Have you had any important or significant experiences since we last caught-up?

Prompts:

- *If yes*, what were these experiences?
- Were any of these experiences unhelpful?
- Were there any of these experiences helpful?

52. Some people say that being unwell can be both a helpful and unhelpful experience.

What are your thoughts about this?

53. I was wondering what recovery means to you?

Prompts:

- Have your thoughts about recovery changed since we caught-up?
- Do you feel like you are recovering?
- When did you start to recover?
- What's helped your recovery?
- Has there been anything that hasn't helped your recovery?
- Do you feel in like your control of your recovery?

54. How do you feel about the future?

Prompts:

- Do you have any plans for the future? What are they?
- Have your plans changed since we last saw each other? In what way have they changed?

Loved Ones' Interview

Through my research project, I would like to develop a greater understanding of the experiences people have when they first become unwell and the changes they may go through since being unwell. I am interested in hearing your viewpoints about x experience's. Therefore, the focus of this interview is about x.

1. Tell me what it was like when x was unwell?

2. What aspects of the experience were difficult for you?

Prompts:

- What aspects of the condition were difficult for you?
- What changes as a result of x condition were difficult for you?

3. How did you first become aware that x was unwell? / How did you notice that things were not going well for x?

Prompts:

- What did you do? / What was your involvement?
- How did you get help?

4. How would you describe x illness?

5. I was wondering what x was experiencing when he/she was unwell?

6. What do you think it was like for x to experience these symptoms? / How did x respond to these symptoms?

7. What do you think it was like for x to see CATT/YAT? / How did x respond to being seen by CATT/YAT?

8. What do you think it was like for x to be in hospital? / How did x respond to being in hospital?

9. Tell me about how things were before x became unwell

10. Did x go through any stressful experiences before he/she became unwell?

Prompts:

- *If yes*, what were these experiences?
- How did x cope with these experiences?
- *If no*, what was going on for x before he/she became unwell? / What was x doing before he/she became unwell?

11. How have things been since x was unwell?**12. How is x condition (e.g. symptoms) now?***Prompts:*

- Are there any aspects of x condition that are still present, e.g. symptoms?

13. I was wondering how x has responded to his/her treatment?*Prompts:*

- Is he/she open to receiving treatment? – compliant?

14. How has x been coping since he/she was unwell?*Prompts:*

- What has helped x coped?
- What has x done to help himself/herself cope?
- What has not helped x coped?

Some people say they go through changes after they have been unwell. These changes might be positive or negative, or helpful or unhelpful. I'd like to talk to you about any changes x might have experienced since he/she was unwell, whether they were positive or negative, or helpful or unhelpful. In general, I've been speaking to x about how he/she views life, relationships with others, and how he/she feels about herself/himself. I've been talking to x about whether his/her attitudes about these things have changed as a result of being unwell. X may not have talked to you about all the things I'm going to ask you about but I would like to get your opinion and comments on them and your understanding of how x is aware of these things.

15. Overall, how has being unwell impacted on x?**16. I was wondering whether being unwell has changed x's life?***Prompts:*

- *If yes*, how has it changed?
- What things have changed in x life?
- Could you please describe what x life was like before he/she became unwell?
- Could you please describe what x life is like now? / Could you please describe what x life been like since he/she became unwell?

17 Has being unwell changed how x thinks about his/her life?

Prompts:

- *If yes*, how has this changed?
- *If yes*, how does x think about life now?
- *If no*, how does x think about life?
- How does x approach life now?
- How did x used to approach life?

18 Have x found new meaning in life since he/she became unwell?

19 What things does x find meaningful in life?

20 What are x dreams and goals? (please describe them)

21 Has x's goals and dreams changed since he/she became unwell?

Prompts:

- *If yes*, how have they have changed?

22 Could you please describe what you think experiencing life to the fullest means to x?

23 Has x been able to experience life to the fullest since being unwell?

Prompts:

- *If yes*, how does he/she do this?
- *If no*, what stops x from experiencing life to the fullest?

24 Some people talk about feeling powerless to influence their life? Do you think x experienced something like this?

Prompts:

- *If yes*, what do you think makes x feel powerless?
- *If no*, what do you think stops x from feeling powerless? / Helps x not feel powerless?
- How does x show he/she is feeling powerless/not powerless?
- Do you think this has occurred because he/she has been unwell?

25 What does spirituality mean to x?

26 Is x a spiritual person?

27 In what way is x spiritual?

28 What does x do to practice/demonstrate her/his spirituality?

29 Has x spirituality changed since he/she has been unwell?

30 How has it changed?

31 Could you please describe x?

32 Has x changed since he/she became unwell?

Prompt:

- *If yes*, in what ways has x changed?
- *If no*, in what ways hasn't x changed?

33 Do you think being unwell has changed how x feels about himself/herself?

Prompts:

- *If yes*, what's changed?
- How can you tell this has changed?

34 Could you please describe what x relationships with others are like?

35 Has being unwell changed x relationship with others?

Prompts:

- *If yes*, how they have changed?
- *If no*, in what ways have they not change?

36 Has x relationship with his/her family changed since becoming unwell?

Prompts:

- *If yes*, in what ways has x relationships with them changed?
- *If no*, what is x relationship with his/her family members like?

37 Has x relationships with significant others (e.g. friends) changed since becoming unwell?

Prompts:

- *If yes*, I was wondering how these relationships have changed?
- *If no*, what are x relationships with significant others like?

38 Has being unwell changed how x generally relates with others?

Prompts:

- *If yes*, how has this changed? How does he/she relate to others?
- *If no*, how does x relate with others?

39 Do you think it is difficult for x to talk about his/her experiences of being unwell with other people?

Prompts:

- *If yes*, how is it difficult for x? What tells you it is difficult for x?
- *If no*, in what way is it not difficult? / how come it is not difficult?

40 Do you think x feels supported by others in coping with his/her experience of being unwell?

Prompts:

- How can you tell he/she feels supported?
- *If yes*, who has supported x? How have they supported x?
- *If no*, how have they not supported x? What kind of support would x like?

41 I was wondering whether x has experienced any other changes since being unwell?

Prompts:

- *If yes*, what other changes has x experienced?

42 Has x gone through/had any important or significant experiences since he/she was unwell?

Prompts:

- *If yes*, what were these experiences?
- Were any of these experiences unhelpful?
- Were there any of these experiences helpful?

I also talked to x about more practical things such as daily living skills, work, school/university, self-care, involvement in social activities, and day-to-day life. I would like to talk to you about whether or not you've noticed any changes in these areas since x has been unwell.

43 Does x work?

What does x do at work?

What is work like for x?

Has x experienced any changes in relation to work (e.g. completing tasks, attendance)?

- *If yes*, what changes has x experienced?

44 Does x go to school/university/TAFE?

What does x do at school?

What is school like for x?

I was wondering if x has experienced any changes in relation to school/university/tafe (e.g. attendance, assignments/school work)?

- *If yes*, what changes has x experienced?

45 Could you please describe what x day-to-day life is like?

How does x manage day-to-day life?

Has x experienced any changes in being able to manage day-to-day life (e.g. getting to places on time, handling money)?

- *If yes*, what changes has x experienced?

46 Could you please describe how x looks after the home?

Has x experienced any changes in being able to look after the home (e.g. cooking, cleaning, shopping, laundry)?

- *If yes*, could you describe what changes x have experienced?

47 Does x do anything for leisure/recreation? (please describe)

Has x experienced any changes in his/her leisure time or recreational activities?

- *If yes*, I was wondering what changes x has experienced?

48 Some people say that being unwell can be both a helpful and unhelpful experience.

What are your thoughts about this?

49 Do you think x found it both unhelpful/unhelpful?

Prompts:

- What aspects were unhelpful/unhelpful for him/her?

50 I was wondering what recovery meant to you?

51 What do you think recovery means to x?

52 Do you think x is beginning to recover?

- *If no*, why do you think x is not recovering? / What tells you x is not recovering? / In what ways is x not recovering?
- *If yes*, could you please describe x's recovery? How is he/she beginning to recover? What tells you he/she is beginning to recover?

Prompts:

- When did x start to recover?
- Could you please describe what has helped x recover?
- Could you please describe has not helped x recover?

- Does x feel in like he/she's in control of their recovery?

53 How does x feel about the future?

Prompts:

- Does x have any plans for the future? What are they?

Clinicians' Interview

1 What does x's current treatment involve?

2 I was wondering how x has responded to his/her treatment?

Prompts:

- Is x open to receiving his/her treatment?/Is x compliant?

I've been speaking to x about how he/she views life, relationships with others, and how he/she feels about herself/himself (e.g. sense of self/identity) and whether his/her attitudes about these things have changed as a result of being unwell. We discussed the positive and negative changes. I was wondering if you could comment on your opinions about these things in relation to x?

3 Do you think he/she has experienced any changes in relation to how he/she thinks about/feels about himself/herself?

4 Has he/she changed as a person since you've worked with him/her?

5 Do you think he/she has experienced any changes with regards to his/her relationships (e.g. friends and family)?

6 Do you think being unwell has changed how he/she relates to others?

7 How do you think being unwell has impacted on x's life?

8 Do you think he/she has experienced any changes with regards to how he/she thinks about life?

9 Have you noticed any changes in how he/she approaches life?

I also talked to x about more practical things such as daily living skills, work, school/university, self-care, involvement in social activities, and day-to-day life.

10 Have you noticed whether he/she has experienced any changes in these areas since you've worked with him/her / as a result of being unwell?

11 How do you think x has been coping since you've seen him/her?

Prompts

- What helped/hasn't helped him/her cope?
- He/she does to help herself/himself cope?

12 What are the main problems/issues x continues to experience and which he/she needs to too/consider at now?

APPENDIX F

Case Descriptions of FEP Participants

Pilot Study

The case descriptions provide a detailed account of participants recruited for the pilot study and main study who were not presented as case studies in the thesis. Background and diagnostic information is reported as well as a description of their psychotic episode and the treatment they received. Their results on the measures over time are also discussed. This information was obtained from participants' medical records, interviews with participants, loved ones, and clinicians, and the measures used in this study.

Participant One – Tom

Background information. Tom, aged 22 years, returned to the family home after becoming unwell interstate. His father, who had a diagnosis of bipolar disorder and misused substances, committed suicide when he was five years old. Tom had completed a university degree and commenced a second one, which he deferred when he became unwell. Tom worked at a call centre when he was recruited for the study. He was considered to have superior functioning prior to becoming unwell. Tom had a history of depressive symptoms and elevated mood and had experimented with speed and ecstasy. Prior to becoming unwell he commenced marijuana and engaged in increased alcohol use.

Diagnostic information and description of the psychotic episode and acute treatment. Tom was diagnosed with bipolar I disorder, with psychotic features after having a sudden onset of symptoms. When acutely unwell he presented with ideas of reference, grandiose, bizarre, non-bizarre, and paranoid delusions, visual and auditory (command) hallucinations, and disorganised speech and behaviour. Tom also experienced reduced appetite, restlessness, irritability, and decreased need for sleep. While unwell he was charged with criminal acts and was involuntarily hospitalised in a psychiatric forensic hospital for approximately 3.5 months. Police were involved in his admission. Tom allegedly experienced an incident of physical assault from another person who had been arrested when he was detained by police. His other hospital experiences included: restraint, sedation, seclusion, and a high dependency unit admission. As an outpatient Tom was

supported by a psychiatrist and case manager.

Time 1. At Time 1 Tom was considered borderline unwell according to his PANSS total scores (36). Negative symptomatology slightly predominated. At Time 1 Tom's total score and mean score on the IES-R (16, $M = .73$) suggested he was experiencing low trauma symptoms. A closer examination of his subscales scores showed low *intrusion* (4, $M = .57$) and *hyperarousal* (3, $M = .43$) symptoms and moderate *avoidance* (9, $M = 1.13$). Tom's overall score (63) on the PTGI at Time 1 suggested he was experiencing high growth, which could be related to his integration recovery style. Specifically, he scored on *personal strength* (14, $M = 3.5$), *appreciation of life* (10, $M = 3.33$), *new possibilities* (16, $M = 3.2$), *relating to others* (20, $M = 2.86$), and *spiritual change* (3, $M = 1.5$) respectively. At Time 1 Tom had an integration recovery style according to the RSQ and he sealed-over on the subscales *fear* and *responsibility*.

Time 2. Tom remained borderline unwell according to his PANSS total scores (38). Negative symptomatology predominated and had increased slightly over time. At Time 2 his intrusion score remained unchanged, however his *hyperarousal* (4, $M = .57$) and *avoidance* (11, $M = 1.38$) symptoms had increased slightly but only the latter was moderate. His overall score (19, $M = .86$) on the IES-R still suggested low trauma symptoms. Tom's overall score (60) on the PTGI had decreased but still suggested high growth. His score on *relating to others* had not changed and his scores on *appreciation of life* (11, $M = 3.66$) and *new possibilities* (17, $M = 3.4$) had increased slightly. Tom did not score on the *spirituality* domain and his score on *personal strength* (12, $M = 3$) had decreased slightly. According to the RSQ Tom had a recovery style of tending towards integration. In addition to sealing-over on *responsibility* and *fear*, he also sealed-over on the subscale *cause*.

Participant Two - Sarah

Background information. Sarah, aged 25, was living with her mother and was born in Fiji. She had completed Year 12 and was unemployed for the duration of the study. Her father died when she was 14 years old and he was alcohol dependent. She had a history of depression, self-harm, and suicidal ideation. Sarah had a history of amphetamine, ecstasy, and marijuana use and the latter increased prior to her becoming unwell as did her alcohol consumption.

Diagnostic information and description of the psychotic episode and acute treatment. Sarah experienced two-year deterioration in the context of increased substance use and depressive symptoms and was diagnosed with bipolar disorder I, with psychotic features. Sarah presented with religious, persecutory, grandiose, and paranoid delusions, and ideas of reference. She was thought to experience fleeting perceptual disturbances but she did not describe clear hallucinations. Police and the crisis assessment and treatment team were involved in her admission. When hospitalised she experienced seclusion, sedation, and admission to the high dependency unit. As an outpatient she was seen by a psychiatrist and case manager and also attended a FEP recovery group.

Time 1. Sarah was quite isolated, was unemployed, and had withdrawn from her friends, was not completing any study, and was sleeping a lot. According to her overall PANSS score (64), Sarah was considered mildly ill at Time 1 and a negative syndrome predominated. Her overall score on the IES-R at Time 1 (.5, $M = .23$) suggested low trauma symptomatology. Her *avoidance* (3, $M = .38$) and *hyperarousal* (2, $M = .29$) symptoms were low across Time 1 and she did not score on the *intrusion* scale. Sarah's overall score on the PTGI at Time 1 (56) suggested moderate growth. At Time 1 her scores on the subscales were: *relating to others* (26, $M = 3.71$), *appreciation of life* (9, $M = 3$), *personal strength* (12, $M = 3$), and *new possibilities* (9, $M = 1.8$). Sarah did not score on the spirituality domain at Time 1. At Time 1 her score on the RSQ showed a tending towards integration recovery style. She sealed-over on the subscales: *continuity*, *responsibility*, *cause*, and *satisfaction*.

Time 2. At Time 2 she had joined a psycho-social rehabilitation support service to increase her day time activities. According to her overall PANSS scores (69), Sarah was considered mildly ill at Time 2 and a negative syndrome predominated but to a slightly lesser extent at compared to Time 1. Her overall score on the IES-R at Time 2 remained unchanged (.5, $M = .23$). Her *avoidance* (1, $M = .13$), *hyperarousal* (3, $M = .43$), and *intrusion* (1, $M = .14$) symptoms were low. Sarah's overall score on the PTGI at Time 2 (47) suggested moderate growth. At Time 2 *relating to others* (19, $M = 2.71$), *personal strength* (10, $M = 2.5$), and *appreciation of life* (7, $M = 2.33$) had decreased but *new possibilities* had increased (11, $M = 2.2$). Sarah did not score on the spirituality domain at Time 2. At Time 2 her score on the RSQ showed an integration recovery style. At Time 2

she had a sealing-over recovery style on the *responsibility* and *satisfaction* scales.

Participant Three – Peter

Background information. Peter, a 24 year old man of Greek/Anglo-Australia origin, lived with his family and was unemployed. He had completed Year 12 and was close to finishing a University course. Peter had a limited social network outside his family and few interests. Peter's father had a serious medical condition and was moved to a nursing home when Peter was unwell

Diagnostic information and description of the psychotic episode and acute treatment. Peter had a limited social network outside his family and few interests. He had no known previous mental health issues but the onset of his psychotic episode was in the context of a 2-3 year psychosocial decline which included poor self-care, insomnia, poor oral intake, and disorganisation. When acutely unwell, Peter experienced ideas of reference and grandiose delusions which involved paranoid, persecutory and religious themes. He also presented with disorganised speech, formal thought disorder, increased irritability, decrease motivation, blunt affect, difficulty focusing on tasks, a decrease in appetite and oral intake, poor hygiene, and was behaving erratically. It was unclear if he had experienced hallucinations. Peter was diagnosed with psychotic disorder not otherwise specified. The CAT team facilitated his involuntary admission and provided follow-up post-discharge. Peter experienced the high dependency unit, seclusion, restraint, and sedation when he was hospitalised. His diagnosis changed to schizophrenia on discharge.

Time 1. At Time 1 Peter was on a Community Treatment Order and was seeing a case manager, psychiatrist, and psychologist. Peter had an overall score of 84 on the PANSS and this suggested he was moderately unwell. Negative symptoms dominated his presentation. On the IES-R Peter had an overall score of 34 ($M = 1.55$) which suggested he was experiencing moderate trauma symptomatology. In particular, he showed low hyperarousal (8, $M = 1.14$) and intrusion (6, $M = .86$) symptoms and moderate avoidance (20, $M = 2.5$). His overall score on the PTGI at Time 1 (49) suggested moderate growth. In particular his scores on the subscales were: *spiritual change* (9, $M = 4.5$), *appreciation of life* (8, $M = 2.66$), *relating to others* (17, $M = 2.42$), *new possibilities* (10, $M = 2$), and *personal strength* (5, $M = 1.25$) respectively. According to Peter's score on the RSQ he tended towards a sealing-over recovery style at Time 1. Peter had an integration recovery

style on the *curiosity, help seeking, impact, and fear* subscales.

Time 2. At Time 2 Peter was no longer on a Community Treatment Order. He had remained at University and his father had recently moved into an aged-care facility. Peter had begun music lessons and had been participating in an indoor soccer competition. Peter's overall PANSS score (75) suggested he remained moderately unwell and again negative symptoms dominated his presentation. At Time 2 his level of trauma symptoms had increased but remained moderate (IES-R total score = 42, $M = 1.91$). He had low *hyperarousal* symptoms (7, $M = 1$) and moderate *avoidance* (19, $M = 2.78$) and *intrusion* (16, $M = 2.29$). At Time 2 Peter responded to the IES-R according to his symptoms which he identified as the most distressing experience when he was unwell. He was experiencing some depressive and negative symptoms. His score on the RSQ suggested a 'mixed picture' recovery style in which integration predominated. He had a sealing-over recovery style on the subscales: *ownership, education, blame, cause, liking, and satisfaction*. At Time 2 his overall score on the PTGI was again 49. His subscale scores were: *spiritual change* (9, $M = 4.5$), *appreciation of life* (10, $M = 3.33$), *new possibilities* (14, $M = 2.8$), *personal strength* (6, $M = 1.5$), and *relating to others* (10, $M = 1.43$).

Main Study

Participant One – Jack

Background information. Jack was 26 year old single man who lived with his father and brother. He had completed Year 10 and was unemployed. However, he had been employed in the past and last worked in 2004. Jack experienced a two year functional and social decline prior to becoming unwell and reported experiencing social anxiety for a number of years. Jack had a trauma history, having been robbed while working at a petrol station. He also had a forensic history and had been treated for depression in the past by his general practitioner and from a private psychiatrist for one year. Further, Jack had a history of gambling, one accidental overdose, and one suicide attempt. He had a history of substance dependence.

Diagnostic information. Jack's initial diagnosis during his acute treatment was FEP and substance abuse. This diagnosis changed to drug-induced first-episode psychosis, substance abuse, and an anxiety disorder when he was referred for outpatient care.

According to the M.I.N.I Jack had the following diagnoses including a lifetime psychotic disorder: major depressive disorder, recurrent, with melancholic features; dysthymic disorder (the M.I.N.I. does not determine which depressive disorder superseded the other); panic disorder without agoraphobia; social phobia; generalised anxiety disorder; alcohol dependence; and substance dependence (marijuana) in the past 12 months.

Description of the psychotic episode and acute treatment. Jack was considered to have experienced a sudden onset psychotic episode. When he was acutely unwell he presented with auditory hallucinations and paranoid, persecutory, and non-bizarre delusions and was unkempt, highly anxious, and hypervigilant. He had also been isolating himself and was experiencing poor sleep and concentration/attention. At the time Jack had been using ice and marijuana. He received acute treatment via the CATT and was prescribed Quetiapine, which he self-medicated with to combat his anxiety. The police were involved when CATT was initially contacted by his father.

Time 1. When recruited for the study Jack was no longer using illicit substances and was seeing an outreach case manager and psychiatrist. He had recently been diagnosed with hepatitis C and had been referred for support for this as well as drug and alcohol counselling. However, Jack did not agree to the latter. On the PANSS Jack had an overall score of 70 which suggested that he was mildly unwell. Negative symptomatology predominated. Jack rated the IES-R items according to the time when his brother told him his father wanted him committed. According to his overall score (.5, $M = .23$) on the IES-R as well as scores on *avoidance* (2, $M = .25$), *hyperarousal* (2, $M = .29$), and *intrusion* (1, $M = .14$), Jack experienced low trauma symptomatology. Jack's total score on the PTGI was 44 suggesting moderate growth. He scored on 4 of the 5 domains with the highest scores pertaining to *new possibilities* (12, $M = 2.4$), *appreciation of life* (7, $M = 2.33$), *relating to others* (16, $M = 2.23$), and *personal strength* (9, $M = 1.8$) respectively. Jack tended towards an integration recovery style during the initial assessment. He had a sealing-over style on the subscales: *cause*, *fear*, *liking*, and *satisfaction*.

Time 2. When seen for follow-up Jack was socially isolated due to high levels of anxiety and he was using alcohol heavily to deal with this. However, he reported increased contact with his family. Jack had discharged himself from the outpatient clinic and ceased medication. His total score on the PANSS suggested that he was borderline unwell (57)

with his score on the negative scale being slightly higher and he reported no trauma symptomatology. On the PTGI Jack's total score (49) had increased but was still indicative of moderate growth. He scored on 4 of the 5 domains with the highest scores pertaining to *relating to others* (20, $M = 2.86$), *appreciation of life* (8, $M = 2.66$), *personal strength* (10, $M = 2.5$), and *new possibilities* (11, $M = 2.2$) respectively. Jack's recovery style was still tending towards integration. Jack had a sealing-over style on the subscales: *fear*, *liking*, and *satisfaction*.

Participant 2 – David

Background information. David was a 25 year old single man who lived with a housemate. He had completed Year 12 and was employed. His file stated that he had become withdrawn and isolated from his friends in the two years preceding his psychotic episode. David had a history of social anxiety and depression since adolescence and had seen a private psychiatrist and was prescribed anti-depressant medication in the past. He had a history of intermittent ecstasy, speed, and marijuana use.

Diagnostic information. When admitted David was given a diagnosis of FEP and discharged with a diagnosis of schizophreniform psychosis and social anxiety disorder with a differential diagnosis of major depressive episode, with psychotic features. This remained his diagnosis throughout treatment. A diagnosis of Schizophrenia was queried when David was receiving outpatient treatment. According to the M.I.N.I. he had experienced a psychotic disorder in his lifetime.

Description of the psychotic episode and acute treatment experiences. David's psychotic episode was considered to be of sudden onset. When David was acutely unwell he was experiencing ideas of reference and was displaying bizarre behaviour. He was anxious, low in mood, and agitated. David was hospitalised for 2 months as an involuntary client after being referred to psychiatric services by his parents. Seclusion and sedation were required during his admission. On overnight leave he had a serious suicide attempt which required him to be admitted to a medical ward with acute brain injury and symptoms caused by carbon monoxide poisoning. David was seen by CATT for a short period to aid early discharge.

Time 1. When recruited for the study David was linked in with an outpatient case manager and psychiatrist, and a private psychologist. David's overall score on the PANSS

(65) suggested he was mildly ill, with negative symptoms predominating. David rated items on the IES-R according to his suicide attempt, in particular the serious physical symptoms it brought about. According his total score on the IES-R (5, $M = .23$) he showed low trauma symptoms. David did not rate on the *hyperarousal* subscale and his *intrusion* score (1, $M = .14$) and *avoidance* score (4, $M = .5$) were low. An overall score of 36 on the PTGI indicated that he was experiencing moderate growth. In particular, this could be attributed to the domain *relating to others* (18, $M = 2.57$) followed by *appreciation of life* (6, $M = 2$), *personal strength* (7, $M = 1.75$), and *new possibilities* (5, $M = 1$). David scored 0 on the domain *spiritual change*. David's recovery style according to the RSQ was a 'mixed picture' recovery style in which integration predominated. He had a sealing-over style on the subscales: *ownership*, *cause*, *fear*, *liking*, and *satisfaction*.

Time 2. At follow-up David was being discharged from the outpatient clinic to a private psychiatrist. David still experienced hopelessness, worthlessness, and low self-esteem. However, his social anxiety had decreased and he remained employed and was planning to return to university part-time to complete a science degree. According David's overall PANSS score (58) he remained mildly ill, with negative symptoms dominating, although his mental state had improved over time. His total score on the IES-R (4, $M = .18$) still indicated low trauma symptomatology. David did not rate on the *hyperarousal* subscale and his *intrusion* score (2, $M = .29$) and *avoidance* score (2, $M = .25$) were low. While his overall score (30) on the PTGI was still in the moderate range it had decreased over time. This could be attributed to a decreased score on the domain *relating to others* (11, $M = 1.57$). His scores on the domains *appreciation of life* (6, $M = 2$), *personal strength* (7, $M = 1.75$), and *new possibilities* (6, $M = 1.2$) stayed relatively the same. Again, he did not score on the *spiritual change* domain. David's recovery style as measured by the RSQ tended towards integration. He was a sealing-over style on the subscales: *ownership*, *fear*, *liking*, and *satisfaction*

Participant Three – Simone

Background information. Simone, aged 23, was living with her family and started an intimate relationship during the study. She had completed Year 12 and was enrolled in a fashion course at University and was working part-time. Simone had a history of being bullied during school, difficulty with interpersonal relationships, and social isolation.

Simone was treated for depression by her general practitioner and also had a history of panic attacks, social anxiety, and attention deficit disorder. She had a history of using ice, ecstasy, marijuana, and abusing Ritalin, as well as occasional binge drinking

Diagnostic information. At the time of her assessment into OYH she was diagnosed with major depressive episode and an anxiety disorder and was considered ultra high risk for developing psychosis. She was given differential diagnoses of double depression, panic attacks, and schizophreniform psychosis. Simone transitioned to psychosis in the context of ecstasy use during her treatment as an outpatient and was given a diagnosis of schizophreniform psychosis. Simone did not require acute intervention. At the time of recruitment she had co-morbid diagnoses of social anxiety disorder and attention deficit disorder, predominately inattentive type. According to the M.I.N.I., Simone had a diagnosis of social anxiety disorder, obsessive compulsive disorder and substance dependence in the past 12 months, and had experienced a psychotic disorder in her lifetime and a past hypo-manic episode.

Description of the psychotic episode. Simone was being treated by a clinic at OYH for clients considered at ultra high risk of developing psychosis as she presented with sub-threshold psychotic symptoms and a drop in functioning. During her treatment Simone was considered to have transitioned to psychosis by her treating clinicians. When acutely unwell Simone was experiencing paranoid delusions, auditory hallucinations, thought broadcasting, anxiety, depressed mood, poor concentration, and attention, and was perplexed.

Time 1. When Simone was first seen for the study she continued to experience social anxiety, feelings that others could read her mind and ego-dystonic intrusive thoughts which were of an obsessional quality. Her overall PANSS score (60) at Time 1 suggested she was mildly ill. She rated slightly higher (one point higher) on the negative subscale. Simone rated the IES-R according to when she heard voices continuously all night one evening which prevented her from sleeping. Her total score on the IES-R (14, $M = .64$) suggested she was experiencing low trauma symptoms. Her scores on the *intrusion* subscale (3, $M = .43$), *avoidance* (7, $M = .88$), and *hyperarousal* (4, $M = .57$) were all in the low range. Her overall score (42) on the PTGI suggested moderate growth which mainly related to *relating to others* (22, $M = 3.14$) and *appreciation of life* (8, $M = 2.67$) followed

by *new possibilities* (7, $M = 1.4$) and *personal strength* (5, $M = 1.25$) respectively. She did not score on the *spiritual change* domain. Her score on the RSQ suggested a tending towards integration recovery style. She showed a sealing-over recovery style on the subscales *responsibility*, *cause*, and *fear*.

Time 2. At stage two Simone had become involved in an intimate relationship and while she still experienced social anxiety she was socialising more. Simone had also begun exercising regularly. Her depressive symptoms fluctuated and she had been experiencing transient auditory hallucinations. Additionally, she continued to experience paranoid ideas and beliefs that others could read her thoughts which varied in intensity and frequency and still had obsessional thoughts of an ego-dystonic nature. Ratings on the PANSS suggested she was borderline unwell (total score = 55), scoring slightly higher (one point higher) on the positive scale. Simone's scores on the IES-R had slightly decreased (total score = 13, $M = .59$). Her scores on *avoidance* (5, $M = .63$), *hyperarousal* (7, $M = 1$), and *intrusion* (1, $M = .14$) were all low. On the PTGI her overall score was 48. Thus, while still in the moderate range it had increased since Time 1. There was a considerable increase in growth on the domains *relating to others* (26, $M = 3.71$) and *personal strength* (8, $M = 2$), while *new possibilities* (6, $M = 1.2$) decreased slightly and *appreciation of life* remained the same (8, $M = 2.67$). Again, she did not score on the *spiritual change* domain. Simone had an integration style at Time 2. She reflected a sealing-over style for the *cause* and *responsibility* subscales.

Participant Five – Alana

Background information. Alana aged 23 lived with her de-facto partner and family at the time of recruitment. She had passed Year 12 after her schooling was disrupted a number of times. She had also finished a diploma at TAFE and was currently on leave from tertiary studies. Alana was also on leave from her part-time work, although she continued to do casual work from home. Her parents separated when she was 12 years old and her mother's subsequent partner died. According to her file her brother had also broken her arm when she was younger. She had a history of school refusal and being bullied. Alana had experienced depression and anxiety, including panic attacks, in the past and had a history of two suicide attempts and self-harm. Alana had used marijuana heavily in the past and ecstasy infrequently. She had a history of psychotic symptoms in the context of low mood

but these symptoms spontaneously resolved and she did not receive treatment for them. Thus, she was considered to have experienced a first-episode of psychosis at the time of recruitment.

Diagnostic information. Alana's diagnoses had changed a number of times during her treatment. During Alana's acute treatment she was diagnosed with major depressive episode with psychotic features and obsessive compulsive disorder, and later schizophreniform psychosis. At recruitment her diagnoses were: generalised anxiety disorder, trichotilomania, social anxiety disorder, obsessive compulsive disorder, and FEP with an affective component, which remained at Time 2. Her treating team was also considering a diagnosis of bipolar disorder. According to the M.I.N.I. Alana was experiencing a current major depressive episode and had a diagnosis of major depressive disorder, recurrent, and current social anxiety disorder, psychotic disorder, and PTSD. According to this measure she had also experienced a past hypomanic episode.

Description of the psychotic episode and acute treatment. Alana's mental state had deteriorated over a one year period in the context of anxiety, low mood, obsessive compulsive features, and the onset of psychotic symptoms. When acutely unwell Alana was experiencing auditory hallucinations, paranoid delusions, ideas of reference, and thought broadcasting. Prior to her engagement with OYH Alana's was assessed by CATT at the Emergency Department in the context of an overdose. She was then referred to OYH and monitored by YAT before being admitted to hospital in the context of an overdose and increased auditory hallucinations. Alana was initially a voluntary patient but later became involuntary. During her hospital admission she experienced being in seclusion and the high dependency unit and was sedated. YAT was also involved in her discharge.

Time 1. At Time 1 Alana was receiving support from a case manager, psychiatrist, and psychologist. Her overall score (70) on the PANSS suggested she was mildly ill, with her score being slightly higher on the negative subscale. Alana rated the IES-R items according to being cut off from her life and family and friends during hospital, which she was particularly aware of when her mother and clinicians would not discharge her. According to her total IES-R score (25, $M = 1.14$) she was experiencing low level trauma symptomatology. However, her *avoidance* score (10, $M = 1.25$) and her *intrusion* score (9, $M = 1.29$) were moderate, while her *hyperarousal* score (6, $M = .86$) was low. According to

Alana's overall score (63) on the PTGI she was experiencing moderate growth. She rated the following domains the highest: *relating to others* (26, $M = 3.71$), *new possibilities* (17, $M = 3.4$), *appreciation of life* (9, $M = 3$), and *personal strength* (11, $M = 2.75$) respectively. She did not score on the *spirituality* domain. Her score on the RSQ suggested she tended towards integration. Alana sealed-over on the following subscales: *fear*, *liking*, *satisfaction*, and *cause*.

Time 2. At Time 2 Alana had returned to casual employment at her old work place and had commenced a TAFE course. She had also increased contact with friends and had been on an overseas holiday. However, Alana's de-facto partner ended their relationship due to her ongoing mental health issues and this had triggered suicidal ideation, which she was hospitalised for. Alana continued to experience mental health issues including auditory hallucinations (including command hallucinations), depressive symptoms, social anxiety, paranoid ideas, and ideas of reference. These symptoms fluctuated in duration and intensity. Alana was receiving psychological therapy for her ongoing psychotic symptoms. Her overall score (59) on the PANSS suggested she was mildly ill, with negative symptoms her main feature. Her total IES-R score (30, $M = 1.36$) had increased over time suggesting she was now experiencing moderate trauma symptomatology. Similar to Time 1 her scores on the *avoidance* (12, $M = 1.5$) and *intrusion* (10, $M = 1.43$) subscales were moderate, whereas *hyperarousal* score (8, $M = 1.14$) was low. According Alana's overall PTGI score (47) had decreased over time and was in the low range. Her score on *appreciation of life* (9, $M = 3$) remained the same and she did not score on the *spiritual* domain. Her scores on *personal strength* (7, $M = 1.75$), *new possibilities* (13, $M = 2.6$), and *relating to others* (18, $M = 2.57$) had decreased. According to the RSQ Alana's recovery style remained as tending towards integration. She sealed-over on the subscales: *fear*, *liking*, *cause*, and *responsibility*.

Participant Six – Scott

Background information. Scott, a 21 year old man of Hawaiian/Anglo-descent and born on the Marshall Islands, was in a de-facto relationship and unemployed. Prior to becoming unwell Scott had been stressed due to a recent promotion and financial debts. Scott had a history of being bullied at school and work and changed schools (and countries) several times due to his father's work. He also had a history of disorderly conduct at school

which had led to expulsion. Scott completed Year 11 and went on to begin an apprenticeship which he ceased. He had experienced a history of family conflict and felt some pressure from his parents to achieve. One of his siblings also experienced mental health issues. Scott had a history of anxiety, social anxiety, and depression and the latter was managed by his general practitioner.

Diagnostic information. Initially Scott was diagnosed with FEP and Major Depressive Episode with psychotic features was considered. According to the M.I.N.I. he was experiencing a current major depressive episode and a current psychotic disorder and had experienced a past hypomanic episode. According to his file notes Scott was using marijuana when recruited and engaged in binge drinking to self-medicate. However Scott denied marijuana use during the last 12 months when assessed for the study. At Time 2 Scott's diagnosis according to file notes was major depression with psychotic features.

Description of the psychotic episode and acute treatment. Scott's general practitioner referred him to OYH and he was initially seen by a clinic specialising in mood and anxiety. Scott was voluntarily admitted to hospital after taking an overdose preceded by a six month history of suicidal ideation. In hospital he disclosed auditory hallucinations, which had been occurring for approximately six months. When Scott was unwell he experienced paranoid ideas and auditory hallucinations. He was also experiencing depressive symptoms and increased anxiety and was self-medicating with alcohol. Scott also saw YAT when he was unwell prior to and after his admission.

Time 1. After disclosing his psychotic symptoms Scott was linked in with a case manager, psychiatrist, and provisional psychologist for cognitive behaviour therapy from the early psychosis team. His overall PANSS score (59) suggested he was mildly unwell, with negative symptoms only slightly predominating his presentation. Scott scored the IES-R according to the experience of his auditory hallucinations impeding his attempt to return to work. Specifically he recalled the voices telling him they would make it hard for him to do so. His ratings suggested he was experiencing a moderate level of trauma symptoms, IES-R total score (35, $M = 1.59$). He scored highest on the *intrusion* subscale (15, $M = 2.14$) followed by *avoidance* (12, $M = 1.5$) and *hyperarousal* (8, $M = 1.14$). Scott's total score (44) on the PTGI suggested moderate growth. He scored the highest on *appreciation of life* (9, $M = 3$), *relating to others* (18, $M = 2.57$), *personal strength* (8, $M = 2$), and *new*

possibilities (9, $M = 1.8$) respectively. He did not score on the *spirituality* domain. Scott had a recovery style of tending towards integration. He sealed over on the scales: *liking*, *satisfaction*, and *ownership*.

Time 2. Since Time 2 Scott had attempted to return to work but this was unsuccessful due to his mental health issues. He had moved in with his family due to financial problems but remained in his long-term relationship. He continued to experience anxiety, depressive symptoms and fluctuating auditory hallucinations which were impacting on his daily functioning. However, he was increasing time spent with friends and attempting to have a healthy lifestyle by exercising and losing weight. Scott was no longer seeing the provisional psychologist and he had decreased his alcohol use. Although Scott's total score (71) on the PANSS had increased since Time 2 he was still considered mildly unwell, and the negative symptoms clearly dominated his presentation. Scott's total score (19, $M = .86$) on the IES-R showed that his trauma symptoms had decreased over time and were low. His *intrusive* symptoms had reduced markedly (6, $M = .86$) followed by symptoms of *hyperarousal* (2, $M = .29$) and *avoidance* (11, $M = 1.38$), the latter only reducing slightly compared to Time 1 and still suggested moderate avoidance. Scott's level of growth had decreased over time, with his total score on the PTGI (31) suggesting low growth. Scores across four of the domains decreased: *appreciation of life* (8, $M = 2.66$), *relating to others* (11, $M = 1.57$), *new possibilities* (6, $M = 1.4$), *personal strength* (5, $M = .25$). At Time 2 Scott rated the spirituality domain (1, $M = .5$). According to the RSQ Scott had tending towards integration recovery style and sealed-over on the subscales: *liking*, *cause*, *ownership*, and *responsibility*.

Participant Nine – Paul

Background information. Paul was a 24 year old single unemployed Vietnamese man living with his mother. He moved to Australia as a child and his parents separated when he was an adolescent. At birth he suffered hypoxia. He socialised well throughout his childhood and adolescents. Paul had completed Year 12 and commenced TAFE but ceased this course. He had been in several long-term relationships, the last one ending around the time he became unwell. Paul had a history of occasional marijuana, ecstasy, and speed use two years prior and had used ice 3-4 times in the past 6 months.

Diagnostic information. Paul was diagnosed with schizophreniform psychosis and

prominent negative features with a differential diagnosis of affective psychosis and this diagnosis remained throughout the study. According to the M.I.N.I he had a current psychotic disorder.

Description of the psychotic episode and acute treatment. Paul appeared to have been unwell for 5 months prior to his family contacting psychiatric services but his prodrome seemed to extend beyond a year. He was seen by YAT when acutely unwell and presented with ideas of reference, paranoid delusions, thought insertion, visual and auditory hallucinations (including command hallucinations), disorganised speech, formal thought disorder, poor concentration and memory, depressed mood, hypersomnia, and reduced appetite and diet intake. Since becoming unwell his social contact had reduced. Paul had a number of outstanding warrants related to traffic fines and debts and a number of these occurred when he was unwell. Subsequently, he had police contact during the period he was acutely unwell.

Time 1. At Time 1 Paul was seeing an outpatient psychiatrist and case manager. He was still experiencing some paranoia and decrease in memory and concentration. According to his PANSS total score (76) he was moderately unwell with negative symptoms predominating. Paul identified not being able to do the things he normally would do, for example drive and work, as the most distressing experience for him when he was unwell. He rated the IES-R according to this and his total score (24, $M = 1.09$) suggested he had low trauma symptomatology. In particular, he had low trauma on the *intrusion* subscale (1, $M = .14$). However, his scores suggested he was experiencing moderate *avoidance* (13, $M = 1.63$) and *hyperarousal* symptoms (10, $M = 1.43$). Paul's overalls score (11) on the PTGI suggested he was experiencing low levels of growth. He did not rate on the changed spirituality domain and his score on *relating to others* (2, $M = .29$) and *personal strength* (1, $M = .25$) was very low. He rated highest on *new possibilities* (6, $M = 1.2$) followed by *appreciation of life* (2, $M = .66$). The RSQ showed that Paul's recovery style at Time 1 was a 'mixed picture' recovery style in which integration predominates. He had a sealing-over style on the *satisfaction*, *impact*, *education*, *continuity*, and *ownership* subscales.

Time 2. At Time 2 Paul had been doing some recent casual work, was in an intimate relationship, and still lived with his mother. He denied mood and psychotic symptoms and was socialising with his friends more. Paul had ceased medication a month ago. According

to his PANSS overall score (72) suggested he was mildly unwell and negative symptoms still predominated his presentation. His total score on the IES-R (11, $M = .50$) had reduced and suggested he was experiencing low trauma symptomatology. His scores on all subscales were low: *avoidance* (5, $M = .63$), *hyperarousal* (4, $M = .57$) and *intrusion* (2, $M = .29$). Paul's overall score (16) on the PTGI had increased but was still low. He rated *relating to others* (8, $M = 1.14$), *new possibilities* (4, $M = .80$), *appreciation of life* (2, $M = .66$), and *personal strength* (2, $M = .50$) the highest respectively. He did not score on the changed *spirituality* domain. Paul's recovery style was tending towards integration. He had a sealing-over style on the subscales: *satisfaction*, *liking*, and *ownership*.

APPENDIX G

Letter of Attestation

This letter of attestation is in relation to the inquiry audit of DPsych dissertation entitled: “Understanding Adaptation to First-episode Psychosis: Trauma and Growth Responses.”

The purpose of this audit is to review research products maintained by the thesis author to establish accuracy of the records. The notion of an inquiry audit is based on the concepts underpinning a fiscal audit where an impartial agent examines record statements. In this instance the inquiry audit focuses on the content of the data records themselves. The process was carried out at the conclusion of the research.

The Audit Procedure

The audit was concerned with the substance of the audit trail for FEP participants from the main study. This involved (a) checking the accuracy of transcripts against audio tapes and (b) checking written quotations in the dissertation against transcripts. Selection of information to audit was random.

Initially the auditor reviewed 10 minutes of 5 randomly chosen interviews.

Specifically the auditor reviewed:

- Paul Interview 2, line 40, page 9 (“thinking about one things and you keep on going in one directions you don’t even”)
- Andrew Interview, 1 line 43, page 3 (“like, if I were you and we were talking with each other and you stood up and you did”)
- Tessa Interview 1, line 2, page 1 (“well I was at the hospital and be here like I have to see case manager to see how I feel”)
- Scott Interview 2, line 14, page 12 (“before I ever had any problems with psychosis I was going out every weekend”)
- David Interview 1, line 46, page 2 (“cause I got really sick. The first week in hospital I lost all my movement”)

These tapes were all transcribed accurately with regard to meaning. Due to the soft spoken voice of three participants a few minor inaccuracies were found which did not affect

meaning.

Further, random quotes from chapters 7 and 8 were selected and checked against their original transcript. Specifically, the auditor examined one quote from each FEP participants' interviews across Times 1 and 2. Therefore, 20 quotes in total were examined. These were:

David: Interview 1, lines 19-20, page 11; interview 2, lines 9-12, page 4

Jack: Interview 1, lines 6-9, page 10; interview 2, lines 42-45, page 11

Tessa: Interview 1, lines 5-9, page 5; interview 2 lines 9-21, page 11

Paul: Interview 1, lines 17-19, page 3; interview 2, lines 10-18, page 12

Simone: Interview 1, lines 28-29, page 1; interview 2, lines 20-30, page 13

Alana: Interview 1, lines 41-43, page 3; interview 2, lines 43-46, page 16

Andrew: Interview 1, lines 1-3, page 4; interview 2, lines 17-19, page 18

Daniel: Interview 1, lines 28-31, page 14; interview 2 lines 32-36, page 23

Chris: Interview 1, lines 48-53, page 12; interview 2 lines 38-42, page 45

Scott: Interview 1, lines 25-27, page 3; interview 2, lines 37-40, page 10

All quotes examined were reported accurately. No transcription errors were found. I, the auditor, testify that the transcripts and citations which I have examined in relation to Jane Dunkley's thesis are true and accurate.



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APPENDIX H

Example Quotes from FEP Participants' Interviews from the Main Study

Additional quotes are given to provide further evidence of the themes that are unique to the present research. Examples of overlapping themes are also listed. Extra quotes are not provided for the descriptive themes *the development of the illness*, *the psychotic experience*, *the experience of acute treatment*, *outpatient treatment*, and *spirituality*. Also, more quotes relating to *perception of the illness as helpful or unhelpful* and *perception of the future* are not given.

Explanatory Model of the Illness

Disintegration

- *Being unwell, I wrote a lot of music and I would always write about how my confidence and ego had been left shattered and that I was left to die alone. So before it was always I'm going to be alone. I'm dying. I have no confidence* (Andrew, 1st, I) 35
- *Just losing control of myself. It's sort of hard to describe (laugh). Just the feeling of not being in control of things* (Jack, 1st, I) 4
- *It's just like a, a dreadful memory. I sort of like, it makes me question what was, what went on like how could this happen sort of thing as well. Like it seems so unreal* (Simone, 2nd)
- *Yeah everyday was like different it was, like it was just, most of the time it got worse and worse and I couldn't eat, couldn't sleep. I was up for like 2 or 3 days. I didn't know when I was sleeping or when I was awake* (Tessa, 1st) 18
- *Well yeah but see the thing is I didn't sleep properly for 6 weeks. So I thought the things, see I was generating them to feel better but it's happening so quickly, it's so impulsive that the paranoia comes in and you think it could be real. This is probably real cause you don't trust anything* (Chris, 1st) 2

Perceived Enforced Treatment

- *They came around every day for about 3 weeks or a month....It was a bit of a pain in the butt...Well I started drinking a lot and they'd want me to be sober and they'd keep trying to put me into alcohol rehab, drug rehab programs and things which I'm not interested (Jack, 1st) 13*
- *Yeah I hated it. Like the first two weeks I just wanted to get out of there as quickly as I could. And I didn't think I was getting better so I pretty much like I was fine when I was in hospital but whenever I got out I was really anxious. But I didn't tell anyone I was getting anxious because I just wanted to get out of there. I didn't think they could help (David,1st) 9*
- *I wanted to get out quickly, as soon as I can.... it was kind of uncomfortable at the hospital at times and just want to go back home and do the usual stuff. I wanted to get better as soon as possible.... I was asking my sister how long I'll be here.... She didn't really give me a like proper time, she didn't know...Just that you didn't want to stay there much longer you wish you knew how long.... I couldn't eat, I couldn't eat properly and I was trying to force myself to eat to get better and sleep well (Tessa, 1st) experience list & 16*
- *And every day afterwards man. Every day afterwards mate. It never went away. From the moment I got locked up to the moment they let me go free. It was the most shit thing on my mind. It was the most pressing, irritating thing on my mind to be locked up against my free will. I haven't broken the law and I'm being locked up for it (Daniel, 1st) experience list*

Awareness of the Impact of FEP

Recognising the Illness as an Ongoing Problem

- *I don't know I'm very grey. I don't know what I want to do. If I do one thing then I miss out on another thing and...it's like you don't know how to make a decision (Chris, 2nd) 27*
- *I get very, very low, very depressed quite often...Yeah but I've got a lot more time to sit and think about things now and yeah so I sort of go round like a goldfish,*

just round and round the same old thoughts...Not running around trying to get, you know trying to score all the time (Jack, 1st) 44

- *I used to be able to play, I used to play computer games professionally. Yeah I said to get, I still get sponsored but **I haven't been playing as good as I used to. I was working on a program as well, like and that's been really hard for me to want to do just finding the motivation and the time to do it** (Scott, 1st) 46*
- *Just when you think about it nothing but **you can't get it off you're head that's why yeah...like all the troubles, yeah all the fines and bills and money wise, problems, financial difficulties** (Paul 1st) 20*
- *I find that when I get sick it, like **if I get a cold or anything**, it really knocks me over yeah **like mentally it just throws everything into the air. I get more symptoms, yeah more depressed. Yeah, yeah whenever I get I could I just feel dreadful not just physically dreadful but I just feel like I can't manage like the simple things or like if my days too busy then it will throw a week into chaos** (Alana, 1st) 47*

Disintegration

- *Yeah whatever, however long I've been sick for that was and **even now you know it's still evident but not, nowhere near as much.....Lack of concentration....it was a concentration thing really like feeling powerless that when someone was talking you know they started moving their hands all of that, that I would just go fucking skitzo... No basically that, that was the powerless thing for me. I mean even now it still has its stints if someone talking and they start frantically moving around I still lose it a bit but more focused you know you're speaking to a person you're not speaking to what the fuck they're doing** (Andrew, 2nd) 24-26*
- *I don't know even before I went through my psychosis I felt like I was in the driver's seat. **There was only one point where I felt I was going to loose control and that was before I went to hospital. Like I never feel I lost control. But on the, like I felt I could. It's more about taking a different direction rather than not being in control** (David, 2nd) 53*
- *At that time was I don't know how to we put it in words....you kept on saying what you went through before like together with your girlfriend, her family, then....your job and your normal life and the you just like **you know standing there and don't***

what to do, where to go, you basically you just at one spot looking at things, your life just went by and you want to get involved but you're already out of it you know so sometimes your thought just get carried away with, you know how your life is normally goes on like that and now it's just different (Paul, 2nd) 2

- *Unhelpful in the way that it's made me so disconnected as well from people when they're talking to me as I might drift off and it can be a bit embarrassing sometimes cause I freak out cause I haven't listened to the entire thing that they've said and I hate that* (Simone, 2nd) 52

Sense of Loss and Deficit

- *Yeah. Well I didn't really think that life would be like so dark like...I just thought things were kind of rosier before and now my opinion on the world is sort of darker....Just like I guess I didn't know there was so much sickness and that life could be just so bad. I didn't know life could be so extreme* (Alana, 1st) 25
- *It's very boring and depressing compared to what it used to be like. I used to be able to got out. Used to be able to, when I used to feel unwell I used to be a bit of a compulsive buyer. Yeah I used to buy things but now I can't do that anymore and it's been really bad. It's also affected my life like, my relationship with (girlfriend) because it's been really hard now cause she's just finding it hard to stay with me because of all the problems I've been going through and things like that. Because financially I'm not as well off as what I used to be so it's really hard because I used to be the one who used to take care of her but now it's the other way around* (Scott, 1st) 23
- *Yeah I used to have this feeling about, I used to feel sort of amazed by technology and engineering and things like that, building things and it's sort of gone a bit I think it's because of the medication and it keeps like a cap on your feelings. I look forward to getting that back yeah that's also another part of my personality I like to build things.* (Chris, 2nd) 31
- *It's taken a hit on my attention span* (Andrew, 2nd) 10
- *I feel like I'm smarter now than I was but I'm also a bit dumber because of all the pot and stuff. I know things that I didn't know when I was younger but also don't know things that I used to know* (Jack, 1st) 34

- *Thinking other, normal other people can still do what they do **and here I can't do what I want to do** (Paul, 1st) 15*

Estrangement

- ***Feel a lot more distant from my parents and things like that. Even though they've come closer in certain ways I just feel a lot like more distant cause I haven't really told them everything. It's been hard to explain everything to them....Just support. Like financial support and things like that... And it's hard to relate to them....Cause they're always just like, my mum well I had depression for about 2 weeks and I got over it sort of thing. So it's been really hard to try to talk to them and relate to them** (Scott, 1st) 37*
- *I don't know people who have been through something similar then it's easier but **people who don't know me, people my own age that's not so easy for me.... I don't know. I guess I feel that they wouldn't really understand or get it and I don't like to talk about myself all that much anyway.... It's always easier to talk to someone that you share a similar history with** (Jack, 2nd) 41*
- ***It's hard to talk to them sometimes because they're judgemental about what I'm thinking. They say to me like that's just wrong you shouldn't be thinking like that and you feel bad about it. So that's also the other thing that I've realised like I'm probably thinking more maturely than my parents you know than my parents are capable to think so I can't expect people my age to think that way. It's hard in a way cause you're alone** (Chris, 2nd) 37*
- ***I've got doctors that shit me up the wall telling me I have to be normal. I have to get a job. I have to do what they want me to do so I'm still trapped. Society gets down on top of you man because society has clear defined goals about what it wants you to be doing man....other people to tell you that you're crazy because you know you judge your own normality based on the people around you** (Daniel, 1st) 30*

Self-stigma and Stigma from Others

- *I don't really like coming here to see the doctors and all that sort of thing...The first day I came here I was having to step over people to get up the stairs. **Some guy was laying down on the stairs like drunk and there was another Chinese guy that was***

talking to the water cooler which I thought was a little bit odd. **I didn't feel like I was in the right place** (laugh) (Jack, 1st) 16

- *Like it got pretty **embarrassing** cause imagine speaking to your best mate and you look down and you go oh looking at his hands you know it's, it was **degrading*** (Andrew, 1st) 2
- *There is a bit of um **shame at the stories that I made up** because I realise that I made them up so really I could see a person that's sick, **I could see why they'd want to hide that and they'd want to believe that it actually happened where it didn't actually happen*** (Chris, 1st) 39
- *It was just very distressing being admitted into hospital. Like I felt that I was crazy because I was going into a psych unit* (Alana, 1st) 9
- *I probably just wouldn't bring it up. I don't know just, yeah probably still, I don't know just having a stigma associated with being mentally ill I think* (David, 1st) 39
- *It was a bit of an eye opener. I still feel that there's some stigma around it. I'm sure a lot of people, my family are sort of amused that I have to come here all the time* (Jack, 1st) 17
- *In society it's like, it's shameful to have a problem, so you don't want to share your problems with your, with your mother or your father that's the rules that your taught um whereas really they should be counselling you because you're young and you don't understand things....I can go to them more and talk to them more because I don't see it as um a shameful thing to have a problem. **It is really viewed as a shameful thing to have a problem in society you know like you have to act a certain way*** (Chris, 1st) 37
- *It's hard because I'm fucking, I don't want to be at home anymore because of my parents and my parents aren't like this man. Nobody I know is like this. They're all materialistic and they all find it weird and strange and people look at me differently now* (Daniel, 1st) 20

Management of the Experience of FEP

Perception of Treatment as Restricting

- *It's hard to wake up sometimes cause of the medication it makes you tired and yeah you have school at 9 o'clock every morning (Tessa, 1st) 44-45*
- *And it's changed in the way that now I'm a bit more, cause I hardly had energy throughout the day to do anything and so I'm always a bit lazy and tired and things like that so it's affected in a way where I can't really help around the house and things like that. Like I try to but they always tell me to look a bit more lively and things like that. I just think it's just the medication that I'm on. The Temazepam does make you a bit sort of tired (Scott, 2nd) 38*
- *I hated taking pills. I hated taking all different kinds of pills. I mean I was never on the same thing for more than a few months you know it was one medication after another medication looking for something that worked and eventually you know I just had enough of it and I said fuck I won't take the pills anymore and that's basically what happened with me that's why I didn't go back to ORYGEN. I wouldn't take the pills. I didn't take the pills for 3 months and they told me that I was doing so well and I was making all this great progress and that I should take more medication and I thought fuck that I've gone 3 months without any medication at all you've told me I made more progress and now you want me to take more pills and I'm not taking fucking anything (Andrew, 2nd) 7*
- *Doctors friggin' pissing me off. This time they've forced me to take blood tests to make sure I take my medication mate. Shit like that helps you not cope man! (Daniel, 2nd) 7*
- *I worked at a data entry place and I was on medication and the medication made me sleepy this was the stuff that I was on before the Olanzapine and because of that I had to go home one day cause I just couldn't work cause I was just too tired and ever since then I didn't get a job there anymore (Simone, 1st) 42*
- *Because of the medication I have to go to sleep earlier so that's one thing that I don't like and I feel restricted by the medication because I'm not, no longer able to stay up til two o'clock in the morning and then still be able to go to work yeah but*

that's one thing that I look forward to I want to get off the medication. I think I'm able to get off the medication then I want to live my life that way you know I like surprises (Chris, 2nd) 28

Estrangement

- *The being cut off from my life bit I feel like I'm just beginning to regain that. It wasn't just when I was in hospital but it was me cutting myself off from my friends because it was too hard whereas now I feel I'm just beginning to get that back (Alana, 2nd) 4*
- *But trying to walk that pathway, you're cutting yourself off from everybody else because you know you're not fitting in with the norm anymore. You're not trying to be sociable (Daniel, 1st) 37*

Conscious Avoidance

- *I didn't cope really well to begin with and during the middle I thought about just hitting the drugs and you know boozing up doing whatever the fuck I could just to forget about it (Andrew, 2nd) 7*
- *Sometimes yeah, it's alright, you get used to what you think really....Sometimes you think about it in kind of, yeah, I don't really want to think about it again...Ok to share with them what I went through (Tessa, 1st) 39*
- *Remorseful really I kind of, I had a bit of angst against her because she was telling me I needed to go to a place you know to be rehabilitated or whatever so I held a lot against her for a long time. Like I kind of hated her for telling me to do the right thing because I didn't want, I didn't want to believe that there was anything wrong to beginI knew there was something wrong. There was something wrong for a long time (Andrew, 1st) 1*

Awareness of One's Vulnerability

- *I understand that now and I believe it can't happen again um, and if I see something, I, I don't believe, I, I very cautious with it now, um I just, I don't believe things. I make sure that they're real (Chris, 2nd) 5*
- *I don't know I guess I'm kind of happy just staying home and drinking and I don't want to go out and risk getting into trouble like I used to (Jack, 2nd) 52*

- *Well now I think I've got more of a chance because I haven't heard the voice that often lately **but I'm still really scared of what will happen if I do actually get to work and hear the voice** (Scott, 1st) 15-16*
- *It was a bad 2 months and you, **sometimes the thoughts just come back and you're scared that it might happen again**...Just your experience be brought up...No, you don't want to, you just don't want that you know the feeling to come back again (Tessa, 1st)*
- *I'm just trying to get through everyday without going crazy again, without going into psychosis. It's sort of a day-by-day thing. **It's easy to get really mad and go crazy. Smashing things and starting arguments and things like that. Trying to be not so angry** (Jack, 1st) 49*

Viewing Recovery as a Journey

- *It's been a bit choppy. It's been a bit up and down (Andrew, 2nd) 8*
- *It's just been one step at time and everything's been getting better and better (Chris, 2nd) 5*
- *I don't know like I sort of feel like, I don't like recovery means sort of enjoying every day and not, I don't know, sort of having really negative sort of thoughts about it but I still do so I don't know recovery still somewhere in the future (David, 1st) 49*
- *Yeah getting there like slowly, getting back to how it used to be...Not being scared, my thoughts, yeah (Tessa, 2nd) 5*
- *Up and down. I've had my good times and I've had my bad. The good times is obviously **when the voices started to calm down a lot and the bad times when I started to get relapses of symptoms and that wasn't good** (Scott, 2nd) 5*
- *I don't know I think I'm still going through it. It doesn't really mean much at the moment...Well I'm supposed to be taking medication but I'm not. **I'm just trying to get through everyday without going crazy again, without going into psychosis. It's sort of a day-by-day thing. It's easy to get really mad and go crazy. Smashing things and starting arguments and things like that. Trying to be not so angry** (Jack, 1st) 49*

Self-direction in Recovery

- *Things have sort of picked up and I started caring about myself. Trying to get the right amount of sleep, trying to get the right kind of food, trying to have a healthy mentality and be positive about things and things got better and still continue to get better (Andrew, 2nd) 8*
- *Every time I thought I was getting better I went into ORYGEN and I left ORYGEN feeling worse every time. Every single time I went in with high hopes and feeling great and you know things are getting better and I'm controlling myself and every things going great and I swear to you every time that I left ORYGEN I felt more crazy than when I walked in (Andrew, 2nd) 9*
- *It was something someone said to me and I've heard it said twice now by a friend who also has bipolar and a psychologist who said that you're not meant to take depression personally you're meant to see it as if you're leg is broken and you can't do things because you're leg is broken not because you're a failure... It does help me kind of depersonalise and not kind of analyse myself for a reason why cause I don't think there is one (Alana, 2nd) 53*
- *Recovery, complete recovery to me means being off the drugs. I realise if I do get off the drugs it's going to happen again but there's also the fact that like I believe that I had a chemical imbalance before I got sick so I've been living with a chemical imbalance all my life. I want to take that risk. I want to be able to live life again but I do, I do think, I don't know when I get off the medication I think that I might be able to become impulsive like I was again perhaps just by me concentrating **but the fact that my emotions are not in control of me being impulsive and I'm in control. I'm able to switch it on and switch it off is that reason why I don't believe, I believe I can't become sick again because I'll never get in, I deal with reality. I make changes in my life to....I make changes, I, I deal with things reasonably and realistically and I realise that I can't, I've got to appreciate the things that I do have and not want the things that I don't because I'm always, it's an impossible situation... I've always wanted to get off the medication. I feel like if I do that I can live life normally and to the fullest again (Chris, 2nd) 53***

- *I think I'm just understanding what was going on. I was using a lot of drugs and was quite paranoid. I'm not doing that anymore. Things are looking better.... Well I've kinda learned to rationalise things. Not to come to jump to conclusions... Yeah. If someone says something where I used to just fly off the handle I'll try and question why they said it and if they have a point or not. If they're having a go at me or they're just saying something (Jack, 2nd) 5*
- *Yeah I don't know I guess I was pretty stressed out about sort of quitting uni. I don't know feeling quite insecure about work and stuff Yeah I don't like there was a few lifestyle changes. Like I don't work as much as I was. Like I'm at a different workplace and I don't work nearly as hard (David, 2nd) 12*
- *Yeah just exercising you know trying to stay fit and healthy and trying to find things to do, entertain myself (Paul, 2nd) 7*
- *Just eating properly and sleep, mange my sleeping patterns and just taking my medications yeah (Tessa, 2nd) 53*
- *Well what I'd sometimes begin to do after I got the paranoia or the noises I'd try to put other words into my head to block out anyone trying to read what I was thinking. Or just words, constant words just blocking it out. Yeah it was, it was difficult and sometimes I would like think of an object in a space and then sort of ground me like there's a tablecloth over there. I'm sitting in this room no one can hear what I'm thinking (Simone, 1st) 4*

The Interpersonal Environment Facilitates Recovery

- *Cause when you talk to them (friends/family) it tends to I don't know just like, you just feel you're you, you yourself, your thoughts doesn't you know take you, your thoughts don't go wild like it doesn't get out of control (Paul, 2nd) 7*
- *I don't know like discussing little stuff with her just sort of I don't know like lets me know whether like sort of getting anxious at work like most of the time it's normal but and so like just being able to differentiate what's normal anxiety and what's sort of excessive (David, 2nd) 9*
- *Talking about anything is really good because you're going somewhere because you have a condition and if you're going there to talk about normal regular things then it's just kind of like a friendly visit. It's not so intense and not so oh you need*

to do this, you need to do that and try to focus on this it's just normal (Andrew, 1st)
21

- *I just started seeing the psychologist and she's been really good as well...Just like making me not feel like I'm crazy or the only person she makes me feel like part of a bigger group of people who just happen to have the same kind of illness (Alana, 1st)* 21
- *My aunty...when I first went through the psychosis she let me stay at her house for like a week. It was really good because I had someone who cared and she was so worried about me and just like reassuring and helping me and stuff and then when, when you know when I went on the medication like mum helps me with my medication she puts it in a little box for me and I know that's just really helpful (Simone, 2nd)* 42
- *If anything since I've met him I've become more outgoing or I can be myself a little bit more just because when I first met him I was so nervous and with the other people I guess I'm more relaxed around people in general. And I think like it was quite challenging for me like have, having a boyfriend so when I got through like challenges, social challenges they sort of make everything else seem less and less anxiety and less stressful.....I've always been like that. I'm the sort of person who grows by experience and if I'm getting challenged on something big then everything else seems less challenging (Simone, 2nd)* 40
- *The talks. It's good to have somebody to talk to, to express...yeah to you know, somebody who can understand you and somebody to express your views you know...Somebody you can, you know, be yourself around. You don't have to always go out and act so, and that's what I do like my whole life I've been acting (Chris, 1st)* 21

Developing Acceptance and Moving Forward

- *I guess I am in control of it. I mean everything that I decide to do is my choice at the end of the day so I am in control of my recovery but at the same time there are involuntary things that will occur as my brain changes that I can't control so it's in my hands but at the same time you know the part that's in my head I can't control it, it's going to fix itself, it's going to fix itself (Andrew, 2nd)* 53

- *Like...I was happy go lucky at the start you know say I lost my job big deal lost a job get a new job then insanity was like I couldn't deal with the way, something wasn't my way I wasn't happy about it **now it's like whatever happens, happens you just keep going you can't just stop and you know get caught-up in your own problems** (Andrew, 1st) PTGI*
- ***It sort of made me realise that I had a bit of a problem and it was something I had to work on.** It's kinda easy to just sit there and say your not the crazy one everyone else is wrong but then **when your family start saying you got a problem you take it on board** (Jack, 1st) 15*
- ***You can never experience life to the fullest you just got to be yourself yeah and believe that things you say and what you hear is true and just get satisfaction from that...** I used to be really calm...**whatever comes will come....** Probably my moods start changing. It's hard to tell why there's many reasons and when you think of the reasons **you tend to think of other reasons but what's the point of thinking these things you've just go to accept what's coming yeah** (Paul, 2nd) 27-28*
- ***The past is the past you know at a stage you've got to move on. Nothings going to be perfect for the whole, the rest of your life you've got to go up and down somehow...learn a lesson from it...Nothing really. Can't do anything you can't change the facts that you lost your licence and you can't drive** (Paul, 2nd) 4*

Restorative Outcomes

Functional Recovery

- ***Recovery means not sort of being, sort of being able to live life without taking drugs. Sort of enjoy life** I guess.... I don't know like I sort of feel like, I don't know like recovery means sort of enjoying every day and **not, I don't know, sort of having really negative sort of thoughts about it** but I still do so I don't know recovery still somewhere in the future (David, 1st) 49*
- *Probably a month after the CAT team came out. **When they stopped coming to my house and referred me to here...** Well they said that. They were coming everyday*

*just to make sure I wasn't going to hang myself or something (laugh) and **when they stopped I guess the thought I was getting a bit better.** That they could stop coming around to see me (Jack, 1st) 49*

- ***Yeah, yeah...being unwell at work...how do I put it? The quality of work isn't the same** because you're working with people that you don't trust so everything that you do you're conscious about whose moving around you and **you can't really focus on your job because you're focusing on what everyone else is doing.** Now **it's just focus on your job and get your job done** (Andrew, 1st) 42*
- ***I just feel so much better now.** I, I, like it's, **I don't have that dope, doped out feeling.** I don't have that, I don't, I don't have those impulsive um, I don't, yeah I, **I don't say things impulsively anymore** (Chris, 2nd) 4*
- *Yeah back to normal....Just being able to study, hang out with my friends, not just having yeah those fearful moments (Tessa, 1st) 19*

Social Recovery

- ***My friends reach out to me** like before they didn't, they didn't because they couldn't help me, they couldn't understand me and **like my social structure is back to the way it used to be** (Andrew, 1st) 20*
- *Well at the start yeah you were kind of like nervous seeing people just scared couldn't talk to people liked to be alone but **I think right now it's just normal....**Yeah the first few weeks probably was kind of, didn't really want to talk to people yeah but **you kind of get back to yourself again...You see people slowly and then you start going out and then yeah, go to school** (Tessa, 1st) 36*
- *I want to recover...**I'm able to accept authority.** I'm able to accept things the way they are now and like I'm able to deal with reality. **Deal with people,** I don't feel this need to be treated...**I don't react to the crappy things that people say like there was...I believe that it's wrong but what can I do I can't, I can't change this person it's so I just like let it go** and you know you create problems for yourself you know (Chris, 2nd) 54*
- ***Yeah my friends actually have more respect for me** because they consider me not to be dopey anymore...**They're actually more accepting of me and I'm more accepting of them you know...I've gotten better you know so it's more of a***

natural...relationship...I'm less stressed about my illness so I behave like....it's more relaxed (Chris, 2nd) 39-40

Constructive Changes

Development of Deeper and Closer Relationships

- *Yeah we've become closer and I'm able to talk to my father more about his illness um and I don't see it as a taboo anymore and like I'm even trying to help my dad with things because he's got the wrong views on some things (Chris, 1st) 37*
- *Gotten stronger. My bond, the bond that I share with my mum and dad is better. Before I didn't want to reach out to them, didn't want to talk to them I mean I did but at the same time, I just got closer to them you know they help me out a lot which is good... Since I started getting better in the last 3 months I got a lot closer with my family whereas before you know they were trying to help me but I was kind of still keeping them in the dark...Just realising you know like I've got nothing to hide so might as well reach out to somebody (Andrew, 2nd) 37-38*
- *No I think it's closer. I do feel closer...Now I really fee like instead of being my boyfriend he's become my partner (Alana, 1st) 38*
- *I think I'm closer with my family like partly because I moved back home and partly because they sort of know that I'm unwell....It's helped because their expectations aren't the same like I felt that I had to fulfil my family's expectations of me...I still feel it a bit but I don't feel the need to do it as much and their expectations have changed...I think it's just to be kind of healthy...They wanted me to complete my degree and to be working and you know just to do things properly...I do feel that I can be more open...yeah like if I don't want to do something...or I can say I don't feel like it (Alana, 1^s) 37*

Increased Desire to Interact with Others and Improve the Relationship

- *Sometimes you need to talk to somebody, you need to talk to someone, you need to get away from, you need to see your friends, you need an escape, you need a release, you need to drink sometimes you know what I mean like. People are important you can't just live life alone you'd just be cooped up and live life like a*

hobbit. Yeah like people are important so it's ok to need someone if you know what I mean (Andrew, 2nd) PTGI

- *Sort of made me think about what's going on and the everything around me. The people around me. I never used to care what people thought when I was smashed all the time. I don't know if that's positive or negative. And I think my dad's happier now that I'm easier to live with.... Well I've stopped smashing things and throwing stuff around (laugh). We don't argue as much (Jack, 1st) 25*
- *Yeah we talk more and previously like, in society it's like, it's shameful to have a problem, so you don't want to share your problems with your, with your mother or your father that's the rules that your taught.... Yeah I talk to her more and like um you know with this town house thing we're talking more and um yeah I can go to them more and talk to them more because I don't see it as um a shameful thing to have a problem. (Chris, 1st) 37*
- *I'm more like able to accept help from other people if wanted. I guess I sort of fought it in a way because I wanted to be independent but now I've sort of relaxed a bit and accepted that it's ok to need help (Simone, 1st) PTGI*
- *Since I've been unwell I've just been better at looking after the home and helping out. Than before yeah just being motivated to keep the family in harmony (Simone, 1st) 45*

Enhanced Perspective Taking and Sense of Unity

- *More compassion for people who are somewhat like me. Who have experienced things that I've experienced. I have more compassion for anyone who you know is experiencing a mental illness... you know just trying to learn and get by in their day (Andrew, 2nd) PTGI*
- *Like in my time of need people were there for me and in there's I would want to be there for them as well.... I'd push, yeah I didn't feel that I should need help and other people when they needed help I kind of felt like they should be able to handle things (Alana, 1st) PTGI*
- *It's certainly opened my eyes to a lot of things cause like before all of this happened I never used to believe in sort of mental illnesses and things like that I was always just like I was always like well why can't people get over it and*

suffering from it myself now I understand. It's opened my eyes a little bit more to what people actually go through when they have mental illness and it's, it's not a good thing (Scott, 2nd) 10

Confirmation of Character of Others and Quality of Relationships

- *I think I know I can rely on my parents and my sister a lot more than I ever thought I could before I was pretty bad..... Yeah they do. Like my sister she would never take me out for dinner or anything like that before, before the illness..... I didn't need to but then, yeah, when I went nuts they started to help me out a lot (Jack, 2nd) PTGI*
- *Well with your family, whether you like it or not they're your family and they'll always be there for you to support you. If your friends go away and make no effort to see you then they're not your real friends especially when you're in need the ones that, even ones that stick around to say hello even though they know you don't have much to say you know that they're your real friends because they were there. Like it didn't matter what they were doing but they were there anyway (Andrew, 1st) 48*
- *The sheer fact that throughout all the good and the bad that (girlfriend) stuck by me gave me a real appreciation that to possibly you know the meaning of life and what love and you know life together long living would be like (Andrew, 2nd) 19*
- *When I was going through it yeah a little but now I don't know I just, not think about it that much....Like you just, may be felt like your friends and family were more special yeah...cause I saw them being there for me (Tessa, 1st) 25*
- *I guess me being more calm and positive with my family is related to the fact that since I've had psychosis I've seemed more grateful that they're there for me and that they care about me cause I've seen that since I've been an illness (Simone, 1st) explored issue raised by participant*
- *I think it's made me more grateful for what I have and I think (case manager) does that as well a lot... Grateful for my family's support, those that are there for me (Simone, 1st) 25*

Greater Appreciation of Life

- *Beforehand I only lived to play music and that's all I did. I had a job as a chef and that was my job it wasn't my life because I was a musician and still am a musician but back then it was just about playing music then it went to worrying about what everyone thinks and now it's about just experiencing the world. It's like you, it was liked being locked in prison and then being let of prison and like the world's changed* (Andrew, 1st) 31
- *Well I tend to take my life a bit more seriously now like it's a bit more valuable like I do try to cut down my smoking and binge drinking and things like that. It's been, it's been really good trying to be, trying to eat healthy, loose some weight* (Scott, 2nd) 16
- *Learnt that there's more to see yeah to be more grateful and to you know see what you've got and what's happening around you Yeah there's more, there's more, like open your eyes and see what you have* (Simone, 2nd) 53
- *When I went through yeah like, you did want to like, yeah appreciate life more. At the time I thought...sometimes you thought you were going to die yeah because yeah cause I knew I wasn't eating, sleeping so I was thinking you know that yeah...like yeah you kind of got scared like why didn't I do this and that....Just like spend time with family more* (Tessa, 1st) 31-32

New Possibilities and Direction

- *I draw a lot more, my interest in music have expanded, I like playing chess now, my interest in French cooking is more than it was before which is great, took a greater interest in soccer, took a greater interest in my family, took a greater interest in my girlfriend and her family (inaudible) and a lot more reading too* (Andrew, 2nd) PTGI
- *I like achieving but um you know you can enjoy other things as well and that's really the great thing because...Yeah you can have both. Before it was just achievement you know to make me feel good and social situations made me feel bad, really bad* (Chris, 1st) 38

- *Now I'm not sure if I want to go back to work and work in such a stressful environment. I'm thinking of doing something a little bit easier and studying and finishing off my studies and hoping to do something that I like* (Scott, 1st) 24
- *To be happy. To, I don't know I'd like to get married. Yeah just be like successful as well and be healthy and like you know have a good family...Shifted I'd say...When I was at school all I wanted to be was like successful, earn money that sort of thing. I didn't really see myself getting married being more a career woman but I don't know now that I'm older I just see I was unrealistic, yeah* (Simone, 2nd) 15
- *I don't know I guess achieving your goal....No in that I still, I don't know, feel like I want to achieve more...I don't know just want to, I don't know, start playing music more. I don't know I feel like I haven't, like I've been at uni a long time but I haven't got anything out of it* (David, 2nd) 27-29
- *My main hobby now is meditation like you know. I used to play lots and lots of games. I used to watch movies and all that. Things to distract my mind and now I just don't do that much anymore* (Daniel, 1st) 46

Deepening of Self-knowledge

- *I think that I've just become more understanding of people like instead of being more judgemental I think I've just become more accepting like people don't have to be perfect people can just get by and that's ok. Like before I was really concerned if I'd hand an essay in late or whatever or if I wouldn't get an A and now I think when go back I'll just be happy if I get a C like if I can do it and that's fine and then it's just, I would rather let it go* (Alana, 1st) 41
- *Look back at myself from what I can remember and you know anything that I didn't like I changed you know for the better. I would lie to impress anymore. I would lie through my teeth about anything. I would lie to my friends. I would lie to (girlfriend). I would lie to anyone just, you know just to be cool. No shit now you can say what you've got to say. No bullshit. Straight down the line. I used to lie a lot. I lied heaps* (Andrew, 2nd) 55
- *It's, it's sort of just a thing like I had to go through and I'm really happy that I'm able to see the world the way I see it now so, so yeah I, you know it's much easier*

for me. I'm happy that I'm able to feel relaxed around people. I'm able to be reasonable with people and now I think a different way about the world. I think a different way about relationships. I can choose who I want to be friends with. Who I want to be close with and....I don't like the fact that I got sick but I like the fact that I'm able to see the world in this way (Chris, 2nd) 52

- *Well it is I mean I used to get really upset and frustrated if things didn't go my way. But I'm starting to realise that things can't always go your own way. Just cause something doesn't go your own way doesn't mean you can't, can't try it again. Try and fix it up again (Daniel, 2nd) PTGI*
- *I don't think I have more appreciation but I have more a realisation that it's my life to do with what I want not...it's not for other people it for me to live how I want....I think I was just doing what I was supposed to do like you're supposed to go and study, you're supposed to have a job, you're supposed to you know go along that path and just check off the boxes and now it's more like I should choose what I want to do... Like sometimes people say that like I'll just make off handed comments and they'll say it's up to you what you want to do and I think I've just learnt to listen to that more. I just feel that it is my life to choose what I want to do more (Alana, 1st) 26*

Development of a Sense of Mastery and Personal Strength

- *Definitely since I've worked, cause I, I met new people again....and one of them was (colleague) and he had to teach me everything and the psychosis sort of played on that a little bit you know and it sort of made it hard to concentrate but I still had to concentrate and learn at the same time so through that I think I've become more strong and yeah....Stronger to fight the psychosis cause I'm forcing myself to learn at the same time (Simone, 2nd) 45*
- *Confidence wise I don't give a fuck about what I say. I don't care who I offend, what I say what I do, I do whatever I want to do within reason of course but I'm not concerned, I more concerned about myself than anyone else now like I put myself first and you know that's, before I would put anyone first except me I would put you know I'd pick up a fucking stone under my shoe and say you know this can go first. Now it's like you know you've got to have a bit of fucking pride.*

Sometimes, at the end of the day you've got to take care of yourself (Andrew, 2nd)
30-31

- ***When I look back just makes me, just stronger I guess...I've become more mentally tough*** like my mentality is very, very, not so manipulated so to speak. After, after looking back at that and realising you know everything was bollocks at the end of the day. ***Yeah I think I got a lot tougher*** (Andrew, 2nd) 4
- ***Yeah man fucking in the past if something was in my way, my life, I'd just get grumpy about it and forget about it. Now I try to get up and do things about it...Work man. Fucking in the past whenever I didn't have a job I wouldn't bother looking. I'd be lazy and complain about it. Now I get up and I do what I have to do man. I don't know how else to put it hey.*** (Daniel, 1st) PTGI

Examples of Overlapping Themes

Conscious avoidance and awareness of one's vulnerability

- Jack: ***I never used to think that I was crazy*** (laugh) until I actually had people coming around to the house everyday to make sure I wasn't dead (laugh)
Researcher: What does that mean to you – crazy?
Jack: ***Frightening to be honest, it's not fun. I hate to think that I'll end one day up in a padded cell with a straight jacket on not knowing my name, that's a bit scary.***
Interviewer: That must be hard
Jack: ***Can be if I dwell on it***
Interviewer: Do you dwell on it?
Jack: ***No I drink, self-medicating with alcohol*** (2nd) 16

Disintegration and sense of loss and deficit

- ***I don't know myself anymore as I said like now I could say that I'm very timid, very shy sort of not confident person...I don't feel as confident about myself anymore.*** (Scott, 1st) 33

Self-direction in recovery and sense of loss and deficit

- ***I want to reduce the medication so I can have my mind back um because I'm not able to use it to a, to it's full potential right now...My imaginations not as strong***

um so I'm not able to visualise things like the way I was before...in engineering like you can visualise, you can visualise the way you want to make things (Chris, 1st)

49

Self-direction in recovery and recognising the illness as an ongoing problem

- *Yeah I let myself go and now I'm back into training got the weights out, looking after my health yeah got to do the right thing, can't let myself just wither away (Andrew, 1st) PTGI*

Enhanced perspective taking and sense of unity and development of deeper and closer relationships

- *It was people that I wasn't especially close to that I've become closer to and like they've shared their experiences like one of my friends has had depression and another one has bipolar and they've shared that of themselves as well. It's sort of good because I'm not the only one in our group. Yeah they know that things can be difficult. I think other friends, like they were great when things were great but when things were difficult they just kind of backed off (Alana, 1st) 38*

Confirmation of character of others and quality of relationships and development of deeper and closer relationships

- *Yeah because again a lot of my friends dropped off completely and the ones that remained have become I think closer to me....just like they're, I think that they're aware that they can be more inclusive like sometimes the relationships not going to be 50/50 and they're prepared to you know stretch the friendships more....they know that things can be difficult. I think other friends, like they were great when things were great but when things were difficult they just kind of backed off. Yeah they've shown their friendship and like what type of person they are as well like you can, it's really easy to be friends with someone when everything's going really well and it's more difficult when things aren't (Alana, 1st) 38*

Deepening of self-knowledge and increased desire to interact with others and improve the Relationship

- *If anything I'm less snappy, more patient. More understanding....Like I'll, especially when it comes to my family I'll like you know watch out to see if they're ok or if they're feeling ok you know just making sure that everybody's happy not*

just myself.... *May be because when, when they got back it was like this sudden change. They got back from, my parents got, overseas yeah and when they got back wow I was suddenly wanting to know how they were and I don't know how that came about it was just like, it just happened* (Simone, 2nd) **30-31**

Increased desire to interact with others and improve the relationship, development of deeper and closer relationship, and confirmation and character of others and quality of relationships

- ***Cause seeing them like, they were like there all the time made me like appreciate them more....I think I'm starting to talk to my mum more... Cause when I was going through the sickness I was like, they were there and then I realised how I didn't spend much time with them*** (Tessa, 2nd) **38**