BEYOND RECOVERY: SENSE OF SELF AND PSYCHOSOCIAL CHANGE FOLLOWING RECENT ONSET PSYCHOSIS

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ABSTRACT

Background: The experience of a Recent Onset Psychosis (ROP) can be traumatic. Framing psychosis using a trauma model has implications for understanding recovery. That psychosis can precipitate Post Traumatic Stress Disorder (PTSD) has been demonstrated. However, little research has explored constructive changes that may occur as a result of the struggle to overcome the traumatic experience.

Aim: This study sought to explore Post-traumatic Growth (PTG) following a ROP and the relationship of this to the re-construction of the self, which is regarded as central to the recovery process.

Method: The study used a constructivist grounded theory approach. Eight individuals who had experienced a recent onset of psychosis, were recruited through NHS and third sector organisations. The participants engaged in semi-structured interviews about their experience of recovery from psychosis and associated perceptions of change (e.g., PTG and Post-traumatic Depreciation (PTD)).

Results: The theme 'the immediate crisis and aftermath' epitomised the trauma of psychosis and ongoing struggle. The remaining themes 'making sense' and 'finding a sense of value and purpose' represented strategies employed by the participants to regain a sense of self. Making sense involved creating a 'narrative of the crisis' and of the future 'recovered self'. 'Re-gaining trust' was central to the development of reinstating a perception of self as having value and purpose alongside 'social participation'. Through participants' engagement in these strategies the core category 'Post-traumatic Growth' emerged reflecting positive change, which included the categories: 'increased self-awareness'; 'increased empathy for others'; 'deeper relationships'; and 'reassessing priorities'.

Conclusions: The findings have numerous clinical implications for clinical psychology and more widely for service delivery. The study recommends fruitful research endeavours in the topic of PTG and ROP. The author calls for a reframing of recovery from ROP. The notion of the emergent 'Post-traumatic self' which integrates the possibility for PTG is suggested.

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CHAPTER 1: INTRODUCTION

1.1 FOCUS OF THESIS

In order to provide context to this study, the nature and notions of 'psychosis' are discussed within this chapter. The author then invites the reader to consider psychosis from the immediate traumatic experience of crisis to the stage commonly termed 'recovery'. The author suggests that recovery models fail to adequately capture the process of recovery and adaptation. Instead they largely focus on restorative and functional outcomes. The reader is invited to consider models of change that incorporate some consideration of wider outcomes of constructive change as a result of the trauma of psychosis, specifically Post-traumatic Growth (PTG: Tedeschi & Calhoun, 2004). The relevance of sense of self to the experience of psychosis, recovery and PTG is considered throughout. A systematic review of the relevant literature pertaining to qualitative accounts of PTG following psychosis will guide relevant exploration of empirical literature.

1.2 THE EXPERIENCE OF PSYCHOSIS

1.2.1 NOTE ON TERMINOLOGY

There is considerable debate regarding the terminology that is traditionally used to describe the experiences explored in this study. This reflects larger contentions about the nature, causes and consequences of such experiences. The author consulted with a Service User Representative in an attempt to adopt the most appropriate and least stigmatizing labels (Appendix A). The term 'psychosis' was used following concern that avoidance of the word could lead to a 'double stigma' whereby it is communicated as a 'thing to be avoided and/or not to be mentioned'. This position is reflected within wider consumer accounts:

> *"It's as if it has become a bogey word used only on the rare occasions when somebody with a mental illness has hurt someone. Not using the word propagates fear and mistrust" (*Hafal, 2014).

It is, however, recognised that not everyone will be comfortable with this term. A psychosis is unique to the person's experience and not everyone with a psychosis agrees with the medical explanation. In recognition of this, the term 'individuals diagnosed with psychosis' is used where possible as

opposed to 'people with a psychosis'. Likewise, the terms 'psychosis' and 'symptoms' appear in quotation marks on occasions to emphasise contentions around such constructs.

1.2.2 'PSYCHOSIS' – A CHANGING PARADIGM

Early notions of psychosis painted it as a crippling disease of the brain leading to pervasive and persistent impairment (Arben 1996; Carpenter 2002; Jimenez 1988; Kruger 2000; Roe, Chopra, Rudrick, 2004; Schiff 2004). Kraepelin's (1913) conceptualisation of schizophrenia represents one of the first notions of schizophrenia and is believed to have created 'profound therapeutic nihilism' (McGorry, 2004). Kraepelin believed that experiences then known as 'hebephrenia', 'catatonia' and 'paranoia' were all characterised by onset in adolescence and followed a progressively deteriorating course with the outcome being 'dementia praecox'. Despite the fact that 12% of Kraepelin's clients made a complete or near complete recovery (Warner, 2004), he asserted that those who recovered had been incorrectly diagnosed as an outcome of dementia was a prerequisite to diagnosis (Read, Mosher & Bentall, 2004). In 1911, in an attempt to advance Kreapelin's notion of Dementia Praecox, Paul Eugen Bleuler coined the term 'schizophrenia'. Bleuler refuted Kraepelin's conceptualisation of dementia as a necessary end point of the experience. Instead, Bleuler argued that symptoms could be experienced as a continuum from the unnoticeable to the most florid. He also argued that although a person may make sufficient recovery to function again socially, they may continue to experience residual symptoms. Bleueler's psychodynamic perspective paved the way for increased consideration of therapeutic input, reduced hospital based care and opportunities for work (Warner, 2004). This may have, at least to some degree, contributed to the increased rate of recovery seen in his patients, with at least 60% recovered well enough to work and maintain a life outside of hospital (Warner, 2004).

The early notions of both Kraepelin (1913) and Bleuler (1911) have had far reaching effects in terms of how recovery from psychosis and schizophrenia is understood. Not only has Kraepelin's belief - that mental 'illnesses' arise from biological causes - dominated psychiatric classification systems (Andresen Oades & Caputi, 2011) but it has also filtered through to professional and societal discourses. In addition, Bleuler's more inclusive definition of schizophrenia and psychosis led to an increase in the number of individuals diagnosed. Therefore, even those diagnosed on the most loosely-defined criteria were subject to the 'chronicity paradigm' (Birchwood, 1999; Ramon, Healy and Renouf, 2007) – the belief that schizophrenia is a life-long disabling 'illness'.

The continued discourse that permeated throughout the twentieth century is somewhat surprising when we consider the positive stories of individuals recovering from psychosis and schizophrenia.

Indeed, these stories have been present throughout the history of the mental health system (Ramon, Healy & Renauf, 2007). However it was not until the 1980's that the notion of recovery gained momentum. Individuals started to publish accounts of their recovery highlighting that many go on to enjoy rich, full and meaningful lives (e.g., Deegan, 1988; Unzicker, 1989). Alongside autobiographical accounts, longitudinal and cross-cultural studies of recovery emerged. One of the most widely recognised of these is the Vermont study (Harding, Brooks, Ashikaga, Strauss & Breier, 1987). This study, spanning 20 years, found that 68% of individuals diagnosed with schizophrenia functioned at a level most people would consider 'normal'.

By the end of the 1980's the recovery model began to emerge in response to the growing body of evidence demonstrating the possibility of positive outcomes following a diagnosis of schizophrenia. It was composed of a diverse range of grass-roots service user led groups which upheld four common aims: the right to be recognised as an individual rather than a diagnosis; the right to accurate information and input into their treatment; the need for changes in societal attitudes; and the need for consumer led support groups (Epstein & Olson, 1998). The recovery movement or paradigm increased in momentum in the 1990's as an increasing number of individuals identified themselves as recovered (Bellack, 2006); consumer developed self-help programs were underway (WRAP; Copeland, 1997) and the Hearing Voices Network was established (Downes, 2001). These developments brought about a more positive narrative of recovery following schizophrenia or ROP, both for the individual service user and the services as a whole. Consequently, the Recovery model was integrated into policy and laid the foundations for not simply service delivery change but a cultural shift - as summarised by Tenney (2000) - 'Recovery is no longer the exception. Recovery is the expectation' (p.1439).

1.2.3 EARLY INTERVENTION

As the recovery model gained momentum the manner in which psychosis was treated began to shift. The Northwick Park Study (Johnstone, Crow, Johnson & Macmillan (1986) discovered associations between delays in treatment and disability. Alongside this, evidence emerged in the efficacy of CBT in treating delusions and hallucinations (e.g., Garety, Fowler, Kuipers, Freeman, Dunn, Bebbington, *et al.,* 1997). Studies then emerged which demonstrated the existence of an early window of opportunity - a 'critical period' of between 3-5 years after initial symptoms (Birchwood, 1999; Harrison, 2001). Whereby, the greatest impact could be made during a period of neuronal and psychosocial plasticity (Birchwood, Todd & Jackson, 1998). This contributed to an increased focus on the early stages of psychosis. In 2001, the formation of early psychosis teams was declared "a

priority" for the UK (Department of Health, 2001). This led to Early Intervention Services (EIS) being widely commissioned in England due to the resounding evidence for better outcomes (e.g., Marshall, Lewis, Lockwood, Drake, Jones, Croudace, 2005; Csillag, *et al.* 2015). It is now accepted that intervention in the formative years of the psychotic condition represents good, ethical practice. The provision of early treatment of psychosis is considered a secondary prevention strategy, preventing relapses and reducing the long term impact of the condition (Birchwood, Todd & Jackson, 1998). Early intervention can improve recognition and access to services, accelerate recovery, minimise co-morbidities and further reduce damage caused by psychosis (McGorry & Yung, 2003). As the evidence for the effectiveness of early intervention continues to mount, spending by local and national Government has risen to reflect it (Department of Health, 2011). With the total health service spend on psychosis resting at an estimated £2 billion per year in England alone (Knapp, *et al.* 2014), investment in effective, prompt treatment by local and national government represents good value for money.

1.2.4 'SYMPTOMS' OF PSYCHOSIS

Current conceptualisations of 'Psychosis' convey it not as a diagnosis itself, but rather an experience or 'symptom,' associated with a number of other diagnoses. Experiences of psychosis are defined in the DSM-5 under the chapter "Schizophrenia Spectrum and Other Psychotic Disorders". This title reflects the common association between schizophrenia and the term 'psychosis'. Also included is: schizoaffective disorder; delusional disorder; schizophreniform disorder; brief psychotic disorder; and psychosis not otherwise specified (The Diagnostic and Statistical Manual of Mental Disorders, 5th ed.; DSM-5; American Psychiatric Association, 2013). Please see Appendix B for further details. Symptoms consistent with those experienced in 'psychosis' have also been found in high functioning autism (Skokauskas & Gallagher, 2010), borderline personality disorder (Yee *et al.* 2005), and Post-traumatic stress disorder (PTSD) (Read Van Os, Morrison & Ross, 2005), to name a few. Clearly there is a diverse array of presentations in which psychotic symptoms may form part of the clinical picture.

'Psychosis,' as it is generally conceptualised within mental health services, includes one or more of the following experiences: hearing voices ('hallucinations'); believing things that others find strange ('delusions'); speaking in a way that others find hard to follow ('thought disorder'); and experiencing periods of confusion where the person appears to be out of touch with reality ('acute psychosis') (British Psychological Society, 2014). The above experiences are widely considered the positive psychotic symptoms (Lewine, Fogg & Meltzer, 1983), and can be contrasted with the group of

difficulties labelled negative symptoms (Andreasen, 1982). Negative symptoms represent aspects of the individual's functioning that are diminished in comparison to those who have not experienced psychosis. They can include the following: affective flattening; anhedonia (the diminished ability to experience pleasure or enjoyment); poverty of speech; and diminished volition. About 3 in 100 people will experience a psychotic episode in their lifetime (Perala *et al.,* 2007). Psychotic symptoms have also been found in 5-28% of the general population not requiring nor presenting for treatment (de Leede Smith & Barkus, 2013).

1.2.5 DEFINING RECENT ONSET PSYCHOSIS (ROP)

The term First Episode Psychosis (FEP) is commonly used within EIS and the literature base. However, there is no consensus regarding an operational definition for FEP, and existing diagnostic systems provide little guidance regarding this construct. Difficulties with this term rest largely on what is defined as a discrete 'episode', for example where it starts ('onset') and finishes. A review exploring the use of the term FEP within the literature base highlighted that it typically refers to either: first treatment contact; duration of antipsychotic use; or duration of psychosis (Breitborde, Srihari & Woods, 2009). Each definition is underpinned by differing assumptions and on this basis Breitborde *et al.* (2009) argue the term FEP is misleading. In line with recommendations emerging from this review, the term 'Recent Onset Psychosis' (ROP) is used within this study to more accurately describe the population studied and in recognition that psychotic experiences do not always follow an episodic course (Flaum, Andreasen & Arndt, 1992). The term ROP refers to individuals who have recently experienced the onset of symptoms (e.g. 0-5 years), rather than individuals in the midst of their *first episode*. It is felt that this term more accurately captures the experiences of the cohort under study and whom might access EIS. The term FEP may be used occasionally when referring to studies specifically employing this language so as not to infer meaning, for example in the systematic review.

1.3 RECOVERING FROM PSYCHOSIS

1.3.1. CONCEPTS OF RECOVERY FROM MENTAL 'ILLNESS'

Despite the widespread uptake of the recovery paradigm in research, policy and practice, the term 'recovery' has become subject to multiple meanings in the absence of a universally accepted operationalised term. Fitzpatrick (2002) summarised the recovery models in the literature by describing them as being on a continuum, with three specific positions: the medical model; the rehabilitative model; and the empowerment model. The medical model assumes that the individual

returns to a former state of health with outcomes focused on rates of hospitalisation and medication and remains the dominant view in mental health (Coleman, 1999). Under this definition the individual is deemed recovered when the person is 'cured' and absolved of symptoms (Whitwell, 1999). The rehabilitative model of recovery is increasingly being adopted within services alongside the medical model. It suggests that an individual can return to a semblance of the life they had before the illness (Anthony & Liberman, 1992). Like the medical model this stance assumes the individual will always experience the 'illness' but may learn to 'live well' within the limitations imposed by it. The empowerment model resists the notion of biological causes and instead emphasises the role of severe emotional distress in the face of overwhelming stressors as the cause of 'symptoms' (Fisher, 2003).

Consumer conceptualisations offer different insights into what recovery means for them. Many individuals do not wish to employ the term recovery at all, instead preferring to think of themselves as 'getting on with life' (Tooth *et al*., 2003). Others feel that the terms 'healing' or 'transformation' better align with their experiences of growing through the experience, rather than simply returning to a former state (Prior, 2000; Ralph, 2000). In their 2011 study of consumer accounts of recovery Andresen, Oades & Caputi concluded that the descriptions do not fit flawlessly with any of the above categories. Rather, they describe accounts of individuals who have undergone changes in self-perception, including attitudes towards the illness and life itself.

1.3.2 OVERVIEW OF MODELS OF RECOVERY FROM PSYCHOSIS

Research indicates that recovery from a psychosis is a dynamic, flexible and ongoing process (Anthony, 1993 & May, 2004). Central to this process is the individual (Rogan, 2000) and their subjective experience of it (McGorry, 1992). Therefore, recovery means different things to different people and consequently encompasses a wide range of characteristics and experiences (Kelly & Gamble, 2005). Research on recovery and psychosis has identified a range of influencing factors that ameliorate recovery including: recovery styles (McGlashen, Docerty & Siris, 1976); cognitive appraisals (Jackson, Knott, Skeate & Birchwood, 2004); attitudes (Soskis & Bowers, 1969); and level of insight (Shaw, McFarlane, Booklers & Air, 2002). Although debate is ongoing regarding the goals and the meaning of recovery from psychosis, more recent research has identified dimensions, processes and stages (e.g., Andresen et al., 2003; Noiseux & Ricard, 2008; Jager, Rhodes, Beaven, Holmes, McCabe, Thomas, *et al.* 2015). Meanwhile a systematic review has enabled some conceptual clarity through five categorical themes of recovery processes (e.g., connectedness; hope and optimism about the future; identity; meaning in life; and empowerment; Leamy *et al.,* 2011).

Theoretical models of recovery from a psychosis have focused on the emotional responses to psychosis, assimilation of the psychosis experience; and the rebuilding process.

1.3.3 EMOTIONAL RESPONSES TO PSYCHOSIS

Recovery models of psychosis describe processes akin to trauma theories. In particular, three theories are drawn upon including the theory of information processing (Rachman, 1980), Horowitz stress-response model (1976) and Janoff-Bulman's (1992) shattered assumptions theory (Jackson & Iqbal, 2000). It is suggested that new material from the trauma is integrated, assimilated or worked through during recovery. This allows for new models and representations of the self and world to develop. For example, Janoff Bulman (1992) suggests that individuals hold three types of pre-existing assumptions: assumptions of personal invulnerability; the view of the self as worthy and good; and the perception of the world as meaningful. The event, in this case psychosis, can serve to shatter these assumptions and it is through the struggle to regain a semblance of meaning that one may experience change. Consumer accounts replicate notions of the traumatic nature of a first experience of psychosis (section 1.4.2). Although recovery theories highlight the possible role of trauma, little attention has been paid to possible constructive outcomes (e.g., PTG) resulting from the individual's struggle in overcoming it.

Recovery models suggest that psychosis is a period of significant disruption and crisis. Terms used in the recovery literature to describe the initial experience of psychosis and treatment include: 'overwhelmed by the illness' (Spaniol, Wewiorski, Gagne & Anthony, 2002); 'loss of control' (Williams & Collins, 1999); 'crisis of psychosis'; and 'identity crisis' (Pettie & Triolo, 1999). Emotional responses immediately emerging from this period reflect this and are described as: 'despair/exhaustion' (Jager., *et al.* 2015); despair and anger (Baxter & Diehl, 1998); sealing-over (McGlashen *et al.,* 1976); and denial (Andresen *et al.,* 2003; Baxter & Diehl, 1998). The emotional impact of the immediate crisis is overwhelming and intense, and often prompts self-preservation strategies (e.g., denial and avoidance) which inhibit adaptation in the long-term (Jackson & Iqbal, 2000). These factors are discussed further in section 1.3.4.

1.3.4 DISRUPTION TO SENSE OF SELF

One particularly well documented and distressing aspect of psychosis is the impact on and loss of identity that transpires in the early stages. Disruption to the individual's sense of self following psychosis has manifested in a number of difficulties: disintegration (Williams-Keeler, Milliken & Jones, 1994); uncontrollability of the self; loss of trust in capabilities (Koivisto, Janhonen & Vaisanen, 2003); loss of a 'future self' (Pettie & Triolo, 1999):

> "*My illness eradicated my sense of self, and now I am engaged in the lifelong process of obtaining, maintaining and slowly modifying my sense of who I am. (Anonymous, 1994, p. 25)"*

There are three main positions with regards to the experience of change or loss of the self during psychosis: the 'illness' itself *constitutes* the loss of the self (Pollack, 1989); the loss of self is a *result of the illness* (Charmaz, 1983)*;* or loss of self stems from the 'symptoms' (e.g., delusion or hallucination) which results in the person no longer feeling they can trust his/her own perception (Davidson, 1994). In order to understand the self-disturbance in psychosis, Parnas (2003) identifies three levels of selfhood from a phenomenological perspective. The first level – the pre-reflective level, refers to a first person awareness. For example, the implicit awareness that this is *my* experience. This has been referred to as the basic self. At a more complex level the reflective self-awareness comprehends the self as a persisting subject of experience and action. For example: "my sense of myself as the same person through time". This level of selfhood presupposes the former and provides a sense of temporal unity. Finally, the social or narrative self refers to individual characteristics ascribed to and incorporating what is realised to be the self. For example: "I am a flexible sort of person, often accommodating others needs and this may be related to being the eldest sibling" (Nelson, Fornito, Harrison, Yucel, Sass, Yung *et al.* 2009).

It has been suggested that basic sense of self as described in the phenomenologial psychiatric literature, are more pronounced in ROP clients who present with a schizophrenia spectrum psychosis compared with other psychoses. Schizophrenia it is argued is characterised more by disturbance in the stream of consciousness (cognitive disturbances) and sense of presence (Nelson, Thompson & Yung, 2013). The consumer research appears to strongly indicate the devastation in terms of the *psychosocial* effects of mental illness on the sense of self and identity (Andresen, *et al.* 2011). Erikson (1968) describes the continuity of the self as crucial and that a crisis of identity occurs when a person loses this sense of continuity. He described a person's identity as a 'progressive continuity between that which he has come to be during the long years of childhood, and that which he promises to be in the anticipated future' (p.87).

A ROP can be particularly dramatic as it typically occurs during the formative age of adolescence or early adulthood, when the individual is developing a sense of self and identity - orientating themselves to the world and forming new relationships with others. These processes often occur in the context of developmental tasks and act as an assault on the processes of separating from parents, pursuing occupational aspirations and establishing a crucial and yet still fragile peer network (McGorry & Yung, 2003; Riedesser, 2004).

Kelly & Millward (2004) differentiate between two forms of identity: *the self* which refers to private identity, and *identity* which refers to social identity - or identity as it relates to others. As Charmaz (1983) points out any chronic illness can have an effect on close relationships and educational or occupational aspirations, thus impacting on one's social identity. Yet, perhaps, none more so than psychosis which often brings with it the 'mentally ill' label, thus robbing the individual of their sense of identity as a valued and functioning member of society (Murphy, 1998; Henderson, 2004).

1.3.5 ASSIMILATING THE EXPERIENCE OF PSYCHOSIS

The process of meaning-making appears to be central for many individuals who have experienced an episode of psychosis. Individuals are believed to go through a process of meaning-making during the acute phase and also into the early stages of recovery (Perry, Taylor & Shaw, 2007). This includes for many a re-appraisal in their perception of who they are, who they continue to be and a re-consideration of their attitude towards the 'illness' (Jackson, Edwards, Hulbert & McGorry, 1999). These processes can be paralleled with the meaning-making processes involved in the PTG models (e.g., Park *et al.,* 2010), discussed further in section 1.4.3.

The process of assimilation or meaning-making have been referred to in recovery literature through the following themes: 'living with the disability' (Spaniol *et al.,* 2002); 'struggling with the disability' (Spaniol, *et al.* 2002); 'struggle for control' (Williams & Collins, 1999); 'integration' (McGlashan, *et al.* 1976); 'awakening' (Baxter & Diehl, 1998) and self-awareness (Coleman, 1999). McGlashen (1976) describes an 'integration' recovery style, whereby the individual displays curiosity and acceptance of their experience of psychosis. 'Integrators' examine their experience for meaning and personal significance and they tend to be less fearful of and negative in their perceptions of mental illness in general. In contrast, for those exhibiting a 'sealing-over style' the psychotic experience is considered a 'hole' in the context of meaning that requires sealing over. They deem the experience to not 'fit' their life as they perceive it. As a result they feel powerless to influence the outcome, continuing to interpret the psychosis as an external traumatic event.

McGorry (1992) in particular emphasised the importance of fostering a unique explanatory model to prevent damage to one's sense of self, which he posits to occur when this is intermeshed with the role of the 'psychotic patient'. This, as McGorry (1992) states, is more likely to occur in individuals experiencing their first episode - typically those in their late adolescence to early adulthood, due to their fragile and undeveloped sense of self. The development of an explanation of the 'illness' that is acceptable to one's sense of self is proposed as a vital first step in overcoming the psychosis. Making

sense of it may involve either a 'letting go' of the illness identity or incorporating the illness into a previously held identity and constructing a different 'future self' (Fekete, 2004).

Yanos and colleagues (2010) offer an empirically supported model of 'illness identity' which outlines how an individual makes sense of their diagnosis. The term 'illness identity' is described by Yanos, Roe and Lysaker (2010) as a set of roles and expectations that a person has developed about themselves in relation to their understanding of the 'illness'. The term is primarily influenced by the sociological concept of identity. It refers to social categories employed by a person to describe themselves (e.g., 'patient', 'survivor') in addition to the social categories that others use to describe them (Thoits, 1999). The 'illness identity' notion advances early terms such as 'engulfment' (Lally, 1989) to allow for other ways of making sense of experiencing mental ill health including positively adapted identities. In his landmark paper, Haslam (2014) outlines the clinical relevance of an applied social identity approach. It is argued that social identity matters for health because all humans seek a sense of purpose and self-worth through social connectedness and group life. If social identity makes this possible, then it should clearly be key to psychological integrity (Haslam, *et al.* 2009; Jetten, Haslam & Haslam, 2012). However, little empirical evidence has focused on illness identity in recovery from ROP as conceptualized by Yanos *et al.* (2010).

1.3.5 'REBUILDING' AS AN OUTCOME OF RECOVERY

Recovery theories highlight an outcome stage which is often referred to as a process of 'rebuilding'. It has also been referred to in models as: rebuilding self: moving from withdrawel to engagement (Glover, 2007); active engagement in meaningful activities (Merryman, & Riegel, 2007); discovering keys to well-being (Noiseux & Ricard, 2008); regaining what was lost/moving forward (Young & Ensing, 1999); awakening: building healthy interdependence (Baxter & Diehl, 1998); and living with the disability (Spaniol *et al.* 2000). Andresen *et al.* (2011) describe re-building as the 'action' stage of recovery in which the person makes strides towards rebuilding a meaningful life through occupation or educational tasks, the practice of illness management, and promoting well-being. Andresen *et al* (2011) also include in this stage the concept of 'taking responsibility' characterised by taking small steps, trial and error, perseverance, and hard work.

Davidson and Strauss (1992) focus on 're-building' of the self whereby the person, having tested new-found agency on simple tasks, begins to go about pursuing more value driven and meaningful goals. It is in this manner a person engages and enhances their sense of self. It is proposed that rediscovering one's strengths and values increase development towards a positive identity. Perceptions of personal strength appear to be crucial in this process:

> *"the third and final pillar of my recovery was discovering how to summon my own personal strengths and resources to go back and reclaim my personal voice and keep my place at the table… like professional meetings and social gatherings" (Weingarten, 2005, p.79).*

The process of re-building a secure sense of self has been referred to as: rebuilding self: understanding self and empowerment (Kilbride & Pitt, 2006); rebuilding life: active participation in life and rebuilding social support (Kilbride & Pitt, 2006); developing an integrated self (Baxter & Diehl,1998); discovering the possibility of a more agentic sense of self (Davidson & Strauss, 1992); and establishing an integrated self (Baxter & Diehl, 1998).

A study by Romano and colleagues (2010) found that the recovery process following a ROP involved 'reshaping' a sense of self. This is in contrast to the notion of re-constructing a sense of self as advocated in other models of recovery (e.g. Davidson & Strauss, 1992). The defining feature of this model was that individuals did not re-construct or redefine their sense of self in the context of the 'illness'. Rather, their sense of self endured as they continued to engage in their roles and life goals following the ROP. A similar concept of 're-defining and developing' a sense of self emerged from the study by Laithwaite & Gumley (2008). Participants in this study spoke of the importance of developing trusting relationships and re-building former relationships, as a process towards the re-definition of the self. The authors concluded that past experiences of loss and social fragmentation in relationships influenced tasks involved in their recovery.

1.3.6 'GROWTH' AS AN OUTCOME OF RECOVERY

In the previous section the process of 're-building' was outlined as commonly described by the recovery literature. A further outcome has been identified by a small number of recovery models, which is referred to aspects of 'growth'. This has either been identified as part of the rebuilding process (e.g., in their category 'maintenance and growth', Leamy *et al.,* 2011) or as a further discrete final outcome to recovery. Andresen *et al.* (2003) formulated the discrete final stage of 'growth' as akin to the concept of resilience, which they defined as:

> *"The person may not be free of symptoms completely, but knows how to manage the illness and to stay well. The person is resilient in the face of setbacks, has faith in his or her own ability to pull through and maintains a positive outlook. The person lives a full and meaningful life, and looks forward to the future. He or she has a positive sense of self, feeling that the experience has made them a better person than they might otherwise have been" (pg. 591).*

'Growth' in other models of adaptation from mental illness has been linked to striving for a better quality of life (Young & Ensing, 1999) or the point at which the person 'gains a sense of meaning or purpose in life' (Spaniol, *et al.* 2002). It is argued that the conceptual clarity around the concept of 'growth' in recovery models is lacking. Furthermore, there appears to be some overlap with other concepts, for example: resilience; recovery or self-actualisation (Jordan, Pope, Lambrou *et al.* 2016).

1.4 POST-TRAUMATIC GROWTH (PTG)

This study suggests that Post-traumatic Growth (PTG) may offer a useful framework to widen our understanding of the constructive processes and outcomes following a psychosis. This may provide conceptual clarification to the element of growth that is referenced in recovery models and begin to provide some direction in terms of ameliorating factors involved in constructive change following ROP. Post-traumatic Growth is a relatively new concept in the trauma literature. It recognises the pain that traumatic experiences evoke but provides a way of examining the positive experience and changes in one's life, and one's self that can occur as a result of trauma (Tedeschi & Calhoun, 2004). A re-conceptualisation of responses to the traumatic experience of psychosis to include constructive changes and in particular elements of PTG may contribute to a deeper and multidimensional approach to our understanding of adaptation to psychosis (Anthony, 1993).

1.4.1 CONCEPTS OF POST-TRAUMATIC GROWTH (PTG)

Despite one of the premises of clinical work resting on the promotion of positive adaptation (O'Leary, Adlay & Ickovics, 1998), it was not until the 1980's that researchers began to consider the idea that positive outcomes can arise from devastating events (Joseph, Linley & Harris, 2005). Studies began to emerge reporting positive changes following a range of traumatic experiences, e.g., rape, myocardial infarction, bereavement, natural disasters and combat. However, findings became overshadowed by the topic of PTSD which was introduced by the American Psychiatric Association in 1980 into the field of veteran studies. It was not until the work of Tedeschi and Calhoun (1995) that interest in how trauma can be transformed into a catalyst for positive change was revived. In the subsequent years various descriptions of constructive change following adversity have surfaced in the literature, including but not limited to: 'stress-related growth' (Park & Helgeson, 2006); 'benefit finding' (Davies, Nolen-Hoeksema & Larson, 1998); 'thriving' (O'Leary, 1998); and 'positive psychological changes (Yalom & Lieberman, 1991). This study adopts the PTG definition coined by Tedeschi & Calhoun (1995), which is defined as positive psychological change that results from engaging in the struggle associated with traumatic or highly challenging circumstances (Tedeschi &

Calhoun, 1996). PTG transcends the notion of being damaged by stressful situations, maintaining equilibrium or returning to pre-existing functioning. Instead it refers to a transformation or qualitative change exceeding the level present before the trauma due to a change in the individuals' schemas (Tedeschi & Calhoun, 2004). Positive outcomes following trauma have been identified, including: improved relationships and deeper connections with others who have suffered; a change in self perceptions including greater awareness of new possibilities; and appreciation of personal strength and new priorities (Tedeschi and Calhoun, 1996).

Research suggests that the majority of individuals who experience a trauma will report some degree of positive life change (Frazier &Kaler, 2006). This has been corroborated by studies exploring PTG following a range of adverse life experiences, including: "bereavement, breast cancer, mastectomy, bone marrow disease, heart attack, rheumatoid arthritis, spinal cord injury, multiples sclerosis, shipping disaster, tornado, plane crash, rape, childhood sexual assault, incest, shooting, HIV, infertility, chemical dependency, military combat and bombing" (Joseph, Linley & Harris, 2005, pp. 263-264). It is somewhat surprising then that limited attention has been given to PTG following psychosis given the evidence detailed above of the highly distressing nature of this experience. Perhaps the long tradition of the deficit orientation and current focus on neurobiological and imaging techniques in psychiatric research might be responsible for the lack of scientific interest in PTG following ROP. This is despite the gaining momentum of PTG as an explanatory model within other fields.

1.4.2 TRAUMATIC EVENTS AND 'PSYCHOSIS'

Many attempts have been initiated to unravel the seemingly complex interrelationships between trauma, Post-traumatic Stress Disorder (PTSD) and psychosis (Morrison, Frame and Larkin, 2003). Among individuals diagnosed with a psychosis rates of PTSD are estimated to be as high as one in three (Jackson, Knott, Skeate, & Birchwood, 2004; Tarrier, Khan, Cater, & Picken, 2007). The existing literature exploring the relationship between PTSD and psychosis centers around three hypotheses. These include the beliefs that: psychosis is misclassified as PTSD (Rosenberg *et al.* 2001); psychotic and PTSD 'symptoms' arise from shared social risk factors (Brewin, Andrews & Valentine, 2000; Morgan & Fisher, 2007); and PTSD is a response to the trauma of the psychosis and treatment experiences themselves (Berry, Ford, Jellicoe-Jones & Haddock, 2015). With the latter in mind, it has been suggested that the experience of a psychotic episode and its treatment, can be so traumatic that up to one in two people report post-traumatic symptoms or disorder as a consequence (Jackson et al., 2004; McGorry et al., 1991; Mueser et al., 2010; Tarrier, Khan, Cater & Picken, 2007).

The psychotic experience does not meet criterion A for of the DSM-5 for a diagnosis of PTSD - which requires an objective direct or indirect experience of death, threatened death or serious injury to potentiate a diagnosis of PTSD. Some researchers argue the symptoms of psychosis are difficult to disentangle from those in PTSD, thus making attributions of causality particularly problematic. Yet, despite these arguments, a growing number of researchers have proposed the experience of psychosis itself could be conceptualized as a traumatic event, associated with the development of PTSD (Bendall, McGorry & Krstev, 2006) Indeed consumer accounts abound with what has been termed 'psychosis-related PTSD' and 'hospital-related PTSD' which has been found to be as high as 30% (Berry, *et al.* 2015).

> *'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).*

The evidence suggests then that framing ROP in a trauma framework may better reflect individual's experience. Research has addressed some elements of this, for example the co-occurrence of trauma and psychosis including PTSD as a possible outcome of the trauma of psychosis. However, to date there remains very little exploring possible constructive change or PTG as it is defined within this study. An outline of the PTG model is presented below to provide background for how one might study the process of PTG following a ROP.

1.4.3 MODELS OF POST-TRAUMATIC GROWTH (PTG)

Various models have been developed to describe PTG. Park and Helgeson (2006) question if PTG is best understood as an outcome or process. Models have attempted to answer this question (Bhushan & Hussain, 2007; Zoellner & Maercker, 2006; Joseph & Linley, 2006). There remains no consensus regarding this matter, however outcome models are most widely accepted in the literature due to their comprehensive nature (Park & Helgeson, 2006; Tedeschi & Calhoun, 2004). These models emphasise PTG as an end to itself, whilst also acknowledging the process that contributes to its development. A brief overview of three predominant models in the literature is provided below. For a more comprehensive overview the reader is directed to: Zoellner and Maercker (2006); Bhushan and Hussain (2007); and Joseph and Linley (2006).

Schaefer and Moos' model of life crisis and personal growth (1992, 1998) is perhaps one of the earliest models accounting for PTG. The model stipulates that personal and environmental systems influence the experience of the life crisis in the aftermath of trauma. This in turn affects cognitive reappraisals and coping responses resulting in positive outcomes. The model of 'thriving' later developed by O'Leary and Ickovis (1995) emphasised the "value added" aspect of their theory. The term 'thriving' was used in this model to suggest that individuals go beyond surviving or recovering from trauma to thrive. The term is suggested to be preferable to 'recovery' which indicates a return to pre-trauma levels of functioning. The authors of this model stipulate that thriving is dependent on environmental and personal characteristics.

A socio-cognitive model developed by Joseph & Linley (2005; 2006; 2008a; 2008b) took a somewhat different stance to the previous models. It was suggested that people are inherently growth oriented and naturally grow towards their ideal path to personal well-being. Similar to other models in the literature however they propose that individuals have a tendency towards integrating trauma-related information as it is either assimilated (trauma information is 'fit' within pre-existing assumptions) or accommodated (pre-existing assumptions are changed to accommodate trauma related information) by the individual (Joseph & Linley, 2008b).

1.4.4 REVISED MODEL OF PTG (TEDESCHI & CALHOUN: 2004; 2006)

Tedeschi and Calhoun's model is the most empirically supported model of PTG and therefore has become the most widely used. It is described as the most comprehensive and established model to date (Joseph & Linley, 2006; Park & Helgeson, 2006). Tedeschi and Calhoun's conceptualisation of 'trauma' is not restricted by the content or type of event (Christopher, 2004), but allows for an appreciation of the subjective experience (Linley & Joseph, 2004). In this way, what is considered 'trauma' is not limited by set criteria, as is the case for a diagnosis of PTSD. They defined the 'trauma' as a 'highly challenging life circumstances' which serve to challenge one's past ways of understanding the world and one's position within it (Tedeschi & Calhoun, 1999).

Tedeschi and Calhoun argued that the term PTG was preferable to other definitions used in the literature, on the basis that it refers to crisis as opposed to stress. This is pertinent when applying to the experience of ROP which (as has been presented above) is described by consumers as a life shattering and devastating crisis. The concept of PTG also signifies a significant threat required to shatter one's fundamental beliefs in a way that the terms 'thriving' and 'positive psychological

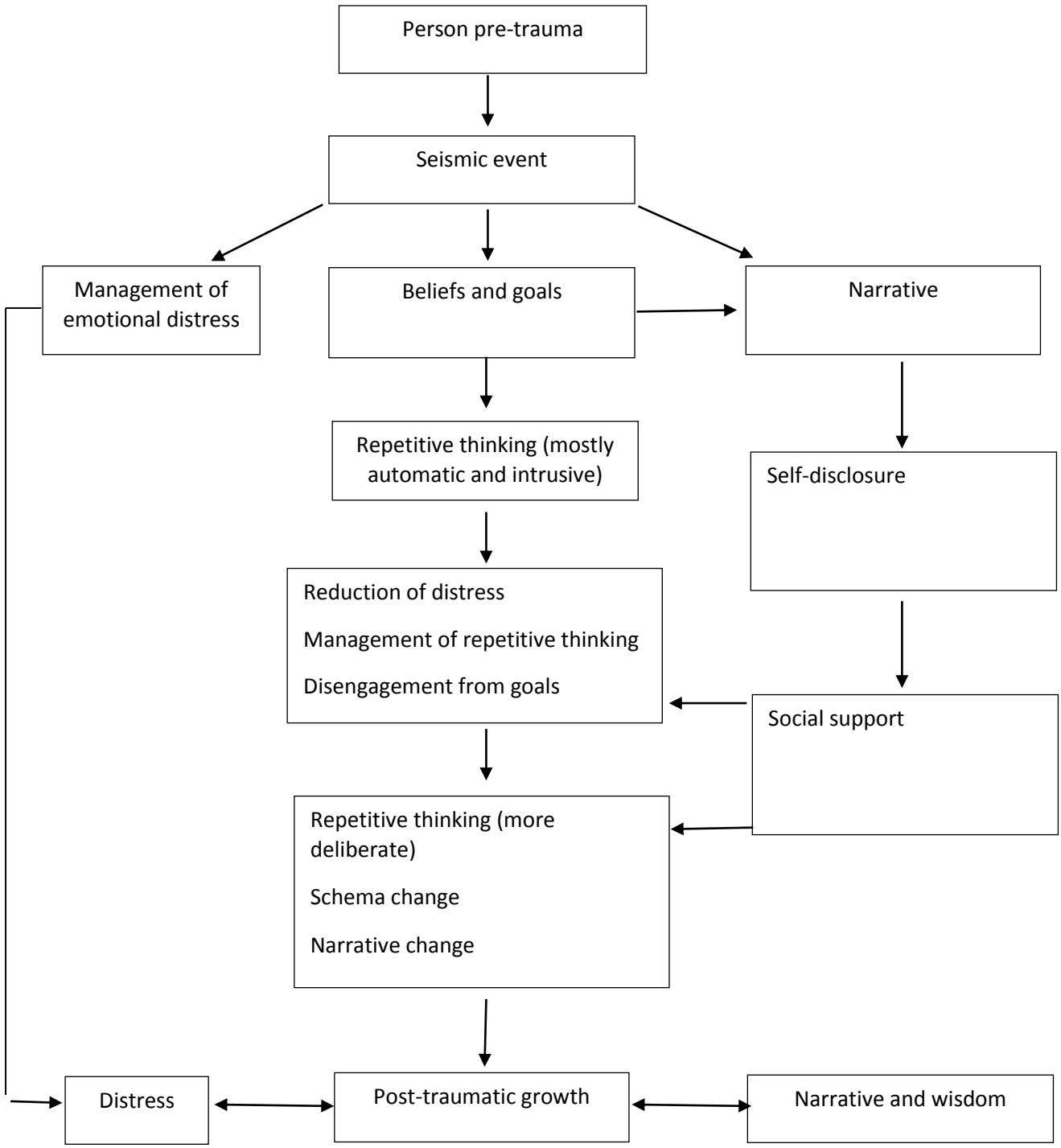
change' do not. For these reasons this study employs the conceptualisation of PTG coined by Tedeschi & Calhoun (1999). Tedeschi & Calhoun (1999) believe the nature of the trauma - in respect to whether it is acute or chronic – does not significantly impinge on the development of growth. This position has been corroborated by research (e.g., Park, Cohen & Murch., 1996). This point is applicable to the experience of psychosis, as although the immediate onset is described as a 'crisis' the trauma is ongoing due to invasive treatments. In these two ways, psychosis is a very different experience to those managed routinely in mental healthcare.

1.4.5 THE DEVELOPMENT OF PTG (TEDESHI & CALHOUN, 2004; 2006)

Tedeschi and Calhoun suggest that trauma challenges an individual's assumptions and beliefs (Janoff-Bulman, 1992) and it is through grappling with the trauma and a new reality that PTG occurs. It is suggested that permitting the trauma to have an impact rather than avoiding the associated distressing aspects is critical in the development of PTG. The degree of direct confrontation with the trauma should however also allow for some distance so that the individual can engage in reconstructing meaning within a reflective space. The immediate distress of the trauma challenges one's ability to manage emotional distress, beliefs, goals and life narrative. Central to the model is the cognitive processing that the individual then engages in, including positive, neutral and negative cognitions, involving deliberate and thoughtful reflection about the event (Tesdechi & Calhoun, 1996).

The model posits that the likelihood of PTG is increased with the degree of cognitive processing focused on: recalling positive pre-trauma experiences and how one will cope and make meaning of their experience. To aid with cognitive processing, self-disclosure and social support are advantageous. This has been supported by quantitative research suggesting that high self-disclosure and low reluctance to talk were significantly related to high PTG following a FEP (Pietruch & Jobson, 2012). The model goes on to suggest that schemas are amended as the trauma is accepted and one's goals for the future are amended in light of the trauma. The final stage of the model sees the stabilisation of the positive effects of growth which has a mutual influence on the development of wisdom and emergence of a new life narrative which includes the traumatic event and manifestation of the effective behaviour (Tedeschi and Calhoun, 2004). The process of PTG as suggested by Tedeschi and Calhoun (2006) is presented in diagrammatic format below.

Figure 1. The development of Post-traumatic growth (Adapted from Calhoun & Tedeshi, 2006, p, 8)



1.4.6 POST-TRAUMATIC GROWTH AS AN OUTCOME (TEDESCHI & CALHOUN, 2004; 2006)

Tedeschi and Calhoun highlight the multidimensional nature of PTG. Growth may be experienced in one single domain or in multiple. The individual may also experience no change in others. Additionally, it is noted that there may be different processes for each domain of growth or other factors may play a role. Five specific domains are identified within this model and in the trauma literature more generally (Taku, Cann, Calhoun & Tedeschi, 2008). These are outlined below:

1. *Greater appreciation of life and changed priorities:* The cognitive reconstruction due to the confrontation with trauma prompts the individual to consider perceptions of vulnerability due to the realisation that they can not predict or control certain events (Calhoun & Tedeschi, 2001). Thoughts about the volatility of life contribute to a shift in importance ascribed to certain events. Attention is paid to things that otherwise were not considered important, thus resulting in a change of priorities and a greater appreciation of life (Lindstron, Cann, Calhoun & Tedeschi, 2013).

2. *Warmer, more intimate relationships with others:* Through attempts to understand and manage the stress and loss incurred from the trauma, support from others is harnessed (Tedeschi & Calhoun, 1996). The process of self-disclosure may result in increased emotional connection with others in addition to feelings of closeness in interpersonal relationships (Tedeschi & Calhoun, 1996, 2004). This may reinforce acceptance of help from others increasing social networks and/or investment in new ones (Calhoun & Tedeschi, 2001). Tedeschi & Calhoun (2004) suggest that increases in reflexive thinking about relationships may result in more meaningful relationships, while others may weaken or end.

3. *A greater sense of personal strength:* Recognition of more capabilities to manage future adversities and challenges foster perceptions of greater individual strength (Tedeschi & Calhoun, 2004). Following the traumatic event the individual comes to recognise the self as having more skills and strengths, compared to before the trauma (Lindstrom, Cann, Calhoun & Tedeschi, 2013). Perceptions of increased vulnerability may however persist alongside (Tedeschi & Calhoun, 2004).

4. *Spiritual development:* The trauma prompts the individual to re-assess beliefs held about the world and within this their spiritual or religious beliefs. Calhoun & Tedeschi (2004) suggest that the persons' belief in a higher entity may increase after the trauma and contribute as a

coping mechanism, particularly in the cognitive process of finding meaning (Calhoun & Tedechi, 2001). For others, PTG may be experienced in a spiritual domain without necessarily having any relevance to religious beliefs.

1.4.7 CRITIQUE OF PTG MODELS

The question of the relationship between PTG and well-being has led some to debate whether growth constitutes a change in 'real' terms or rather represents a 'positive illusion' (Zoellner & Maercker, 2006). Previous empirical work has found little evidence for objective growth (Frazier & Kaler, 2006) and suggests that growth is related to perceptions that the past was worse than it is (McFarland & Alvaro, 2000). Contrary to this, researchers have identified growth as being independent of social desirability (Wild & Paivio, 2003) and impression management (Weinrib, Rothrock, Johnson & Lutgendorf, 2006) through drawing evidence from neurological experiments (Rabe, Zoellner, Maercker & Karl, 2006). In an attempt to align these two opposing positions the Janus Face Model (Maercker & Zoellner, 2004) posits that objective constructive change and illusory growth co-exist. It may be that *beliefs* about growth are more important in understanding their psychological experience than whether or not their experience is supported by objective measures (Park & Helgeson, 2006). 'Illusory growth' may in itself lead to later actual change (Park & Helgeson, 2006). In line with a constructivist methodology this study is concerned with self-perceptions of growth as opposed to verifiable objective growth.

Researchers have critiqued measures of PTG in their failure to account for depreciation (Tomich & Helgeson, 2004; Park & Lechner, 2006). The effect of failing to account for negative change may inadvertently lead to overly positive self-reports (Tedeschi & Calhoun, 1996). In addition, attention should be paid to the negative changes to fully account for the psychological distress that trauma survivors experience. Indeed the positive and negative sequelae following trauma are not likely to be mutually exclusive (Keane, Marshall & Taft, 2006; Park & Lechner, 2006). While the presence of growth and depreciation existing in the same domain seems paradoxical, research has consistently found this to be the case (Park & Lechner, 2006; Taku, *et al.* 2008; Morris, Shakespeare-Finch, Rieck & Newbery, 2005).

1.4.8 CLINICAL UTILITY OF PTG

The notions of PTG following a ROP may have considerable clinical implications, for example in informing the development of psychological well-being and capacity to cope (Tedeschi *et al.* 1999).

Well-being and adjustment are not being necessarily directly related to growth (Park & Helgeson, 2006; Tedeschi & Calhoun, 1999) and PTG is not considered a coping strategy of itself (Tedeschi, 1999). Yet the cognitive strategies promoted by Tedeschi & Calhoun's PTG model (2006) such as focusing on positive appraisals, finding meaning in the trauma and understanding the experience as one that can be mastered are related to positive adaptation (Schaefer & Moos, 1998). Not only could the development of constructive changes serve helpful in managing the crises but may also aid the individual to manage future episodes. Furthermore, facilitating growth may reduce other secondary difficulties pertinent to this population, for example PTG is associated with positive mood (Park & Fenster, 2004; Weinrib *et al.,* 2006) and lower level of substance misuse (Milam, *et al.* 2004). Perhaps of most significance however is that through striving for PTG, and working through the associated processes (e.g. repetitive thinking and integration) the trauma of the ROP is recognised and 'worked through'. This could potentially substantially decrease secondary effects of ROP. The clinical value of PTG to ROP is explored in further detail in Chapter 4.

1.5 SYSTEMATIC REVIEW

Chapter 1 thus far has presented background to the topic of psychosis. The reader has been invited to consider the immediate impact of ROP including the threat to one sense of self and the following 'recovery' processes and outcomes. Models of recovery were considered and critiqued. It is suggested that a re-conceptualisation of adaptation to ROP, to include constructive change may contribute to a deeper and much needed multidimensional approach (Anthony, 1993). An attempt here is made to systematically review the research pertaining specifically to self-perceptions of PTG following a psychosis. A systematic review sources peer reviewed literature that is considered to meet a high level of methodological rigour and synthesises it by using a structured and critical process, as outlined in the following sections.

The first scoping review to explore PTG following First Episode Psychosis (FEP) was published very recently (18th May 2016). The following themes emerged: greater empathy maturity and resilience; making positive lifestyle changes; stronger connection with family and wiser understanding of friendship; greater religiosity and appreciation of life; and integration of the psychotic experience in to the self. This review conducted by Jordan, Pope, Lambrou, *et al.* (2016) took a broad approach to the search. They concluded that there is a paucity in articles describing positive outcomes from psychosis. In addition the majority of studies retrieved were embedded in the recovery literature. This meant that it was unclear whether the positive outcomes were illusory or reflecting other constructs such as resilience or coping.

Findings derived from scoping reviews should be interpreted with caution. As is the case with many of these reviews quality assessment of included articles is infrequently performed (Pham *et al,* 2014). Indeed the review by Jordan *et al.* (2016) failed to perform a quality assessment which brings into question the rigour of the studies included and hence the trustworthiness of conclusions drawn from this review. Daudt *et al.* (2013) highlighted the need for all reviews including scoping reviews to assess the quality of included studies using validated tools. This is likely to increase transparency, clarity and ultimately rigour of findings. The current review attempts to systematically review the literature pertaining to PTG and psychosis using a valid and reliable measure of quality assessment.

1.5.1 REVIEW STATEMENT OF FOCUS

This study seeks to explore elements of self-reported PTG following ROP including how this is experienced by the individual and the proposed underlying psychological mechanisms. A secondary aim relates to an exploration of the relationship between PTG and sense of self. An initial scoping of the literature rendered very few studies which examined PTG and sense of self *following* a psychosis. Rather the literature to date focused on the diagnosis of schizophrenia and deficits in sense of self during the acute phase. Therefore, the research statement was broadened (as below) to include a consideration of the overall PTG following a psychosis. In addition, due to the paucity of research in this area, the studies were not limited to those specifically using samples for whom it is a ROP. However time since first episode will be accounted for in the results and any differences/similarities based on this trend will be observed.

Does PTG have any relevance to a change in sense of self and self perceptions of change following a recent onset psychosis?

1.5.2 REVIEW METHODOLOGY

A number of procedures were used to conduct the systematic review. An initial search of major databases using OVID included searches of OVID Medline, PsychARTICLES Full Text, EMBASE, and PsycINFO. The following search terms, associated variants and Boolean operators were applied: (qualitative OR “grounded theory” OR “interpretative phenomenological analysis" OR narrative* OR thematic OR “repertory grid”) *AND* (psychosis OR schizophreni* OR voice) *AND* (Post-traumatic OR post-traumatic OR stress-related OR transform* OR thriv* OR flourish*). The terms were searched as

key words and applied to the abstracts of generated articles. A time period was applied between 1990 to current so that the most relevant articles could be retrieved. From 1990 onward the literature started to include notions of recovery rather than a focus on the debilitating sequela, which is abundant in the literature prior to this time. The search strategy has been diagrammatically summarised in Appendix C.

The search of the OVID database was completed on the 8th May 2016. Further searches were made using ProQuest, CINAHL and Scopus database on the 9th May. A total of 1184 hits were generated from these searches. In order to identify any 'grey' literature, a search of 'Google' and 'Google Scholar' in addition to articles produced by third sector organisations and professional societies (e.g. Young Minds, Hearing Voices, Mind Rethink) were reviewed but excluded due to not being published within peer reviewed journals. Academic journals relating specifically to the research into psychosis, namely 'Psychosis: Psychological, Social and Integrative Approaches' and 'Schizophrenia Bulletin', were also searched. The references from a key systematic review and textbooks exploring the literature pertaining to recovery more broadly were screened (O'Leamy *et al.* 2011; Andresen, Oades & Caputi, 2011; Williams, 2015). Key authors were contacted via email as were authors of recent dissertations to ascertain if any peer-reviewed work was in press.

All articles were manually reviewed for suitability. Titles, abstracts and later whole articles were screened for their accordance to the following inclusion and exclusion criteria. The vast majority of the 1184 articles were excluded at the initial stages of reviewing titles and abstracts (see Appendix C) as they were irrelevant to the thesis aims. The remaining 43 articles were reviewed against the following inclusion and exclusion criteria.

1.5.3 INCLUSION AND EXCLUSION CRITERIA

- *Qualitative studies exploring individuals' experience. Studies utilising mixed methods were included in the review, however only the qualitative component of the study was subject to quality review.*

It has been suggested throughout the literature that a qualitative approach is best suited to develop an improved appreciation of the complex individual, social and cultural influence on an individuals' experience of psychosis (Romano, *et al.* 2010). By exploring only qualitative studies in this review, the author seeks to allow a rich understanding of PTG to be emergent. This is in line with the underlying philosophy of the study's methodology - to avoid the imparting of meaning through psychometric tools, theories/models and statistical analysis. This may be particularly important at

this stage where little empirical research is available with regards to PTG following ROP. An exception has been made to include studies which employ repertory grid interviewing techniques, as unlike quantitative research, it is not the investigator but the participant who provides the constructs to be analysed and therefore it is they whom impart the meaning on the items.

- *Studies in which participants considered themselves to have experienced an episode of psychosis (e.g. episodes of delusional beliefs, auditory or visual hallucinations and or disordered thoughts).*

The author is aware of nosological debates particularly surrounding constructs such as 'psychosis' and 'schizophrenia' and the validity of these terms (BPS, 2014). Therefore, participants were not necessarily required to have a diagnosis. However, to ensure that they were exhibiting the experiences under study, each study was screened and included only if all of the participants: were receiving or previously received care from an Early Intervention Service (EIS) for psychosis; self-identified as having at least one or more symptoms as outlined in Appendix B (DSM-5 criteria); were receiving medication for the treatment of psychosis; or had received a diagnosis.

Studies were excluded where individuals were not over the age of 18. Although the recent changes to the way in which EIS in Wales are organised means that they now support those from the age of 14, this study pertained to the experiences of adults. It is suggested that adolescent onset psychosis may present with a different clinical presentation to adult onset (Ballageer, Malla, Manchanda, Takhar & Haricharan, 2005). For pragmatic reasons studies in languages other than English were also excluded. Furthermore, papers that had not been published in peer review journals (e.g., dissertations, conference and government papers) were not included.

1.5.4 REVIEW RESULTS AND QUALITY FRAMEWORK

After applying the above criteria a total of 10 articles were retained for review and were included in the quality appraisal. In performing a critique one can draw conclusions in relation to the systematic review question with increased confidence based on the findings from studies with adequate rigour. The application of what constitutes 'quality' in qualitative research is however contested (May and Pope, 2000). The reason for such debate lies predominantly in the wide ranging epistemological philosophies that inform a multitude of qualitative approaches. Despite the epistemological counterarguments, there has continued to be a call for the development of frameworks that ascertain the quality of qualitative research. This has been emphasised by the societal move towards

evidence-based medicine, which emphasises the need for policy and practice to be informed by 'robust' and 'credible' research (Pope, 2003).

Although there is no standardised tool, various checklists have been developed for this purpose (e.g. CASP, 2010; Elliott *et al.* 1999; Law *et al.* 1999; Spencer *et al.*2003; Tracy, 2010). Following a review of available evaluation tools the author adopted the Critical Appraisals Skills Programme (CASP) framework. The framework has been developed and tested over time and is recommended for use within the NHS (Campbell *et al.* 2011). It is considered a robust framework by which to assess the validity and usefulness of qualitative and quantitative studies for synthesis (Khakbazan, et al., 2014). The tool is concerned with three main areas issues; 1) Rigour: has a thorough and appropriate approach been applied to key research findings in the study? 2) Credibility: are the findings well-presented and meaningful? 3) Relevance: how meaningful are the findings?

The tool explores these three issues systematically through consideration of 10 questions with 34 prompts in total (CASP, 2013). Using this framework each study was examined and the extent to which it met each of the 10 questions was recorded using a scoring system. The use of a scoring system has been suggested as a useful means of contrasting the quality of studies (Chenail, 2011). The following scoring system was applied to each question:

0 A score of 0 indicated that the reviewer judged the study to have given little or no consideration to the domain in question, or there were significant limitations to outcomes within the domain.

1 A score of 1 indicated that the reviewer felt that the author answered some elements of the domain in hand but there remained limitations and uncertainties.

2 A score of 2 indicated that the author covered issues in the domain in a clear and robust fashion.

The critique of the papers is presented in table format below. Scores in each of the 10 domains are added to provide an overall 'quality' score out of a total of 20. Despite the drive for a systematic approach to the critique, it is understood that the review of literature remains to some extent influenced by the reviewers' judgement and it is possible that another reviewer may ascribe different scores. However, it is hoped that the process remains clear and transparent by providing a clear rationale and description of the basis on which scores have been deduced (outlined in Appendix E). A narrative account and critical appraisal of the study's findings follow.

Table 1: Summary of scores ascribed to each study as defined by the CASP

CASP CRITERIA	**Connell *et al.* (2015a)**	**Connell *et al.* (2015b)**	**Waite *et al.* (2015)**	**Jager *et al.* (2015)**	**Dunkley & Bates**	**Mapplebeck,*et al.***	**Nixon *et al.* (2010)**	**Dunkley *et al.* (2007)**	**Thornhill *et al.***	**Barker *et al.* (2001)**
Clear statement of the aims of the research?	2	2	2	2	2	2	2	2	2	2
Is a qualitative methodology appropriate to aims?	2	2	2	2	2	2	2	2	2	2
Research design appropriate to aims?	2	2	2	2	2	2	2	2	2	2
Recruitment strategy appropriate to aims ?	2	1	2	2	1	1	1	1	1	1
Data collection applicable and sufficient?	2	2	2	2	1	1	1	2	2	1
Issues of reflexivity considered?	0	0	2	1	1	0	0	0	2	2
Ethical issues addressed sufficiently?	2	2	2	2	2	2	2	1	1	1
Data analysis sufficiently rigorous?	1	1	2	1	1	1	1	1	2	2
Clear statement of findings?	2	2	2	2	2	1	1	1	2	2
Is the research of value?	2	2	2	2	1	1	1	1	2	2
TOTAL	17	16	20	18	16	16	13	13	18	17

1.5.5 RESEARCH AIMS AND DESIGN

Research aims varied between the studies. Two studies explore recovery in general (e.g., Thornhill *et al.,* 2004; Jager *et al.,* 2015) and a further two focused on aspects of recovery in terms of identity or sense of self and internal relationships e.g. self-criticism and self-compassion (Connell *et al.* 2015a; Connell *et al.* 2015b; Waite *et al.* 2015). One study (Barker *et al.,* 2001) aimed to explore the development of psychosis and the impact on sense of self. Two studies (Dunkley & Bates, 2007; Mappelbeck *et al.,* 2015) developed on the pilot study by Dunkley *et al.* (2007) and explored PTG following FEP. One study focused exclusively on the experiences of individuals who had experience a spiritual transformation (Nixon *et al.,* 2010).

A strength of the studies making up this review was the clarity of the expression of their aims and rationale, and the way in which these were cross referenced with the evidence base. The majority of

the authors justified their choice of a qualitative methodology because of the paucity of previous research in this area and because qualitative methods can generate rich data which in turn can produce new understandings and be used for hypothesis generation (Willig, 2008). The exception is the study by Dunkley, Bates, Findlay & Foulds (2007) which utilised a case study approach but failed to make the case as to how this method was suited to their research question. This appears particularly troublesome when using a case study approach which has sometimes been criticised for lacking scientific rigour (Yin, 2009).

1.5.6 SAMPLING

Four of the studies were conducted with a UK population. The majority of participants across the studies presented with a diagnosis of schizophrenia and one study focused on the experience of 'voice-hearing' in the context of psychosis. Three studies also explored the perceptions of significant others (Dunkley *et al*., 2007; Dunkley & Bates, 2015; Barker *et al*., 2001), for the purpose of data triangulation. A mean of 10.1 participants were recruited across the 10 studies. Ages ranged from 18-68 with the majority of participants being under the age of 35 which reflected a focus on the experience of a ROP (e.g., Connell, Schweitzer & King, 2015a; Connell, Schweitzer & King, 2015b; Dunkley, Glen & Bates, 2015). One study (Nixon *et al.,* 2010) recruited participants with five years following the onset of the psychosis. The notion of 'acceptable sample size' is nuanced in qualitative data. Some authors have suggested it is dependent on many different factors, for example: quality of the data; scope of the study; and the qualitative method and study design used (Morse, 2003). O'Reilly and Parker (2013) argue that saturation is used as a 'marker for sampling adequacy' within some qualitative methods. They go on to elaborate: *"saturation does not refer to the point at which no new ideas emerge, but rather means that categories are fully accounted for, the variability among them explained and the relationships between them are tested and validated"* (Green and Thorogood, 2004)" Cited in (O'Reilly and Parker 2013, p. 3). A sample of between 8 and 12 participants has been estimated as being a sufficient to conduct grounded theory (Dey, 1999). The study by Barker *et al.,* (2001) lies within the lower end of this range (8 participants) and consistent with the others studies reviewed, they do not detail their point of saturation so it is not possible to use this as a marker of appropriate sample size. Two studies (Dunkley *et al.,* 2015; Mapplebeck *et al.,* 2015) recruited a sample of 6 participants and used interpretative phenomenological analysis (IPA) methodology which emphasises that homogeneity is more important (Reid, Flowers & Larkin, 2005; Smith, Flowers & Larkin, 2009).

All studies used either purposive or convenience sampling. Purposive sampling allows for the selection of the most applicable sample in relation to the research question, but also increases the

probability of researcher bias. For example, through disproportionate attention to hypotheses developed *a priori*. This limitation could be compounded further by the lack of reflexivity present within the studies. Although in line the research aims, Nixon *et al.* (2010) recruited only those who considered themselves to be at a higher level of functioning than their pre-psychotic level. This could lead to those Individuals with less extreme views, or not experiencing any change being overlooked. Potential for bias in this study was further exacerbated by the lack of information regarding non-respondents. Two further studies recruited through a support group and Hearing Voices Network (HVN) (Jager *et al.* 2015; Mappelbeck, 2015). A selection bias may be more likely when recruiting through such groups due to the recovery status and the added potential that their stories were influenced by a group narrative.

1.5.7 ETHICAL CONSIDERATION AND DATA COLLECTION

The majority of the studies adequately considered ethical processes and associated issues of consent and confidentiality. However, three studies failed to comment on whether ethical approval had been obtained (e.g., Barker *et al.,* 2001; Dunkley *et al.,* 2007; Thornhill *et al.* 2004). Data collection processes were generally transparent, with the majority of studies providing detailed accounts of the content and procedure used in the interviews. Two studies (e.g., Barker *et al.,* 2001; Dunkley; Bates & Findlay, 2013) disclosed that modifications were made to the interview schedule based on findings from a pilot interview. The main limitation for many studies was the lack of discussion around the saturation of data, where this was applicable to the research methodology. Reference to the quality of the data gathered within the interviews is largely absent, with the exception of one study (Dunkley *et al.,* 2015). This is somewhat surprising given the acknowledgement of metacognitive difficulties (MacBeth *et al.,* 2014) and problems with autobiographical memory (Wood, Brewlin & McLeod, 2006) typically displayed by those who have experienced a psychosis.

1.5.8 REFLEXIVITY

Issues of reflexivity represented a significant area of weakness. This is at odds with the key sentiment that is typically upheld by qualitative researchers who strive for “a methodologically self-critical account” of how the research was completed (Richardson, 2000). Only four out of the ten articles provided sufficient consideration of the researcher’s position, potential bias and the use of reflexivity to minimise this (Waite, Knight & Lee, 2015; Thornhill *et al.* 2004; Barker *et al., 2001;* Mapplebeck *et al.,* 2015). This calls into question the reliability of results, particularly given the centrality of reflexive processes in relation to research rigour.

1.5.9 DATA ANALYSIS, FINDINGS AND LIMITATIONS

The studies all involved data collection via tape recorded and transcribed individual interviews. Six of the ten studies used IPA (Dunkley & Bates, 2015; Nixon *et al.,* 2010; Mapplebeck et al., 2015; Connell *et al.,* 2015a; Connell *et al.* 2015b; Waite *et al.* 2015), two narrative analysis (Jager *et al.* 2015; Thornhill *et al*., 2004); one used grounded theory (Barker *et al*., 2001) and one unspecified 'thematic analysis' (Dunkley *et al.* 2007). While all of the studies provided sufficient data to support the emergent themes, studies varied in the level of specification of the analysis process. A significant limitation across the studies in terms of data analysis was the lack of consideration of researcher bias. Mappelbeck (2015) describes the use of a reflexive diary, audit trail and respondent validity. Additionally, the authors describe the process of validation of emerging themes and the Inter-rater reliability of data assigned to particular analytic categories.

A similarly robust consideration of researcher bias was offered by Waite *et al.,* (2015) Connell *et al., (*2015a); and Connell *et al.,* (2015b). Studies demonstrating less credibility include: Dunkley *et al*., (2015); Thornhill *et al., (*2004); Dunkley *et al.*, (2007); Nixon, et al., (2010). Dunkley *et al.,* (2007) discuss a 'checking-in' process to ensure that understanding of the participants' responses was accurate but failed to provide a description of what this entailed. Limitations were acknowledged in the studies regarding: lack of objective validation of accounts of growth (Mappelbeck, 2015); issues related to causality (Waite *et al.,* 2015); heterogeneity of sample (Waite *et al.,* 2015); capacity of participants to provide in-depth accounts (Dunkley & Bates, 2015) and bias in participant selection strategies (e.g., Jager *et al.,* 2015; Connell *et al.,* 2015). Some studies noted the small sample sizes as a potential limitation (e.g., Nixon *et al.,* 2010), however sample sizes in these studies were suitable in relation to the study design. Many of the studies failed to recruit or to exclusively study the experiences of individuals from minority ethnic groups. Under-representation of ethnic minority groups in health research affects not just the generalisability of study findings but can ultimately contribute to inequities in access to healthcare (Macneill, Nwokoro, Griffiths, Grigg & Seale, 2013).

Three papers (Mappelbeck, 2015; Barker *et al.,* 2001; Jager *et al.,* 2015) discuss the impact of relying on retrospective accounts of change after a psychosis. Previous studies have found that the accuracy of self-reported trauma in people with psychosis may be affected by confusion secondary to their experience of intrusive delusions associated with their condition (Tarrier, 2005). Two studies sought to address this via a longitudinal design. The studies (Connell, 2015b; Dunkley & Bates, 2015) assumed a period of early adjustment (Brunet, Birchwood, Upthegrove, Michail & Ross 2012) for example, between 1-3 months and 3-6 months respectively. This period of time is questionable in

terms of the gestation of PTG following closely from a psychosis (Brunet *et al.* 2012). The validity of the concept of PTG can itself be questioned as it remains unclear whether it represents 'real' change or positive illusion (Park & Helgeson, 2006), and in order to address this, some studies used informants as a way to triangulate participants' accounts (Barker *et al.* 2001; Dunkley, 2015; Dunkley *et al.* 2007). However this debate may be somewhat artificial. It has been argued that it is people's *belief's* about growth that are important in understanding their psychological experience more so than if their perceptions are supported by objective measures (Park & Helgeson, 2006) or 'verified' by the corroboration of others.

1.5.10 QUALITY ISSUES SUMMARY

The quality of the research identified in the search is somewhat variable with CASP scores ranging from 13-20. Although there is no set cut-off in relation to what is considered 'acceptable' quality in the CASP framework, it is recognised that excluding studies judged to be of 'poor quality' from further discussion is recommended. One study (Dunkley *et al.,* 2007*)* was at a threshold level in terms of quality, gaining the lowest score (13/20). This appears to be an initial pilot study in preparation for a further study which was included in the review by Dunkley & Bates (2015). This study will be retained for further consideration but the findings will be viewed and reported with caution. Strengths within the majority of the studies included clear and justified aims and research design. The weakest area for the majority of papers related to reflexivity and in particular the lack of acknowledgement of the researcher's philosophical position. The centrality of reflexivity to rigour in relation to data collection, ethical consideration and data analysis further calls into question quality and confidence in these research findings. A summary of the articles is provided in table 2 which is followed by a narrative review.

Table 2: Summary of studies retained from the systematic search and quality analysis

Authors	Aim	Sample	Method	Results/main themes	Conclusion
Connell., *et al.* (2015a)	Explore subjective factors associated with FEP and the very first stages of the recovery process	<u>Demographics:</u> N=26 Gender: 20 male and 6 female Age: 18-25 Country of residence: Australia <u>Diagnoses/Symptoms:</u> All diagnosed with a psychotic disorder <u>FEP?:</u> Yes <u>Time since FEP:</u> One month	<u>Design:</u> Qualitative using IPA <u>Recruitment:</u> Purposive sample of Participants referred to FEP service within the last month <u>Data collection:</u> Semi structured interviews. Questions emphasised interpersonal dialogues and social roles. <u>Interview schedule:</u> Based on the Indiana Psychiatric Illness Interview (Lysaker *et al.* 2002).	Two superordinate themes emerged: 1. *self-estrangement:* a) Altered experience of self and world: strong sense of something being 'wrong' with themselves and the world around them. Hospitalisation exacerbated vulnerabilities, social roles and anchors of self b) Apprehension: feeling of vulnerability persisted as a result of stigma. Apprehension regarding return to social roles. c) Experience of loss of self: loss of 'old self', instead occupying 'sick' or 'mad' role. 2. *Self-consolidation*: a) Strengthening close bonds: social support minimised stigma b) Making sense of experience: personal reflection and dialogue formed integral part of meaning making process. Developing personal narrative of psychosis enabled reestablishment of life story c) Forging a stronger self: narratives of how they had grown and developed as a result of psychosis	The period after a FEP is critical. The concept of dialogical self helps to illustrate the importance of restoring internal self-positions and interpersonal dialogue so that sense of self can be repaired and recovery supported. The findings of this study relate only to immediate recovery e.g. participants were one month post FEP. This approach is also applicable with PTG. Further research is warranted on the restoration of the self after FEP and avenues this is achieved over time.

Connell *et al.* (2015b)	Explore subjective factors associated with FEP and the very first stages of the recovery process – 3 month follow up of earlier study	<u>Demographics:</u> N=12 Gender: 9 male and 3 female Age: 19-24 Country of residence: Australia <u>Diagnoses/Symptoms:</u> All diagnosed with a psychotic disorder <u>FEP?:</u> Yes <u>Time since FEP:</u> 3 months	<u>Design:</u> Longitudinal Qualitative using IPA <u>Recruitment:</u> Purposive sample of Participants referred to FEP service within the last month <u>Data collection:</u> Semi structured interviews. Questions emphasised interpersonal dialogues and social roles. <u>Interview schedule:</u> Based on the Indiana Psychiatric Illness Interview (Lysaker *et al.* 2002).	Two superordinate themes emerged: loss of self and strengthening of self which appeared to be mutually exclusive – participants reporting loss of self did not report strengthening of self. 1. Loss of self: a) Revisiting the past: participants spoke about the disturbing nature of re-visiting their past experience of psychosis which led to rumination and self-recrimination. b) Consumed by illness: participants felt more consumed by illness dominated experiences than they did one month previous, including waiting to recovery, living in the 'sick' role and not being in control of thoughts. c) Feelings of loss: focus on what was missing, loss of their previous sense of self lifestyle and friendships. 2. Strengthening of self: a) Expressing agency b) Coping with disturbing thoughts: the development of strategies to manage thoughts c) Finding the positives: FEP resulted in changed self-perceptions for all and positive those who reported strengthening self-reported having gained something from FEP.	Participants reflected on processes of their recovery over the past 3 months and how they had changed. *Loss of self* participants experienced a diminishment in sense of self and reduced social roles. Instead they took up illness related identities. Participants in the loss of self group lacked the sense of initiative and motivation to recover that was evident in the strengthening of self group. The strengthening of self group demonstrated a sense of being effective agents in their life having a self-world view allowing a capacity to take action for change. Many were attending work and study to restore a sense of self narratives were being created about themselves in the past, present and future including 'self-as-wiser, self-as-better-person' this provided a sense of closure from the FEP. The development of a narrative of agency, coping and self-growth is a fruitful area for intervention.

Waite *et al.* (2015)	To increase understanding of internal processes of recovery with consideration to self-compassion and self-criticism	<u>Demographics:</u> N=10 Gender: 7 male and 3 female Age: 25-52 Country of residence: UK <u>Diagnoses/Symptoms:</u> Majority diagnosed with schizophrenia and 1 undiagnosed. <u>FEP?:</u> Yes <u>Time since FEP:</u> One month	<u>Design:</u> Qualitative using semi structured interviews analysed by IPA approach <u>Recruitment:</u> Purposive sample of Participants from a CMHT with positive symptoms of psychosis. <u>Data collection:</u> Semi structured interviews. Questions emphasised interpersonal dialogues and social roles. <u>Interview schedule:</u> Open ended interview schedule	There were a total of 5 superordinate themes as below: 1. 'My mind can't take the load; curse of psychosis': Including: the 'extreme' torture of psychosis; stigma; psychosis overwhelmed resources; plodding on versus getting life back on track; threat of relapse. 2. The trap of self-criticism: Including: psychosis as a source of self-blame; self-criticism; putting self- criticism 'behind bars' 3. Coming to terms and moving on: 'Couldn't understand psychosis'; 'trying to figure out what was wrong'; 'feeling content' with self; the challenge of 'acceptance'. 4. 'On my own two feet': Learning 'to deal with it'; 'I helped put in the help'; 'people tried to help me'; 'I treated myself with kindness' 5. 'An opportunity for growth': 'life is worth living'; finding hope for the future; 'it's given me some important tools for life'; acknowledging progress in recovery	<u>Understanding recovery:</u> Findings are in line with research indicating the complex and multifaceted concept and process of recovery in psychosis. Participants note that as self-reliance increased, confidence and self-belief also improved resulting in a more coherent and positive self-concept. <u>Relationship with self:</u> Internalised stigma resulted in a challenge to participant's self-concept. Participants struggled to identify as being someone who *has but is not* the illness. Participants described a vicious cycle of psychosis triggering self-criticism and self-criticism perpetuating psychosis. <u>Post-traumatic growth:</u> Researcher highlight the novel finding of PTG in the domains of personal strength, recognition of new possibilities, closer relationships and appreciation of life. Authors highlight process of recovery may not be about returning to prior functioning, but about moving forward, or beyond and relationship with self might influence this capacity for growth. Authors call for further research in this area.

Jager *et al.* (2015)	To explore the process of recovery from voice hearing over time.	<u>Demographics:</u> N=11 Gender: 4 male and 7 female Age: 23-63 Country of residence: Australia <u>Diagnoses/Symptoms:</u> Schizophrenia (n=4) Schizoaffective disorder = 4 Psychosis NOS = 3 <u>FEP?:</u> Unspecified <u>Time since FEP:</u> Unspecified	<u>Design:</u> Qualitative using narrative analysis <u>Recruitment:</u> Purposive sample of: 6 Participants from a Hearing Voices Network and 5 from the Australian Schizophrenia Research Bank <u>Data collection:</u> 1.Diagnostic interview 2.self-report measures: STORI, MANSA & KI0*) 3.semi structured interview <u>Interview schedule:</u> Interview involved completion of a timeline and open ended questions	Results showed that stages were cyclical in nature, with participants repeating processes a number of times. 1. Context of voice onset and initial responses 2. Reaching a point of despair/exhaustion 3. Divergent recovery typologies: Turning away – characterised by less room for reflection and meaning making and seeking medical explanations. Turning towards – characterised by curiosity about the experience and a transformation of the self through their voice hearing experience. 4. Common processes across typologies: engaging in meaningful activities, connecting with others and re-developing a positive sense of self were key.	Turning toward narratives involved a transformation of the self, active engagement with voices, adopting a normalising view of the voices and integrating them into one's life. These narratives align with McGlashen *et al.* (1975) recovery styles. Participants who were deemed to 'turn away' recovered in terms of symptoms, quality of life and psychological distress. The focus was on the management of symptoms and leaving those experiences behind rather than integration. This typology was thought to parallel McGlashen (1975) sealing over style. Participants described being less distressed by critical voices when they had developed a stronger sense of self

Dunkley, & Bates (2015)	The research sought to expand the concept of recovery following FEP to include the possibility of PTG, particularly in improved relationships and views of others.	<u>Demographics:</u> N=10 Gender: 7 male and 3 female Age: 22-28 Country of residence: Australia <u>Diagnoses/Symptoms:</u> Diagnosis: 3 FEP (not specified), 5 schizophreniform psychosis, 1 schizoaffective disorder, 3 major depressive disorder. FEP?: Yes Time since FEP: 3-6 months <u>Additional participants</u>: 8 family members	<u>Design</u>: longitudinal qualitative study including IPA analysis. <u>Recruitment:</u> Recruited from 2 outpatient services. <u>Data collection</u>: 3-6 months after their acute episode (time 1) 3-4 months after the first interview (time 2). Significant others and clinicians were interviewed also at time 2. <u>Interview schedule:</u> Designed to be open ended an adaptable. Significant others and clinician interviews were used for triangulation. <u>Data analysis</u>: Thematic analysis performed which was guided by IPA approach	Results revealed 3 clusters of themes: <u>Management of FEP:</u> Maladaptive themes: *1.* Perceptions of treatment as restricting *2.* Conscious avoidance *3.* Awareness of one's vulnerability Adaptive themes: 1. Developing acceptance and moving forward: recognising the illness as a changeable experience. 2. Viewing recovery as a journey 3. Self-directed recovery: desire to actively achieve change and overcome/manage impact of FEP. 4. The interpersonal environment facilitates recovery: Interactions with others facilitates recovery. <u>Recovery Process and Outcomes</u> Restorative themes: 1. Functional recovery: re-engagement in prior activities 2. Social recovery: prior relationships resumed <u>Constructive Themes</u> 1. Development of deeper and closer relationships 2. Increased desire to interact with others and improve the relationship. 3. Enhanced perspective taking and sense of unity 4. Confirmation of characters of others and quality of relationships 5. Greater appreciation of life 6. New possibilities and direction 7. Deepening of self-knowledge: captured the development of the self which allowed for increased self-awareness 8. Development of a sense of mastery and personal strength	A person can experience both restoration of previous levels of functioning and constructive change following an experience of psychosis. Three groups of themes: management of the experience, restorative recovery and constructive change occur in parallel and have a reciprocal relationship within a broader sense of active adaptation which reflects a person's explanatory model of FEP. Constructive change was prominent in recovery from FEP. Although the theme development or deepening or spirituality was not identified, the themes expanded those identified in Tedeschi & Calhoun's model of PTG (2004). A consideration of both positive and negative outcomes following FEP is encouraged. Clinicians need to be aware that in recognising growth they may also paradoxically increase discomfort as the person copes with fundamental changes in how they perceive themselves, others and the world.

Mapplebeck,*et al.* (2015)	To explore the relationship between psychosis and PTG through a qualitative approach.	Demographics: N=7 Gender: 5 male and 2 female Age: 28-68 Country of residence: UK Diagnoses/Symptoms: All participants had a diagnosis on the schizophrenia spectrum FEP?: not specified Time since FEP: unspecified	Design: Qualitative using IPA Recruitment: Purposive sample recruited from a national charity and a local support group. Data collection: Semi structured interviews with a focus on spontaneous disclosure with little prompting/questioning Interview schedule: Author notes questions from the schedule were rarely used allowing for free narration. Data Analysis: IPA	The adapting self The key theme "the adapting self" emerged. Within this four themes emerged reflecting the concept of PTG: 1. Finding meaning and purpose: Participants looked for meaning and purpose behind the psychosis. Participants described their lives having changed for the better since the psychosis, from embracing life to contemplating their life in context. 2. Support and understanding: The importance of loved ones was important in helping people to move forwards. It increased feelings of being understood, a sense of belonging and having someone to talk to. 3. Inner strength and determination: For some regaining control and power played a significant role in the positive changes they made in their lives. Inner strength was also highlighted as important for one participant, helping her to cope and adapt to her experiences. 4. Self-acceptance and awareness: A key theme for 6 participants and was pivotal in their experiences of PTG. One of the most important factors of PTG was acceptance and self-integration. Participants described a move to understanding their psychosis as part of themselves – and the voices seen as an "inner self".	For the participants who experienced psychological growth, there was a greater feeling of appreciation of life and finding meaning and purpose, inner strength and determination, and understanding and self-awareness. The majority of individuals portrayed a new sense of self by viewing their psychotic symptoms as a part of the self. There was also a feeling that participants had fully accepted this new self. The findings reflect aspects of models of PTG. In particular in Andresen, Oades and Caputi's (2003) five stage model of recovery the final stage of growth included having a positive outlook on life, living a full and meaningful life and having a positive sense of self. Other aspects of the model also reflected the findings such as a reestablishment of identity and finding meaning in life. It is important that clinicians are aware of the potential for growth after a psychosis. However the authors caution that this topic be approached carefully, if at all, as not every person will experience growth and it is crucial not to promote unrealistic expectations.

Nixon *et al.* (2010)	A phenomenological study examining the experiences of 6 individuals who self-identified themselves as having psychotic experiences that were spiritual and/or transformative in nature.	<u>Demographics:</u> N=6 Gender: 2 male and 4 female Age: 25 to 60 Country of residence: Canada <u>Diagnoses/Symptoms:</u> Diagnosis of psychosis in the past <u>FEP?:</u> No <u>Time since first symptoms</u>: Atleast more than 5 years.	<u>Design:</u> Qualitative study informed by IPA. <u>Recruitment:</u> Convenience sample through 'word of mouth' and an ad placed in an alternative health magazine. Only those who felt they had a 'transformative' psychosis and not on medication. <u>Data collection:</u> Individual interviews. <u>Interview schedule:</u> A narrative method for interviewing with the use of specific probing questions to aid elaboration where necessary. <u>Data analysis:</u> Qualitative data analysed using thematic analysis	<u>Pre-psychosis phase:</u> *1*.Childhood foreshadowing: reports of atypical thoughts in childhood and the experience of having "no self". 2.Negative childhood events: history of abuse and trauma <u>Psychosis phase:</u> 3.Sudden psychosis: abrupt and dramatic start to psychosis 4.Psychic/intuitiveness and unusual visual experiences 5.Comprised day-to-day functioning: loss of functioning 6. Experiences of dying: All participants felt that they were nearing death either at the point of crisis or in the emotional aftermath. 7. Communication with god: Five of 6 participants described communication with a 'divine spirit'. <u>Transformation of psychosis phase</u> <u>8.</u>Detachment and mindfulness: The developing ability to detach from the 'crazy-making' thoughts and overwhelming sense of panic. *9.Accepting the dissolution of time into now:* The experience of no time and no self during the acute stage led to a shift of consciousness, leading them to question traditional concepts and experiences of time. *10.Embracing a spiritual pathway:* *11.Re-alignment of career path*	The participants in this study understood the dramatic shifts of psychosis as an invitation to embark on a transformational journey. Each participant experienced positive changes in terms of their day-to-day functioning and ability to cope with life stresses. Mindfulness was essential for the participants to move beyond the panic inducing nature of psychotic symptoms. In addition, routine, structure and process of interpretations are all helpful in working through psychotic episodes or alternative states of consciousness. Few stories of transformation following a psychosis are readily available in the literature. Stories of transformation provide hope and direction for recovery.

Dunkley *et al.* (2007)	An examination of recovery of FEP in terms of models of trauma and Post-traumatic growth.	<u>Demographics:</u> N=2 Gender: 1 male and 1 female Age: 22 and 25 Country of residence: Australia <u>Diagnoses/Symptoms:</u> Diagnosis: Both participants had a diagnosis of Bipolar 1 Disorder with psychotic symptoms. FEP?: Yes Time since FEP: Interviewed at 5 months and 8 months post FEP <u>Additional participants:</u> Participants' Mothers also recruited.	<u>Design</u>: Prospective study involving qualitative and quantitative. Qualitative analysed by thematic analysis <u>Recruitment:</u> Participants identified through hospital database. <u>Data collection</u>: 5 months and 8 months. At each: 2 semi-structured interviews and 2 self-report measures. At stage 2 family member was also interviewed. <u>Interview schedule:</u> Open ended semi structured interviews. <u>Other measures:</u> RSQ and PANSS. <u>Data analysis</u>: Thematic analysis performed which was guided by IPA approach.	Participants demonstrated that FEP was a distressing experience. One participant focused on the stressful nature symptoms and treatment whilst the other focused on loss of control, powerlessness and the awareness of being unwell as stressful. Elements of Post-traumatic growth were evident including increases in: 1. <u>appreciation of life:</u> *"I don't take life for granted, I feel like I've been given a second chance and I want to make the most of it"* 2. <u>deeper relating to others:</u> *"I'm closer to them [family] than I ever was before*" 3. <u>enhanced perceptions of personal strength:</u> *"I've had my downs, I've been personally strong enough to overcome them… if before you told me what I was in for I would have maybe caved in"* 4. <u>new possibilities:</u> "*I want to get my life back on track…. And getting a law degree will be proof"* Recovery styles changed over time and with this in mind it seemed that the relationship of growth with sealing- over and integration is complex.	The results indicate that FEP can be a traumatic experience and that elements of growth are relevant. The recovery styles of sealing over and integration can be conceptualised within a trauma framework but their relationship with growth is complex. People who have FEP can have some self-awareness and capacity to reflect on their experiences despite the nature of the illness which causes them to lose touch with reality. It is important to start to have meaningful conversations which include the topics of the helpful and unhelpful impact of FEP. Impact on one's sense of self, relationships, perceived vulnerability, feeling of hopelessness and the awareness of being unwell are all important foci in treatment. Considering growth may be important in considering outcomes. Considering the possibility for growth with individuals could also provide a sense of hope, recognise their capacity for strength and resilience and help disband the pessimistic view of psychosis.

Thornhill *et al.* (2004)	An exploration of individuals' narrative accounts of psychosis. Narratives were explored in respect to genre, tone and core narratives.	<u>Demographics:</u> N=15 Gender: 6 male and 9 female Age: 30-70 Country of residence: UK <u>Diagnoses/Symptoms:</u> Diagnosis: 7 Schizophrenia; 2 schizoaffective; 4 bi-polar; 2 psychotic episode; 2 depressive psychosis. FEP?: N0 Time since FEP: unspecified	<u>Design:</u> Qualitative study using a narrative approach <u>Recruitment:</u> Purposive sample through advertisements and word of mouth <u>Data collection:</u> semi structured interview <u>Interview schedule:</u> Interviews were led by participant's accounts and the interviewer's reflections on what they said. <u>Data analysis:</u> Accounts taken as a whole to represent narratives in their wider sense. An analysis of narrative genre, narrative tone and identifying core narratives.	The narrative genres fell into 3 overarching groups; narratives of escape, enlightenment and endurance. Tone and core narrative were closely related to narrative genre. 1. <u>Narratives of escape</u> Broad genre of 'escape' narrative includes stories of avoiding natural disaster or breaking free from imprisonment. The tone is one of anger and protests of damaging attitudes and treatment. 2. <u>Narratives of enlightenment</u> Also often referred to as the quest, conversion or growth narrative. A key element is the sudden or gradual dawning of understanding, bringing a new perspective and the tone was one of educating. For the participants enlightenment meant a gradual understanding of the self and the experience of psychosis, for some accompanied by a spiritual, political or personal insight. 3. <u>Narratives of endurance</u> Psychosis is seen as akin to a chronic health condition which must be continually monitored. A stance of endurance and even acceptance of psychosis did not however necessarily preclude a definition of oneself as recovered. The tone was of resignation.	The genre of the escape narrative has not been identified in previous studies of health and illness. We should consider whether the experiences of psychosis and treatment is fundamentally different from how other illnesses are experienced. 'Escaping' from unwanted treatments may for some individuals may become a key part of their recovery story. An important aspect for all participants was escaping from the identity of chronic psychiatric patient. Participants endorsing the enlightenment narrative held an emphasis on an ongoing journey involving a search for meaning. For some individuals their narratives were of recovering from both past trauma/abuse and psychosis which were understood to be closely related. The narratives of endurance map on to narrative genres of 'normalising story' and 'acceptance'.

Barker *et al.* (2001)	An exploration of the narratives used by clients and family members to explain how schizophrenia impacts on the clients sense of self and social relationships over time. Also, how the narratives used by professionals contributed to 'sense making'.	<u>Demographics:</u> N=8 Gender: 6 male and 2 female Age: 25-50 Country of residence: UK <u>Diagnoses/Symptoms:</u> Diagnosis: Schizophrenia FEP?: Yes Time since FEP: unspecified <u>Additional participants</u>: 8 significant others (6 mothers, 2 fathers)	<u>Design:</u> Qualitative study using grounded theory <u>Recruitment:</u> Individuals currently living in a hospital, hostel or supported accommodation were identified. <u>Data collection:</u> Semi structured interviews. Areas covered: unusual experiences; impact of time; perceived usefulness of professional explanations; beliefs about mental health problems; impact of these on sense of self; change in relationships with others. <u>Data analysis:</u> Grounded theory analysis	A 4 stage model is presented with 3 categories in each of the stages. Within each stage a comparison of clients' and family members' narrative is also presented. 1. Events preceding first psychotic episode 2. The first psychotic episode 3. The first hospital admission 4. Current experiences: i. *Disability:* Clients talk of the continual effort needed to manage their problems, while relatives speak of control and stigmatisation. ii. *Relationships:* Descriptions of how adversely affected and some lost following the psychosis. Clients felt that friends can be a vital support whilst relatives spoke of clients being separate from society. iii. *Self-development:* Clients saw development of the self as a positive aspect of developing schizophrenia but relatives did not share this view. For clients the major theme was becoming more 'themselves'. *iv.* *Coping and services:* A period of less alienation and confusion. Ambivalence around the use of medication. Some individuals still did not feel fully understood by professionals.	Nearly all clients' narratives included accounts of the development of their sense of self and several relatives also discussed this. The authors suggest that the fact that clients highlighted the centrality of the self-development in their narratives may suggest that this area should be researched further. The authors suggest that the emphasis on the need to develop an identity occurs after the onset of the 'illness', which is experienced as a biographical disruption much like any other illness. Thus the need to adapt one's identity following a psychosis is not specific to schizophrenia, but reflects the need to adapt after an illness and disability. The finding suggest that focusing on issues with identity may be more beneficial to clients than considering the diagnosis of schizophrenia. In highlighting that client's view the development of the self as central to recovery this study has implications for interventions.

Note: 1) Definitions of acronyms: PTG = Post traumatic Growth; IPA =Interpretative phenomenological analysis; FEP = first episode of psychosis
2) STORI = The Stages of Recovery Instrument; MANSA = The Manchester Short Assessment of Quality of Life; K10 = The Kessler Psychological Distress Scale; RSQ=Recovery Style Questionnaire; PANSS =* The Positive and Negative Syndrome Scale

1.5.10 RESULTS – NARRATIVE REVIEW OF FINDINGS

Walsh and Downe (2005) suggest an analytical technique for synthesizing results from qualitative research. This involves tabulating themes across studies to allow for comparisons to be made. This review followed aspects of this method whereby the results section of each article was taken in isolation to explore similarities and differences between all emerging themes. Common themes were then grouped together. Themes generated from each article and how they were combined into larger themes is provided in appendix 5.

Table 3: Synthesis of results from systematic review articles

	Immediate crisis responses	Recovery processes , styles and outcomes	Finding meaning	Stigma	Relationships	Appreciating life	New possibilities	Impact on self
Connell., *et al.* (2015a)	x		x		x			x
Connell *et al.* (2015b)		x		x				x
Waite *et al.* (2015)	x	x	x	x	x	x		x
Jager *et al.* (2015)	x	x		x	x			x
Dunkley, & Bates (2015)	x	x			x	x	x	x
Mapplebeck,*et al.* (2015)			x		x			x
Nixon *et al.* (2010)	x	x					x	x
Dunkley *et al.* (2007)					x	x	x	x
Thornhill *et al.* (2004)	x	x						x
Barker *et al.* (2001)	x	x			x			x

1.5.11 IMMEDIATE 'CRISIS' RESPONSES

Immediate extreme emotional responses to the psychosis was evident through the themes: 'extreme torture of psychosis'; 'curse of psychosis' (Waite *et al.* 2015); 'sudden psychosis' (Dunkley *et al.* 2007); and 'experiences of dying' (Nixon *et al.* 2010). Nearly all of the participants across the studies reflected on the emotionally distressing nature of the psychosis. The 'crisis' period was characterized as having a sudden onset for many, however participants in a study by Jager *et al.* (2015) reflected on distal and proximal stressors and a general disconnection from others prior to the onset of symptoms. Initially strategies to maintain health were attempted until they noted 'reaching a point of despair/exhaustion' (Jager, *et al.,* 2015). Consumers and family members in the study by Barker *et al.* (2004) reflect on the treatment experiences, describing contact with services and professionals as having compounded their distress. For many the distress of the 'crisis' was closely linked to a perceived loss of self or loss of an accepted/positive self: 'feelings of loss of self' (Connell *et al.* 2015b); 'loss of self' (Connell *et al.* 2015a); 'psychosis as a source of self-blame' (Waite *et al.* 2015). Participants described the "the initial onset of schizophrenia as a catastrophic disruption of their sense of self and their life world" (pg.203).

1.5.12 RECOVERY PROCESSES, STYLES AND OUTCOMES

Themes emerging from the studies included descriptions of processes recovery in addition to the anticipated and realised outcomes of recovery. Three studies (Barker *et al.* 2004; Dunkley & Bates, 2015) described participant's desire to "just be normal again" (Waite *et al.* 2015) and this for many meant a return to prior roles and occupation. Recovery was described as a long and effortful process. There was an acknowledgement in two studies regarding the need to contend with ongoing difficulties, placing psychosis akin to a chronic physical illness (Thornhill *et al.* 2004; Connell *et al.*2015). Interestingly, participants appeared to discuss the process of recovery rather than recovery as an outcome itself (Thornhill *et al.* 2004; Waite *et al.* 2015). Two studies described particular recovery styles which reflected the participants' engagement in the recovery process (Waite *et al.* 2015; Dunkley & Bates, 2015; Jager *et al.* 2015). Jager et al. (2015) describe two typologies of recovery similar to the recovery styles of 'sealing over' and 'integration' proposed by McGlashen's (1976). Those who adopted a 'turning toward' style led to an active engagement with voices, a process of normalisation and integration and a transformation of the self (e.g. becoming less angry and more empathetic towards others, becoming more communicative of their voice hearing

experience and acknowledging a stronger sense of self). A 'turning away' style however was characterised by those whose stories were void of reflection or the engagement in meaning making and they were more likely to manage their 'symptoms' by use of medication. Parallels can be drawn with this approach and that outlined by Dunkley & Bates (2015) in which participants avoided reflecting on the 'illness'. This research was restricted to those who had an experience of 'voice hearing' and all of the participants were active members of the Hearing Voices Network and as the authors note the selections procedure was "more likely to attract people who had positive experiences of Hearing Voices" (Jager *et al.,* 2015).

1.5.13 FINDING MEANING

'Recovery styles' can be understood in terms of the extent and style by which the individual appears to engage in a process of meaning making (McGlashen, 1976). The process of finding meaning was a feature of many studies and was an explicit emergent theme in three studies: 'making sense of the experience' (Connell *et al.,* 2015a); 'couldn't understand the psychosis'; 'trying to figure out what was wrong' (Waite *et al.* 2015); and 'finding meaning and purpose' (Mapplebeck *et al.* 2015). There appeared to be an overall acknowledgement that making sense of psychosis could at times be a difficult and painful process, but recognition of the importance of this process to recovery and restoration of the self. This appeared to be particularly the case in the initial stages as participants struggled to make sense of their symptoms and diagnosis before making attempts to understand the greater meaning or purpose behind the experiences (Mapplebeck *et al.*, 2015). Connell, *et al.* (2015a) noted the role of personal reflection and dialogue with others as being key in meaning making. The development of this personal narrative that made sense of their psychosis, particularly with reference to the causal factors, played a significant role in re-establishing continuity in their life story and moving forward.

However, not all participants found the process of meaning making helpful. Nixon *et al.* (2010) describe how one participant engaged in "letting go" of his need to understand the psychosis and to notice and relinquish judgement associated with it. This paradoxically led to greater clarity. Thornhill, Clare & May (2004) through the emerging theme of enlightenment discuss psychosis in terms of existential (e.g. Laing 1960/1991) and psychodynamic (e.g. Alanen 1997; Jackson, 2002; Jackson & Williams, 2004) frameworks. They suggest that the psychosis can trigger a journey of self-discovery whereby psychotic thought processes are seen as offering valuable clues to important psychological and emotional issues and thus the individual can begin to make sense of wider/deeper issues.

1.5.14 STIGMA

External and internalized stigma is recognised as a negating factor in individuals' recovery by two studies (Waite *et al.* 2015; Connell *et al.* 2015a). Stigma is considered to impact recovery as a whole and thus is apparent in a number of themes within these two studies. Connell *et al.* (2015a) described the persistent feelings of vulnerability following the crisis period as participants struggled with the stigma attached to psychosis and the impact of this on perceived social acceptance and further self-acceptance. This was paralleled by nearly all participants in the study by Waite *et al.* (2015). Waite *et al.* (2015) observed the negative impact that stigma had on not just the participants self-concept but also their social positioning and resulting feelings of estrangement, as one participant summarised: *"you're at the bottom, climbing the rope to get up to be with other people"* (pg. 1207). The role of family and friends was highlighted in the study by Connell *et al.* (2015) as reducing feelings of estrangement through reassurance and through serving to assuage internalized stigma based fears. Unlike the previous studies discussed, Jager *et al.* (2015) did not discuss stigma in terms of recovery but as a distal factor in the development of voice hearing. Participants were anxious about the consequences of disclosing their experiences for fear that they would be judged negatively and this contributed to a lack of support, and coping resources being overwhelmed, leading to crisis.

1.5.15 SOCIAL RELATIONSHIPS

The majority of studies cited the role of relationships or significant others as both a facilitative factor and growth outcome of recovery. Improved relationships with others was noted as occurring in a number of studies through the following themes: 'deeper relating to others' (Dunkley *et al.* 2007); 'confirming character of others and quality of relationships'; 'increased desire to interact with others and improve relationships'; 'development of deeper and closer relationships' (Dunkley & Bates, 2015); and 'strengthening close bonds' (Connell, *et al.* 2015a). Waite *et al.* (2015), through the theme 'people try to help me', noted the importance of social relationships in the process of acceptance which was viewed as key to recovery. Mappelbeck (2015) noted that whilst most PTG was derived from intrapsychic processes, the role played by others enabled the process of 'moving forward' through having someone to talk to, a sense of belonging and feeling understood. Jager *et al.* (2015) described how the factors of mental health skills, meaningful activity, connecting with others, changing responses to the voices and positive sense of self were interconnected with the common goal of increasing feelings of competence, being valued and purposeful.

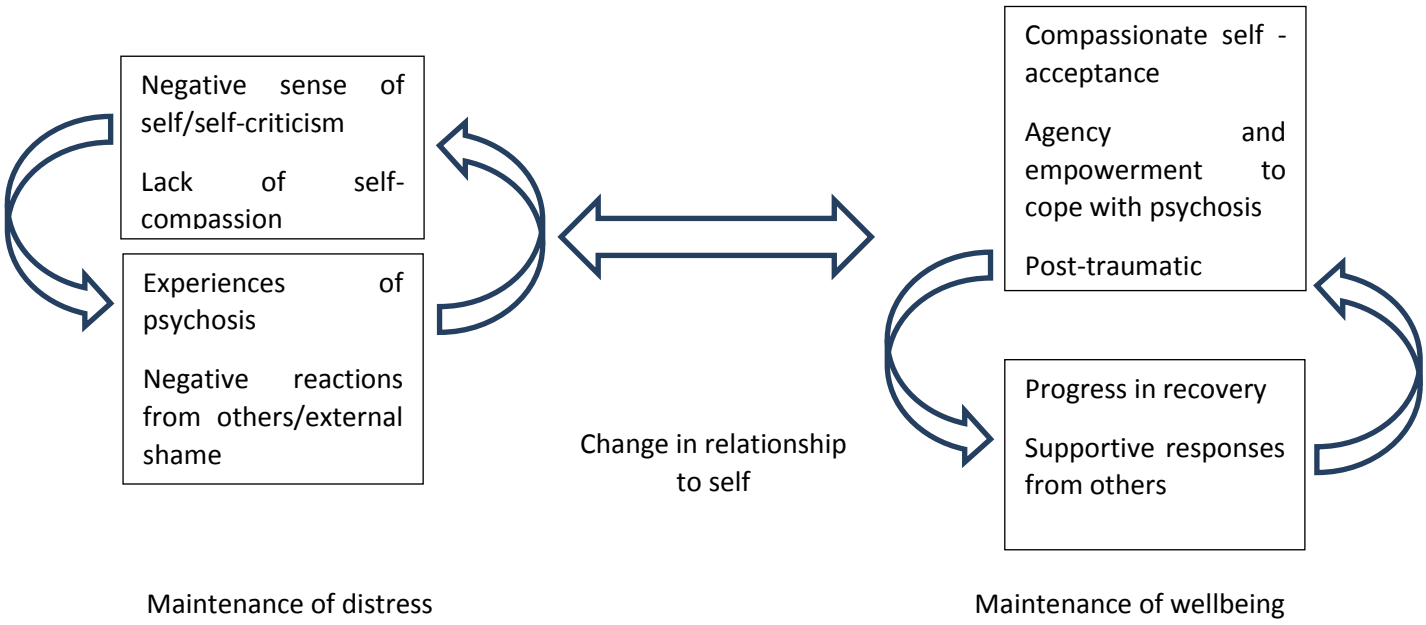


*Figure 2: T*he relationships between self-criticism and self-compassion in recovery and PTG (*Waite et al.,* 2015).

Waite *et al.* (2015) focused on specific aspects of self-criticism and self-compassion. They described a complex pattern whereby the development of compassionate self-acceptance can lead to a sense of empowerment and belief in one's capacity to cope and hope. This may result in progress in recovery and supportive responses from others. This in turn leads to greater capacity to relate to oneself with compassion and potentially results in PTG. This is presented in diagrammatic form (see figure 2 above). The majority of studies described relationships with professionals as positively impacting the recovery experience and contributing to growth with the exception of one study (Barker *et al.* 2001), whereby professional input was viewed as detrimental in the acute stages of psychosis.

1.5.16 APPRECIATING LIFE

Three studies described themes relating to a greater appreciation of life following an experience of psychosis: 'appreciation of life' (Dunkley *et al.* 2007); 'life is worth living' (Waite *et al.* 2015); and 'greater appreciation of life' (Dunkley *et al.* 2015). Waite *et al.* (2015) described participant's process of reviewing pre-existing ideas about the value of life and discovering a life worth living and the positive impact that this had on perceptions of hope for the future. Participants in Dunkley and Bates (2015) study discussed the psychosis as a re-framing opportunity. Providing greater recognition that life is precious, valuable and fragile and is to be taken more seriously.

1.5.17 NEW POSSIBILITIES

Three studies described the realisation of new possibilities following a psychotic episode through the themes: 'new possibilities' (Dunkley *et al.* 2007); 'realignment of career path' (Nixon, *et al.* 2010) and 'new possibilities and direction' (Dunkley & Bates, 2015). The study by Nixon (2010) which recruited individuals who felt they had a spiritual transformation following psychosis, described a re-alignment of career path to reflect their newfound spiritual awareness. For some this resulted in a greater spiritual creativity: *"I don't think I was creative until (my psychosis) happened. Not anymore than anybody else. But now my creativity has grown".* (pg. 539). There were also tacit references to a reassessment of life priorities in particular engaging in more self-care*: "my dreams are a lot different cause I no longer want things I used to want… well I used to be heavily into drinking, I used to love it and now I don't"* (pg. 135; Dunkley & Bates, 2015).

1.5.18 SENSE OF SELF

Four studies aimed to specifically explore aspects of the self in PTG following psychosis. Two focusing specifically on the application of a dialogical perspective at one month and three months post crisis (Connell, 2015a; Connell, 2015b), one explored specific concepts of self-criticism and self-compassion (Waite, 2015), and another explored the narratives used by clients and family in the development of schizophrenia and how this impacted on their sense of self (Barker *et al.* 2001). However, issues relating to the self and identity was emergent in all 10 studies to varying degrees, thus indicating that the role of self or rebuilding the self-following psychosis is crucial to recovery and PTG.

Mapplebeck, Joseph and Sabin Farrell (2015) argue that growth in the area of sense of self requires an acceptance and integration of symptoms as part of the 'inner self'. This idea reflects work by Davidson & Strauss (1992) outlined in section 1.3.4, where it is argued that reconstruction of an enduring sense of self as an active agent is a crucial aspect in recovery. The dialogical self theory as proposed by Lysaker & Lysaker, (2008) however disputes the idea of a stable sense of self. Dialogical self theory as applied to the understanding of the experience of psychotic disorders (Lysaker & Lysaker, 2008) was drawn on by Connell *et al.* (2015a; 2015b). The theory suggests that sense of self arises through intra-and interpersonal dialogue that occurs with the interaction between different self-positions (Hermans, 2003). It dismisses the idea of a core integral self that maintains executive control of the person, rather sense of self is thought to emerge via self-positions that become recognised as self. Self-positions take three forms according to the theory: character positions (how

we become aware of our self through the role we inhabit e.g., self-as-student, self-as-friend); organism positions (awareness of self through monitoring our needs e.g., self as frightened); and meta-positions (conscious reflection on self-positions lead to meta-positions including judgement of performance in roles e.g., self-as-disappointing son). Meta-positions may arise in retrospective assessment of self-positions or in anticipation of future self- positions and play an important part in how we tell our story. Lysaker & Lysaker (2010) suggest the concept of dialogical self in psychosis has particular utility in describing the experience of self-diminishment and the feeling of no longer being an effective agent. It is suggested that this occurs as a result of the reduction in self-positions and ultimately meta-positions following lack of engagement in social roles after the psychotic crisis.

Connell (2015b) conclude that participants in the 'loss of self' group experienced a diminishment in sense of self by their experience of passive and controlled activities (e.g, taking medication and attending appointments) and reduced participation in previously occupied roles (e.g., study, occupation and friendships) leading to a reduction in character self-positions and meta-positions. Instead their self-positions related to 'self-as-sick' and self-as-dependent'. There are parallels here with the identity theory proposed by Yanos *et al.* (2010) which posits that the evolution of the 'illness identity' from one of 'patient' to 'survivor' is fundamental to overcoming a mental 'illness'. Conversely, those participants in the 'forging a stronger self' (Connell, 2015a) engaged in reflective processes and interpersonal dialogue with others enabled a relevant and enabling narrative of self-growth: "because I've dealt with such hard times, I just feel like I can take on quite a lot, so you know, I am tougher" (Connell *et al.* 2015a). Narratives of growth in terms of becoming stronger was re-iterated in other studies (Dunkley *et al.* 2007; Mapplebeck *et al.* 2015; Dunkley & Bates, 2015; Waite *et al.* 2015).

1.5.22 CONCLUSIONS FROM SYSTEMATIC REVIEW

The aim of this systematic review was to explore whether PTG has any relevance in changes in sense of self and self-perceptions of change following a recent onset psychosis. This review has met these objectives. The results indicate that sense of self is heavily implied following a recent onset psychosis in so far as a rebuilding of one's sense of self appeared to be key to recovery. In addition, this review found that PTG does have relevance to individual's experience of change following psychosis with PTG being identified in the areas of: new possibilities; deeper relationships and greater appreciation of life.

There is a paucity in the empirical evidence base for PTG following psychosis, despite consumer accounts stating otherwise. Four studies have contributed to the concept of PTG over the past year.

Interesting outcomes in terms of PTG in the areas of new possibilities, deeper relationships and appreciating life more following an episode of psychosis has been highlighted. Stigma was evidenced as a negating factor. The recent increased interest in PTG associated with psychosis demonstrates that the topic is one of clinical value. However, the studies reviewed share the limitation of a lack of reflexivity which is essential to qualitative research. Sense of self has been shown to be key in overcoming psychosis and in the development of PTG. Despite the exploration of PTG being stated as a main aim in a number of these studies, they continue to be driven by self-identity theories. This systematic review develops on the findings in the scoping review published by Jordan *et al.* (2016) by maintaining a focus on constructs relating specifically to positive change following adversity (e.g., PTG, stress-related, thriving) as opposed to those referenced in recovery literature.

1.6 STUDY RATIONALE AND AIMS

It is acknowledged within the literature base that a ROP can be experienced a highly stressful event and can serve to shatter one's assumptions held about the world, others and the self. This is recognised by research exploring the prevalence of PTSD resulting from psychosis and hospital related experiences (Berry *et al.,* 2015). It is of note that research has failed to extend in the same way to consider positive changes that may occur as a result of an experience of psychosis. Research into PTG is growing substantially in health settings, however Reeves (2000) suggests that services fail to recognise or foster constructive change within mental health. The systematic review has demonstrated the lack of studies exploring PTG following psychosis, although the last year has seen an increase in publications (Mapplebeck *et al.* 2015; Dunkley & Bates, 2015; Jager *et al.* 2015 & Connell, 2015a, 2015b). The quality assessment has shown these to be somewhat flawed particularly in relation to the lack of reflexivity and resulting impact of rigour on data collection and analysis (with the exception of Waite, *et al.* 2015). Furthermore, the application of the results of these studies is limited considering the empirical evidence that growth typically occurs following a period of 6 months or longer to allow for a period of rumination appropriate to the development of PTG (Tedeschi & Calhoun, 1996).

This study attempts to develop on previous accounts of change following a psychosis. The study will adopt a constructivist grounded theory approach. Specifically the study seeks to:

1. Explore how self-identity and self-perceptions change following a recent onset psychosis
2. Explore perceptions of constructive and depreciative changes that occur following a recent onset psychosis.

CHAPTER 2: METHOD

2.1 OVERVIEW OF CHAPTER

This study explored perceptions of change following a recent onset psychosis. With the aims in mind a qualitative constructivist grounded theory was adopted. Details of the methodology are outlined in this chapter.

2.2 DESIGN

The study used a qualitative methodology guided by principles of constructivist grounded theory (Charmaz, 2014). A purposive sample of individuals who had experienced a ROP was recruited from NHS Early Intervention Services (EIS) and a third sector organisation in South Wales. Details of the inclusion and exclusion are provided in section 2.7.2. Eight participants completed semi-structured individual interviews, which were audio recorded and transcribed. Analysis followed the constructivist grounded theory approach (Charmaz, 2014). This study utilised a retrospective approach. While the evidence that this approach may be less accurate than recording events as they occur (e.g., Schroder & Borsch-Supan, 2008) this may, in itself, not be problematic. Indeed, this study seeks to understand how the individual understands and engages in the continual sense making process which inevitably relies on autobiographical memory and narrative sense making.

2.3 QUALITATIVE METHODOLOGY

2.3.1 EPISTEMOLOGICAL UNDERPINNINGS

The selection of research methodology, depends on the paradigm that guides the research activity, and specifically beliefs about the nature of reality and humanity (ontology), the theory of knowledge that informs the research (epistemology), and how that knowledge may be gained (methodology) (Tuli, 2010). A consideration of epistemology, ontology and methodology must be a central feature of any discussion of social science research design, as these elements shape and define inquiry (Popkewitz, Tabachnick & Zeichner, 1979). Essentially, epistemology prompts the questions: What is the relationship between the knower and the known? How do we know what we know? And what counts as knowledge?

Quantitative and qualitative research methodologies vary in their stance to these questions. Quantitative research assumes a positivist social reality which rest on the beliefs that objective facts

exist in absence of personal ideas. That they are governed by the law of cause and effect and perceive social reality to be stable (Crotty, 1998; Neuman, 2003; Marczyk, DeMatteo and Festinger, 2005). Therefore quantitative researchers set out to test how variables cause outcomes and interact with one another. Qualitative research however, largely assumes a constructivist position whereby the world is seen as constructed, interpreted and experienced by people within their interactions with others and their social systems (Maxwell, 2006; Bogdan & Biklen, 1992; Guba and Lincoln, 1985; Merriam, 1988). The qualitative researcher seeks to understand a particular phenomenon experienced by individuals and does not attempt to generalise to a population (Farzanfar, 2005).

2.3.2 RATIONALE FOR AND USE OF A QUALITATIVE APPROACH

Historically, psychosis has been viewed as an illness that leaves the person out of touch with reality and lacking in insight (Davidson, 2003). The view of psychosis as a permanent disablement started to shift with the advent of the Recovery Movement. However, research exploring the meaning-making process that individuals go through and their perceptions and beliefs about their experience of psychosis continued to lag for some time after (Davidson, 2003). Individual's account of those who have experienced ROP however demonstrate capacity of introspection and integration of internal experiences (Lipner, 1985) and highlight the importance of making meaning (Roe & Davidson, 2005; Geekie, 2004). By focusing on the individual, a comprehensive picture of the course and possible outcomes of ROP can be achieved (Roe *et al.* 2004). Indeed, authors examining the outcomes of ROP have called for more interview based methodologies to better capture how individuals adapt to the subjective stress of psychosis (McGorry *et al.* 1992). The adoption of a qualitative approach may be particularly useful given that the notion of PTG, as opposed to functional recovery as an outcome, is a relatively new and evolving phenomenon in the psychosis literature (Zoellner & Maercker, 2006).

2.4 CONSTRUCTIVIST GROUNDED THEORY

2.4.1 OVERVIEW AND KEY PRINCIPLES

There are various distinct qualitative paradigms which have been summarised by Guba and Lincoln (2005) into five main domains: positivism, post-positivism, critical theories, constructivism and participatory/cooperative paradigms. Each of these differ in epistemological and ontological underpinnings with implications for data collection, analysis, control and legitimacy. Whilst this study does not provide the scope to discuss each of these paradigms in detail the choice of methodology for this study - constructivist grounded theory, will be discussed and justified in terms of the aims.

Constructivism as a paradigm refutes the existence of an objective reality. Beginning in the 1990's scholars started to move grounded theory away from the positivism of Glaser's and Strauss' (1967; 1968) and Corbin's (1990) use of grounded theory (Bryant, 2002; Clarke 2003). As a way of addressing the criticism which undermined the epistemology of existing grounded theory approaches (Conrad, 1990; Ellis, 1995, Richardson, 1993), Charmaz (2000) developed Constructivist Grounded Theory. She reasoned that the approach "takes a middle ground between postmodernism and positivism" (p.250). Charmaz (2000) transports the epistemological and ontological ideas of constructivism through grounded theory strategies. Constructivist grounded theory adopts the inductive, comparative, emergent and open ended approach of Glaser and Strauss's original statement. It also includes the iterative logic proposed by Strauss in his early teaching and the dual emphasis on action and meaning ingrained in the pragmatist's tradition (Charmaz, 2014).

2.4.2 RATIONALE FOR THE USE OF CONSTRUCTIVIST GRONDED THEORY

The research methodology is informed by the research aims. This study sought to explore perceptions of PTG following a ROP with an emphasis on sense of self. Whilst Interpretative phenomenological analysis (IPA) allows for an exploration of how individuals make sense of their experience which is in line with the aims of this study, the focus of IPA rests on understanding the impact of a phenomenon rather than making inferences (Smith, Flowers & Larking, 2009). Grounded theory however allows for inference and the questions of 'how' and 'why' (Forrester, 2010). A grounded theory approach would provide added empirical evidence to the studies described in the systematic review – the majority of which adopt an IPA approach. Thus, a grounded theory study may serve to further foster ideas regarding the links between empirical and theoretical mechanisms/processes (Charmaz, 2014) involved in PTG following ROP. Moreover, grounded theory is particularly suited to the exploration of the social processes (Crooks, 2001) that appear key to overcoming or living with a ROP.

Grounded theory itself can be conducted according to a number of different perspectives, the primary one's being objectivism and constructivism. It has been proposed that a further effective strategy to the decision making involved in deciding between the approaches is to select one that complements the researcher's philosophy (epistemology and ontology), goal and cognitive style (Fendt & Sachs, 2008). The co-construction of narratives and rejection of objectivism resonated with the researcher's epistemological and ontological stance in addition to learning objectives emphasising systemic approaches. The researcher has provided a statement pertaining to beliefs and epistemology in section 2.4.1.

2.4.3 THE CONSTRUCTIVIST GROUNDED THEORY PROCESS

Researchers can use the grounded theory approach with a variety of data collection strategies. This study utilised individual semi-structured interviews which were audio recorded and transcribed. The use of intensive interview, as it is termed by Charmaz (2014), is an emergent technique that combines both flexibility and control. Data analysis of interview transcripts according to constructivist grounded theory included: initial coding; focussed coding; theoretical coding; memo-writing; constant comparative analysis; negative case analysis and triangulation. These are described in further detail in section 2.9.

2.4.4 ENSURING QUALITY

The notion of quality in qualitative research has been widely contested as seen in Chapter 1. Researchers have argued that issues of validity in qualitative studies should not be linked to 'truth' or 'value' as they are for the positivists, but rather to 'trustworthiness', which *'becomes a matter of persuasion whereby the scientist is viewed as having made those practices visible and, therefore, auditable'* (Sandelowski, 1993; *p. 2*). Despite the controversy, a number of guidelines have been developed to enhance methodological rigour (e.g. Elliott et al., 1999; Henwood and Pidgeon, 1992; Mays and Pope, 2000; Pearson, Jordan, Lockwood et al., 2014; Goldberg and Allen, 2015). A review of these frameworks alongside wider reading of issues of trustworthiness in qualitative studies was undertaken at the outset of the study.

A framework developed by Elliott *et al.* (1999) is adopted here to discuss issues of trustworthiness and how these informed the design. This framework is drawn upon specifically due to the breadth of issues that are relevant to qualitative research. Additionally, Elliott *et al.'s* (1999) framework is grounded in extensive review of existing principles of good practice and feedback from qualitative researchers. The set of 7 guidelines (based on 40 quality standards) are summarised below in addition to a description of how these are addressed in the study as highlighted in italics.

1. Owning one's perspective – Authors specify their theoretical orientations (including values, interests and assumptions) in advance of and during the research process and acknowledge the impact of these (Elliott *et al.* 1999). *This study achieved this through providing a statement of position (section 2.4.1.1). Further, the author provided reflections on the ways in which her position evolved and potential implications of this at different stages of the research through maintaining a reflexive journal* (Appendix A).

2. Situating the sample - Authors describe the research participants in sufficient detail so as to make clear the range of persons and situations to whom the results may be relevant (Elliott *et al.* 1999). *This study presents basic demographic information pertaining to each participant (age range, sex, spirituality) in addition to information regarding their situation and experiences (e.g. age at onset of psychosis; symptoms experiences). In order to further situate the participants, they each completed two psychometric measures assessing subjective wellbeing (WEBWMS) and post-traumatic growth (PTGI). A flow chart is provided in appendix F illustrating the early intervention care pathway.*

3. Grounding in examples - Examples of data used by the researcher are provided to illustrate the analytic procedure to allow for an appraisal of fit between the data and the author's interpretation of them. Data should be presented in a way that will allow the reader to conceptualise possible alternative meanings and understandings (Elliott *et al.* 1999). *Chapter 3 includes two or more examples of each theme generated. Examples of coded interview transcripts (Appendix G) are provided in addition to examples of memo-writing (Appendix H). Negative cases were explored and discussed in Chapter 3 and 4.*

4. Providing credibility checks - Researchers employ strategies to check for the credibility of categories (Elliott *et al.* 1999). *Participants in this study were asked to check transcripts for any errors and confirm accuracy. Transcripts and emerging codes and categories were discussed with the academic. Emerging theory was also discussed with the clinical supervisor and differences in perspectives were explored. Notes from an academic supervisor where emerging categories were discussed are provided in the example reflexive diary extract (Appendix A).*

5. Coherence - A coherent and integrated summary of results should be provided whilst preserving the nuances in the data (Elliott, *et al.* 1999). *Narrative and diagrammatic illustrations of the findings are provided in the results and discussion section. Clarity of meaning was carefully considered in the presentation (e.g., use of difference fonts and sizes of texts) to ensure it was easily accessible to the reader.*

6. Accomplishing general versus specific research tasks – Researchers should make clear the extent to which research findings can be generalised. The research should make clear whether the aim is for a *general* or *specific* understanding of a phenomenon (Elliott *et al.* 1999). *The current study is representative of a specific sample of individuals (N=8) who: have*

experienced a ROP; have received secondary care input for their symptoms; and who currently reside in South Wales, UK. Demographic information along with information gained from psychometric measures is provided in section 2.7.3. The researcher acknowledges that the theory reflects meaning co-constructed between these specific participants and the researcher. However the extent to which the results reflect similarities and differences with themes within existing literature may provide some indication of the generalisability of themes. Limitations of the current study are discussed in Chapter 4.

7. Resonating with readers - Research should be presented in a way that readers judge it to accurately represent the subject matter or to have clarified or expanded their understanding of it (Elliott, *et al.* 1999). *The author seeks to present material that is easily accessible to readers and which most closely represents the participant's experiences. The grounded theory diagrammatic formulation was shared with the Service User Representative. This was particularly useful in exploring the use of language employed as descriptive of each category/theme. Draft chapters were also reviewed by the academic supervisor and clinical supervisor. This ensured that the work resonates with service users and professionals across different specialities and clinical and academic fields.*

2.4.5 QUALITY ISSUES SPECIFIC TO CONSTRUCTIVIST GROUNDED THEORY

Elliott and Lazenbatt (2005) suggest a continuous cycle of data collection and analysis is an essential feature of constructivist grounded theory. Constant comparative methods (Glaser & Straus, 1967) are used to establish analytic distinctions and thus make distinctions at each level of analytic work. This involved first making comparisons within the same interview noting similarities and differences and progressing to compare statements and incidents across interviews, categories and later existing empirical and theoretical knowledge (Charmaz, 2014). Memo-writing contributes to the credibility and trustworthiness of qualitative research, providing a transparent record of meanings made from data (Groenewald, 2008). The use of a reflective journal aids critical self-reflection on the content of memos and corresponding generation of codes/categories (Ortlipp, 2008). These features specific to constructivist grounded theory will be discussed in greater detail in section 2.9.2.

2.5 PERSONAL AND PROFESSIONAL REFLEXIVITY

Reflexivity as termed by Elliott *et al.* (1998) as 'owning one's perspective', defines the process of the researcher's self-reflection throughout various stages within the research (Charmaz, 2014). It

enables the researcher and the reader to determine how understandings and interpretations have been made and the possible influence of the researcher's preconceptions. In this way, reflexivity promotes transparency of the co-constructed meaning and acts as a conduit between the participant and researcher (Charmaz, 2014; Allem, 2014). Qualitative methods differ in the emphasis they place on reflexivity in research (Willig, 2008).

In constructivist grounded theory reflexivity is central to the process whereby the researchers' interests, positions and assumptions are felt to influence the inquiry (Charmaz, 2014). Indeed, standpoints such as race, gender, class, age and culture may influence preconceptions about what a particular experience means and may permeate an analysis (Charmaz, 2014). Therefore the process of becoming aware of preconceptions is considered imperative in constructivist grounded theory and can serve to acknowledge and minimise the extent to which these determine what we attend to and how we make sense of experience. In order to make transparent to the reader, the interests, positions and assumptions of the researcher are provided in a statement of position is provided below (section 2.4.1.1). An example taken from the main researchers reflective journal is also provided (Appendix A) which serves to make transparent reflections made at different time points throughout the research process.

2.5.1 POSITION OF AUTHOR

I am a 31 year old female of a white English background having re-located to South Wales in 2012 from the South East of the UK. I align myself as having an English background from Irish parentage. I am in my final year of a doctoral training in Clinical Psychology and recently returned to the course from a period of maternity leave. I have an academic background in psychology (BA Psychology & MSc Forensic Psychology) and clinical and research experience in mental health settings. Prior to training I worked in a Medium Secure Unit and a Learning Disability Team for Children where a common strand between the two emerged for me - enabling the telling of individual's stories and advocating for their rights.

These notions have been furthered through my elective placement in a forensic Child and Adolescent Mental Health Service (CAMHS). I have become increasingly aware of the lack of resources for these young people and prejudice against them, which I believe to be influenced by negative and punitive media discourses. This has fuelled my belief in advocating and ensuring the voice is heard for populations at risk of societal stigma. I have become aware of the volume of developmental trauma in these young people's lives. I feel particularly aligned with notions of

trauma and neglect, coupled with ideas borrowed from attachment theory when seeking to understand others' experiences. My current placement exposes me to individuals who have not been able to adjust and cope with developmental trauma and this has made me at times question the impact of trauma on outcomes and well-being. However, I am equally aware that my current clinical work exposes me to a very specific population, where I am only witnessing those predominantly severely traumatised and exhibiting the extremes of behaviour and affect as a result of their past experiences.

The author is aware that the majority of her experience of individuals experiencing a psychosis is drawn from her pre-training experience in the medium secure setting. The medical model was widely endorsed within this setting and therefore initial views of psychosis were no doubt shaped accordingly. However, as my interest in clinical psychology deepened I became aware of the social construction of labels such as schizophrenia and arguments around the validity of the diagnostic process as a whole. I believe my scepticism around mental illness as an objective truth was also influenced by teaching, reading and placement opportunities which increased my knowledge of narrative therapy and associated ideas of social discourse. Pursuing my training also furthered my interest in positive psychology and the belief that despite overwhelming adversity human beings are capable of adjustment.

A reflective journal was completed by the author throughout the research process to make explicit such beliefs and preconceived ideas as outlined above. The principles of bracketing described by Ahern (1999) have been used to inform this statement. It is suggested that the principles of bracketing occur throughout from preparation to post-analysis. This necessitates the researcher engaging in continued reflection of personal interests and values in relation to the research which enables bias to be addressed through for example re-analysing the transcripts (Ahern 1999). The researcher also adopted the process of reflecting on factors such as whether one participant is quoted more frequently than others and considering any potential bias that may have been involved in this in addition to considering how supporting literature is selected when reporting the theory.

2.6 CLINICAL GOVERNANCE

2.6.1 RESEARCH & DEVELOPMENT (R&D) AND ETHICAL APPROVAL

The research received favourable ethical approval by the National Institute for Social Care and Health Research (NISCHR) Research Ethics Service for Wales (Appendix I). Scientific approval was granted by Cwm Taf University Health Board (Appendix K) and Aneurin Bevan University Health

Board (Appendix J). The researcher undertook a Good Clinical Practice and Regulatory Requirements for Clinical Trials course prior to the commencing the study. This course provided an overview of clinical governance procedures and ethical issues pertaining to research with a clinical population. Relevant ethical considerations are outlined below.

2.6.2 INFORMED CONSENT

Consent capacity for those who experience a psychosis have been studied more extensively than for any other mental health condition (Candia and Barba, 2011). Early research conceptualised ability to give informed consent as a static epiphenomenon of the illness syndrome (Benson, Roth & Winslade, 1985). However, more recently studies suggest only modest correlations with psychotic symptoms and more strongly with cognitive dysfunction (Palmer *et al.* 2004; Saks *et al.* 2002). Various strategies were employed to ensure that individuals were in a position to provide fully informed consent. Inclusion criteria were developed to exclude those with cognitive impairments including a learning disability and/or other neurological condition and those whose decision making ability may be hampered by significant mental health problems (e.g., receiving treatment under the Mental Health Act and/or currently involved in a crisis team) and/or those who are using substances to a degree that it is deemed to impair decision making as defined by the involved care co-ordinator/manager.

Guidelines developed by the British Psychological Society (BPS, 2009, 2011) and the Health and Care Professions Council (HCPC, 2012) informed the consent procedure. This ensured that participants received adequate and accurate information about the research and their involvement at various points to ensure informed consent. Care co-ordinators/service managers in each of the Health Boards discussed the research with service users and provided the information sheet (Appendix O). The information sheets included the following information: background to the research; aims and objectives; a description of why they have been invited; what participation would involve and processes; freedom to dissent, and withdraw at any time with no implications on treatment and service provision; confidentiality and anonymity; risks and benefits of participating; financial reimbursement; contact details of researchers involved and process and contact details to lodge concerns about the research. Care co-ordinators were asked to read the information sheet aloud for any service users with reading difficulties. This was not necessary for any of the participants involved in this study. Individuals with a learning disability were not included in this study. From receipt the participants were given two weeks to consider the information sheets before being contacted either via telephone or during their next clinic appointment. If the participant agreed to partake their contact details were then provided to the researcher.

Participation in the study required a re-reading of the information sheet in the company of the researcher (with the option of the researcher reading it aloud if preferred). This process allowed the researcher to consider whether the participant had sufficient decisional capacity to consent to be involved in the research. If consenting, the participant was required to sign and date the consent form (Appendix M) after having read and initialled 10 statements.

2.6.3 CONFIDENTIALITY

Legislation and professional guidelines that informed the design and processes involved in the study, includied: the British Psychological Society Code of Human Research Ethics (BPS, 2011); the British Psychological Society Code of Ethics and Conduct (BPS, 2009); Data Protection Act (1998); and the HCPC Code of Conduct (2012). At the outset of the study each participant was asked to provide a preferred pseudonym to be used to identify the transcripts, completed questionnaires and appended quotes in the final write-up. Demographic information obtained from participants was in the form of ranges and categories of information (e.g. age ranges) as opposed to specific information so as to protect participant identities. Any other potentially identifiable information was altered during the transcription process (e.g., names of services and specific geographical locations). With regards to process matters, the interviews were tape recorded using a digital Dictaphone and deleted immediately following transcription. Printed transcripts and completed questionnaires were stored in a locked filing cabinet in line with the Data Protection Act (1998).

The participants were made aware of the limits of confidentiality during the consent process and were required to acknowledge this again when completing the consent form (see point 9 of consent form). Immediately following the consent process participants were asked to complete the demographic information form (Appendix N) including contact details for the GP. A risk management protocol was established to ensure the safety of the participants, which is outlined in the following section.

2.6.4 ENSURING PARTICIPANT WELFARE & RISK MANAGEMENT STRATEGY

At the outset the researcher outlined the following points: that the participant should only talk about subjects they feel comfortable sharing; the participant has the right to terminate the interview at any point and not return to it; and the participants has the right to request breaks. The researcher was able to manage any distress should it occur in the interview through brief emotional support. Given the recruitment strategy it was likely that participants were in receipt of support (e.g. third sector or an NHS secondary service provider). If sufficient concerns regarding the participants' well-

being emerged during the interview this information was to be shared with relevant involved and/or external professionals (e.g. GP, Police and Crisis services). If concern was raised participants were to be informed of the protocol that the researcher was bound to follow (unless this was to the further detriment of the individual's safety). It was not necessary for the protocol to be activated for any participants. All participants were offered a verbal de-brief at the end of the interview which centred on: exploring participant's emotional affect; sign-posting; and distraction and grounding techniques (e.g. discussing with the client their plans for the rest of the day with a particular focus on time and place).

The interview invited the participants to focus on a period of time following the psychotic episode and what has changed since for them, therefore participants were not invited to discuss the more distressing elements of their experience. As discussed further in Chapter 3 & 4, many participants referred back to their crisis point despite the researcher reiterating aims at the outset of the interview. Where this occurred, the researcher allowed the participant to express their story and offered validation before proceeding with the remaining questions from the interview schedule. Following the interview each participant completed the Warwick Edinburgh Mental Well-Being Scale which was scored following completion of the interview and any participants scoring particularly high were then offered sign posting to relevant agencies (e.g. MIND; Hafal).

2.7 PARTICIPANTS

2.7.1 SAMPLE

The term 'psychosis' is a contentious construct often comprised of incongruent ideas and knowledge of what it means (Barker *et al* 2010; Bentall, 1990). This study recruited individuals who self-identified as having had a ROP (defined as 'an experience of hearing voices, seeing things or having unusual fixed thoughts' to a degree that impairs functioning). Perhaps due to the nature of the recruitment strategy, the majority of the participants had received a diagnosis and/or were in receipt of ongoing support from services. The participants were recruited from NHS secondary care service EIS and one was recruited from a third sector organisation. The services were within South Wales. Participant demographics (section 2.7.3) and additional participant descriptions (section 2.7.3) are provided.

2.7.2 INCLUSION AND EXCLUSION CRITERIA

In order to be eligible to participate in the study individuals were required to satisfy the following criteria:

- Be a person who self identifies with having experienced a ROP no less than 6 months previously
- Be accessing the relevant recruiting agencies (e.g., 4 Winds; Hafal; specified NHS secondary care services)
- Be an adult (defined as being over 18 years of age)
- Be a person with the capacity to understand information provided detailing the study and requirements of participation and consent to partake
- Be sufficiently fluent in English to engage in an interview for a period of up to one hour

For the purpose of ensuring informed consent and to maintain homogeneity of the sample the following exclusion criteria were specified:

- Those who use substances to a degree whereby it is felt to limit their ability to provide informed consent
- Those who self-identify with having experienced clearly isolated and discrete subsequent episode of psychosis
- Those currently involved in a crisis management team and/or receiving care under the Mental Health Act
- Those who have a learning disability and/or neurological condition.

Table 4 Characteristics of Sample Interviewed

	Pseudonym	Age	Ethnicity	Diagnosis	Self-reported symptoms	Duration of symptoms	WEMWBS Score*	PTGI Subset Scores**					
								Relating to others	New possibilities	Personal strength	Spiritual change	Appreciation of life	TOTAL ***
1	Simon	40-49	Caucasian, Welsh	Schizophrenia	Hallucinations (auditory and visual)	Ongoing	30	3.6	2.6	3.8	4	3.7	72
2	Geoffrey	30-39	Caucasian, Welsh	No	Hallucinations (auditory and visual); delusional thoughts	2-3 months	35	0.7	0	0.8	0.5	1	12
3	Peter	20-29	Caucasian, Welsh	Schizophrenia	Hallucinations (auditory and olfactory)	8 months	48	3.4	4.2	2	2	3.3	68
4	James	20-29	Caucasian, Welsh	No	Delusional thoughts	5 weeks	61	3	4.2	3.3	2.5	3.7	71
5	Chris	30-39	Caucasian, Welsh	Schizophrenia	Hallucinations (auditory, visual and tactile) and delusional thoughts	6 weeks	36	3.3	3.6	3.5	4.5	2.6	72
6	Kelly	30-39	Caucasian, Welsh	Schizophrenia-NOS	Hallucinations (auditory and visual) and delusional beliefs	1 year	41	4.4	3.2	3	3	3.3	72
7	Lucy	20-29	Caucasian, Welsh	'Psychosis'	Hallucinations (auditory) and delusional thoughts	3 months	56	4.6	5	4.3	4	5	97
8	Rich	20-29	Caucasian, Welsh	'Psychosis'	Hallucinations (auditory)	Ongoing	43	2.6	1.8	2	0	1.7	63

*Note: *WEMWBS scores range from 14-70 with a higher score indicating a higher sense of well-being. There are no 'cut off scores' but a population mean score with an English population has been found scores between 50.9 -52.4 (NHS Health Scotland, 2016); ** PTGI scores is the average of scores for each subtest ranging from 0-5 with a score of 5 as indicative of endorsing the subset area of change to a very great degree; ***Total score represents the total across all of the subtests areas, scores can range from 1-126 with higher scores reflecting greater perceived growth.*

2.7.3 PARTICIPANT DEMOGRAPHICS

Eight participants took part in the study. All of the participants resided in South Wales and were of a white Welsh background. Six participants were male and two female and the majority were aged between 20-29. Six had a diagnosis at the point of interview, half having a formal diagnosis of schizophrenia. Symptoms experienced by the participants included: visual, auditory and/ or olfactory hallucination; and delusional thoughts. The majority of the participants experienced more than one of these symptoms. The time period in which participants experienced symptoms ranged from 5 weeks to ongoing. Demographic information of each participant is summarised in table 4.

2.8 PROCEDURE

2.8.1 RECRUITMENT PROCEDURE

The study received ethical and scientific approval. The researcher sought the engagement of stakeholders by attending team meetings at the respective NHS EIS and a meeting with a manager from a third sector service user led organisation. The rationale of the study including inclusion criteria was discussed. Care Co-ordinators and managers then reviewed their caseloads independently identifying service users who met the criteria. During their next meeting with the service user they provided a brief overview of the project and the Information sheet (Appendix L). The participants were then given a 'cooling off' period of at least 14 days to read the information provided and consider whether they wished to partake. After this period there was a follow up by the care co-ordinators/manager either in person at their next appointment or via telephone. If they agreed to partake their contact details were given to the researcher. A convenient time was arranged to conduct the interview. All interviews took place at an NHS or third sector establishment during office hours. A total of 6 service users declined to partake in the study following identification for suitability, thus indicating that the process was not coercive in nature (Palmer & Ward, 2007). Reasons for declining included a decline in mental health and travel difficulties. Once participants arrived at the venue the information sheet was again reviewed with participants being given the opportunity for the researcher to read it aloud. Participants were given the opportunity to ask questions. If partaking, the participant was then asked to read and sign the consent form.

2.8.1 QUESTIONNAIRES

Prior to the commencement of the interview, each participant was asked to complete a demographic information questionnaire (Appendix N). Following the interview procedure the participants were asked to complete two psychometric questionnaires: The Warwick-Edinburgh

Well-Being Scale (WEMWBS) and the Post-Traumatic Growth Inventory (PTGI). The completion of these measures enabled the researcher to situate the sample.

2.8.2 THE WARWICK EDINBURGH WELL BEING SCALE (WEMWBS: TENNANT, ET AL. 2007)

The WEMWBS is a 14 item tool provides an indication of well-being (as opposed to mental illness or disorder). It assesses two aspects of well-being: positive feeling (feeling of optimism, relaxation and cheerfulness); and positive functioning (energy, clear thinking, self-acceptance, personal development, competence and development). The 5 response categories can be summed to provide a single score ranging from 14-70. The WEMWBS does not have a 'cut off' score to differentiate levels of well-being. A number of studies have concluded that it a robust and valid measure (Stewart-Brown *et al.* 2009; Gremigni & Stewart-Brown, 201, Lopez *et al,* 2012; Lloyd *et al,* 2012). A marked strength of this measure appears to rest on its use of positive words. A study by Crawford *et al.* (2011) found that individuals with psychosis and affective disorders found worth in the tool and particularly appreciated the inquiry about positive aspects of mental health (e.g. a focus on well-being as opposed to deficits).

2.8.3 POST-TRAUMATIC GROWTH INVENTORY (PTGI: TEDESCHI & CALHOUN, 1996)

The PTGI is a 21 item scale developed by Tedeschi and Calhoun (1996) developed to assess the presence of positive outcomes following a traumatic event. The areas of growth considered in the measure include: relating to others; new possibilities; personal strengths; spiritual change; and appreciation of life. Answers are given on a Likert scale from 0 ('I did not experience this change') to 5 ('I experienced this change to a very great degree') There is no specific cut-off score, although Creamer, Bell & Failla (2003) reported a total score of 33 to be diagnostically accurate. Studies have shown the PTGI to have high internal consistency, good test-retest reliability (Bates, Trajstman, Jackson*,* 2004; Tedeschi & Calhoun, 1996), discriminant validity, concurrent validity, and construct validity (Tedeschi & Calhoun). Results from the PTGI are provided in table 4.

2.9 DEVELOPMENT AND DESIGN OF INTERVIEW

2.9.1 SERVICE USER CONSULTATION

Research demonstrates that the involvement of service users can enhance the quality and ethics of studies (Barber *et al.* 2012). Appropriate guidance and policy publications designed to promote and support good practice were reviewed prior to recruitment of service users. These included: Mental Health Researcher's Toolkit for Involving Service Users (Armes *et al,* 2011); Good Practice Guidance

for Service User Involvement in the MHRN (MHRN, 2013); and Good Practice Guidance for Carer Involvement in Research (Repper, Simpson & Grimshaw, 2012). A Service User Representative with previous experience of psychosis was recruited from a third sector service user involvement organisation in South Wales. The Service User Representative attended two meetings with the researcher before the study began and then provided consultation throughout the research. Consultation was provided on the aims and scope of the research, ethical issues, study documents (e.g. information sheet) and dissemination strategies. Consultation and advice was also provided on the interview schedule through a pilot interview session. The initial interview schedule is discussed below. The consultation provided was invaluable particularly in allowing for explorative discussions of ethical (e.g. use of the term psychosis and personal implications) and conceptual issues (e.g. understanding of psychosis as a chronic remitting illness, and the blurred boundaries of the category of a 'first episode' of psychosis).

2.9.2 INTERVIEW SCHEDULE

This study used individual interviews which aimed to be "open ended yet directed, shaped yet emergent and paced yet unrestricted" (Charmaz 2014, pg 85). In line with the principles of grounded theory, the use of a semi-structured interview schedule aimed to facilitate an in-depth exploration of an individual's experience whilst reducing the risk of the interviewed pursuing their own agenda (Pope, Van Royen and Baker, 2002). An initial draft of the schedule was devised and this was then taken into consultation with the Service User Representative where issues of suitability of language and understanding of the questions were discussed. The schedule was also reviewed by the Academic Supervisor. On a separate occasion a pilot interview was conducted with the Service User Representative. This led to further amendments to the interview schedule, demographic sheet and information sheet. The initial interview schedule is provided in Appendix N. Consistent with the inductive nature of constructivist grounded theory (Charmaz, 2014) the initial schedule was adapted in order to facilitate emerging themes following consultations with supervisors. This occurred after interview 3 to explore further the emerging themes 'finding purpose and meaning' and 'making sense'. Reflections made in relation to the initial questions during a consultation with a supervisor are provided in Appendix A to enhance transparency. The amended questionnaire is provided in Appendix (P).

2.9.2 INTERVIEW PROCEDURE

All research appointments lasted no more than 90 minutes. Once the participant had completed the consent process they were then provided with support to complete the demographic questionnaire.

The interviews were then commenced and lasted an average of 54 minutes (ranging from 45 to 70 minutes). Interviews were audio recorded using a digital dictaphone and data protection protocol was adhered to as outlined in section 2.6.4 to ensure that confidentiality was maintained. Participants were offered a copy of the transcript and summary of results. Completion of the WEMWBS and PTGI followed the interview. The WEMWBS informed the debrief input, specifically the provision of sign posting to ensure that appropriate steps had been taken to minimise any risks associated with the participants' involvement in the study.

2.10 DATA ANALYSIS

2.10.1 TRANSCRIPTION

The researcher made notes, which formed entries in the reflexive diary, during and immediately following each interview. These notes recorded the emergence of thoughts and ideas. Transcription was completed within two weeks of the interview taking place. All interviews were transcribed by the researcher to allow for greater immersion in the data (Charmaz, 2014). Non-verbal communication was noted in the transcripts though non-word utterances were excluded.

2.10.2 ANALYSIS OF INTERVIEW DATA

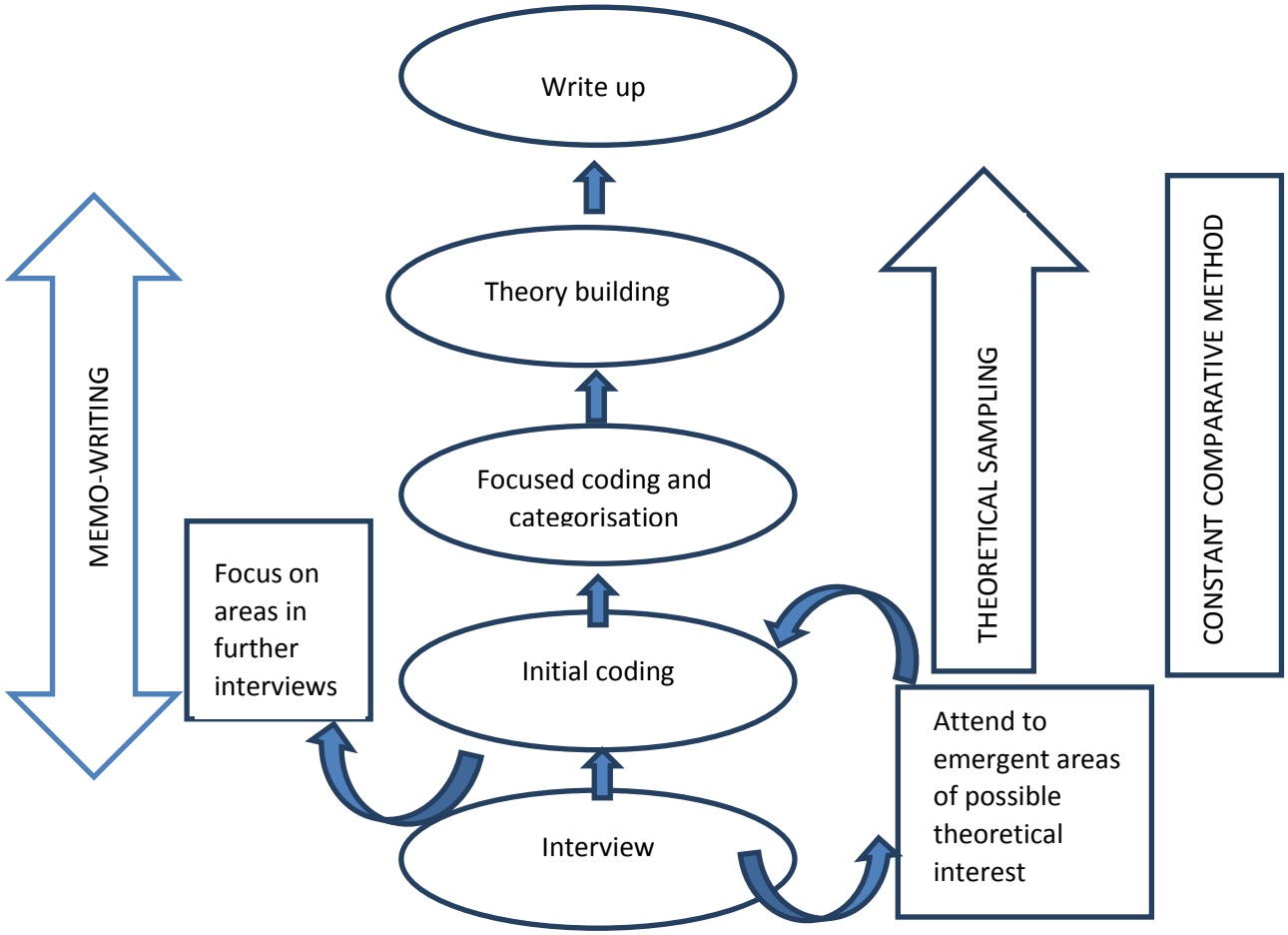
The initial steps of data analysis were preceded by the researcher becoming fully immersed in the data through transcription and multiple readings of the data. A process of analysis then followed as presented diagrammatically below. A narrative account is also provided here.

Initial coding describes the process of naming segments of data with a label that simultaneously categorizes, summarizes and accounts for each piece of data (Charmaz, 2014). Further, coding serves to "*move beyond concrete statements in the data to making analytic sense of stories, statements and observations"* (Charmaz*,* 2014, p.111). Coding is therefore the necessary link between collecting data and developing an emergent idea or theory to explain the data. Codes can portray feelings, meanings and actions. Charmaz (2014) describes the questions that should be posed when conducting initial coding which include: 'what is this data a study of'? (Glaser 1978, Glaser & Strauss, 1967); what does the data suggest? Pronounce? Leave unsaid?; from whose point of view?; what theoretical category does this specific datum indicate? (Glaser, 1978).

A number of different techniques may be used to code the data (e.g. word-by-word; line-by-line; and incident with incident). The researcher used line-by-line coding which involved providing a code for each line of data as this method is believed to work particularly well with detailed data about

fundamental empirical problems or processes (Charmaz, 2014). Coding for implied meaning was completed using gerunds where possible (action focused language). It is a "heuristic device to bring the researcher into the data, interact with them and study each fragment of them" (Charmaz, 2014, p.121). Throughout the process of coding the researcher remained open and reflective about where the data pulled them whilst examining the researcher's past and preconceptions.

Figure 3: Overview of constructivist grounded theory analytic process as adapted from Charmaz (2014).



2.10.3 FOCUSSED CODING AND CATEGORISATION

A secondary phase of coding, termed focussed coding, describes the process of using the initial codes to sift, sort, synthesise and analyse large amounts of data. Furthermore, focussed coding required decisions about which initial codes make the most analytic sense to categorise the data and can involve coding the initial codes (Charmaz, 2014). The aim of this process is to advance the theoretical direction of the work. As the codes were sifted and sorted through focussed coding the researcher attempted to define the properties of categories, its operative conditions, conditions by

which it changes and its relationship with other codes. The categories were therefore composed of codes that shared themes or patterns. Emergent categories in the current study were either descriptive (e.g. 'low mood') or analytic (e.g. 'Post-traumatic growth'). Through an increasing level of abstraction categories and sub-categories were subsumed into higher level analytic categories (willig, 2008).

2.10.4 CONSTANT COMPARATIVE METHOD

Constant comparative methods were employed in this study, as defined by Charmaz (2006) as *'a method of analysis that generates successively more abstract concepts and theories through inductive processes of comparing data with data, category with category, and category with concept. Comparisons then constitute each stage of analytic development'* (p.187). Sampling, analysis and data collection were viewed as a continuous cycle rather than distinct procedural steps (Elliott & Lazenbatt, 2005). The above described processes, of initial, focused and theoretical coding were not therefore linear. At points throughout the analysis the researcher returned to previous data when the implicit became explicit or when new ideas and insight emerged.

2.10.5 NEGATIVE CASE ANALYSIS

The identification of negative cases (e.g. individuals, situations or themes within the data) that refute the developed categories increase the robustness of the research (Charmaz, 2014). Codes that did not fit with developing categories were re-examined and explored in more depth which enhanced the robustness of the research in addition to allowing for the refinement of the emerging theory. Negative cases are described in chapter 3 and 4.

2.10.6 MEMO WRITING

Memo-writing refers to the process whereby the researcher stops, analyses and records any ideas that emerge about their codes and emerging categories (Glaser, 1998). This is a crucial step, that enables the researcher to develop their codes into categories early in the research, maintains an involvement in the analysis throughout the research process and increases the level of abstraction. An example of memo writing can be found in Appendix H.

2.11 TRIANGULATION

Copies of the transcripts following line by line coding were given to the Academic Supervisor prior to a meeting whereby the development of focused codes and categories was discussed. This allowed for any differences in perspectives to be considered. Once the grounded theory was developed it

was shared with the Clinical supervisor. In addition, the results of the psychometric questionnaires, particularly the PTGI was reflected on in order to explore whether they resonated with the theory and in terms of how they situated with the sample. A draft of the emergent theory was discussed with the EIS during a team meeting in addition to the Service User Consultant.

CHAPTER 3: RESULTS

3.1 OVERVIEW OF CHAPTER

This chapter presents the constructivist grounded theory that emerged during the analysis of the interview data. Three key **THEMES** emerged (in bold and underlined and capital font), in addition to 6 **CORE CATEGORIES** (in bold blocked capital font) 22 CATEGORIES (in block capitals) and 14 *sub-categories* (in italics). A narrative summary and diagrammatic summary of the constructivist grounded theory is presented in section 3.2. The concepts are described alongside narrative quotes illustrating and evidencing the constructs.

3.2 SUMMARY: A CONSTRUCTIVIST GROUNDED THEORY OF RE-CONSTRUCTION OF SENSE OF SELF AND PTG FOLLOWING ROP

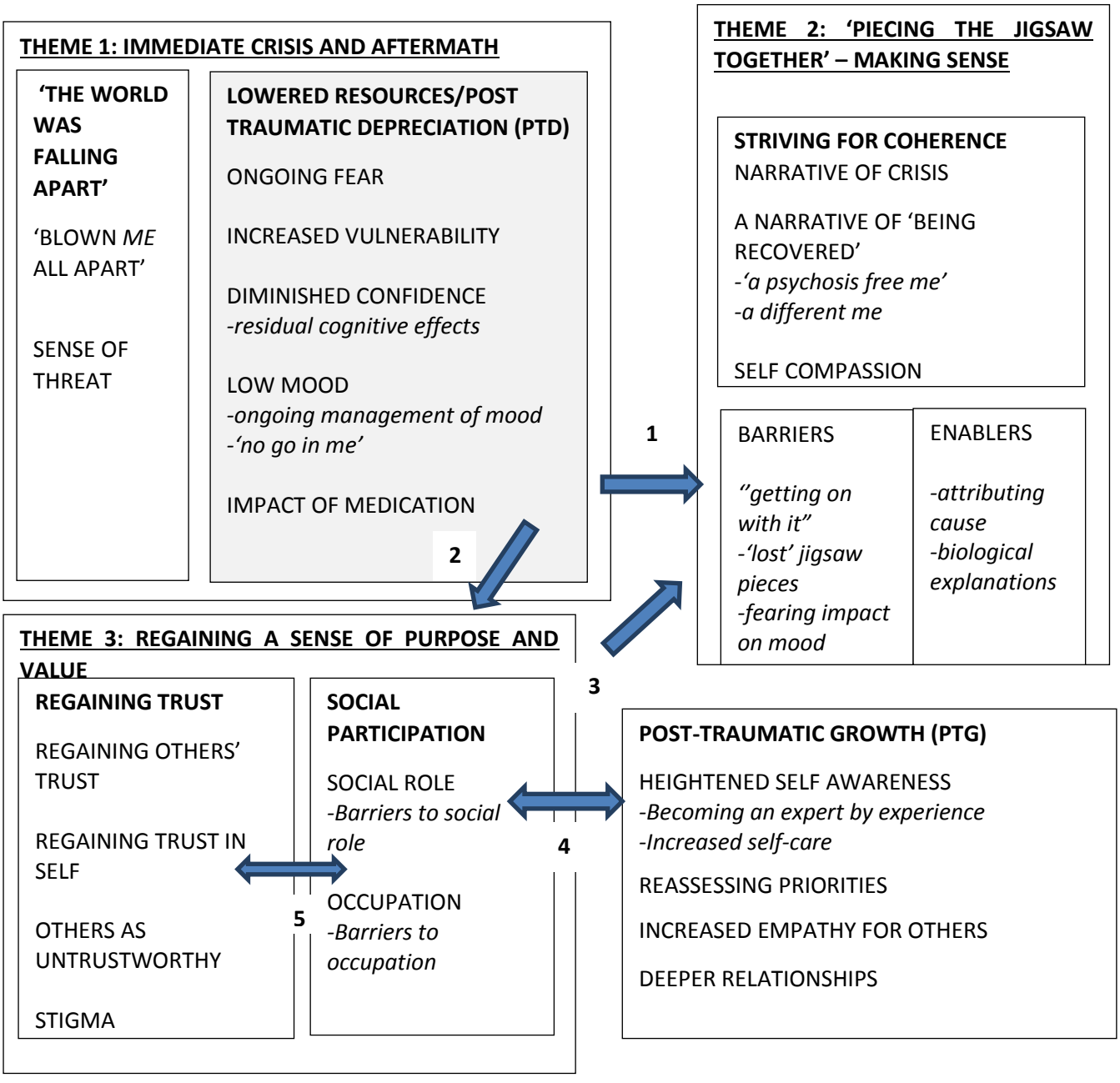
The theory arising from the data reflected participants' retrospective accounts of the psychotic 'crisis' and its immediate and ongoing consequences **(IMMEDIATE CRISIS AND AFTERMATH)**. The crisis point is described by the core category **'THE WORLD IS FALLING APART'** and marks participants' reflections of a shattered sense of self ('BLOWN *ME* ALL APART') and overwhelming SENSE OF THREAT. Participants' main concern appeared to be regaining a sense of self with 'recovery' being secondary to this. Participants went about reconstruction the self by '**PIECING THE JIGSAW TOGETHER' – MAKING SENSE** to create both a NARRATIVE OF THE CRISIS and a NARRATIVE OF 'BEING RECOVERED'. The making sense process was hindered however through **BARRIERS TO COHERENCE**, including: '*fearing the impact on mood*', the drive to '*get on with it*' and perceptions of a fragmented or unreliable memory of events preceding, during and immediately following the 'crisis' ('*lost jigsaw pieces'*). Central to rebuilding a sense of self was the process of **REGAINING A SENSE OF VALUE AND PURPOSE.** This involved REGAINING TRUST, specifically: REGAINING TRUST IN SELF; REGAINING OTHERS' TRUST; and managing perceptions of OTHERS AS UNTRUSTWORTHY. The task of regaining trust was undermined by external and internalised STIGMA. Additionally**,** participants regained a sense of purpose and value through **SOCIAL PARTICIPATION** which involved regaining an element of a perceived 'normal' lifestyle and engagement in SOCIAL ROLES and OCCUPATION.

Participants described **POST-TRAUMATIC GROWTH (PTG)** in the areas of HEIGHTENED SELF AWARENESS, REASSESSING PRIORITIES, INCREASED UNDERSTANDING FOR OTHERS and DEEPER

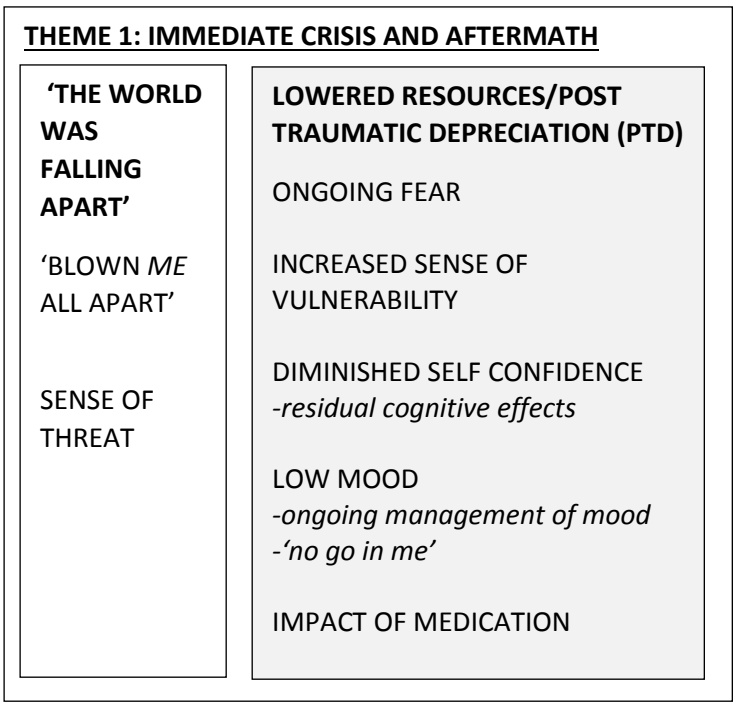
RELATIONSHIPS. However, the majority of participants did not appear to contemplate these changes with particular enthusiasm or sense or importance. Rather, participants were more concerned with immediate and ongoing **LOWERED RESOURCES/POST-TRAUMATIC DEPRECIATION (PTD)** such as ONGOING FEAR, INCREASED VULNERABILITY, DIMINISHED CONFIDENCE, LOW MOOD AND IMPACT OF MEDICATION. These factors form a context to the process of recovery and the re-construction of the self. They appeared to negatively influence the processes initiated by participants aimed at regaining a sense of self, including meaning making and regaining a sense of purpose and value. Elements of PTG (as outline above) resulted from engagement in the processes aimed at re-construction of the self.

Theoretical saturation of the above theory whereby "no new properties of the pattern emerged" (Glaser, 2001, P.191) occurred in interview 7.

Figure 4: A constructivist grounded theory of the re-construction of sense of self and PTG following a ROP



3.3 THEME 1: IMMEDIATE CRISIS AND AFTERMATH



This theme reflected participants' narratives of the point of crisis and the immediate aftermath. It represented participants' reflections on their recent onset of psychosis (ROP) and generated the core category **'THE WORLD WAS FALLING APART'.** Their reflections captured the most distressing elements of the experience which was described by many as the 'crisis' point. Participants' tone and words conveyed a sense of importance and urgency for their story to be heard (please refer to the Reflective Journal, Appendix A). Indeed, nearly all participants were candid and open in sharing their experiences of psychosis. The process of discussing their immediate experiences of the crisis appeared to be important to each participant and enabled them to explore further how they managed throughout their ongoing recovery. Participants described the consequences of the crisis in terms of **LOWERED RESOURCES** and **POST TRAUMATIC DEPRECIATION.** This core category represented a contextual category which limited perceptions of progress in recovery and engagement in processes attached to that. This included: **PIECING THE JIGSAW TOGETHER- MAKING SENSE. -** This is represented in the diagram as arrow 1 and is evidence through quotes 5; 6; 7; 14; 15; 43; 45); in addition to **REGAINING A SENSE OF PURPOSE AND VALUE) -** This is represented by arrow 2 and evidenced through quotes 16; 17; 18; 19; 25; 26; 27; 32; 37).

Recognition of growth (which emerged as a result of engagement in said processes) was also directly reduced as participants were more concerned with the distress arising from depreciation/lowered resources.

3.3.1 CORE CATEGORY: 'THE WORLD WAS FALLING APART'

This core category was characterised by an overall sense of internal and external crisis. Participants described the crisis as being a catastrophic event, which interrupted and changed the course of their lives at that point. There was a general sense of chaos. This seemed to continue for many throughout their early treatment experiences with tacit references to feeling helpless and out of control. Participants were able to retrospectively identify various cumulating factors that led up to the psychosis however at the point of the crisis the events were perceived to unravel in a sudden, unexpected and catastrophic manner.

> *"it was just like crashing everywhere and I didn't know where to turn and at first it was like it just gradually sort of built up then and over a couple of days cos I weren't sleeping I weren't eating you know" – Chris: 1*

> *"I thought the world was falling apart and that we were not an apocalypse but something was going to happen erm like economy collapse or something was going to happen – Geoffrey: 2*

> *"They took me down to [hospital name] and when they saw my neck, because it was open wounds at the time, they just all came in to the room at the same time. They put drips in my arm and things like that. They then sent me straight here" – Kelly: 3*

> *"I went to choir and then astronomy club and doing all the things and then my life was changed and I felt happier until obviously I had my psychosis you know it changed me then to sort everything just went upside down it sort of went boom boom" – Chris: 4*

3.3.2 CATEGORY: 'BLOWN *ME* ALL APART'

The phrase by Geoffrey – "BLOWN *ME* ALL APART" - best reflects this category because it captures participants' reflections of the devastation to their sense of self during the crisis period. Participants described the sudden shattering of previously held ideas of themselves (e.g. perceptions of their own personality; religious beliefs and perceptions of self as strong/capable). There appeared to be a general move from viewing the self as one cohesive structure to being in some way fragmented – as one participant described into "different personas" (Peter). There was a general sense of the participant's re-evalating their previously held notions of themselves, which generated feelings of doubt and uncertainty. The impact of the psychosis on the self was experienced by the participants with fear and confusion.

"it's scary and like when you look back it's probably even more scarier, at the time it is just it changes you I think at the time for me, my personality become more outgoing, when I'm usually quite shy and quiet person, erm that made me louder, yeah I didn't like going out, but then I was saying random things that didn't really make sense, and things like that so my personality has changed again" – Geoffrey: 5

"oh yeah I'm still struggling with my identity I think at that point so I'd have different personas, and cos, I, it would depend on who I was with as well, so if there was louder patients that I was in with, I would put on a different persona, cos I wanted to fit in and if they were quiet then I could be me and so you know it all was a bit confusing" – Peter: 6

"*where I cut my wrist I cut off the feeling to three fingers, well the two fingers and thumb and you know was that a part of myself which I tried to destroy when I tried to kill myself? I mean it's difficult to kind of know what the self is and some people with schizophrenia have that kind of problem where they you know, you know where they are not able to be themselves" – Peter: 7*

"I feel like I'm living in a different body… I feel like I'm in somebody else's body." – Rich: 8

3.3.3 CATEGORY: SENSE OF THREAT

A sense of immense and overwhelming threat and fear was experienced by participants primarily in relation to their symptoms of psychosis, but also in terms of treatment experiences. Participants spoke of the fear relating to visual and auditory hallucinations and delusions, and the overriding threat to one's sense of safety. Some of the participants implied an inability to escape or find a place of sanctuary leading to despair. One participant (Kelly) reflected on her experience of severe self-harm in relation to delusional beliefs and her sense of being petrified as a result of this.

"I was frightened myself you know cos I thought I was going to combust cos every time I ate food I thought I was going to combust and that frightened me after you know and that's why in the beginning if I ate so much then I wouldn't eat and then I wasn't sleeping and then like nightmares came of hell all the time you know literally they were nightmares, you know I'd wake up like that I was shaking you know and I couldn't sleep I wouldn't sleep then and then the voices came and I was suicidal" – Chris: 9

"I was petrified. Yes. I cut my neck. This was in the later stages of it. And I had to walk to the Severn Bridge to jump off at a certain time. This one I did, at first, the first cut on my neck was to try and die in bed so I didn't have to go to the Severn Bridge. The second time I cut my neck it was so that it would be even and I would have fish gills ready for when I was under water as a zombie" – Kelly: 10

"I was watching the religion channels and it was just so horrific, there was one night and I still remember it I was lying on the settee and my mum was watching it and she seen just normal tele and I seen just his face melting as he was reading the bible" – Chris: 11

"I didn't think it was safe anymore and where I live, when I, when I did go into psychosis I wanted to get out, I wanted to go somewhere else so I didn't feel safe" – Geoffrey: 12

3.3.4 CORE CATEGORY: LOWERED RESOURCES/POST-TRAUMATIC DEPRECIATION

This core category reflected the negative impact that psychosis had on participants' resources and ongoing Post-traumatic Depreciation (PTD) following the immediate crisis. The theme included the four categories: ONGOING FEAR, INCREASED SENSE OF VULNERABILITY, DIMINISHED CONFIDENCE, and IMPACT OF MEDICATION. Some participants reported experiencing these consequences immediately following the crisis whereas others reported noticing them as an ongoing experience within their recovery period. The core category can be thought of as contextual category in which participants went about their recovery processes of making meaning and regaining a sense of purpose and value. Therefore, the process themes **'PIECING THE JIGSAW TOGETHER'** and **'REGAINING A SENSE OF PURPOSE AND VALUE'** are threatened by the impact of **LOWERED RESOURCES/PTD,** as is the outcome core category perceptions of **POSTTRAUMATC GROWTH (PTG).**

3.3.5 CATEGORY: ONGOING FEAR

This emergent category reflected an ongoing sense of horror and fear that the participants experienced in relation to the symptoms they were exposed to in the crisis period. The fear related to memories of their symptoms experienced during the crisis. Ongoing fear was experienced to varying degrees, and for some participants there seemed to be elements of fear which could be associated with PTSD symptoms (e.g., intrusive flashbacks; nightmares). Participants spoke of this fear as increasing their overall level of anxiety and as having a negative impact on their sense of well-being, recovery and occupation/social engagement.

> *"it's scary, and like when you look back it's probably even more scarier" – Geoffrey: 13*

> *"You know it has changed me in a way a bit of a lot. After the psychosis I think I'm more on edge than anything you know there's a bit of anxiety they say there's a little bit of it but to me it feels like I got a lot of anxiety cos if they see the things that I saw they would be quite frightened" - Chris: 14*

> *"it actually changed me from that moment then that's when the nightmares started coming in and of hell and all that and it was horrible you know" – Chris: 15*

3.3.6 CATEGORY: INCREASED SENSE OF VULNERABILITY

An overall feeling of vulnerability persisted since the crisis. Perceptions of vulnerability related to an ongoing awareness of possible future episodes of psychosis/onset of symptoms in addition to the consequences that this may have for them (e.g., hospital admission, increased suicidal behaviour). Within this there seemed to be a sense of loss of control and limitation of choices.

"*What isn't helpful is I need, or I want people to be with me all the time when I go out. That's not just because of the psychosis" – Kelly: 16*

"I probably a weaker person than I was. And like I say I lost loads of interests, I don't take enjoyment, my self-esteem gone down" – Geoffrey: 17

"*I've done three very serious attempts with over 200 tablets they said if you do it again we're going to put you in a residential home and I'd lose my cat and my car and I'd lose a lot of stuff" – Simon: 18*

"It's very easy to take advantage of the fact that someone's in a mental health ward and tell them you know what the score is if that makes sense you know" – Peter: 19

Contrary to this, one participant (Simon) noted increased vulnerability in terms of risk of future suicide attempts, yet also recognised a sense of inner strength. Simon spoke of appreciating the 'small victories' and celebrating these as an achievement. There seemed to be a sense of reappraising one's targets and goals into small manageable tasks so that one can derive a sense of achievement and enjoyment from succeeding with these. It might be worth noting here that Simon, unlike the other participants, was recruited from the third sector and could be considered as being further into his recovery.

"If I can do it once I can do it again. And they're [the voices] are like yeah you just got lucky that's all, you know you really just got lucky, I go you know I beat you that time. I beat you. If you do something and the voices tell you not to do it and you do it, I say go and buy yourself a bar of chocolate, or a packet of crisps or a cup of coffee or something, you know reward yourself, yeah…yeah it only a small battle, haven't won the war, I'm unlikely to win the war but its small battles, another one you've lost, I've won" – Simon: 20

A second participant spoke of feeling stronger having come through the psychosis. However, this was expressed with a cautionary stance:

"Even if something happens sort of in reality what's going on in your own head is about as bad as it can get I think so when it feels like a really dark place in your head and horrible I think sort of coming out of that does make you feel sort of stronger" – James: 21

3.3.7 CATEGORY: DIMINISHED CONFIDENCE

Participants discussed a perception of diminished self-confidence as a result of their experience of psychosis. Persistent and ongoing reductions in self-confidence influenced perceptions of progress in recovery so that achievements that were being made were often not attributed to oneself. An exception was in the account of one participant (Simon) who spoke of reassessing goals and celebrating the 'small victories'. Lack of confidence for the remaining participants manifested in a

reduced perception of ability to reach occupational aims. Geoffrey describes a lack of confidence in his personality and in perceptions of who he has become since the psychosis. The majority of participants attributed the reduction of confidence to residual cognitive deficits from the psychosis and the impact of these in engaging in tasks and with others.

> *"I was quite self-confident because I had listened to the Buddhist talks and self-affirmations on YouTube and I was in a good place before it started" – Kelly: 22*
>
> **"**M*y personality was a better one, more confident" – Geoffrey: 23*
>
> *"I think very often I'm thinking without actual knowledge of what I'm actually talking about you know which leads back to the self-confidence thing – Peter: 24*
>
> *"I'm not so confident in my writing anymore – Kelly: 25*

Sub-category: residual cognitive effects

Participants noted a lack of cognitive capacity following the psychosis and discussed the impact of this on their confidence and functioning in occupational and social settings. Participants described their cognitive difficulties (e.g. lowered ability to concentrate and attend to information) as being noticeable to others and this impacted how they felt others viewed them and consequently their self-confidence. Participants appeared to interpret and accept these cognitive changes as permanent, but the extent of the changes in cognitive capacity and associated impact varied between participants.

> *"my attention and things like that they've noticed and my attention went when I had psychosis still and I couldn't do anything but now I'm better, but I'm still not brilliant but I'm still…"*
> *– Geoffrey: 26*
>
> *"I blame the tablets. Because I'm on Olanzapine now and that's given me writer's block" – Kelly: 27*

3.3.8 CATEGORY: LOW MOOD

Nearly all of the participants described low mood either immediately following or sometime after the crisis point. Participants described this as a 'depression', feeling worthless or helpless. Participants also disclosed other feelings associated with low mood such as frustration, anger and anxiety. One participant (Geoffrey) spoke of experiencing depression as a co-morbidity to the psychosis (i.e. occurring alongside the symptoms of psychosis). This category in particular impacted greatly on how the participants viewed their progress in recovery, how they managed the recovery

processes (e.g., making meaning and social participation) and their perceptions of PTG. Related to LOW MOOD was the *ongoing management of mood* and poor motivation or the feeling of having *'no go in me'.* These are discussed in turn below.

> *"I sort of, the belief as well if I can prove people wrong then I was right all along and that will make my existence validated you know. I mean cos when someone says oh you're wrong well that makes me feel like I shouldn't exist you know" – Peter: 28*
>
> *"Erm depressed. I used to be very positive before I had the psychosis and now I always seem to be negative" – Geoffrey: 29*
>
> "*it's just changed my moods you know one minute I feel great and hey halleluiah and then the next and depressed and angry or frustrated more than anything you know and then the next day I'll be up again" – Chris: 30*
>
> "*if anything it's just the depression really you know it ain't so much the psychosis now it's just more of the depression you know and it's the anxiety is the main thing and if that can go then…"- Chris: 31*
>
> *"more negative outlook on life as well, don't see the purpose really for day to day, I struggle with day to day now, whereas before I'd be out and about and I'd be happy and you know I never, until I had that psychosis, I never questioned anything like that"- Geoffrey: 32*

Sub-category: ongoing management of mood

Participants struggled to manage low mood. There was a sense of an altered life and future as participants 'made room' for the low mood and developed strategies to manage this. For some participants these strategies were informed by professionals and for others they were self-taught. There was a sense of the individuals' need to focus purposeful energy to the task of monitoring and managing mood and of the resulting strain and fatigue. The researcher felt that this sub-category overlapped to some degree with the category *becoming an expert by experience* but that the crucial difference between the two was that this sub category represented the participants' struggle to manage the effects of low mood, whilst *becoming an expert by experience* related to gaining a greater degree of self-awareness.

> *"it's basically like some kind of repeating invasive thought that you know like reminiscence that, er which, er kind of pops into my mind every now and then and sometimes I'll indulge and sometimes I'll just you know just get it out of my head you know and erm you know then I'll you know try to just move on with every day things" – Peter: 33*
>
> *"If you're busy colouring in, your mind isn't thinking over and over. I've got a pile about this big now of colouring books to get through" – Kelly: 34*
>
> *"The voices though they say oh you're condemned you're not worthy stuff like that you know and if I let that continue in my mind it sort of affects my mood than and I sort of go down*

like that and I need to stand up and say I'm not afraid of you and stand up and he sort of backs off in a sense" – Chris: 35

Sub-category: 'no go in me'

Participants described an associated effect of low mood as having 'no go in me' or a lack of motivation. This was experienced as an ongoing struggle to go about their daily routines (e.g. personal hygiene) and engage in social activities. For nearly all the participants this lack of motivation served to reduce their ability to engage in occupation, hobbies and socialising with others.

"Just my personal hygiene. I've got to be nagged to have a shower. I can't be bothered" – Rich: 36

"I used to have more go in me but then when the depression kicks in I just don't do anything you know I used to listen to music to worship songs and that and they used to uplift me and now they just don't uplift me not cos of the psychosis but the depression" – Chris: 37

"I was quite active and my mood is probably low quite all the time now really this, there's moments when I probably have a good day but more often than not its low mood and unhappy and depressed really" – Geoffrey: 38

"I've got a big pile of paperwork at my auntie's and I can't be bothered to sort through it. It's there, but I don't want to go through it so I'll be there sat for hours with this paperwork pile going up" – Lucy: 39

Participants contrasted this to their former pre-psychosis self and remarked on their disappointment and frustration with the impact on their routines. However, there was an overall sense of resignation to a life changed and an acceptance of a loss of energy or 'no go in me', with it being almost perceived as a natural consequence of psychosis.

"I had to have these specific goals which I wanted to achieve and I'd work towards relentlessly and never mind what got in the way of achieving those goals erm I do miss that approach" – Peter: 40

"I just need to forget the world for a minute and go to sleep and that was a negative cos I get frustrated that I'm not going out and enjoying myself where I just don't want to, I just wanna curl up and just be left alone really" – Geoffrey: 41

"If it wasn't for my appointments and meetings I would be in bed. But my ideal self would be to have more energy and more motivation – Kelly: 42

3.3.9 CATEGORY: IMPACT OF MEDICATION

Participants spoke of the impact of medication on their progress in recovery. Specifically, how they perceived it to reduce their ability to engage in occupation and recreational tasks which served to provide them with a sense of achievement and/or well-being. One participant spoke about the impact of medication as jeopardising his sense of who he was as he believed it responsible for changes in his personality. Another spoke of how he believed medication to be used by professionals as a way of control and/or to manage risk. There was a sense that medication hindered recovery. Participants described feeling as though they could not attribute their progress to themselves whilst taking medication. They described not being able to 'test out' their progress due to a belief that the medication was continuing to mask difficulties.

> *"After I came out of hospital I think the medication was the biggest thing that changed me it really sort of sort of set me off balance it sort of made my brain do the opposite of what I classed as normal so I didn't like I didn't really agree with it and it I wasn't really happy and I just felt unnatural and I know that's not my personality it's not how I'm designed to be erm so that was probably the worst bit but then when I came off the medication I kind of didn't feel all that different to be honest than what I class as normal and I suppose now cos it's been a while" – Peter: 43*

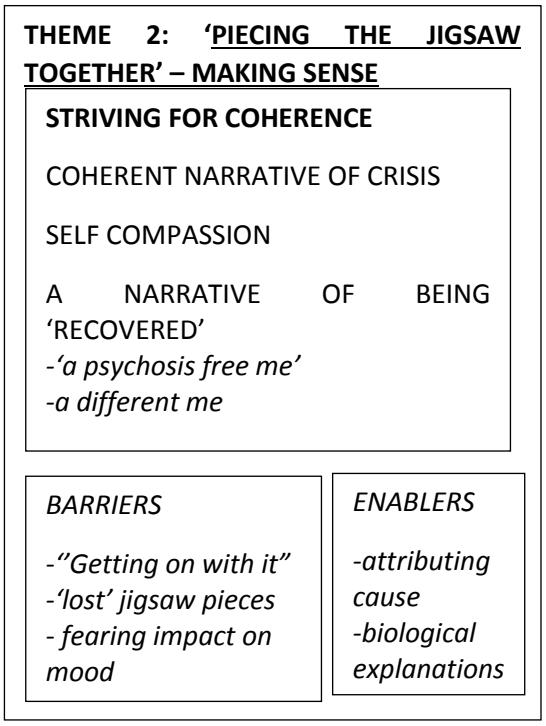
> *"if I told my psychiatrist that she'd say.. ok we've got to up his medication, zonk him out or bung him in a crisis house" – Simon: 44*

> *"I think it's still ongoing for me erm cos I'm still on medication so I'm still, I don't know what effects are still there for me erm and what the medication is controlling so the end will be when I'm off it for me I think. I think I'll think right I'm back to me, but that hard anyway is being on medication, I find that quite difficult erm but we wait – James: 45*

One participant (Peter) recognised that medication can help at times although this belief was doubted

> "*they [professionals] don't really have all the answers, but you know medication has helped I think, for in my instance but you question that as well" – Geoffrey: 46*

3.4 THEME 2: 'PIECING THE JIGSAW TOGETHER' – MAKING SENSE



Participants spoke of the process of making sense of their experiences of psychosis. This was described as a necessary component to recovery for many and instilled a sense of SELF COMPASSION. Making sense for many represented **STRIVING FOR COHERENCE** to re-gain a COHERENT NARRATIVE OF THE CRISIS and a NARRATIVE OF BEING 'RECOVERED'. Sense making was hindered by the contextual theme **LOWERED RESOURCES/PTD.** For example, participants described how an INCREASED SENSE OF VULNERABILITY led to a sense of trepidation regarding the extent to which they engaged in the 'looking back' and reflecting on the past for fear that it would have an adverse effect on their mood (*'fearing impact on mood')* and general well-being. Specific sub-categories also acted as BARRIERS in creating coherent narratives, including a drive to *'get on with it'.* This was an approach which seemed to emphasise practical recovery in line with the medical model understanding of recovery, which leaves little room for reflection. The sub-category 'Lost jigsaw pieces' represents participant's struggle to gain a COHERENT NARRATIVE OF THE CRISIS. It refers to missing pieces of information due to the participants' ongoing questioning of the reality of their past experiences and/or amnesia of certain events around the crisis period. Enablers to creating a coherent narrative of the crisis included 'attributing cause' and 'biological explanations'. Furthermore, SOCIAL PARTICIPATION and OCCUPATION influenced the process of making sense (**PIECING THE JIGSAW TOGETHER: MAKING SENSE**). Participants spoke about how new roles, occupation and engaging with others contributed to their ongoing sense making process as

evidenced through the following quotes: 58; 69; 72; 81; 82. This has been illustrated in the constructivist theory through arrow 3. In terms of creating a NARRATIVE OF 'BEING RECOVERED' participants acknowledged that they now occupied another dimension of themselves 'as being someone who has experienced psychosis'. Participants appeared to have considered how they understand this in relation to their wider identity. They described pursuing a recovered self as one that is *'psychosis free'*. Whilst also recognising that they do not wish to return to a previous self but were somehow different ('*a different me'*) as a result of their experience.

3.4.1 CORE CATEGORY: STRIVING FOR COHERENCE

All of the participants engaged in the process of making sense to varying degrees with the end of goal of obtaining a coherent account of the crisis and discerning what being recovered means to them. A NARRATIVE OF BEING RECOVERED emerged whereby participants made sense of a future 'recovered' self. This was influenced by elements of LOWERED RESOURCES/PTG (e.g. IMPACT OF MEDICATION, INCREASED SENSE OF VULNERABILITY, DIMINSHED CONFIDENCE), SOCIAL PARTICIPATION AND OCCUPATION. Participants struggled to ascertain why they experienced the psychosis, how much control they had over it, the timeline of events surrounding the crisis and the consequences of it (COHERENT ACCOUNT OF CRISIS). Creating coherent accounts was enhanced by the process of a*ttributing cause.* Participants were most likely to attribute their psychosis to biological causes, which appeared to increase SELF COMPASSION.

> *"I think if you can make sense it frees you from the past in a sense you know cos worrying about was it my fault cos I got psychosis you know was it something I done to God you know*
> *I thought God was angry at me or something like that and erm just thinking back through things it sort of its not over straight away but you know bit by bit like a jigsaw when you look back on things" – Chris: 47*

> *"there were lots of things to happen which I didn't really understand you know and unless I find out then I'm not going to really be at peace if that makes sense you know that makes me think maybe we should just move on you know" – Peter: 48*

> *"Its [making sense] confirmed for me that some of the things were not real. The movement in the dark, anytime something moved in the dark I thought that it was CIA guys behind the bushes" – Kelly: 49*

The majority of participants spoke of engaging in meaning making with a degree of urgency and importance. However, one participant approached it with a degree of ambivalence and resignation, due to perceptions of the illogical nature of the crisis experience.

> "*Its ongoing sort of process trying to make sense of everything, but especially when you have that psychosis, it is sort of trying to, well to try to think logical, for me it's to try and think more logical to try and figure out what it is, but it was illogical" – Geoffrey:50*

3.4.2 CATEGORY: COHERENT NARRATIVE OF CRISIS

Participants spoke of their desire to piece together the events from the crisis. This seemed to provide participants with a coherent life story and enabled the processing of the traumatic memories surrounding the events (e.g., horror of symptoms and distressing treatment experiences). In addition, making sense of the crisis provided insight into potential triggers – information that could be used to stave off future episodes. One participant spoke about the effect of information that is not 'made sense of' and feelings of frustrations that may arise because of this.

> *"It [making sense of crisis] meant I knew why it happened, so if it happens again, I know what to look for" – Lucy: 51*
>
> *"I used to think you know it just doesn't make sense and that's when I got frustrated then" - Geoffrey: 52*
>
> *"there were lots of things to happen which I didn't really understand you know and unless I find out then I'm not going to really be at peace if that makes sense you know that makes me think maybe we should just move on you know" – Peter: 53*

3.4.3 CATEGORY: SELF COMPASSION

Considering the causes (*attributing causes*) enhanced self-compassion. Participants described a process whereby attributing cause - in particular *biological causes*, diminished feelings of self-blame. It seemed both important and beneficial for participants to consider the causes as being beyond their control so that they did not perceive themselves to be liable for contributing to the onset or maintenance of symptoms.

> *"I like to think that you know it was an effect of it that it was not all bad you know if that makes sense, like erm I hope that it [cannabis] didn't cause the psychosis and maybe I could have avoided it somehow" – James: 54*
>
> *"if anything happens, if I put links together and I think, "Oh dear. What's going to happen?" If I know I'm Schizophrenic, I'm expected to see these things so I've got something that I can blame it on – Kelly: 55*
>
> *"you do question, why has this happened to me. Umm what have I done? What have I done wrong to deserve this sort of thing Erm and if I think , a lot of it you regret as well, what with mine it was a lot of regret after really and it's just like I couldn't help myself when you look back, you do, you do question why" – Geoffrey: 56*

3.4.4 CATEGORY: NARRATIVE OF BEING 'RECOVERED'

Participants were aware of a new facet of their identity. In a similar way that an individual identifies with becoming 'a parent' following the birth of a child, these participants now considered themselves to be 'a person who is recovering from a psychosis'. An important part of this appeared to be a consideration of how they perceive themselves to be when they perceive themselves to be 'recovered'. None of the participants felt that they had reached a stage in which they considered themselves as being recovered. Rather, they saw themselves as working towards recovery. Therefore, this category can be thought of as involving a prospective element. Participants tried to create a coherent narrative of their 'recovered' ideal, grading the success of their recovery in terms of how close they were to this ideal recovered self. They described pursuing a 'psychosis free me' but at the same times did not wish to return to pre-existing version of themselves. Instead they identified that from the psychosis they pursued and indeed were becoming 'a different me'.

> *"my ideal recovered self would be to be 100% in control of my thoughts…. it has changed the way I think a little bit I suppose or the way I react to my own thoughts maybe" – James: 57*

> *"I don't think I'm there now [recovered]. Because I'm still staying in bed all the time. I just go out for appointments. Because I'm on a Valium reduction programme, so I have to go out every day to pick up the Valium… if it wasn't for my appointments I would be in bed but my ideal self would be to have more energy and more motivation – Kelly: 58*

Sub-category: 'a psychosis free me'

Participants largely understood recovery in the medical sense – gaining or returning to a 'normal' state of functioning, devoid of symptoms. In order to consider themselves recovered patients felt they would need an absence of the symptoms associated with psychosis and no longer have a need for medication or medical support. Alongside this they also valued a secure sense of self-awareness as a foundation of recovery.

> *"I think It's still ongoing for me erm cos I'm still on medication so I'm still, I don't know what effects are still there for me erm and what the medication is controlling so the end will be when I'm off it for me I think. I think I'll think right I'm back to me" – Geoffrey: 59*

> *"I just want to be me again I just want to be psychosis-free if that makes sense" – Geoffrey: 60*

> *"I'm at risk still, cos they're only, it's been my first one so you do question is it going to happen to me again" – Geoffrey: 61*

Two participants spoke of accepting who they had become in terms of individuals who have experienced/continue to experience psychosis. For each of these participants acceptance played a role. Kelly discussed the process of accepting the term 'schizophrenic' to describe herself. Simon described accepting the ongoing and unchangeable nature of symptoms. However, alongside notions of acceptance there was a feeling of resignation.

> *"I call myself a Schizophrenic now. And I've accepted it and I'm okay with it. But I've lost a lot of my confidence" – Kelly: 62*
>
> *"It's just always been there, you know I think, I hear voices, just accept it. I don't think they'll ever go away, I hope they do, but I don't think it will. At the moment I'm doing ok, you know like I said at the moment I'm having a good day today" – Simon: 63*

Sub-category: 'a different me'

Although participants spoke of the need for an absence of symptoms to feel fully themselves again, they also acknowledged that they are and will continue to be somehow different for their experience. A return to a former state was not the ambition of any participants. However they struggled to see or describe how they perceive their alternative future selves and how this might be different. One participant (James) described how his feeling of being a 'different' self since the psychosis has led him to question his previous pre-psychosis and younger self.

> *"I felt myself picking myself back up again you know it wasn't quick it was gradual until then it's like up and down and up and down and I believe I have changed since then" – Chris: 64*
>
> *"erm I think if I met my younger self now I wouldn't recognise myself, I think I have changed so much that I don't even think I know who I was before" – James: 65*

3.4.5 CATEGORY: ENABLERS

Participants described factors specific to enabling the process of STRIVING FOR COHERENCE. They also outlined a process whereby they considered the causes of the onset of the 'illness' almost immediately following the initial 'crisis' point. There were tacit indications of a desperation to find answers in terms of what caused the psychosis ('*attributing the cause')* and for many this involved ascribing *'biological explanations'.* These sub-categories are described below.

Sub-category: attributing cause

For the majority of participants considering causes for the onset of psychosis was seen as important and doing so aided the development of a coherent narrative. Causes ranged from external (e.g., financial stress; substance misuse; childhood issues) to internal factors (e.g., biological), or some

combination of the two. Some participants spoke of the ability to 'move on' (Chris) once they felt they had reached a degree of attribution of cause, even if some questions remained. Others spoke of practical benefits of attributing cause such as being better enabled to cope with or avoid any future episodes. One participant spoke of discerning the cause as further clarification that her experiences were indeed not real and this was perceived as a comfort. Participants considered their own role in the development and maintenance of the psychosis. For example, Chris discussed witnessing other people 'seeing' the same thing as him and how this prompted further questioning about the origins of the hallucinations and James remarked on time alone with his own thoughts.

> *"unfortunately yeah ate the forbidden fruit if you want to call it smoking marijuana which was just a terrible idea erm and I think that was a large proportion what lead to the psychosis" – James: 66*

> *"Clearly I had all financial stress got on me and I think that took an impact as well" – Lucy: 67*

> *"I was under a lot of stress and I was smoking cannabis at the same time. I think that's why it happened to me" – Kelly: 68*

> *"I was with that had similar symptoms to me and that sort of exacerbated it for me because then we were a group and we were all seeing the same thing, doing so, you know, um and that took time to [inaudible] question it as well and that takes time to get over" – Chris: 69*

> "there is no sort of trigger, I don't think, I think, its time on your own, as well, time, time with your own thoughts can be that worse enemy as well" – *Geoffrey:70*

Sub-category: biological explanations

All of the participants considered biological explanations. Ascribing biological causes seemed to provide the sense that "it would have happened whatever I did" (Chris). The biological explanations in this sense gave participants an initial understanding that they could not have controlled or acted in a way that would have contributed to the events around the crisis point. Thus increasing immediate SELF-COMPASSION. However, participants did not appear to be convinced by the explanation, questioning the benefit of such explanations in the long term. Lucy explicitly spoke of searching for meaning so that she would be able to identify future episodes, however her medically orientated explanation ultimately abated her own feelings of being in control of the 'illness'.

> *"I understand that my brain was broken and that it was an illness" – Kelly: 71*

> *"I looked into the synapses and that they don't reach other when they're damaged and it doesn't cure what I'm thinking but it sort of helped me" – Chris: 72*

> "*if I get diagnosed that might answer but then like I said that might pose other questions as well … people who went through the hospital had symptoms similar to mine and have all got diagnoses of different things and so, it was like well did I not get assessed properly, did I, I was out a lot, you know I did go out about and about but I don't know if it would bring me anything really erm you just sort of get on with it I think really and just thing, there'll be days when you think about it but then most of the time for me I just wanna dismiss it, but it's still there" – Geoffrey: 73*

One participant made an attribution of chance in an attempt to make sense of their experience of psychosis. There was a sense that this provided a degree of normalisation - that 'chance' could affect anyone and that he was not to blame for the way in which the situation unravelled.

> *"I just needed a bit more time to calm down I think and ground myself and it all sort of went downhill before I tried to ground myself. Which I think I could have done to be honest without having all this but I think it's just the way it went. I think some people might be lucky and be able to kind of make the decision to calm down and chill out on the cannabis and stuff and just have a couple weeks of relaxing and stuff" – James: 74*

3.4.6 CATEGORY: BARRIERS TO COHERENCE

Participants spoke of factors which acted as barriers to making sense. For many there was an underlying fear that re-visiting the crisis point to consider why it happened may negatively impact on their mood ('fearing the impact on mood'), and thus halt the recovery process There was a sense of striking a balance between ruminating over causes and going about a purposeful and meaningful exploration to create a coherent story of events. For many participants this appeared to be a difficult balance to strike, yet the desire to make sense remained. A narrative emerged throughout the interviews to '*get on with it*' and for participants this involved making practical efforts at recovery rather than spending time and effort 'ruminating' or making sense of the crisis. Participants appeared to be torn by the dichotomy of their desire to make sense and their motivation to 'get on with it'. The final category related to memory occurring at the time of crisis and thereafter and how this impacted on participants' sense making process for example, loss of segments of information ('*lost jigsaw pieces'*). These are discussed below.

Sub-category: 'getting on with it'

A number of participants spoke of the pull between sense making and 'getting on' with life. *'Getting on with it'* referred to striving towards measureable outcomes of recovery that could be thought of as being in line with the medical model of recovery. For example, one participant spoke of doggedly

paying off debts as a matter of course (Lucy) but failed to see any sense of achievement or success in this. The effect of 'getting on with it' appeared to reduce the individual's engagement in sense making. The 'getting on with it' narrative included terms such as "should" or "have to" when speaking about "getting on with it". It was therefore unclear whether participants were reciting another voice (e.g. societal views) or beliefs that they themselves held.

> *"I don't think there's much positive to it [making sense]. You've just got to deal with it and go on with life" – Lucy: 75*
>
> *"you have to accept it to try and move on really…. Hmm… hard" – Geoffrey: 76*
>
> *"maybe we should just move on you know" – Peter: 77*

Sub-category: 'lost jigsaw pieces'

Participants were making sense of the trauma in the context of difficulties specific to the condition. Many of them found themselves questioning the authenticity of available information regarding the trauma and thus struggled to decipher what was and what was not real. Indeed for some participants segments of information seemed to be 'missing' altogether and this hindered the process of making sense. Some of the participants also struggled to come to the terms with the role their belief systems played in generating their trauma

> *"I'm still not sure which parts on the conspiracy forum were real and which were not" – Kelly: 78*
>
> *"yeah you, pick it at the time, umm what happened, why, you try to make sense of what happened but then you, you don't know what was delusional, what was real, erm and you sort of question that as well. And so like for, for example I had it on my phone and I lost my phone so I couldn't go back and see if it was real or not so that's a question you can't answer then and you've, you a lot of it will come to no answer really" Geoffrey: 79*
>
> *"When I first went I could never remember going into hospital. It's always a blank. I spent every admission, months and months on ward 22" – Rich: 80*

One participant spoke of strategies to test out the authenticity of his memory. He described the process of engaging members from his social support network as active members in building coherence and the benefits of this.

> *"other people have been quite helpful cos I ask them questions cos I can't quite remember what I was presenting like so they've been key then for me – Geoffrey*: 81
>
> "*yeah its sort of piecing it together for me, erm and how I viewed things to how they viewed it differently and erm sort of comparing and arguing my case how that was just me being*

quirky, yeah it's been helpful to do that with them and they're quite good as well" – Geoffrey: 82

Sub-category: fearing impact on mood

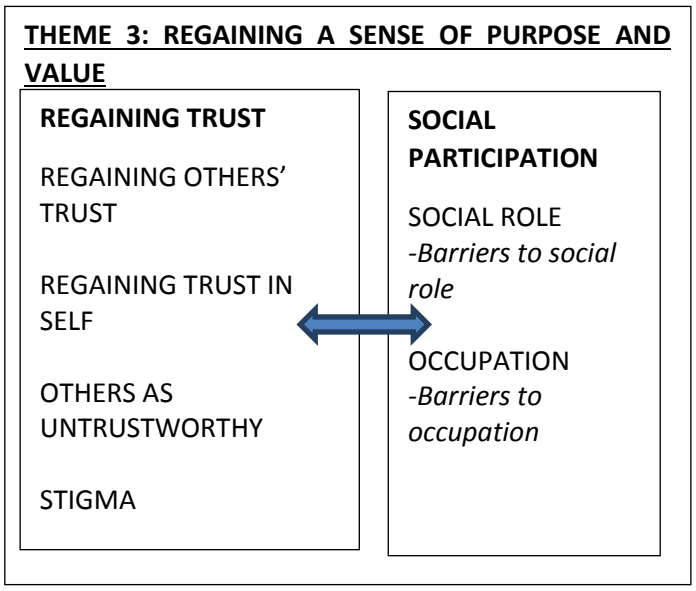
Whilst many participants spoke of a desire to make sense of their experiences some also described a sense of trepidation, believing that the process may impact on their mood. Participants reasoned that if they thought about the crisis point too much this could have a negative impact for them, nevertheless not thinking about it also appeared to represent a struggle as they were naturally pulled towards making sense.

"it happens and that's the only sort of explanation I try to give myself.. closure.. cos otherwise it will keep on my mind and then you just think about it too much then" – Geoffrey: 83

"cos for me that is a trigger for depression then as well so before I probably thought about it every day where now I make a conscious effort now, I try and dismiss it and like I say that part of my recovery to kind of dismiss it, but I do want to make sense of it and I still do search for those sort of answers but the answer will come back you know.. I don't know" – James: 84

"You still go into those modes and I think it depends, like for me I've got to be active otherwise I'll start thinking about it more, so then I'll question things more, and trying to unpick it and still not finding any answers really. But you still look" – Geoffrey: 85

3.5. THEME 3: REGAINING A SENSE OF PURPOSE AND VALUE



Central to the recovery process and regaining a sense of self was **REGAINING A SENSE OF PURPOSE AND VALUE.** Participants spoke of their drive to feel valued once again, hence implying that the psychotic crisis had dissipated any pre-existing sense of worth and value. For the participants it seemed that regaining a sense of purpose and value involved **REGAINING TRUST.** This was a crucial task as nearly all expressed difficulties surrounding trust. Regaining trust involved either REGAINING TRUST IN SELF, REGAINING OTHERS' TRUST or TRUSTING OTHERS once again. These tasks were hindered by external and externalised STIGMA. Participants also attempted to regain a sense of purpose and value through **SOCIAL PARTICIPATION**, however engagement in social participation was made more problematic given previously mentioned trust difficulties. Limited social participation also limited the development of trust. The relationship between these two categories is illustrated in the constructivist theory by arrow 5 and is supported by the following quotes: 86; 87; 90; 93. Nevertheless, participants sought a lifestyle which reflected what they perceived to be 'normal', through SOCIAL ROLES and meaningful OCCUPATION. Improvements/decrements in **REGAINING A SENSE OF PURPOSE AND VALUE** appeared to be associated with perceptions of POST TRAUMATIC GROWTH. This is demonstrated by arrow 4. This is evidenced by the following quotes: 113; 119; 121; 125.

3.5.1 CORE-CATEGORY: REGAINING TRUST

Participants spoke of issues relating to trust which continued well into their recovery. To varying degrees participants set about: REGAINING OTHERS' TRUST; REGAINING TRUST IN SELF*;* and TRUSTING OTHERS. Perceived lack of trust appeared to be intimately linked with stigma, so that internalised or internalised stigmatising views hampered participants trust, social participation, meaning making and ultimately the development of a positive sense of self.

> "*yeah I think so I'm a bit more wary of people now, so obviously I didn't agree at the time I was getting sectioned so a lot of negative did come with the relationships so I sort of shut myself off from it and now I'm a bit more wary of people" – Geoffrey: 86*
>
> "*I ask would it be alright if I take [nephews name] out for a bit or and she says... no … she just, she [pause] she doesn't let, she doesn't always, if I, when, she never leaves me alone with [nephews name] [said quickly] and I feel like, I'm not, I'm not going to hurt him"- Simon: 87*

3.5.2 CATEGORY: REGAINING OTHERS' TRUST

Following their psychosis nearly all the participants felt they were no longer trusted by others. They described others' perceptions of themselves as being permanently tarnished through the knowledge that they had experienced or were continuing to experience symptoms. For example, one

participant spoke about others being on the 'look out' for a re-emergence of symptoms. The perceived doubt in capabilities or ability to notice and manage any symptoms of psychosis left participants feeling undermined.

> *"um I think we've got stronger as a team now which is good, they question me but we're strong" – Geoffrey: 88*
>
> *"paranoid about talking about certain things because then they might think, oh he's going into psychosis or things" – Peter: 89*

3.5.3 CATEGORY: REGAINING TRUST IN SELF

The loss of trust in oneself was discussed by participants. Although participants went about trying to regain trust in the self they struggled to do so. Lack of trust manifested in doubt regarding the degree to which they can manage their symptoms. In addition, participants questioned the reliability and stability of their personality in the future and of others perceiving changes as evidence that they are 'going crazy'. One participant (Rich) questioned his influence over other people. There appeared to be an overlap between this theme and 'attributing causes'.

> *"You're afraid of what you can do or how I influence other people. When you think people are talking about you, obviously it is frightening being out of the house" – Rich: 90*
>
> *"when I was in psychosis the quirky side of me come out and I like the quirky side of me but er you know, they link that with oh he's going crazy again but it's not it's just my confidence you know you try to build it up and then you over think you think oh am I doing this right or what you know what do they think of me and it is, you're a bit more paranoid as well I think" – Geoffrey: 91*
>
> *"I'd like him back, to know myself better and trust myself" – Rich: 92*

3.5.4 CATEGORY: STIGMA

Participants were aware of society's stigmatising views of people who have experienced mental health issues and for some these views were internalised. Stigma was interlinked with the processes of REGAINING TRUST which together had an impact on the extent to which individuals engaged in activities or social roles which furthered a sense of purpose and added value to their lives. These stigmatising views related specifically to ideas of: attention seeking; being believed; and perceiving self as someone who can be trusted. For example, one participant (Simon) spoke of an incident in which he took his young nephew out alone and his sister's "checking in" that "everything was OK". This was perceived to be indicative of his sister's lack of trust in his ability to take care of a younger family member and to recognise and manage any emerging symptoms or reductions in well-being.

"I take him out once and my sister, I took him when my parents live in [name of place] and I took him in [name of place] for a baby chino, you know milk and froth and marshmellows, we were there probably an hour and she phoned four times and she said is everything ok… so yeah that's the only time she let me take him out and she phoned four times and I was like… maybe she doesn't trust me or she's not sure about me and that and I can understand if I was particularly bad, and if I was I wouldn't even go in there with [nephew's name] anyway… yeah" – Simon: 93

"since my psychosis I felt more outcast sort of feeling. You know like my friends I know my friends know I've got psychosis in the church but it's still that sort of voice in the back of your head sort of well can I trust you know, in your head and you know he said… yeah. Cos of my mental illness I think is anyone gonna believe me and like that you know you know like attention seeking and stuff like that" – Chris: 94

3.5.5 CATEGORY: TRUSTING OTHERS

Nearly all the participants spoke of their difficulties in trusting others but also the integral role regaining trust plays in the recovery process.. They expressed how this lack of trust hampered their participation in social and occupational settings. Ultimately this impacted on the initiation and maintenance of relationships. Despite an overall deepening of family relationships (Peter) noted how his questioning of others led him to question his close family.

"I was better at trusting people and interacting with people" – Rich: 95

"yeah I became a lot closer to family, but yeah even now I look at them and think are they actually on my side you know" – Peter: 96

"Because I think when you have a psychotic episode, you do mistrust for a bit until you are given the right medication and then you can trust properly" – Lucy: 97

3.4.6 CORE CATEGORY: SOCIAL PARTICIPATION

Regaining a sense of value and purpose through social participation appeared to be central to recovery and the recovered 'self'. Social participation represented functional outcomes in the sense of a return to a former state or to some degree of perceived 'normal lifestyle' which seemed to be based on social norms of what a 'normal life' entails (e.g., *"Out working, house, girlfriend, kid, car, just the normal things in life. I don't want money"- Rich).* These outcomes have been presented under the categories ROLES and OCCUPATION.

"I've lost a lot of who I was as well that's changed like I've no motivation I don't want to socialise and I don't want friends, when I used to be even though I was quieter I still liked having friends like I'd go see them lots and now I don't even want to bother, but I don't like my own company so it er it's a two edge sword really" – Geoffrey: 98

"I no longer have the strength that I once had so I'm having to adapt so I create a different kind of strength which I can relate to kind of societal engagement erm yep its sophistication" - Peter: 99

"I think part of me thinks that philosophy and talking about that sort of thing is like a defence mechanism against people who you know want to kind of disprove what I'm saying as right and you know I, I sort of, the belief as well if I can prove people wrong then I was right all along and that will make my existence validated you know. I mean cos when someone says oh you're wrong well that makes me feel like I shouldn't exist you know, cos if I'm wrong then you know that's gonna be going against the wishes of society and we're all social animals so you know it's, I think we live and die by the approval of others you know" – Peter: 100

3.4.7 CATEGORY: SOCIAL ROLES

Participants described how psychosis stripped them of their social roles. Two participants also spoke about how their psychosis had particularly impacted on their ability to engage with the role of 'helper' or caregiver for other family members. A further participant (Geoffrey) spoke of how he was able to fulfil a helping role in the psychiatric ward following his admission leading to feelings of heightened confidence and empowerment. However, upon his discharge he was unable to maintain this status in the community.

"It stopped me in my tracks cos I used to take my mother every day shopping and I care for my mam I do and I've been doing that for a few years and when I had psychosis it hit me off course you know and I was just disconnected from everyone" – Chris: 101

"*She [participant's mother] said I hold the family together. But my mum, my brother, my aunt and my cousin. They all live together in a tiny flat and they are all addicted to heroin…So I'm the normal one. Even though I'm not normal" – Kelly: 102*

"yeah I had confidence and I had a purpose, you know I was helping others as well, cos you know, they took on that sort of role with others so I was more empowered really and now that's gone so it is a bit of a loss as well really, sort of like, I liked elements of that but obviously I wasn't, my personality was a better one, more confident" – Geoffrey: 103

Sub-category: Barriers to social roles

DIMINSHED CONFIDENCE and *'no go in me'* appeared to reduce the participant's engagement in social roles. Despite this, participants continued to see the benefit that social participation could elicit in terms of their recovery and well-being. For one participant (Geoffrey) there was a belief that an increase in confidence is a prerequisite to an engagement in regaining social functional outcomes. Peter also spoke of how purposeful attempts to create confidence in another aspect of the self could be used as a tool for social engagement.

"the pieces all slowly come together erm but I'm rebuilding my confidence first and then then I'll move back to right let's get a house, let's try and find a partner that's, you know carryon but I'm not at that stage at the moment, I don't see any benefit of anything really" – Geoffrey: 104

"I no longer have the strength that I once had so I'm having to adapt so I create a different kind of strength which I can relate to kind of societal engagement erm yep its sophistication" - Peter: 105

3.4.7 CATEGORY: OCCUPATION

The importance for recovery of finding an occupation was noted by the majority of participants. While occupation provided a source of social engagement for many, for some it also contributed to a sense of well-being, enjoyment and/or structure. Occupation, therefore, did not specifically imply securing a source of employment, rather occupation was referred to by the participants as an activity with which the individual can meaningfully engage to obtain some desired outcome.

"I love reading books so you know books cost what five pounds each and they last about, well they last me about a week yeah that's er in terms of looking for something to do and finding an occupation I think I could probably spend the rest of my life doing that you know" – Peter: 106

I keep myself busy, I'm out every day, erm Monday morning I normally go to the pub and have a few squashes' with the boys, I've been drinking there for years, I've been 6 years sober in September so but I've still got to have my squash and a chat and breakfast normally, and then come here, and go to Hafal, Tuesday morning I do up there, and then I come and do my Hearing Voices group here and then Wednesday I go to open doors and Thursday I'm here and at my parents and Friday I'm here and Saturday and Sunday I'm also here, so I'll always keep myself busy – Simon: 107

"a structure I think helps for me whereby if I had no structure I wouldn't do anything but people will sort of see that as laziness as well but it's not being lazy it's just can't do it, don't know why it's just a barrier there and can't seem to jump over it not at this moment" – Geoffrey: 108

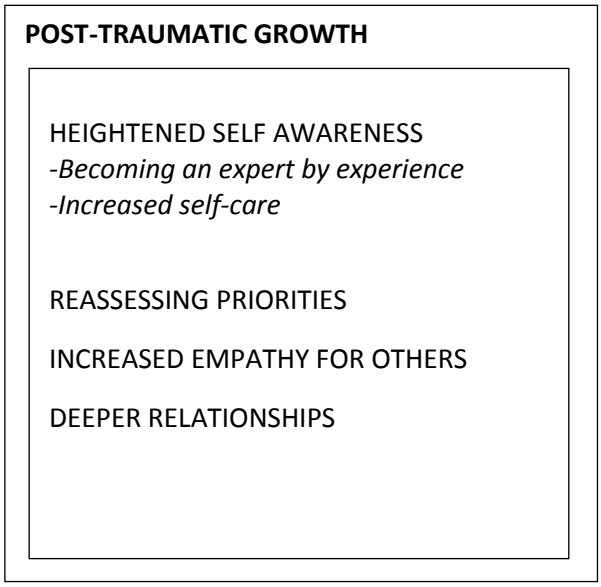
Sub-categories: Barriers to occupation

Practical difficulties (e.g. navigating income and benefit allowance), DIMINISHED CONFIDENCE and *'residual cognitive difficulties'* also impacted on the participant's ability to seek and maintain occupation. For example one participant (Geoffrey) spoke of the impact of loss of initiative since the psychosis and lack of confidence and how this intercepts his ability to gain enjoyment and a sense of self-worth from his occupation:

"I'm probably still good at care work but I can't go to it because ESA stops that. I was doing a training course, doing level 3*, but because obviously the last bits involve work, I had to cut the course because not being able to go back to work does stop it" – Lucy: 109*

"I used to love my job and now I don't really want to do it anymore I find it difficult to do it when I'm there, whereas before, you know I had initiative I could just do stuff and I'd be fine but now I question my ability, I question can I do this job and its, and that's final really cos that's a negative and I need to recover when I get home and it's not a good quality of life really" – Geoffrey: 110

3.8 CORE CATEGORY: POST-TRAUMATIC GROWTH (PTG)



Individuals set about trying to re-construct their sense of self. As we have seen thus far, this involved: the process of **'PIECING THE JIGSAW TOGETHER'** - **MAKING SENSE** and **REGAINING A SENSE OF PURPOSE AND VALUE**, through **REGAINING TRUST** and **SOCIAL PARTICPATION**. These processes have been attempted in the context of **LOWERED RESOURCES/PTD.**

Interestingly participants appeared to view recovery as an endeavour that is secondary to the reconstructions efforts and strategies aimed at rebuilding the sense of self that had been dismantled from the point of crisis. Strategies focused on obtaining meaningful roles and relationships and re-gaining trust. Although participants spoke of constructive change occurring at some point after the psychosis, many did not actively recognise these changes as positive elements of growth that occurred as a result of the psychosis.

Despite PTG being poorly recognised, there were clear indications of PTG emerging through the categories: HEIGHTENED SELF AWARENESS, REASSESSING PRIORITIES, INCREASED EMPATHY FOR OTHERS and DEEPER RELATIONSHIPS.

"years ago one of my psychiatrists asked me if there was a button you could press and the voices would go away would you press it? And I said no…. (quiet voice) and I had to think then, and she said erm, why would you want them to stay then? Oh well they made me who I am today, Iwouldn't have the friends I've got today, I wouldn't have the, you know I wouldn't have the I wouldn't have the life I've got, ok you know it's been hard, I've had my own business for a while, I've been in partnership with another business for a while, I've had periods where the voices have been down to a whisper, but, they've never gone away since I started hearing them, they've never gone away [takes a deep breath]" – Simon: 111

"it does feel like I was meant to have this breakdown and do what I did and, cos I did help other people and now it's like my mission done and I can recover" – Geoffrey: 112

3.8.1 CATEGORY: HEIGHTENED SELF-AWARENESS

Participants appeared to have an acute awareness of factors that affect their recovery. For some this increased their sense of well-being whilst for others this awareness helped them maintain progress in their recovery. Some spoke of an increase in insight in the period following their experience of psychosis and the early stages of recovery. They also spoke of being better able to manage themselves; being more open with others, and becoming increasingly aware of negative influences on their well-being. Also important was a greater awareness of triggers. This awareness allowed them to halt any decline in their well-being and translated to practical changes in their environment (e.g. living arrangements) or in how they navigated their environment (e.g. through increased structure and routine). For a number of participants increases in self-awareness led to '*becoming expert by experience*' – the notion that they themselves were expert in their experience and this provided a sense of efficacy in their recovery, albeit at times fragile.

"I am making more sensible decisions since it happened. Sort of just sleep pattern and eating pattern cos before when I got ill the first time both of those just went out the window really I was just I only cared about weed and how long I could be constantly smoking it when I was awake so I would go to bed at five o'clock in the morning and then get up at 10 and then go out all day and just smoke it and not come home and just go back in at 3am again, just go and drive somewhere and get food once a day one meal a day, it wasn't very sensible at all. Now I've got more of a routine, now most evenings even the weekends I will go out go to college and then stay in in the evenings until the next day and I never done that before one in my life before I would always just go straight out after work every day but now I kind of stay in and do productive stuff every day… I have to" – James: 113

"Because I used to live with my dad. He was really nice but he's like two different people…He can be the nicest person and he can be the most cruel person. He was making the psychosis worse, playing on it. He would talk about the SAS and things like that… So now that I've moved out and I'm in supported accommodation, I am happier now because I haven't got that to deal with" – Kelly: 114

"Yes, it's like I became more aware. I know now I've got to pay back debts, so I've got to keep a clear head so I can pay them back" – Lucy: 115

Sub-category: Becoming an expert by experience

Participants spoke of being active drivers in symptom management. Linked with INCREASED SELF AWARENESS participants described increased confidence in managing and controlling their symptoms. They appeared to place importance on developing their own solutions (e.g., coping strategies). Similarly participants highlighted the role of other factors in their recovery (e.g., social support network, professional support, medication). Strategies developed and applied by the participants themselves during the process of becoming an expert by experience were deemed to be most effective.

"*I think, that's why I recommend that I don't do that, cos for me that is a trigger for depression then as well so before I probably thought about it every day where now I make a conscious effort now, I try and dismiss it and like I say that's part of my recovery to kind of dismiss it" – Geoffrey: 116*

"People kind of saying things that you think you know better to judge the situation cos it's you you're talking about rather than them saying oh I've read this I can't do this sort of thing "- James: 117

"if I'm having a particularly bad day and I'm in town or whatever what I do is I take my mobile phone out and I put it up to my ear and I talk to the voices see and everyone thinks you're talking on the phone, cos if you're talking to on the phone, no one realises you're talking to the voices. So it's a good little trick I learned" – Simon: 118

The process of becoming an expert by experience prompted three participants to pursue further study. For Chris this was via self-directed study of the brain and biology; for Peter it was through pursuing an academic programme in neuroscience and for James it was through training to become a Community Psychiatric Nurse (CPN).

"I know, you know cos I studied the brain myself you know cos I studied neuroscience and I know all about the nervous system you know and I don't really know to be honest with you but all the chemical changes and everything. You know I looked into the synapses and that they don't reach other when they're damaged and it doesn't cure what I'm thinking but it sort of helped me and I don't know to be honest with you" – Chris: 119

Sub-category: self-care

Heightened self-awareness also enabled participants to understand how and when to provide self-care. This was experienced as a positive change when compared to their former pre-psychosis self. Participants described being better able to 'manage' themselves and being more willing or able to

access social support through being more open to others. Improvements in self-care became apparent during the later stages of recovery as a consequence of an increase in self-awareness.

> *"Managing myself better now I think, definitely managing myself better than how I was living before" – James: 120*

> *"I'm trying now to let people know if I'm stuck cos I'm very good at hiding, cos when the voices are really bad, I don't need to hide here cos everyone knows, you know if I'm quiet, you know one of the boys we always muck about and if I go [anonymised name] no not today, he knows the voices are bad and he won't bother" – Simon: 121*

3.8.4 CATEGORY: REASSESSING PRIORITIES

Reassessing Priorities emerged as a category from the interviews. Participants spoke of a reassessment of life choices and changed priorities occurring as a result of their experience of psychosis. This category represents the shift in focus that participants experienced in relation to their life choices, which ranged from: occupational paths, considering long term consequences; financial commitments; and the importance of family. The changes in perspective occurred at some point following the period of psychosis or the very initial recovery stage. For participants this represents a positive outcome.

> *"Well my first priority now is taking my tablets every day… And to do my Valium reduction. And my family. I used to put my activism and things like that first but now I'm putting- I'm more concerned about family and things like that" – Kelly: 122*

> *"I put my family first now… I try and help my family out as much as I can. I appreciate them more now as well." – James: 123*

> *"Yeah I think more towards the long term and the future now whereas before I used to think very short term but then again I don't know if that's just part of growing up as well" – James: 124*

> *"it's given me more of an idea of where I might be happy as a job, like where I might working with mental health but that's about it really its opened my eyes in that respect but I don't know actually, cos I do therapies as well which has given the opportunity to sort of help others so it has given me that sort of opportunity and I relate to people better, but yeah I just want to be in that sector probably. I probably wouldn't have gone down that route, no, so it's given me, I think I can probably help so I think that, you know it's given me more direction to maybe be an occupational therapist or things like that so it's given me food for thought" – Geoffrey: 125*

3.8.5 CATEGORY: INCREASED EMPATHY FOR OTHERS

Participants described an increased understanding of psychological suffering. For some, this challenged pre-existing beliefs or stigmatising views that they previously held about others with mental health difficulties. There was a general understanding that as a result of their experience they had been taken from a "naïve" (Kelly) position to a better, more informed and emphatic place from which they could interact with others who are experiencing mental health difficulties. This was seen as a positive change by the participants. It is interesting to note that although empathy replaced stigma towards others with mental health difficulties this did not translate to deeper self-compassion.

> *"when I'm well and people are shouting, you don't judge them for it because you know what they're going through. That makes me a better person I suppose" – Rich: 126*

> *"Well I've got more understanding now. I was quite naïve before… Well I have with my cousin because he's been through psychosis and I can understand – Kelly: 127*

> *"yeah like, like to me everyone was normal we were all normal in the hospital and that was and then you see their difficulties after then so it give me an understanding to like say treat them as people whereas before if someone said oh that's a schizophrenic I would say like oh stay away from them erm but its more my understanding more improved now cos there was lots of different mental health problems in there it wasn't just one so I've got a better understanding and what they needed as well cos I used to do their taxes, not their taxes, but like filling in a form for them cos no one sat down and said what's stressing you out and then I used to do that for them and so it's given me a better understanding to say right how can I help?" – Geoffrey: 128*

3.8.6 CATEGORY: DEEPER RELATIONSHIPS

Participants spoke of both the cessation of certain friendships and the development of deeper relationships. In this sense both elements of PTG and PTD were evident in this category. Participants described how the psychosis enabled them to identify friendships worth pursuing. However, this invariably meant a loss of friendships immediately following the crisis and a feeling of isolation. Overall however, the majority of participants felt that a small number of friendships had become closer. The largest impact of growth in this domain related to family relationships which were judged to have improved and become deeper since the crisis.

> *"existing people um my family we probably got closer because of it erm not at the time, we were very negative towards each other at the time but we are coming out of it and I can see that they were there they were only trying to do their best but you don't see that at the time" – Geoffrey: 129*

“Erm my relationships with the family have got better definitely erm not so much my friends I think, we were good before and they sort of stuck by me through everything that happened, so it helped, things with my friends haven’t really changed that much” – James:130

“I would say I’m closer to my family now and more forgiving. I was very, very angry with my mum and my brother because of the heroin”- Kelly: 131

“It was good but it wasn't as strong. She understands me more now, it's much better” – Rich: 132

CHAPTER 4: DICUSSION

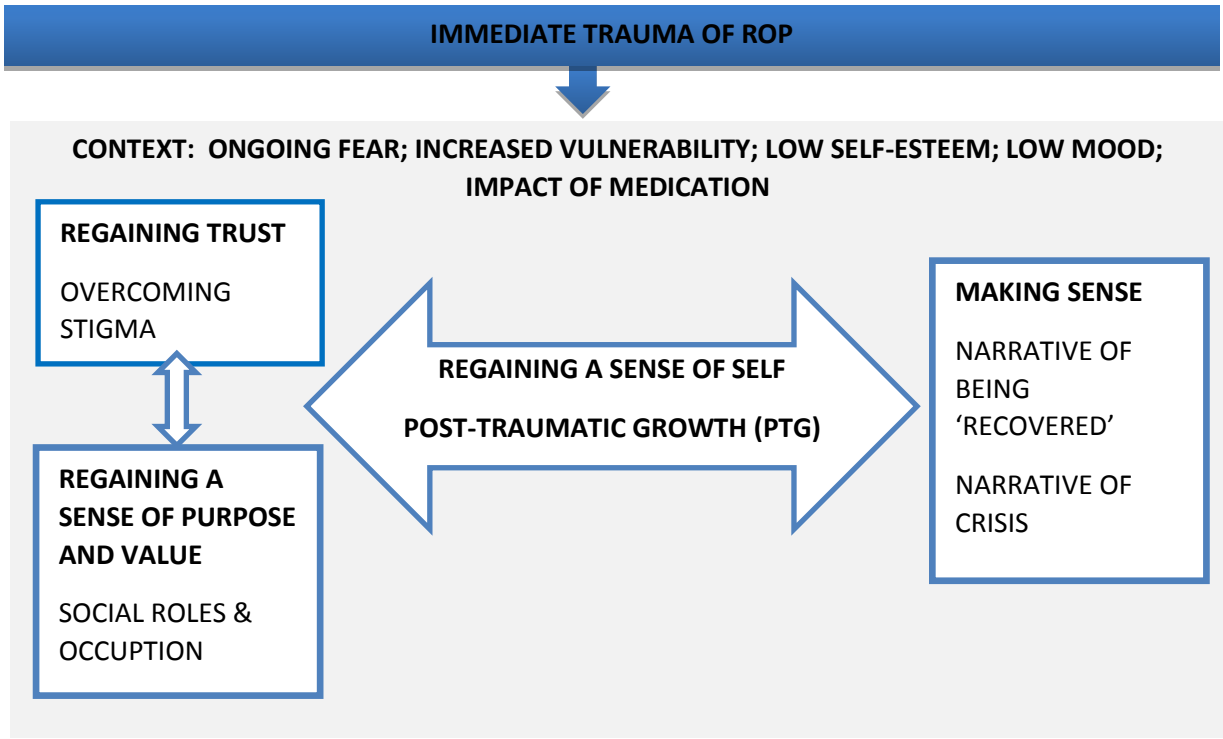
4.1. CHAPTER OVERVIEW

An overview of the findings of the current study and how these relate to existing literature and theory is provided within this chapter. Clinical and service implications are explored before consideration is given to methodological strengths and limitations of the study.

4.2. SUMMARY OF FINDINGS

A narrative summary of the research findings will be provided within this next section. Figure 5 Provides an overview of the findings in diagrammatic format.

Figure 5: Psychosis and the 'Post-traumatic Self'



The **IMMEDIATE CRISIS AND AFTERMATH** of the psychotic episode was experienced as a traumatic life threatening event. Ongoing distress was experienced for a number of participants as symptoms akin to those found in PTSD (e.g., re-experiencing and hyperarousal). The most significant impact of the crisis was reported as a shattering of their sense of self. An important finding in this study is that individuals went about re-constructing their sense of self, with 'recovery' being pursued as a secondary goal. Participants did not appear to recognise recovery as it is conceptualised by the recovery model. Elements of PTG were experienced through the re-construction strategies aimed at

restoring a sense of self. For example, through MAKING SENSE, REGAINING TRUST and attaining SOCIAL ROLES AND OCCUPATION. Such reconstruction efforts were hampered however by **LOWERED RESOURCES** and elements of **POST-TRAUMATIC DEPRECIATION (PTD)** which occurred following the crisis period (e.g., ONGOING FEAR, INCREASED VULNERABILITY, DIMINISHED CONFIDENCE and the negative reported IMPACT OF MEDICATION). Consideration of PTD particularly in perceptions of the self (e.g., self as vulnerable; self as worthless) and the ongoing impact of this on recovery represented a novel aspect of this study.

MAKING SENSE appeared to occur for participants immediately following the crisis. It was an ongoing process without any fixed end point. Participants were STRIVING FOR COHERENCE in the meaning they had extracted from the experience. However this meaning was formed against a backdrop of specific *barriers* and in the context of LOWERED RESOURCES. Individuals had seemingly considered how they envisage '*self as recovered*' (NARRATIVE OF BEING RECOVERED). In this sense individuals were constructing a new aspect of their identity and aligning it with their re-developing sense of self: participants were not seeking to return to their former state. Rather, they accepted and welcomed a different version of themselves for having experienced the psychosis. Individuals also made attempts to build a NARRATIVE OF THE CRISIS.

MAKING SENSE prompted reflection and processing of the trauma experienced in the crisis. However, unlike PTSD, the memories of the trauma for individuals following a ROP included the metacognition that their delusional thinking may have magnified or manufactured some of the trauma. It is this metacognition that makes psychosis and PTG a unique and fascinating area. Participants spoke of how the resonance between the content of their delusions and their pre-existing belief systems (e.g. fearing God; aspects related to activism), challenged their ability to attribute the psychosis to chance or medical causes. The meta-cognition that an aspect of themselves (e.g. their beliefs) may have in some way contributed to their experience represented a key task in the re-construction of their self.

REGAINING TRUST in self, trust in others and feeling trusted by others, represented key tasks in the re-construction of the self. Individuals went about regaining their sense of trust in themselves through the development of SOCIAL ROLES and OCCUPATION, which also served to provide a **SENSE OF VALUE AND PURPOSE**. STIGMA, however, impacted this process.

Although the majority of themes and categories were very much interlinked, the theme **REGAINING A SENSE OF VALUE AND PURPOSE** emerged early in the data analysis process. This theme represented a core variable that marked participants' main concern and pre-occupation in the struggle to regain a sense of self.

Individuals in this study experienced **POST-TRAUMATIC GROWTH** through the strategies aimed at the reconstruction of self. Participants described the development of a HEIGHTENED SELF AWARENESS and how this manifested in greater appreciation and/or recognition of their self-care needs. For some participants this led to enhanced well-being. Participants viewed changes in their occupational pathways and prioritisation of family as two major examples of positive change resulting from RE-ASSESSING LIFE PRIORITIES.

ENHANCED EMPATHY was described as following on from the psychosis. Participant's described being taken from a 'naïve' position to a better, more informed and emphatic place (INCREASED EMPATHY FOR OTHERS) from which they could interact with others. Relationships (DEEPER RELATIONSHIPS) were also experienced as becoming deeper and stronger (DEEPER RELATIONSHIPS), and this seemed to be the case particularly in relation to family ties. Indeed elements of PTG were evident throughout the majority of individual accounts of recovery, however for many these were poorly recognised. Rather, participants continued to struggle with the ongoing distress caused by the ROP and associated decrement in the range of resources that they could access for support (friendships, financial and occupational). Thus PTD was also present in the domain of relationships, perceptions of strength and self-efficacy.

4.3 RESEARCH FINDINGS IN RELATION TO EXISTING LITERATURE

The findings of the current study will now be considered in relation to the existing theoretical and empirical literature. The themes and categories are presented and discussed under the headings: The trauma of psychosis; meaning making; regaining a sense of value and purpose and PTG. The relevant categories will be discussed in relation to these.

4.3.1 THE TRAUMA OF PSYCHOSIS

Participants described the ROP as a catastrophic, sudden and overwhelming event. A sense of threat was experienced, which represented the life threatening nature of psychosis particularly in relation to their experiences of the psychotic symptoms and consequences (e.g., hospitalisation and threat of self-harm). This reflected both consumer and empirical accounts of the trauma of a ROP (Jackson et al., 2004; McGorry *et al.* 1991; Mueser *et al*. 2010; Tarrier *et al.* 2007). Of most concern to the participants in the current study was the perception of a shattered sense of self as a result of the crisis - a finding in line with previous literature (Davidson & Strauss, 1992; Pettie & Triolo, 1999). Pettie & Triolo (1999) believe that the recovery journey following a psychiatric 'illness' can be

defined as “a quest for identity” (pg. 258). The current results support this notion. The primary aim for the participants in this study rested on the re-construction of the self with functional and practical recovery aims being secondary to this.

The results of the current study show that the distress from the psychotic episode did not abate but was ongoing to varying degrees for most participants. The model of PTG, as devised by Tedeschi & Calhoun (2006), recognises that it can accompany distress. Participants experienced symptoms akin to those found in PTSD, this reflects notions of ‘psychosis-related PTSD’ (Berry *et al.* 2014). For other participants there were subtle indicators of ongoing distress. For example, increased perception of vulnerability and low confidence. Participants were also continually struggling with the most distressing element: loss or reduction in sense of self. In line with previous results (Davidson & Strauss, 1992) participants were seeking to re-construct their shattered sense of self.

It has been suggested that the notion of PTSD does not fully capture the range of negative responses to the trauma of psychosis. Dunkley *et al.* (2013) propose that a broader notion of traumagenic distress of psychosis warrants consideration. The author of the current study suggests that drawing on the notion of Post-traumatic Depreciation (PTD) (Cann, 2010) could further our understanding of the wide range of negative responses that occur following a ROP. Further study into the ongoing distress of psychosis drawing on the PTD framework may provide greater insight into the distressing negative sequelae of psychosis that is not currently recognised under the umbrella of PTSD.

PTD refers to negative changes resulting from the crisis and can occur in the same domains as those observed in growth (Cann *et al.* 2010). For example, the finding that individuals perceived themselves to be more vulnerable as a result of the psychosis could be explained in terms of Janoff-Bulman’s (1992) shattered assumptions theory. It may be that participants perceptions of themselves as ‘invulnerable’ had been dismantled through the crisis. Participants in this study experienced an ongoing increased sense of vulnerability which hampered engagement in the recovery processes and the reconstruction of a positive sense of self. Connell *et al.* (2015a) describes a sense of ongoing ‘apprehension’ (vulnerability) and how this impacted on a return to familiar social roles. In contradiction to the present findings, however, Connell *et al.* (2015a) then goes on to suggest that forging a ‘stronger self’ was an outcome for many participants and critical in restoring sense of self. Participants in the current study did not appear to embrace the perception of themselves as stronger for having experienced the psychosis. The domain of increases in personal strength (Tedeschi & Calhoun, 2006) did not apply to the experiences of these individuals.

Participants either expressed elements of PTD (sense of being less strong) or a re-assessment of one's strengths. The latter reinforces the ideas proposed by Davidson and Strauss (1992) indicating that individuals 'take stock of their personal strengths and weaknesses' as part of developing a new identity. This is exemplified succinctly by one participant in the current study:

> *"I no longer have the strength that I once had so I'm having to adapt so I create a different kind of strength which I can relate to kind of societal engagement erm yep its sophistication" - Peter*

Diminished confidence was found to reduce recognition of recovery and self-attributions of progress. Although not a significant factor in the literature, self-confidence alongside associated terms (e.g., self-esteem) has been identified as enhancing recovery (Coleman, 1999). Low mood was also identified in the current study as an ongoing problem in the task of re-constructing the self. Specifically, participants noted the negative impact of low mood on their motivations to engage in tasks associated with their recovery (e.g meaning making or social participation) for fear that it would reduce their mood. The occurrence of low mood following a psychosis is well evidenced in the literature, with an incidence rate of 'post-psychotic depression' (Birchwood, 2003) reported as high as fifty percent in some studies. Although there are contentions, there is some evidence to suggest that PTG is related to lower depression in a sample of Iraqi students (Magruder,KilicMehmet &Koryurek, 2015). Given the high prevalence rate of depression following the initial psychotic period it may be beneficial to explore further the relationship between PTG and depression following a ROP.

Participants in this study regarded the impact of medication with ambivalence, both acknowledging its role in managing symptoms and its negative impact on the re-construction of the self. Participants described not being able to 'test out' self-assumptions (e.g. self as managing symptoms; self as symptomatic) relating to their progress in recovery. Participants felt that they could not fully feel 'themselves' until they were no longer reliant on medication. This sense of ambivalence is reiterated in the literature (Barker *et al.* 2001; Jager *et al.* 2015). Jager (2015) describes how the uptake of a medical approach, including the use of medications, was indicative of a 'turning away' style, synonymous with a 'sealing over' approach, whereby integration is limited (McGlashen, 1976).

4.3.2 MEANING MAKING

Similar to the findings in the literature, meaning making represented a central component of recovery and PTG following the psychotic episode (Connell *et al.* 2015a; Mapplebeck, *et al.* 2015; Waite, *et al.* 2015). Participants were actively making sense of their experience and what it means for them and the future from the point of the psychosis. There was a sense that gaining some degree of meaning would enable them to move forward and rebuild their sense of self. There has been an abundance of literature exploring sense making in terms of 'recovery styles', for example how one integrates the meaning of their psychosis. (McGlashen, 1976; Williams-Keeler *et al.* 1994; Jager *et al.* 2015). This study offers a different perspective because individuals appeared to be creating a narrative of meaning around the crisis (e.g., causes of onset, a timeline of events of the crisis and consequences) and a narrative of what this means for their identity and their new and future role as 'being in recovery from psychosis'. This parallels the re-construction of self process described by Pettie & Triolo (1999) whereby participants considered '*who am I? what happened? Where is the me I thought I would be?*'

Parallels can also be drawn with the notions of creating an 'illness identity' proposed by Yanos *et al.* (2010). The majority of participants accepted the notion that they had a 'mental illness', the first stage considered in the model (Yanos *et al.* 2010), and in fact they actively pursued this ('attributing cause') as an alternative to beliefs that they may have, in some way, contributed to their psychosis. The finding that participants appear to be seeking a degree of self-compassion through attributing cause may support recent evidence that self-to-self relating such as self-compassion, promoted recovery and growth from psychosis (Waite *et al.* 2015).

Although ascribing medical explanations can be experienced as contributing to a positive sense of self (Fekete, 2004), it appeared to amplify participants concerns that they would be unable to manage future episodes. The 'illness identity' model (Yanos *et al.,* 2010) suggests that the immediate positive impact of ascribing medical causes is jeopardised by stigma, leading to loss of hope and low self-esteem. An interesting finding in this study is that individuals appeared to focus on what their 'illness' meant for their future self. McAdams (2001) describes through the notion of 'narrative identity' how a person constructs a story of their past, present and future in a way that increases understanding of how they 'fit' in the world. Although there has been little empirical research exploring the future self-concept following psychosis, the results of this study imply that building on this narrative is important for restoring a sense of future self that is as valued as the previously

imagined future self. This is particularly important given the finding that participants were not striving to return to a former state of self, rather they acknowledged that they are and will be someone quite different.

4.3.3 REGAINING A SENSE OF VALUE AND PURPOSE

In line with the literature base (Davidson & Strauss, 1992; Jager *et al.,* 2015; Waite., *et al.* 2015) participants pursued a sense of self that they identified as having a sense of value and purpose. The theme 'regaining a sense of value and purpose' identified in the current study draws close resemblance to the key processes identified in Jager's (2015) study of growth following voice hearing whereby recovery processes were centred around meeting needs to feel competent, valued, purposeful, and connected to others. Participants in the current study went about re-engaging in their social roles and occupation after the psychotic experience severed these (e.g. through hospital admission and loss of employment). The re-establishing of social roles (e.g., self as uncle; self as helper) could be understood in terms of the illness identity model (Yanos, 2010) as participants forge a sense of self and identity other than for example: 'patient'; 'schizophrenic'. This aspect of recovery reflects the concept of 'social recovery' defined by Anthony (1993) and exemplifies the role of a relational sense of self in recovery.

Participants also pursued a sense of purpose and value through meaningful occupation. Davidson and Strauss (1992) note that achieving incremental successes can result in the increase of one's personal agency and finding a meaningful role can be a catalyst rather than an outcome of the recovery process (Andreasen *et al.* 2011). Occupation meant a range of things for participants. For example, they shared the view that occupation provided them with a purpose to live and thus reflecting the literature (Andreasen, 2011). In line with previous research is the finding that 'helping others' appeared to be a valued goal in occupation (Emmons, Colby & Kaiser, 1998). This can be seen as representing a form of 'benefit finding' (Davies, *et al.* 1998) in which individuals can gain a greater sense that some good can come from their experience. For two participants, striving for a meaningful activity resulted in vocational pursuits. In line with existing literature, the vocation was born out of the psychotic episode and the struggle with its aftermath (Lynch, 2000). Whether the goal leads to a vocation or writing for enjoyment, this finding demonstrates the importance of the development of intrinsically motivated goals that aid a sense of purpose, and re-construction of the world and the self. The new 'possible' self must be as 'elaborate and emotionally engaging' as the one it replaces, in order to give life meaning (pg. 123, King, 1998).

The diminishment of trust impacted on participant's ability to engage in their social roles and to foster a sense of purpose and value through occupation. Research has found that cognitions such as 'others are untrustworthy' serves to minimise recovery progress (Bentall *et al.* 2001; Garety *et al.* 2001; Morrison, 2001). The findings of this study demonstrated that trusting others again was a substantial task and appeared to be linked to perceptions of increased vulnerability. The trauma of the psychosis and enforced treatment had initiated or maintained the belief that others are untrustworthy, and this finding is replicated in other studies (Nixon & Hagen, 2010). Although participants were asked about perceived changes since the psychosis, and therefore increased vulnerability can be assumed to be arising following the psychosis, due to the methodology causal factors cannot be confirmed. It may be the case that the participants had pre-existing trust difficulties given the evidence suggesting the incidence of attachment related difficulties in people who experience psychosis (Berry, Barrowclough and Wearden, 2008). Participants in this study however were not only seeking to trust others again, but were also seeking to regain the trust *of others* and *trust in themselves.* Regaining trust was approached in the context of stigma which, in line with other studies, impoverished individuals' capacity for recovery (Connell, 2015b; Waite *et al.* 2015; Jager *et al.*2015).

Specifically, participants' endeavoured to regain trust in themselves was a key process in overcoming the trauma of ROP. According to Tedeschi & Calhoun (2006) some elements of intrusive and repetitive thinking foster integration of the trauma and enhance PTG. The nature of the ROP however is somewhat different to other traumatic events. Primarily, as the results show, due to the participants being aware that a part of themselves (e.g. their own beliefs system) is involved in the manufacture of the horror. The task of recovery and fostering a sense of self then becomes particularly challenging for individuals following ROP. Not only does acknowledgement of this meta-cognition amplify the trauma experience, but also highlights that their belief system could be implicated again in the future. This represents a novel finding and the role of this meta-cognition which is specific to psychosis warrants further study.

4.3.3 POST-TRAUMATIC GROWTH (PTG)

The participants did not appear to be actively seeking to "gain something" from their psychotic experience, as found in previous studies (Connell, 2015a). In fact participants in this study did not appear to recognise the positive changes that occurred or derive a sense of achievement in the gains

they made. Nevertheless, there were clear elements of PTG in the participant's reports in line with previous research. Including in the areas of: heightened self-awareness (Mapplebeck *et al.* 2015; Dunkley & Bates, 2015); reassessing priorities (Dunkley & Bates, 2015; Dunkley *et al.*2015; Nixon & Hagen, 2001); increased empathy (Dunkley & Bates, 2015; Waite *et al.*2015) and deeper relationships (Dunkley *et al.* 2007; Connell, 2015a; Dunkley & Bates, 2015; Waite *et al.*2015).

Notions of increased self-awareness manifested in an increase in well-being through being more open with others and being better able to manage their self-care needs. A number of participants in this study describe the process of identity transformation from 'patient' to 'expert by experience' and the associated feeling of becoming empowered. This finding provides further support for the 'illness identity' model (Yanos, *et al.* 2010). It is proposed in this model that the transformation from 'patient' to 'survivor' or 'expert' enables the individual to reframe the experience of mental illness so that it no longer carries a negative connotation, but instead is seen as something that is 'acceptable'. It is suggested that an essential part of the recovery process involves transforming undervalued identities associated with internalised stigma and replacing them with more individualised empowered identities (Yanos *et al.* 2010). There is limited research exploring the role of illness identity in recovery from psychosis, future avenues of research could focus on the role of illness identity in relation to well-being and PTG following psychosis.

In line with the PTG literature, participants noted an increase in empathy for others (Calhoun & Tedeschi, 2006; Tedeschi, 1999). They described drawing on their own experience of being 'a mental health patient' to empathise with others experiencing mental health difficulties. This appeared to challenge stigmatising views, however it did not seem to translate to deeper compassion for oneself. The relationship between PTG in terms of increased empathy and the impact of this on stigma following psychosis is unclear but offers an interesting avenue for further enquiry. A further area of growth was apparent in the reassessment of priorities and involved a re-consideration of one's goals, interests, life path and priorities. For many this resulted in prioritising family and thus linked with deeper relationships. Participants reported both elements of PTG and PTD in terms of relating to others. In particular participants reported relationships with family members becoming deeper in a number of ways: greater appreciation for others; closer relationships, spending more time together; shared activities and putting more effort into relationships. This also related to some friendships and in line with previous research, the trauma of the psychosis appeared to sift those friendship worth pursuing, so that those who remained close were seen to 'prove' the worth of their friendship (Mapplebeck *et al.* 2015). However, participants also reported a sense of estrangement

from the friendships that did not continue after the initial psychotic period. The finding that participants report both gains and losses within the same domain supports the notions that PTG and PTD can co-exist and therefore may well be separate constructs (Cann, 2010).

4.4 CLINICAL IMPLICATIONS

The findings of this study suggest a number of clinical implications with particular significance for therapeutic interventions and the role of clinical psychology. The current findings suggests a number of ways in which individuals may be supported to overcome the psychotic experience. The results from this study clearly support recent findings emphasising the traumatic nature of the psychotic episode (Berry *et al.,* 2015) which has important implications. Understanding the trauma attached to the experience of psychosis is a critical stage in the development of a compassionate approach to the conceptualisation of psychological interventions aimed at enabling recovery from and staying well after psychosis (Larkin, *et al.* 2015).

The findings support previous notions regarding the importance of engaging individuals in conversations about their ROP to facilitate their capacity to create narrative and explanatory models (McGorry, 1992). Additionally, the current results highlight the importance of supporting the individual to engage in valued social roles and occupation. These processes have been found to be key in the essential task of piecing together the jigsaw of the self. Yet the focus of early psychosis treatment continues to hinge on symptom management, psychoeducation, restoration of functioning and relapse prevention (Connell, 2015a).

Cognitive Behavioural Therapy (CBT) remains a recommended psychological intervention for first episode psychosis by NICE (National Institute of Health Care Excellence, 2014), despite the controversy over its effectiveness for psychosis (Jones *et al.* 2012; Zimmerman, 2005, Lynch *et al.* 2010). The results of this study could support the use of existing psychotherapeutic work that synthesises positive psychology interventions. For example, Padesky and Mooney's (2012) Four Step Strengths-Based CBT approach requires individuals to seek out their valued strengths. This approach complements the finding that individuals following a recent onset psychosis experience growth, but are 'hidden' or obscured by the ongoing difficulties.

Onken & Colleagues (2007) highlight a process of 're-authoring' as a pivotal recovery process. 'Re-authoring' involves the process of narrative production with one's self. In line with the current results from this study, Onken & Colleagues (2013) identify the relational aspect of one's sense of self and adopt a systemic model whereby the individuals significant others are integrally involved in

the process. The model involves a shift from perceiving a person plagued by mental health difficulties, to viewing the individual who is experiencing and overcoming life difficulties. The individual is invited to consider the positive value and meaning in their experience that contributes to a re-construction of identity (McCarthy-Jones, 2013) - to a 'better than new' sense of self. The aims of 're-authoring' interventions are supported by the current finding emphasising the role of illness identity and the fostering of social roles and connectedness in rebuilding of the self in addition to the very real possibility of positive change. The role of the clinical psychologist and other health professional rests not simply on facilitating recovery through therapy.

Promoting co-production in partnership with consumers to create opportunities for re-authoring, or 'narrative recovery' (Williams, 2015) can have consequences not simply for the individual alone. For example, taking stories from those of distress and trauma and evolving those to ones of survival and growth enable people to build individual and communal resilience against stigmatising societal actions. An example of one such study is provided in a user led project described by Taylor, Leigh-Phippard & Grant (2014). The group was a collaborative, co-produced, re-authoring-focused recovery intervention, engaging members in therapeutic self-reflection through creative writing. The Deleuzian perspective adopted by this group acknowledged that a 'strand of participants' traumatic past is related to institutional psychiatric treatment (Williams, 2015).

Few authors have recognised the benefit of exploring the experience of psychosis in the context of both depreciative and constructive change. PTG was poorly recognised by the participants in this study but exploring this further in a therapeutic endeavour may have potential to increase self-efficacy, challenge internalised stigma and ultimately create a positive sense of self. Participants in this study did not recognise or take achievement in their accounts of growth, rather they were more focused on managing the ongoing distress associated with the psychosis. In line with previous recommendations caution must be given to growth is integrated into interventions (Calhoun & Tedeschi, 2004). Reidesser (2004) describes an individual who identified psychosis as an opportunity to get to know oneself but warns against the risk of downplaying individual suffering. The participants in this study clearly wanted and appeared to need to communicate the horror and suffering they continue to experience. Constructive change should not be assumed to preclude distress (Tedeschi & Calhoun's, 2006). Likewise, neither should the absence of growth be considered a negative outcome. Rather clinicians should be aware of and allow for in their practice, the *possibility* of both positive and negative outcomes.

4.6 SERVICE DELIVERY IMPLICATIONS

Undertaking projects such as those described above (Taylor *et al.* 2014) would require a significant shift in professional function. However policies such as Together for Mental Health (2010) clearly state the role that clinicians and services have in tackling stigmatising and discriminatory practises. Embracing service users in service development necessitates organisational support for wider and previously unrecognised forms of activity. De Silva (2011) recommends a 'co-productive' service which emphasises true collaborative partnership of service-user and service provider. Examples of co-productive practices could include joint crisis planning and personal recovery planning. Joint crisis planning could lead to the service-user feeling more in charge of their mental health care and treatment (Henderson *et al.*2004).

The current study supports existing literature describing the traumatic experience of treatment, particularly enforced hospitalisation (Berry, *et al.*2015). Furthermore, the incidence (50-98%) of trauma and PTSD in individuals presenting with a psychosis (Read, Os, Morrison &Ross, 2005) demonstrates the importance of assessing for trauma and incorporating this into psychological formulation. Important implications also lie in respect of service provision and the clinical psychologist's role in training and supervision. For example, although the need to assess and identify trauma in respect to ROP is specified within guidelines (NICE, 2014), services may benefit from training and supervision integrating a Trauma Informed Care (TIC) approach. This should focus on understanding, recognising and responding to the effects of trauma and physical, psychological and emotional safety. This may go some way towards decreasing the probability of individuals being traumatised or re-traumatised as a result of the experiences associated with enforced care (e.g. lack of control; powerlessness) This will lead to an increasing sense of empowerment in those under the care of mental health services.

People who work in clinical settings may benefit from training in and an increased consideration of attachment styles. This is borne out by the results of this study which illustrates the distrust that recovering individual feel for others. Support for this course of action can also be found in the findings of Picken, Berry, Tarrier & Barrowclough (2010) who demonstrated high levels of attachment related problems in those presenting with psychosis.

The fact that each person's experience of recovery is very much individual to them has contributed to concerns about how to best capture the richness and meaning of recovery (Jacobson & Truax, 1991). Thus it is vital that measures of individual and service orientations towards recovery actively and meaningfully involve the perspective of service-users in their development. This is particularly

the case in the context of 'payment by results' (now payments system) and commissioning decisions being centred on outcome measurements. In a systematic review of existing measures (Williams *et al.* 2012) found that the (Recovery Enhancing Environment) measure was most strongly aligned with those areas of recovery identified in the review by Leamy *et al.* (2011). However, even this tool contained relatively fewer questions in relation to hope and identity. This may be indicative of a political-organisational bias of what is considered significant in recovery (Williams, *et al.* 2015). The current results amplify the need for identity to be considered pivotal in any tool assessing recovery orientation. At present there is no particular measure that has sensitivity to outcome change and if recovery orientated practice is to withstand the drive for empirical evidence and service evaluation, this represents a key task.

The results of the current study demonstrate that individuals who have a ROP may not necessarily wish to align themselves with the medical model of recovery. It has been suggested that mental health services were devised as 'mental illness services' first and foremost (Anthony, 1993). Some critics (e.g., Andreasen *et al.*, 2011) have suggested that this leads to the position that there is 'something wrong with the person' (Beresford, 2012). This study depicts the narrative not just of ideas of complete recovery, but of a self-transformation. The priorities for the current participants in this study centred on feeling valued, establishing connections and developing trust which enabled them to feel more themselves following the traumatic experience of ROP.

4.7 METHODOLOGICAL STRENGTHS AND LIMITATIONS

4.7.1 LITERATURE REVIEW

As outlined in chapter 1, there is considerable conceptual overlap with reference to what is considered 'growth'. Although there are disagreements concerning the conceptual boundaries separating the terms included in the systematic search (e.g., 'thriving'; 'benefit finding'; 'stress-related growth'), it is felt that these terms best capture changes associated with traumatic events. The recovery literature also defines 'growth' but the conceptual basis is somewhat different, with notions akin to resiliency or self-actualisation. It generally does not necessitate the occurrence of a trauma nor do recovery models always conceptualise a ROP as a trauma. Excluding terms associated with the recovery literature maintains conceptual clarity and a focus on the traumatic experience of ROP, in line with the study aims. However, this may have resulted in some accounts of growth being undetected. This possibility is furthered where recovery is the focus of the study and accounts of 'growth' appear only in the results section without prior mention or focus, and therefore go undetected by the review process (Jordan, *et al.* 2016).

4.7.2 SAMPLE

Metacognitive (MacBeth *et al.* 2014) and autobiographical memory difficulties (Wood, Brewin & McLeod, 2006) appeared to hinder the ease at which participants could provide in depth accounts of their experiences. However, it should be noted that despite these difficulties participants provided rich and insightful accounts of their experiences. The symptoms of psychosis can fluctuate over time, with individuals alternating between periods of lucidity and capacity and periods of florid symptoms and incapacity. Consequently a unique feature of psychosis and schizophrenia is that capacity is often fluctuating (Roberts, 2006). Instead of this leading to additional care and consideration it has been suggested that in the past it has precluded individuals with such symptoms from participating in research based on diagnostic status (Cuenod & Gasser, 2003; Osborn,1999). This lack of flexibility has contributed to further stigma and led to their voices not being heard. This study has demonstrated that individuals experiencing psychosis can not only meaningfully engage in the process but can do so with insight to produce rich and meaningful accounts of their experience.

As has been the case with previous literature men are over-represented in this sample (6 out of 8 participants). This is not surprising given the gender difference in the epidemiology of psychosis (insert). However, this may have introduced bias towards lower levels of PTG, given the literature suggesting a small to moderate gender difference with women reporting more PTG than men (Vishnevsky, Cann, Calhoun, Tedeschi & Demakis, 2010). Additionally, two participants had not received a formal diagnosis and, given the role of stigma identified in the study, this may have impacted on how they viewed themselves in relation to the remaining six. Two participants considered themselves to have ongoing symptoms whilst the remaining categorised themselves as 'symptoms free' though this was not reflected in the qualitative interview as the majority spoke of experiencing at least some form of ongoing symptoms. All but one individual was recruited from the EIS and the one recruited from third sector had previously been in receipt of support from the EIS. The fact that all but one was recruited from the EIS illustrates that the results are likely to be generalizable to the majority of individuals accessing such EIS across Wales.

It was not possible to employ theoretical sampling, as recommended by Charmaz (2014), due to the difficulty encountered in recruiting participants. This meant that categories identified during data analysis were not explored in more than one population. The use of theoretical sampling permits richer material to develop categories further in accounting for similarities and idiosyncrasies. However, data saturation occurred with the relative small number of participants and the data gathered allowed for sufficiently rich development of categories.

4.7.3 METHODOLOGY

This study addressed a number of methodological issues present in previous studies exploring psychosis and PTG. Participants were recruited to this study if they had experienced their ROP *at least* six months ago or longer. As illustrated in chapter 1, multiple processes have been indicated in the development of PTG (e.g., narrative and schema change, Tedeschi & Calhoun, 2006), and some authors have suggested that the processes leading to PTG take at least 6 months to emerge (Tedeschi & Calhoun, 1996). The inclusion criteria in this study therefore ensures that individuals in this study have been given the necessary time to proceed through such processes. This overcomes the limitation of other studies (e.g., Connell, 2015a) which assessed for PTG only one month post psychosis.

The use of constructivist grounded theory was selected based on the research questions in hand. This method compliments the exploration of social processes which are key to the development of the areas under consideration (e.g. sense of self and PTG). In addition, and in line with both the epistemological viewpoint of the researcher and the subjective nature of the experience of recovery, the method allowed for the unique perspectives of the individuals to emerge. The researcher considers avenues of future research that may be optimally researched via quantitative methods (section 4.9).

Research exploring PTG has been criticised for a reliance on retrospective accounts of the experience of psychosis and recovery. While the evidence that this approach may be less accurate than recording events as they occur (e.g., Schroder & Borsch-Supan, 2008) this may in itself not be problematic. Indeed, the current study aimed to understand how the individual understands and engages in the continual sense making process which inevitably relies on autobiographical memory. It is, however, acknowledged that a longitudinal study would allow for observation of change over time and therefore deeper insight could be gained into both the process of change and causal relationships and this is considered in relation to future research recommendations pertaining to the examinations of specific processes involved in PTG.

4.7.4 CREDIBILITY OF RESEARCH FINDINGS

The credibility particularly in terms of the emphasis placed on reflexivity was deemed to be a strength of the current study and addressed limitations in this area from previous studies as highlighted in the systematic review. The author of the current study adopted quality criteria devised by Elliott *et al.* (1999) to ensure that the study was of high quality. A reflexive journal was used throughout the study and regularly reviewed, particularly during the data analysis process to

ensure that the author's contributions to the research were continually explored. In addition, guidelines produced by Ahern (1999) outlining reflexive bracketing were followed. The author's position with regards to assumptions and prejudice was explored independently and in discussion with supervisors.

The analysis was conducted by the author but emerging themes were discussed with the academic supervisor throughout the process to ensure good fit with the data. Additional credibility checks were completed with a qualified clinical psychologist working in an adult crisis team who recently completed a constructivist grounded theory thesis project. Emerging themes were discussed with stakeholders of EIS to explore applicability of the theory with their experience of supporting individuals with a ROP. Draft copies of the results were discussed with the clinical and academic supervisor of the current study. The service user consultant also reviewed the theory and considered it to resonate with his own personal experiences. Ideally additional triangulation to aid reliability through the use of a focus group would have been beneficial but was not possible due to time restraints.

Overall, it is therefore felt that the results of the current study are credible and can be translated to individuals who are accessing ROP services.

4.8 RESEARCH RECOMMENDATIONS

The current study has highlighted areas of research that could be explored further in relation to the experience of PTG and re-building of one's sense of self following a recent episode of psychosis. The most pertinent of those are outlined here:

1. Drawing on a PTD framework, further longitudinal quantitative research into the ongoing distress of psychosis (e.g. perception of personal strength) may provide greater insight into the distressing negative impact of psychosis. This may contribute to a broader understanding of the ongoing negative impact of the trauma of ROP.

2. The research findings have supported elements of the illness identity model (Yanos *et al.* 2010). A qualitative study recruiting those who have successfully adopted 'acceptable' social roles (e.g., 'survivor'; 'expert by experience') may inform potential factors that promote PTG. Quantitative research could be used to further knowledge of processes involved in illness identity and the relationship of this to well-being.

3. The results of this study demonstrated that participants experienced PTG in self-awareness, deeper relationships, increased empathy and reassessing priorities. The methodology employed in this study was exploratory in nature due to the limitations of the small number of studies conducted in this specific topic. A quantitative longitudinal study may allow for deeper insight into the processes and outcomes related to PTG following psychosis.

4. This study has offered a unique perspective to the process of PTG following psychosis. Participants described the metacognition of an awareness of one's beliefs system as contributing to or maintaining the trauma of the psychosis. This finding makes the study of PTG in the context of ROP particularly unique and interesting and warrants further study.

4.9 CONCLUSIONS

Despite a recent surge in publication, there remains a lack of studies into the experience of PTG following ROP. The studies that have been conducted are either lacking the reflexivity which is central to rigour or adopted short time points (e.g. up to three months) which brings into dispute whether the processes associated with growth were able to fully occur (e.g., meaning making and reflection). More importantly however, is that the studies continue to be driven by theories relating to identity, thereby losing the focus on what has been demonstrated as key to the experience of ROP – that of overcoming trauma.

The current study has highlighted that individuals experience a range of distress and negative outcomes following ROP. These range from symptoms that could be associated with PTSD to less obvious but distressing responses (e.g. lower levels of perceptions of strength) in line with the concept of PTD. The participants sought to make sense of their experience of psychosis through ascribing a cause. A biological cause provided participants with heightened self-compassion as it abated fears they were in some way responsible for the onset. However, this served to erode self-efficacy over their management of future episodes. Participants considered what the 'illness' meant to them now and to their future 'recovered' selves. Further to making sense participants went about seeking a sense of purpose and value through social participation (e.g., roles and occupation). A central element to the re-construction of the self rested on regaining a sense of trust. The meta-cognition that the individual's own belief system played a part in the crisis magnified the distress of the trauma. This recognition also contributed to concerns regarding managing their own future relapse through ongoing distrust of an essential part of who they are.

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APPENDIX A: REFLEXIVE JOURNAL

July 2014

NHS ethics forms have been completed. Overall an overwhelming experience and I don't think I was prepared for the amount of paper work and processes involved, despite the warnings! However, I have to hand on to the main aims of the research and the thought of the end goal. I find myself thinking about the ethics meeting and what sort of questions might come up. I am aware of all of the caution surrounding doing research with those with a 'psychosis'. Although I can see that you might have to be extra careful with the remitting symptoms and the impact of this on capacity to provide consent I can see how this might lead to others not doing research in the field. This would clearly have a big impact, although I hope opinions are changing there still seems to be a lot of assumptions around this client group.

September 2014

Today I met with the Service User Representative. I feel very lucky to have been directed to him and grateful to him for his support. I'm wondering how I can pay this back somehow afterwards in terms of service users events and dissemination of the research findings. The pilot interview went well and I got some valuable feedback about the use of terms I am using things like "how do you view your world?". I think I have been immersed in psychological language for too long as I hadn't questioned service users understanding of this. Although the use of prompts discussed might help.

I'm due to go off on maternity leave now for 6 months. Seems in one way a shame to leave this project hanging for that time as I'm keen to start. Although ethics is still dragging on so it may be fortunate. Hopefully by the time I come back to work I will be able to get stuck into recruiting.

July 2015

Completed my first interview today. I hadn't expected to discuss the crisis period in such detail. There seemed a real need for this participant to share his trauma and I needed to give this space. The extent of the trauma discussed was eye opening. I was expecting the psychosis to be discussed in this way but the terror of not being in control of yourself and experiencing the horror inside your own head seemed to really emerge. I found myself wondering where these narratives end up and the extent to which FEP front line staff hear them. This could make an interesting enquiry in itself.

Lots of rich data gathered from this interview. Gaining an occupation and role was especially important for this participant. He was leading a Hearing Voices group which gives him a great sense of purpose. I wonder how much this theme might emerge for the other participants or if it is unique to his story. This participant had had psychological in out and his descriptions of the meaning made seemed quite detailed. I guess this might have an impact on the extent and way in which participants make sense. Although even with a psychologist involved the explanations were medically based.

November 2015

After coding the third interview and reviewing the memos it seemed like a good time to pause from interviewing. It was good to meet with my academic supervisor to explore the emerging codes and themes and also to know that we were both thinking along the same lines. It is quite exciting actually to have very similar thought about what the data mean and start to discuss this with someone equally inspired by it. There are certainly themes emerging around finding meaning and a purpose. The interview schedule has been changed and I am looking forward to testing it out. The participants so far have been different in their cognitive styles and I think the amendments made will also help with regards to making sure they can engage as fully as possible.

December 2015

I'm really struggling to recruit participants. Only four so far and I'm starting to get anxious about getting it all finished on time. The majority of participants are either not considered suitable (due to eligibility) or their care co-ordinators don't feel that they are 'well enough'. I am wondering what well enough means? Although the team whom I am accessing regularly for recruitment are very used to research and recruiting (which is also fortunate as they are all on board) so I don't think there is a significant bias here.

January 2016

Just completed my seventh interview and I think I have reached a point of saturation. This interview did not introduce any new themes but added some richness to those already emergent. It's surprised me how the narratives seemed so different in the moment but through the coding they all presented with very similar ideas. It makes me think about the meaning we give to people's experiences and I'm feeling quite pleased that I chose constructivist grounded theory as it seems to 'fit' with me more and more as I develop clinically. It's exciting to hear the different narratives too of growth. Though these aren't as exciting to the participant sometimes I'm aware. I'm wondering why that is and whether it might be that these aren't given the attention and elaboration to bolster them into more dominant stories. I think this study could have some exciting implications.

APPENDIX B: QUICK QUIDE TO SCHIZOPHRENIA SPECTRUM AND PSYCHOTIC DISORDER (MORRISON, 2014)

Schizophrenia and Schizophrenia-Like Disorders

Schizophrenia. For at least 6 months, these patients have had two or more of these five types of psychotic symptom: delusions, disorganised speech, hallucinations, negative symptoms, and catatonia or other markedly abnormal behaviour. Ruled out as causes of the psychotic symptoms are significant mood disorders, substance misuse, and general medical conditions (p.64).

Catatonia associated with another mental disorder (catatonia specifier). These patients have two or more of several behavioural characteristics (defined on p.100). The specifier can be applied to disorders that include psychosis, mood disorders, autistic spectrum disorder, and other medical conditions (p.100).

Schizophreniform disorder. This category is for patients who have the basic symptoms of schizophrenia but have been ill for only 1-6 months – less than the time specified for schizophrenia (p.75).

Schizoaffective disorder. For at least 1 month, these patients have had basic schizophrenia symptom; at the same time, they have prominent symptoms of mania or depression (p.88).

Brief psychotic disorder. These patients will have had at least one of the basic psychotic symptoms for less than 1 month (p.80).

Other Psychotic Disorders:

Delusional disorder. These patients have delusions, but not the other symptoms of schizophrenia (p. 82).

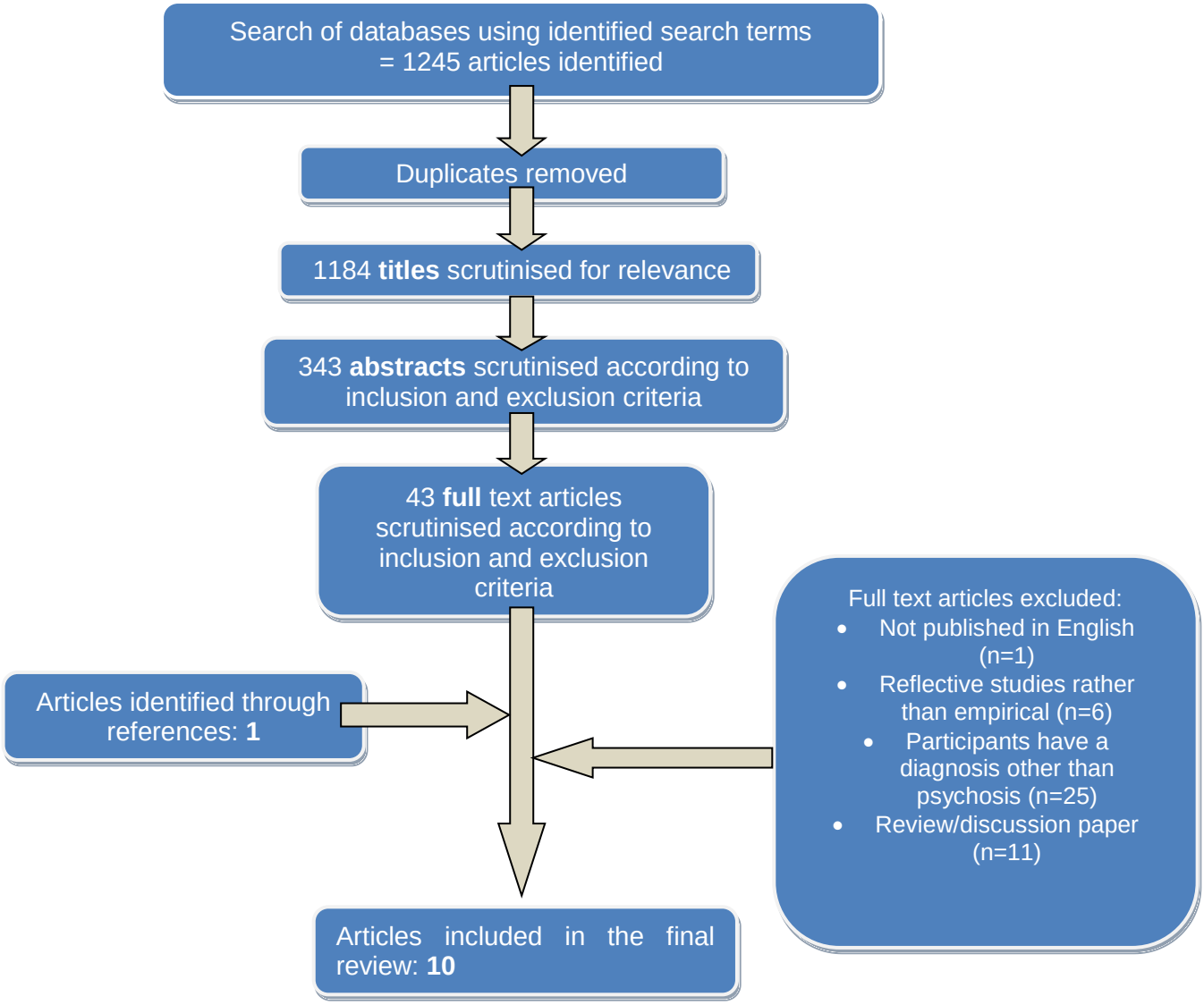
Psychotic disorder due to another medical condition. A variety of medical and neurological conditions can produce psychotic symptoms that may not meet criteria for any of the conditions above (p.97).

Substance/medication-induced psychotic disorder. Alcohol or other substances (intoxication or withdrawel) can cause psychotic symptoms that may not meet criteria for any of the conditions above (p.93).

Other specified, or unspecified, schizophrenia spectrum and other psychotic disorder. Use one of these categories for patients with psychoses that don't seem to fit any of the categories above (p.106).

Unspecified catatonia. Use when a patient has symptoms of catatonia but there isn't enough information to substantiate a more definitive diagnosis (p.107).

APPENDIX C: DIAGRAMMATIC PRESENTATION OF THE SYSTEMATIC SEARCH STRATEGY



APPENDIX D: SCORING OF ARTICLES SOURCED FROM THE SYSTEMATIC REVIEW USING CASP

KEY: 0 = Criteria not met (Not addressed and /or unclear); 1 = Criteria partially met (i.e. addressed but some limitations and lack of clarity); 2 = Criteria fully met (i.e. clearly addressed and explained)

Author	Research aims	Qualitative Methodology Appropriate?	Design	Recruitment strategy	Data collection	Reflexivity	Ethical issues	Data analysis	Statement of findings	Value of research	Total score
Connell, Schweitzer & King (2015a)	Clear goals specified Importance and relevance discussed in detail and in context of research relating to informing treatments **SCORE = 2**	Rationale for use of qualitative based on subjective experience of participants sought. Reasons for choice of approach clearly discussed **SCORE = 2**	Design clearly discussed in relation to research aims and consideration given to applicability of design **SCORE= 2**	Descriptions provided of: 1.How participants were selected 2.why they were applicable e.g., early FEP 3.reasons for refusal explored **SCORE = 2**	Following sufficiently described: 1.setting for data collection 2.how data collected 3.justification of methods 4.Adaptations not highlighted 5.methods explicit 6. form of data Saturation was n/a **SCORE = 2**	Researchers failed to document critical Examination of own role Researchers response to events during study and changes in design not discussed **SCORE = 0**	Ethical approval described Issues regarding consent discussed Consent process described **SCORE = 2**	Analysis process described in detail Generation of themes and process of gathering data to present discussed Sufficient data to present findings Contradictory data or potential bias not discussed **SCORE = 1**	Statement of findings explicit and evidence well argued More than one analyst used Findings discussed in relation to original aims **SCORE = 2**	Researcher considers contribution of research identify new areas of study consideration of how findings can be transferred to other presentations **SCORE = 2**	17/20
Connell, Schweitzer & King	Goals stated clearly	Discussed choice of qualitative	Longitudinal design to explore	Descriptions provided of: 1.how	Following sufficiently described:	Researchers failed to document	Ethical approval described	Thorough description of data analysis	Explicit account of findings	Clear and detailed account of	16/20

(2015b)	Importance clearly discussed in relation to existing theories and individuals' Recovery **SCORE = 2**	methods in the context of aims and objectives of study **SCORE = 2**	perceived changes over 3 month as specified by the aims **SCORE = 2**	participants were selected 2.why they were applicable e.g., 3 months post FEP 3. Details not provided for those not partaking **SCORE = 1**	1.setting for data collection 2.how data collected 3.justification of methods 4. Adaptations not highlighted 5.methods explicit 6.form of data Saturation was n/a **SCORE = 2**	critical Examination of own role but do recognise possible impact of researcher's position Researchers response to events during study and changes in design not discussed **SCORE = 0**	Issues regarding consent discussed Consent process described **SCORE = 2**	Sufficient data to present findings Generation of themes; decision regarding presentation of data and potential bias not discussed **SCORE = 1**	Evidence given for and against Themes audited by second and third authors Findings discussed in relation to original aims **SCORE = 2**	implications including theoretical and clinical New areas of research identified Researcher discussed applicability of findings **SCORE = 2**	
Waite Knight & Lee (2015)	Clear and concise objective provided Aims and relevance stated in relation to theory, practice and service developmen t **SCORE = 2**	Design clearly and separately discussed and reasoned **SCORE = 2**	Qualitative design using semi structured interviews to explore self-to- self relating. **SCORE = 2**	Descriptions provided of: 1.How participants were selected 2.why they were applicable 3.Number of drop outs given but not reasons, otherwise thorough discussion **SCORE = 2**	Following sufficiently described: 1.setting for data collection 2.how data collected 3.justification of methods 4. Changes to prompts discussed 5.methods explicit 6.form of data Saturation was n/a	Researcher highlights potential of bias and opportunities to minimise this e.g., reflexive journal, bracketing interview and discussion in supervision **SCORE = 2**	Ethical approval described Issues regarding consent discussed Consent process described **SCORE = 2**	Detailed discussion of data analysis procedure Sufficient data to support findings Potential bias of researcher in theme generation considered **SCORE = 2**	Explicit account of findings Evidence given for and against Themes audited by second and third authors and independent IPA expert Findings	Clear and detailed account of implications including theoretical and clinical New areas of research identified Researcher discussed applicability of findings	20/20

					SCORE = 2				discussed in relation to original aims **SCORE = 2**	**SCORE = 2**	
Jager, Rhodes, Beaven, Holmes, McCabe, Thoma, McCarthy-Jones, Lampshire & Hayward (2015)	Goals presented in a clear manner Importance and relevance discussed in detail and in relation to hearing voices network (interventions) and existing theoretical constructs **SCORE = 2**	Discussed choice of qualitative methods in the context of aims and objectives of study **SCORE = 2**	Qualitative using narrative enquiry. Reason for choice clearly discussed In relation to aims **SCORE = 2**	Descriptions provided of: 1.Selection of participants 2. why they were applicable e.g. HVN group 3. Number and reason for not taking part described **SCORE = 2**	Following sufficiently described: 1.setting of data collection 2.how data was collected 3.interview method described and justified 4. form of data was clear changes to interview not discussed **SCORE = 2**	Researcher discussed the use of a panel of consultants but this was discussed as input into the model rather than from a reflective stance Researchers position not discussed **SCORE = 1**	Ethical approval described Issues regarding consent discussed Consent process described **SCORE = 2**	In depth description of analysis process Sufficient background to generation of themes and data to support findings. Potential bias of researcher not considered **SCORE = 1**	Statement of findings explicit Against arguments given to some degree Researchers discussed respondent checks **SCORE = 2**	Clear and detailed account of implications including theoretical and clinical New areas of research identified Researcher discussed applicability of findings **SCORE = 2**	18/20
Dunkley, & Bates (2015)	Goals specified clearly Importance and relevance not discussed in context of	Qualitative approach considered in terms of the aims and description provided **SCORE = 2**	Longitudinal qualitative approach considered and reasoned in terms of past research and study aims	Selection of participants explained in part Suitability explained in terms of length of recovery	Setting of data collection not described Semi structured interviews described and justified Modification of	Researchers' position not specified. Researcher describes use of second author to validate findings and	Ethical approval described Issues regarding consent discussed Consent	Analysis procedure described with some detail Sufficient data to support themes and checks on the generation of	Statement of findings explicit Against arguments given to some degree Researchers	Detailed and through description of clinical and theoretical implications. Future research described but no	16/20

	clinical work but thoroughly in context of research **SCORE = 2**		**SCORE = 2**	No discussion regarding opt out **SCORE = 1**	methods not discussed **SCORE = 1**	an agreement rate of 80% **SCORE = 1**	process described **SCORE = 2**	themes were described. No reference to role of researcher though in theme generation **SCORE = 1**	discussed validation checks Findings discussed in relation to aims **SCORE = 2**	consideration to other populations or individuals at a different stage of recovery **SCORE = 1**	
Mapplebeck, Joseph and Sabin Ferrell (2015)	Goals specified succinctly and clearly Implications for clinical context not discussed but relevance and importance thoroughly considered due to previous research limitations **SCORE = 2**	Qualitative approach considered in terms of the aims and description provided **SCORE = 2**	Qualitative approach informed by IPA and the use of semi structured interviews coherently reasoned **SCORE = 2**	Selection of participants discussed and the choice of participant selection No details regarding those who did not respond to invite or dropped out **SCORE = 1**	Setting for interviews not discussed. Use of semi structured interview schedule described Modification of interview not discussed **SCORE = 1**	Researcher described use of: a reflexive journal; data comparison of emerging themes; triangulation; and audit trail **SCORE = 2**	Ethical specified as granted but not by whom Issues regarding consent discussed Consent process described **SCORE = 2**	In depth description of analysis process Sufficient data used to support findings Author critically examined own role in generation of themes **SCORE = 2**	Explicit findings Slightly limited discussion of the evidence for and against arguments Detailed consideration of credibility Findings discussed in relation to aims **SCORE = 2**	Contribution of research to existing literature and treatment of psychosis New areas of research were not highlighted No consideration of how findings could be transferred **SCORE = 1**	16/20
Nixon, Hagen & Peters	Thorough discussion of importance	Qualitative design with an IPA approach	Full description and	Sampling and recruitment described in	Setting for interview not described	Researcher considers the impact of own	Ethics obtained from	Analysis not described in detail	Findings are clear	Researcher considers contribution	13/20

(2010)	and relevance in relation to research/theory Clear goals **SCORE = 2**	discussed in detail and in relation to study aims **SCORE = 2**	justification in regards to the design used **SCORE = 2**	detail and thorough description of participants No description of those not partaking **SCORE = 1**	'narrative' approach to data collection and justification given Authors note use of 'probing questions' but no examples provided **SCORE= 1**	ideas on themes but no attempt address this e.g., credibility check No use of data checking specified **SCORE = 0**	university board Informed consent and confidentiality discussed **SCORE =2**	Two researchers completed interviews but effect of bias not discussed Sufficient data to evidence themes Some contradictory findings discussed **SCORE = 1**	Credibility of research findings not discussed Findings are presented in terms of the original aims **SCORE = 1**	of research to practice and theory Researcher does not account how findings can be generalised New areas of research highlighted **SCORE =1**	
Dunkley, Bates, Foulds & Fitzgerald (2007)	3 specific research questions formed following a discussion of importance and relevance **SCORE = 2**	Qualitative and quantitative methods used and justification provided **SCORE = 2**	Prospective design used and clear reason for this provided **SCORE = 2**	Sampling process and reasoning clear. No discussion given for those not partaking **SCORE = 1**	Clear details provided in relation to setting of interview, interview schedule and justification of these. Setting not described Form is clear e.g., tape recordings **SCORE = 2**	No consideration given to the impact of researcher's position in relation to potential bias **SCORE = 0**	Ethics obtained from university board Informed consent and confidentiality discussed **SCORE = 1**	Analysis and approach to analysis described briefly Sufficient data to evidence themes Contradictory findings discussed but only two case studies so this was not unusual in the data **SCORE = 1**	Findings are clear Credibility of research findings not discussed Findings are presented in terms of the original aims **SCORE = 1**	Researcher considers contribution of research to practice and theory Researcher does not account how findings can be generalised New areas of research highlighted All discussions brief	13/20

										SCORE =1	
Thornhill, Clare & May (2004)	Goals clearly stated and importance and relevance of those goals well defined **SCORE = 2**	Qualitative design with an narrative approach discussed in detail and in relation to study aims **SCORE = 2**	Full description and justification in regards to the design used **SCORE = 2**	Sampling process and reasoning clear. No discussion given for those not partaking **SCORE = 1**	Setting for interview not specified Interview schedules described in very good detail. **SCORE = 2**	Researcher carefully and thoroughly notes own position and position of other researchers and possible implication for bias **SCORE = 2**	Process of obtaining ethics was not detailed Informed consent and confidentiality discussed **SCORE =1**	In depth discussion of analysis process Sufficient data to support findings Contradictory data discussed **SCORE = 2**	Findings are clear Considers contribution of own bias Findings presented in terms of aims **SCORE = 2**	Researcher considers contribution of research to practice and theory Credibility checks New areas of research highlighted **SCORE = 2**	18/20
Barker, Lavender, & Morant (2001)	Three specific research questions asked Importance and relevance discussed in a number of contexts **SCORE = 2**	Description and Justification of choice of qualitative method given **SCORE = 2**	Full description and justification in regards to the design used **SCORE = 2**	Sampling and recruitment described in detail and thorough description of participants No description of those not partaking but thorough description of processes **SCORE = 1**	Setting for interview appropriate Interview schedules described. No discussion around those not partaking **SCORE = 1**	Researcher notes own position and use of discussion with other researchers. Independent researcher interrater reliability found at 94%. This is discussed in terms of ensuring impact of	Process of obtaining ethics was not detailed Informed consent and confidentiality discussed **SCORE =1**	Analysis described in good detail. Use of an audit trail was specified Sufficient data to support themes Researcher explains how data presented was selected **SCORE = 2**	Findings are clear Credibility checks discussed Findings are presented in terms of the original aims Consideration given to researchers 'position **SCORE = 2**	Researcher considers contribution of research to practice and theory No credibility checks New areas of research highlighted **SCORE = 2**	17/20

						interviewer/analyser bias minimised **SCORE = 2**					
TOTAL ACROSS STUDIES FOR EACH DOMAIN	**20**	20	20	13	16	10	17	14	18	16	

APPENDIX E: THEMATIC ANALYSIS OF SYSTEMATIC REVIEW FINDINGS

	Themes												
	Immediate emotional responses	Processes involved in recovery	Recovery styles	Ongoing management of symptoms	Return to premorbid functioning	Finding meaning	Meaningful activity	Stigma	Inner strength	Relationships	Appreciating life	New possibilities	Impact on self
Connell., *et al.* (2015a) 1	x					x			x	x			x
Connell *et al.* (2015b) 2				x				x	x				x
Waite *et al.* (2015) 3	x	x	x		x	x		x	x	x	x		x
Jager *et al.* (2015) 4	x		x				x			x			
Dunkley, & Bates (2015) 5	x		x		x				x	x	x	x	x
Mapplebeck,*et al.* (2015) 6						x			x	x			x
Nixon *et al.* (2010) 7	x	x										x	x
Dunkley *et al.* (2007) 8									x	x	x	x	
Thornhill *et al.* (2004) 9	x			x		x							x
Barker *et al.* (2001) 10	x				x					x			x

1. Three factors 'processes involved in recovery', 'recovery styles', 'ongoing management of symptoms' and 'return to premorbid functioning' were combined into one factor: recovery processes, styles and recovery'. Meaningful activity with only one citing was moved into 'recovery processes styles and recovery'
2. Merge inner strength and sense of self.

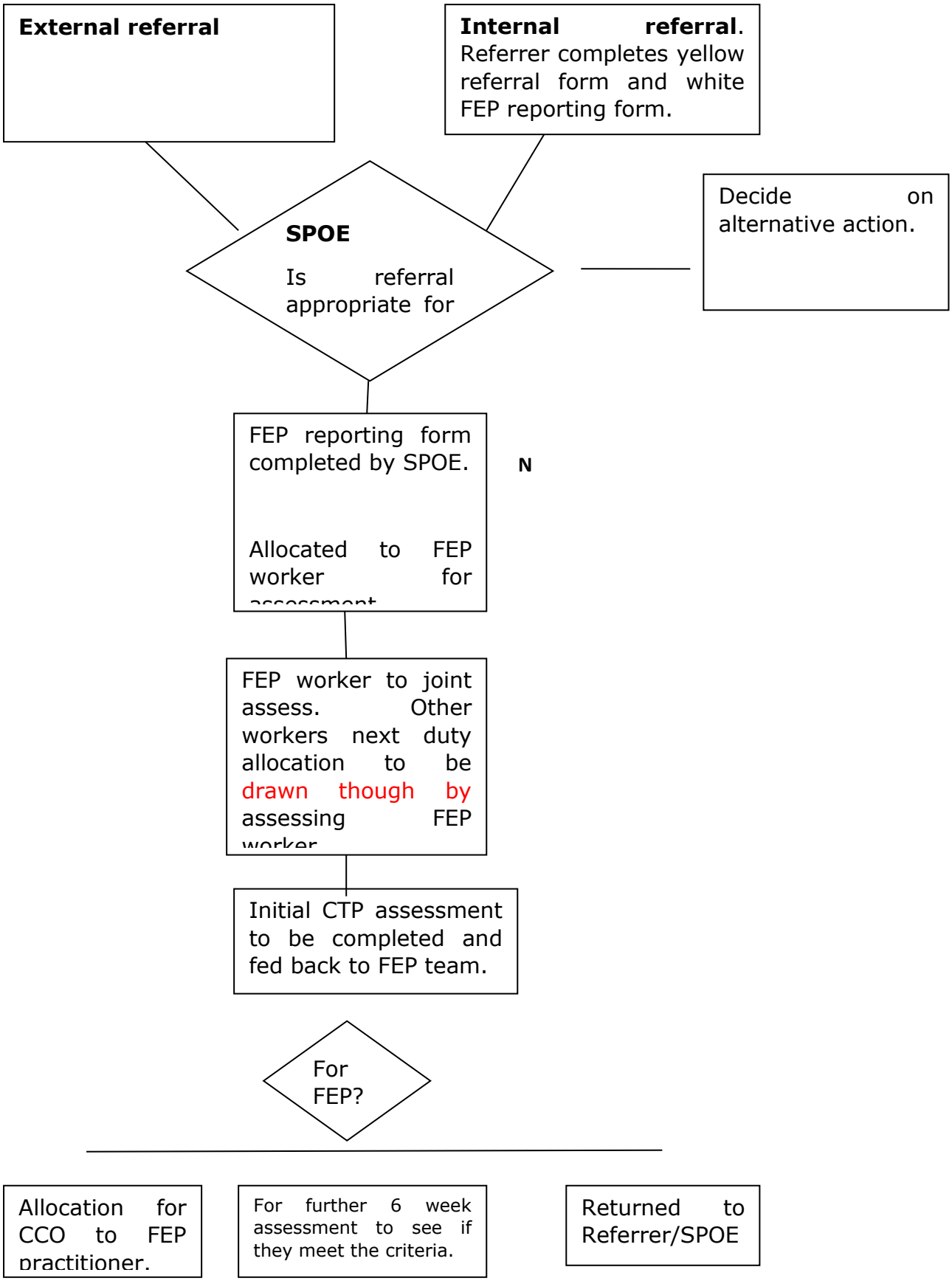
Immediate emotional responses	**Processes involved in recovery**	**Ongoing management of symptoms**	**Return to former state**	**Recovery styles**	**Finding meaning**
Disability (10) First psychotic episode (10) First hospital admission (10) Narrative of escape (9) Experiences of dying (7) Comprised day to day functioning (7) Psychic intuitive ness (7) Sudden psychosis (7) perceptions of treatment as restricting (5) Reaching a point of despair/exhaustio n(4) Context of voice onset and initial responses (4) My mind cant take the load (3) curse of psychosis (3) extrememm torture of psychosis (3) psychosis overhwlmed resources altered epereince of self and world (1)	Detachment and mindfulness (7) Finding hopefor the future (3) Its given me some tools for life (3) Acknowledging progress in recovery (3) Learning to deal with it (3) Treated myself with kindness (3**)**	Narrative of endurance (9) Coping with disturbing thoughts (2) Consumed by the illness (2)	Coping and services (10) Social recovery (5) Functional recovery (5) On my own two feet (3)	Self directed recovery (5) Viewing recovery as a journey (5) Developing acceptance and moving forward (5) Conscious avoidance (5) Divergent recovery typologies (4) Finding hopefor the future (3) Coming to terms and moving on (3) The challenge of acceptance (3) Plodding on versus getting life back on track (3**)**	Finding meaning and purpose (6) Couldn't understand psychosis (3)trying to figure out what was wrong (3) Making sense of the experience (1)

Meaningful activity	**Stigma**	**Inner strength**	**Relationships**	**Appreciating life**	**New possibilities**	**Impact on self**
Engaging in meaningful activity (4)	Stigma (3) Strengthening close bonds (2)	Enhanced perceptions of personal strength (8) Inner strength and determination (6) Sense of mastery and personal strength (5) Awareness of one's vulnerability (5) threat of relapse (3) Expressing agency (2) forging a stronger self (1) Apprehension (1)	Relationships (10) Deeper relating to others (8) Support and understanding (6) Confirming characters of others and quality of relationships (5) Increased desire to interact with others and improve relationships (5) Development of deeper and closer relationships (5) The interpersonal environment facilitates recovery (5) connecting with others (4) People tried to help me (3) strengthening close bonds (1)	Appreciation of life (8) Greater appreciation of life (5) Life is worth living (3)	New possibilities (8) Realignment of career path (7) New possibilities and direction (5)	self development (10) narratives of enlightenment (9) accepting dissolution of time (7) childhood foreshadowing (7) self acceptance and awarenedd (6) deepening of self knowledge (5) re-developing a positive self feeling content with self (3) trap of self criticism (3) psycosis as a source of self blame (3) self criticism (3) putting self criticism behind bars (3) finding the positive (2) feelings of loss (2) consumed by the illness (2) re-visiting the past (2) loss of self (1)

Miscellaneous

Events preceding first psychotic episode (10)
Embracing a spiritual pathway (7)
Communication with God (7)
Negative childhood events (7)

APPENDIX F: ASSESSMENT AND REFERRAL PROCESS TO EIS



Early Intervention Criteria

- Age 14-35 years inclusive
- First episode of untreated psychosis
- DUP of under 3 years
- Any single positive symptom that attracts a PANNS score of 4 or more
- Any combination of 3 or more positive symptoms on PANNS
- Confirmed diagnosis of psychosis

Essential Assessments

- CTP
- PANNS
- MANSA
- GAF

APPENDIX G: EXAMPLE OF CODED INTERVIEW TRANSCRIPT

	INTERVIEWER: Lots of people ask themselves the questions why me? After a psychosis and I was interested whether you've ever asked the question why me?	
1	PARTICIPANT: Yeah I think everyone will. I think It is a question which gets on my mind, it is like why did it	Asking why me
2	happen? Like why you know, kind of like with mine, it was kind of like spiritual, so it feels a bit different. Yeah	Psychosis as spiritual; differing to others' experiences
3	you do question, why has this happened to me. Umm what have I done? What have I done wrong to deserve	Asking if deserved the psychosis
4	this sort of thing. Erm and if I think , a lot of it you regret as well, what with mine it was a lot of regret after	Regretting
5	really and it's just like I couldn't help myself when you look back, you do, you do question why	Feeling helpless during the psychosis
	INTERVIEWER: Do you feel that you ever arrived at any answers?	
6	PARTICIPANT: no, no answers….. no. it's just.. it happens and that's the only sort of explanation I try to give	Having no answers; it happens
7	myself.. closure.. cos otherwise it will keep on my mind and then you just think about it too much then. You,	Getting closure
8	pick it at the time, umm what happened, why you try to make sense of what happened but then you, you	Making sense
9	don't know what was delusional, what was real, erm and you sort of question that as well. And so like for, for	Questioning what was real and not real;
10	example I had it on my phone and I lost my phone so I couldn't go back and see if it was real or not so that's a	relying on other sources; sources failing you; self failing
11	question you can't answer then and you've, you a lot of it will come to no answer really, but you have to	Having to accept it;
12	accept it to try and move on really…. Hmm.. hard [emphasis].	moving on
	INTERVIEWER: It sounds hard. So are you, do you consider yourself at that kind of acceptance stage?	
13	PARTICIPANT: erm. You still go into those modes and I think it depends, like for me I've got to be active	Keeping active
14	otherwise I'll start thinking about it more, so then I'll question things more, and trying to unpick it and still not	Avoiding thinking; Avoiding questioning
15	finding any answers really. But you still look.	looking for answers
	INTERVIEWER: yeah, sounds really frustrating when you don't find those answers	

	PARTICIPANT: yeah like for me I'm not diagnosed with anything so I have answers like, cos I do research, cos	Undiagnosed; Source information
16	you know that's not the best thing to do but you, you'll think alright am I schizophrenic? Because there were	Looking for a label; looking for answers
17	symptoms that won't come under that sort of category, but those questions come up then as well, when	Questioning what am I
18	especially, when you're undiagnosed, you sort of question well what is wrong with me for that to have	Being undiagnosed; Asking if deserved psychosis
19	happened? And you know, led by doctors and I think for me in my case, this, there really isn't, nothing else, do	Finding blame in self
20	you know what I mean, it was just, just a psychotic breakdown.	Having no answers; being led by doctors
21	INTERVIEWER: it sounds like you couldn't quite find the answers?	
	PARTICIPANT: Yeah like cos I don't know, cos by an episode I thought I was like Jesus, so and I, I looked that up	Experiencing delusional self
22	and I was quite, you know it wasn't just me, that's ever had those symptoms, erm and like there was people in	Questioning origin of delusions
23	the hospital I was with that had similar symptoms to me and that sort of exacerbated it for me because then	Questioning origin of delusions
24	we were a group and we were all seeing the same thing, doing so, you know, um and that took time to	Questioning origin of delusions
25	[inaudible] question it as well and that takes time to get over as well and that and you think about it when you	Taking time to get over
26	don't when you're not wanting, it just pops into your head really and then for me, I've been told now you've	Intrusive sense making
27	got to take that thought and try and discard it um as part of my therapy but um, it's harder to do, you know	Being a recipient of professional advice
28	it's easier to do than say really and you just spiral then and think about other things and then for me I get	Continuing to question; having a low mood
29	depressed than and then I'll sleep more erm as a way of coping really and I think it dies, it gets you down after	Having a low mood
30	a whilst er I have good days and I have bad days where I'll think about it more and it there is no sort of trigger,	Remitting condition' having no trigger
31	I don't think, I think, its time on your own, aswell, time, time with your own thoughts can be that worse	Thoughts as contributing
32	enemy aswell. That's why I recommend that I don't do that, cos for me that is a trigger for depression then as	Having self-awareness; triggers
33	well so before I probably thought about it every day where now I make a conscious effort now, I try and	Low mood; getting on with it
34	dismiss it and like I say that part of my recovery to kind of dismiss it, but I do want to make sense of it and I	Dismiss questions; want to make sense of it
35	still do search for those sort of answers but the answer will come back you know.. I don't know	Ongoing sense making

APPENDIX H: EXAMPLE OF MEMO WRITING

Memo One – Early memo-writing while transcribing an interview

Date of memo: 03/09/2015
Point of Analysis: While transcribing first interview (Simon)

Initial thoughts while transcribing:

- Participant speaks of his role as a peer support mentor. This seems to provide him with a great sense of achievement. I wonder how much his role has contributed to his recovery? Or perhaps it's less about the role of leading the group and more about connectedness or perhaps the two?
- There is strong sense of feeling worthless and the voices seemed to play on these thoughts. Simon seems to be aware of this and although he can challenge them to an extent the emotional struggle continues.
- Societal views – Simon seems to be aware of societal views equating mental illness with ideas of dangerousness. He then goes on to discuss stigmatising views as impacting on his ability to engage in his role as an uncle. This was quite an emotional point of the interview. There was such a sense of estrangement and loss. The term 'coming out' was used.
- Exploring the causes was key to making sense of his experience. For Simon biological causes seemed to fit. There was an importance placed on developing a description that one can really understand. He described a metaphor as being helpful.
- "Oh well they made me who I am today" – seems to be some elements of PTG emerging already. But I am wondering how much these positive really mean to simon? He almost seems to want to engage and develop that narrative but perhaps not really believe it or feel it or perhaps the ongoing nature of the distress of the voices is impacting on his he see positive changes.
- Self – simon speaks about being able to be himself again. There's a sense that psychosis stopped him from being able to be himself. He speaks about the role of others as really important in this. The role of other people who have gone through the same thing seems to be valuable. A sense that they 'really understand'. Talks about occupation 'I'm a carpenter' – the onset of the psychosis stripped his role which clearly seems to contribute to how he sees himself. He talks of his carpenter 'strong' self and his less strong less. I wonder if the 'less strong' self is the post-psychosis him. Outwardly though he speaks about winning 'small victories' there is an element of heightened strength here, even though his expectations have had to be re-assessed. I wonder if other interviews will reveal similar?

Implications for future interviews:

- How individuals go about making sense – when dos this occur and what aspects does it involve?
- What do roles means and how do people go about re-establishing these after a ROP?
- Are others as aware of stigma as Simon was? If so how does this impact on their perception of themselves and their recovery processes?

Memo Two –The use of memo-writing in the development of initial ideas about an emerging theme

***Date of memo*:** 17.12.2015
***Point of Analysis*:** After initial coding of Interview 5 (Chris)
Specific Theme/Codes Explored: Finding a sense of value and purpose

Codes that related to identified theme (from all five interviews)

- Gaining occupation
- Re-engaging with roles
- Stigma 'getting in the way'
- Failing to trust self
- Feeling trusted by others

The above codes have been present in all 5 interviews so far. All participants spooke about wanting to re-engage socially which seemed to mean through occupation and through roles. Some had re-engaged with roles (e.g., helping others), although one spoke about actually losing his role of 'helping' through leaving the hospital. Not many have re-gained pre-existing occupation or new occupation though.

Something very interesting has also emerged with the idea of trust. I wasn't expecting this and I'm not sure yet what it relates to although stigma certainly seems to come into play in reinforcing thoughts that they cannot trust themselves. But there seems to be an element of not completely trusting the 'self'. This needs exploring in future interviews.

The adaptation to the interview schedule has been helpful in obtaining ideas about individuals roles, how they were impacted by the psychosis and the ongoing struggle to re-engage in roles. It seems that trust serves to impact on engagement in roles. One participant speaks of not being able to care for his nephew without being questions, another talks of being questioned at work. For the latter there was a sense that others are monitoring him in a sense that their judgement of him is forever clouded by the knowledge he has had psychosis. I wonder if the participants feel they will ever re-gain others trust?

I'm struck by the idea that individuals take on an additional role as a 'someone who has had a psychosis'. The last four interviews have been different to the first. The initial participant spoke about having a well-practised role as peer support facilitator and this seemed to be beneficial. The remaining participants however seem to be 'stuck' almost in the role of 'someone with a psyhosis'. I am hopeful that the next participants might have made a positive role transition life participants 1 so that this can be explored further.

Things to consider in future interviews:

- Explore participant's perceptions of a lack of trust in themselves, where does this arise from? Perhaps this is something that is influenced by their attachment styles or perhaps it is something specific to psychosis. Needs exploring. Clearly internalised stigma plays a role but I'm not convinced this is the sole factor.
- There appear to be specific barriers to the process of developing occupation and social engagement. Are these specific or do they impact other themes too. Need to explore further.
- Further thought needs to be given to the role played out of 'someone with a psychosis'. What does this mean for individuals? How do they emerge from this? What impedes/facilitates the emergence from such a role?

APPENDIX L: INFORMATION SHEET

NHS WALES GIG CYMRU

School of Psychology
Ysgol Seicoleg

South Wales Doctoral Programme in Clinical Psychology
De Cymru Rhaglen Doethuriaeth mewn Seicoleg Glinigol

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PRIFYSGOL CAERDYDD

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70 Park Place
Cardiff CF10 3AT
Wales UK

www.psych.cf.ac.uk

Prifysgol Caerdydd
Adeilad y Tŵr
70 Plas y Parc
Caerdydd CF10 3AT
Cymru Y Deyrnas Unedig

Participant Information Sheet

Title of Project: Perceptions of Personal Strength and Sense of Self following an Experience of Psychosis

We would like to invite you to take part in this project. It is a research study by a Trainee Clinical Psychology student at Cardiff University, who is interested individual's experience of psychosis. The term psychosis is used here to describe an experience of hearing voices, seeing things or having unusual fixed thoughts. People use different words to describe these experiences, but the word psychosis is used here until we get a better understanding of what word best fits with you and your experience.

The study does not have any impact on the care and support you are receiving or will receive in the future. Before you decide whether to take part, we would like you to understand the purpose of the study and what it will involve for you. The project lead, Caroline Hoskins, will read the information sheet with you and answer any questions you may have. We suggest that this should take 5-10 minutes. Please do ask Caroline if there is anything that it not clear or if you have any questions.

The purpose of this study

This project is looking at how people make sense of their experience of psychosis, with a focus on exploring changes in an individual's sense of self (e.g. own and perceived others' beliefs about self) and personal strength (e.g. the belief that you can handle difficulties well) following an episode of psychosis. It is hoped that this study will help us to identify how individuals can positively adjust following an episode of psychosis.

Why have I been invited to take part?

You have been invited to take part because you have experienced a first episode of psychosis and have accessed health or charity services in respect of your experience. We would like to find out

ways that you have adapted to your experience. We are aiming to speak to a maximum of 12 people who have had a similar experience of a first episode psychosis. It is important to remember that participation in this study will have no bearing on your present or future care or treatment.

What will happen?

If you agree to take part in this study you will be asked to join Caroline Hoskins in a confidential room at Kier Hardie University Health Park, Merthyr/Forglen House, Gwent or other local Psychiatric Hospital within Gwent/Outreach and Recovery Team Pontypridd/ 4 Winds, Grangetown (directions and a map will be provided). You will be asked to complete three questionnaires: a demographic and information questionnaire (age, ethnicity, spirituality, symptoms experienced, time since symptoms occurred, age of onset and GP contact details); a questionnaire asking you about your general well-being and a measure of post traumatic growth (positive changes after your experience of psychosis). The questionnaires are tick box and will take around 15 minutes to complete all three. Caroline will provide you with any support you might need to complete these. You will then be interviewed about your experiences for up to 60 minutes. The interview will be audio-recorded. Following this Caroline will write out the interview 'word for word' – this will be called the interview transcript.

What will happen next?

After your interview has been transcribed, Caroline will look for common themes between what you and others have explained. This will form the basis of the report.

Do I have to take part?

It is entirely up to you to decide to take part in the study or not. Please ask Caroline if you have any questions after reading this information sheet. If you are interested in participating, you will be asked to sign a consent form and offered another opportunity to ask questions about the study before the interview begins. During the interview you will be welcomed to take a break at any point or to withdraw from the project without consequences for your care and treatment now or in the future.

What are the potential disadvantages of taking part?

It is important to know that during the interview you will be asked about your experience of psychosis (e.g. how you coped after your experience of psychosis) and it is possible that you could find this distressing. We do not have to talk about anything that you do not wish to, and you will be encouraged to talk only about those things which you feel able and comfortable discussing. If you would like to bring someone along with you, either to sit and wait outside or join you throughout part or all of the interview, that is fine. It will take about 90 minutes to read through the information sheet and consent form, complete three questionnaires and be interviewed. Following this, you will also be given the opportunity to discuss the experience of being interviewed and any thoughts/feelings that this brought up for you and ask further questions about the study - this is known as a debrief.

What are the benefits of taking part?

Whilst taking part in the study will not benefit you directly, it is hoped that the project will lead to an increased understanding of how people make sense of their experience following a first episode of psychosis and how this might lead to positive changes. This may help services to be better able to support people through their journey of psychosis to reach a positive outcome and provide a sense of hope to those making their journey.

Will my taking part remain confidential?

All information will be made anonymous and you will not be able to be identified by reading the report. This means that names of participants, services and specific geographical locations will not be specified to protect your identity. Direct quotes will however be used in the final report but will not be paired with any identifiable information. Non-gendered pseudonyms (made up names e.g. Sam) will be used to replace your name and will appear next to the quotes only. Transcriptions and audio recordings will be stored on a computer which is password protected. You will be offered a copy of the transcript and will be given the opportunity to confirm if it is accurate. Recordings will be deleted following transcription and the transcripts will be kept for 5 years in a secure location to maintain confidentiality.

Your confidentiality may not be maintained if you disclose information which relates to your own or others safety. In this case your GP will be notified and if necessary the Crisis Team, Mental Health team and/or police. Clinical discussions regarding how to best ensure your own and other's safety will also be held with the other named researchers (as below).

Will I be paid?

You will not be paid to take part in the study. Travel expenses can be paid at a rate of 27p per mile if you use your own car. If you travel by public transport you will be able to claim the full amount back, but you will be asked to provide a receipt (e.g. bus/train ticket). You will receive cash refund when you attend for your interview.

Who else is involved in this research?

Project Lead: Caroline Hoskins

Role: Trainee Clinical Psychologist

Email: HoskinsC@cardiff.ac.uk

Telephone: 02920 870545

Address: South Wales Doctoral Programme in Clinical Psychology, 11th Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT.

Clinical Supervisor: Dr Julian Pitt

Role: Consultant Clinical Psychologist

Email: julian.pitt@wales.nhs.uk

Telephone: 01443 443777

Address: Taff Ely & Rhondda Outreach and Recovery Team, Y Bwythyn, The Common, Pontypridd, CF37 4AL.

Academic Supervisor/Chief Investigator: Dr Jenny Moses

Role: Consultant Clinical Psychologist/Academic Director

Email: jenny.moses@wales.nhs.uk

Telephone: 02920 870582

Address: South Wales Doctoral Programme in Clinical Psychology, 11th Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT.

What if I have concerns about this research?

If you have any concerns or complaints about this project, please direct these in the first instance to: Reg Morris (Honorary Professor and Director of the Doctoral Programme in Clinical Psychology). Address: 11th Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT. Telephone: 02920 870582

You can also contact Tessa Liburd in the Concerns Department at Cardiff and Vale University Health Board. Address: Cardiff and Vale University Health Board, Whitchurch Hospital, Park Road, Cardiff CF14 7XB. Telephone: 02920 336365.

APPENDIX M: CONSENT FORM

NHS WALES GIG CYMRU

School of Psychology
Ysgol Seicoleg

South Wales Doctoral Programme in Clinical Psychology
De Cymru Rhaglen Doethuriaeth mewn Seicoleg Glinigol

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

Cardiff University
Tower Building
70 Park Place
Cardiff CF10 3AT
Wales UK

www.psych.cf.ac.uk

Prifysgol Caerdydd
Adeilad y Tŵr
70 Plas y Parc
Caerdydd CF10 3AT
Cymru Y Deyrnas Unedig

Participant Consent Form

Perceptions of Personal Strength and Sense of Self following an Experience of Psychosis

Participant Identification Number:

Research Team:

Project Lead: Caroline Hoskins

Role: Trainee Clinical Psychologist

Email: HoskinsC@cardiff.ac.uk

Telephone: 02920 870545

Address: South Wales Doctoral Programme in Clinical Psychology, 11th Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT.

Clinical Supervisor: Dr Julian Pitt

Role: Consultant Clinical Psychologist

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Telephone: 01443 443777

Address: Taff Ely & Rhondda Outreach and Recovery Team, Y Bwythyn, The Common, Pontypridd, CF37 4AL.

Academic Supervisor/Chief Investigator: Dr Jenny Moses

Role: Consultant Clinical Psychologist/Academic Director

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Telephone: 02920 870582

Address: South Wales Doctoral Programme in Clinical Psychology, 11th Floor, School of Psychology, Tower Building, 70 Park Place, Cardiff, CF10 3AT.

Please initial each of the following statements if you agree:

	Please initial
1. I confirm that I have read and understood the information sheet (Version 6.0) for the above named study	
2. I have been given the opportunity to ask any questions, and have had any questions answered to my satisfaction	
3. I understand that taking part in the study will have no impact on my care and treatment either positively or negatively presently or in the future	
4. I understand that my participation is voluntary and that I am free to withdraw from participating in the study at any time, without giving any reason, and without my care and treatment being affected	
5. I understand that relevant sections of the data collected during the study may be looked at by members of a Cardiff University research team, from regulatory authorities or from NHS Health Boards, where it is relevant to my taking part in this research.	
6. I understand that information I give will be published as part of the project (in the form of quotations), but I will not be able to be identified by this information (quotations will be made anonymous). I give consent for anonymous quotations of mine to be published in the study write-up	
7. I consent to completing three questionnaires; a questionnaire collecting demographic and other information; a questionnaire about my general well-being and a measure of post traumatic growth (positive changes occurring after my experience of psychosis).	
8. I consent to the interview being recorded and transcribed. I understand that the audio recordings will be destroyed once they have been transcribed, but the transcriptions will be kept securely for a period of 5 years.	
9. I understand that my GP may be contacted in the event of concerns about my safety or the safety of others. I am aware that where necessary the Crisis Team, Mental Health Team and/or police will also be notified.	
10. I agree to take part in the above study	

Signature of Participant: _____ Date _____

Signature of Researcher: _____ Date _____

APPENDIX N: DEMOGRAPHIC INFORMATION QUESTIONNAIRE

Demographic Information

Sex: Male/Female

Age:

Ethnic origin:

Address: GP Details: *

Do you have any other diagnoses?

Age at onset of psychosis:

Duration of psychotic symptoms:

Symptoms of psychosis:

Do you consider yourself spiritual? Do you align yourself with any religion?

APPENDIX O: INITIAL INTERVIEW SCHEDULE

INTERVIEW SCHEDULE (INITIAL)

[Can I start by checking out what words you use to describe your experiences? People have used many different terms to describe the experience that we will be discussing, including: a psychosis, hearing voices, having unusual beliefs or you may like to refer to the experience as 'when you were unwell', 'when you had your breakdown'…….. How do you describe your experience? I will try to use these terms throughout the rest of our discussion.

Warm up question: Lots of people ask themselves the question 'Why me?' when they experience a change in their health and well-being. Did you ever ask the question 'Why me?' after you experienced [preferred term]?
If so, how did you resolve/answer this question for yourself?

- Do you feel that you have made sense of your experience of [preferred term] (e.g. do you now understand it differently?)
- How did you make sense of your experience of [preferred term]?
- What did 'making sense' of your experience enable you to do?
- What was life like for you before you made sense of your experience?
- How did life change for you after you made sense of your experience?

- Do you feel you are somehow different after your experience?
- Did your experience go against/challenge any ideas/beliefs you already held about yourself?
- Did it strengthen any of your beliefs/ideas about yourself?
- If so, does this 'new' perception of yourself 'fit' more or less with how you think others view you?
- Can you tell me about any particular events or realisations that you think might be relevant to changes in your ideas about yourself?
- Do you feel that you view the world somehow differently after your experience?
- Did your experience of psychosis go against or reinforce any ideas you already held about the world? (prompts … ideas that the world is ordered and predictable)

- How do you see yourself now having come through your experience?
- Did your experience alter any ideas you had about yourself?
- In particular, did your experience alter in anyway your perception of personal strength (e.g. how well you can handle difficulties, being inclined to change the things that need to be changed, sense of self confidence, seeing yourself as being strong enough to overcome unseen and unusual problems).

- Have you taken any positives from having had your experience and come through it?
- Do you feel that making sense of your experience was important in how you now see yourself?
- Do you feel that making sense of your experience was important in how you see yourself in terms of having more/less personal strength?
- Do you see your experiences as opening up any new opportunities for you?

APPENDIX P: AMENDED INTERVIEW SCHEDULE

INTERVIEW SCHEDULE (AMENDED)

[Can I start by checking out what words you use to describe your experiences? People have used many different terms to describe the experience that we will be discussing, including: a psychosis, hearing voices, having unusual beliefs or you may like to refer to the experience as 'when you were unwell', 'when you had your breakdown'…….. How do you describe your experience? I will try to use these terms throughout the rest of our discussion.

We are not so curious about the how, when, what, why of the psychosis (preferred term) but we are very interested in your efforts to make sense of this experience and how you now see yourself.

Warm up question: Lots of people ask themselves the question 'Why me?' when they experience a change in their health and well-being. Did you ever ask the question 'Why me?' after you experienced [preferred term]? If so, how did you resolve/answer this question for yourself?

1. To what extent do you feel that you have made sense of your experience of [preferred term] (e.g. do you now understand it differently?)
    - How did you make sense of your experience of [preferred term]?
    - What did 'making sense' of your experience enable you to do?
    - Before you made sense of your experience, did you try to get help?
    - How did life change for you after you made sense of your experience?

2. To what extent, has how you see yourself changed?
    - Do you see yourself differently after having your experience?
    - Do you feel OK about who you are now?
    - What is your ideal recovered self? (e.g. pre-episode self or a different self?)
    - What has been helpful/not so helpful in making you feel yourself/different self?
    - How have others contributed to this process?

3. Has your belief in yourself changed?
    - Some people say that experiencing (preferred term) has made them a stronger person. Would you agree or disagree that this has been the case for you? Do you think others would say you have got stronger?
    - What did you/others think you were good at before the psychosis?
    - What do you/others think you are good at now?

4. Have your close relationships/roles and/or occupation changed since the psychosis?
    - How has the way you see yourself as a parent/son or daughter/uncle or aunt changed, if at all as a result of the psychosis?
    - Have you become aware that people you are close to see you differently now? If so, what have you noticed had changed?
    - Have you noticed any changes in the way you express yourself in your close relationships?

- To what extent have you become closer to/more distant from others? Why?
- Has how you think about your work or other interests changed? What are the pros and cons of this change?

- How do you now view your world after the psychosis? do you now view it somehow differently after the psychosis? Has your view of your world as ordered/predictable or controllable changed?
- Have you noticed any change in your priorities?